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Access to Inclusive Early Childhood Development and Education Services for Refugee Children who Experience Communication Disability, in Rwanda

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Access to Inclusive Early Childhood Development and Education Services for Refugee Children who Experience Communication Disability, in Rwanda

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A thesis submitted in partial fulfilment of the requirements of Manchester Metropolitan University for the degree of Doctor of Philosophy

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i. Abstract

Background: Refugee children who experience disability (the interaction of impairment(s) with barriers to participation in their social and physical environments), have been shown to have low levels of access to education. The United Nations High Commissioner for Refugees (UNHCR) in Rwanda recognises that, within this group of children, some are at greater risk of exclusion due to impairments that are difficult to identify, such as those related to communication. This exclusion impinges upon their right to education and is contra to the 'leave no-one behind' agenda expounded in Agenda 2030 – an ambitious global agenda for a more equal world.

This research aimed to investigate the extent to which refugee children who experience communication disability (CD), in Rwanda, realise their right to education. The research examined factors influencing access to inclusive early childhood development (ECD) and education services, including barriers and facilitators, from a holistic perspective.

Methods: A two-phase, sequential, transformative, mixed-method (primarily qualitative) research study was conducted as a critical inquiry, within a pragmatic research paradigm. Methods of data construction included: analysis of secondary administrative data; thematic analysis of documents, interviews and focus group discussions with humanitarian service providers and refugee communities; and content analysis of classroom observation notes. Both phases of the study were analysed and interpreted independently and were then integrated to form an Interpretive Description.

Results: Eighteen key findings were constructed from the analysis of six data sets, across phases one and two of the study. These key findings were integrated to produce three thematic areas for discussion: power, priorities, and potential. These findings were related to three theoretical frameworks that guided the research: human rights, critical refugee studies, and critical disability theory.

Discussion and conclusions: This research provides valuable insights into the barriers and opportunities for refugee children who experience CD, in relation to fulfilment of their right to education within the global humanitarian system. The insights enrich understanding of the need for a collaborative, systems-thinking, approach to humanitarian action in relation to inclusive education, and for affected populations to be empowered to influence decision-making. These findings are relevant to Governments, humanitarian and development actors, health and education professionals, and disability and social inclusion practitioners in humanitarian (and similar resource constrained) contexts.

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iii. Acronyms

Acronym	In full
AHC	Ad Hoc Committee
CAQDAS	Computer Assisted Qualitative Data Analysis Software
CD	Communication disability
CI	Communication impairment
CRC	Convention on the rights of the child
CRID	Communication related impairment and/or disability
CRPD	Convention on the rights of persons with disabilities
CRRF	Comprehensive refugee response framework
CSD	Community service desk
CSR	Convention on the status of refugees
DFID	Department for International Development
DRC	Democratic Republic of the Congo
DS	Disability
DS-DF	Disability: Hearing impairment/deafness
DS-MM	Disability: Mental disability moderate
DS-MS	Disability: Mental disability severe
DS-SD	Disability: Speech impairment/disability
ECD	Early childhood development
ECE	Early childhood education
ESA	Education sector analysis
FDLR	Democratic forces for the liberation of Rwanda
FGD	Focus group discussion
GCR	Global compact on refugees
GLR	Great Lakes Region
GoR	Government of Rwanda
HDI	Human development index
HDN	Humanitarian-development nexus
HDPN	Humanitarian, development and peace nexus
ICF	International classification of functioning, disability and health
ICIDH	International classification of impairment, disease and handicap
ID	Interpretive description
IDP	Internally displaced person
INGO	International non-governmental organisation
IO	Implementing organisation
KMR	Kaupapa Māori Research
LMIC	Low- and middle-income country/ies
LRRD	Linking relief, rehabilitation and development
M23	March 23rd movement
MIDIMAR	Rwanda Ministry of Disaster Management and Refugee Affairs
MINEDUC	Ministry of Education (Rwanda)
MINEMA	Rwanda Ministry for Emergency Management
MMR	Mixed-method research

MMU	Manchester Metropolitan University
NISR	National Institute of Statistics, Rwanda
NRA	National Resistance Army
OECD	Organisation for Economic Cooperation and Development
OOS	Out of school
PIS	Participant information sheet
POC	Person(s) of concern
PHAP	International Association of Professionals in Humanitarian Assistance and Protection
PRS	Protracted refugee status
RDC	Refugee disability committee
RDF	Rwanda defence force
REB	Rwanda Education Board
RPF	Rwandan Patriotic Front
SNC	Specific needs code
SSI	Semi-structured interview
STPs	Systems, tools, and processes
TA	Thematic analysis
TUAC	Trade Union Advisory Committee to the OECD
UDHR	Universal declaration of human rights
UNDESA	United Nations Department for Economic and Social Affairs
UNDP	United Nations Development Programme
UNGA	United Nations General Assembly
UNHCR	United Nations High Commissioner for Refugees
UNHRC	United Nations Human Rights Council
UNICEF	United Nations Children’s Fund
WBG	World Bank Group
WHO	World Health Organisation
WEIRD	Western, educated, industrialised, rich, and democratic
WRC	Women’s Refugee Commission

iv. Acknowledgements

In fond memory of Oksana Olifirovych, UNHCR Rwanda

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And last, but certainly not least, to my family: **Stephen, Oscar, Lucas, Mum, Paul, Stephanie, and Michael**. For everything you have done every step of the way to make me believe I could do this and to make sure it happened, there are no words. I love you all.

Phuket, 8th July 2023.

v. ‘Invisible’: Manchester Metropolitan University Images of Research Competition Winner, 2022 (PGR category).

This image depicts a refugee camp in Rwanda where my PhD data were collected. The camp is high on a hill, often hidden in the mist. On some days you may not even notice it is there as it can barely be seen.

Like the camp in the picture, communication impairments (CIs) are also ‘invisible’ and can be difficult to identify. Refugees with CIs in Rwanda are often misunderstood and stigmatised within their communities. In a context where specialist communication support, such as speech and language therapy, is limited, humanitarian service providers are unable to meet communication support needs, resulting in disabling exclusion.

My research has shown that ‘invisibility’ impacts upon the ability of refugee children with CIs to realise their right to an appropriate education, as well as to accessing other essential services such as health and protection. We may not see them, but they are there…hidden from view.

Chapter 1: Introduction to the thesis

1.1 Overview

In this chapter, I introduce the research project by providing an overall description of the research, its context, and how the project was collaboratively conceptualised and designed (section 1.2). I then state the research question, aims, and objectives (section 1.3), and outline the thesis structure (section 1.4). In section 1.5, I provide the rationale for the choice of terminology used within the thesis. I then summarise the chapter in section 1.6.

1.2 Research description

This research project investigated the factors influencing the extent to which refugee children who experience communication disability (CD) in Rwanda's refugee camps, realise their right to education. The research examined factors influencing access to inclusive early childhood development (ECD) and education services, including barriers and facilitators, from a holistic perspective. The camps host refugees from Burundi and Democratic Republic of Congo (DRC), in various stages of emergency response. At the time of data construction, camps included in the study were in emergency phase (0-2 years post-crisis), post-emergency phase (2-5 years post-crisis) and protracted phase (5 years plus post-crisis) responses.

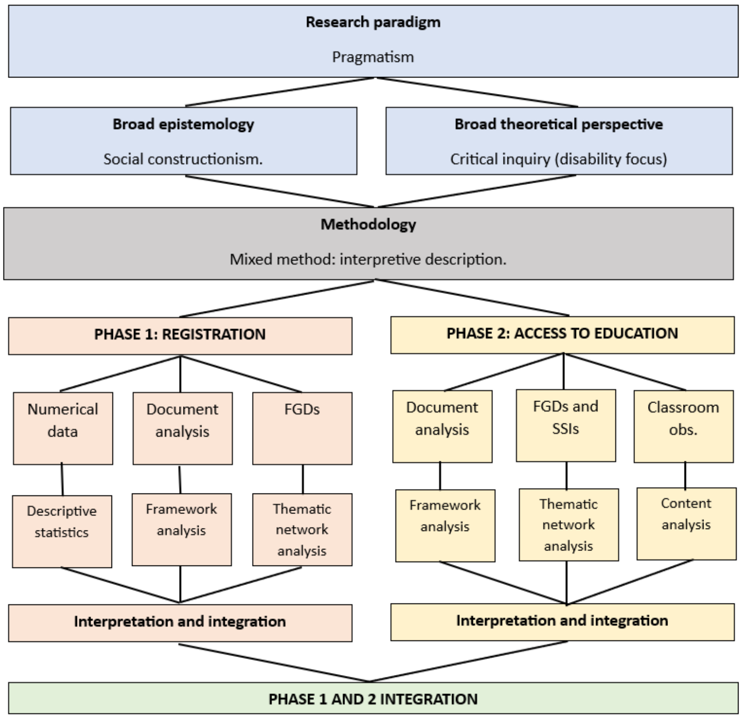
The mixed method (primarily qualitative) research was conducted within a pragmatic research paradigm (see Crotty, 1998), responding to a complex, practical, real world research context. This research was undertaken from a broadly social constructionist epistemological stance and was conducted as a critical inquiry with a disability focus and advocacy worldview. Although conducted sequentially**,** phase 1 - identification and registration of refugees with communication impairments - contributed to the understanding of findings in phase 2 – access to ECD and education services – within a sequential transformative research strategy (Creswell, 2009) (see chapter 4 for an in-depth discussion on research philosophy and methodology, as well as rationale for these choices).

The two phases of the study were analysed and interpreted independently and were then integrated as an Interpretive Description (Thorne, 2016) (see figure 1). Methods used across the two phases consisted of:

1. Secondary United Nations High Commissioner for Refugees (UNHCR) registration data analysed using descriptive statistical methods.
2. Document analysis analysed using Framework analysis.
3. Focus group discussions (FGDs) and semi-structured interviews analysed using thematic network analysis.
4. Classroom observations analysed using content analysis.

A more detailed description of the philosophy on which the research was based, as well as methodological choices, can be found in chapter 4. Further discussion on research methods can be found in chapters 5 and 6.

Figure 1: Research philosophy, methodology and methods



1.2.1 Research context

1.2.1.1 ECD and education in crises

The average duration of a forced migration experience stands at seventeen years (Betts and Collier, 2017), and three 'durable solutions' to forced migration (naturalisation, resettlement in a third state, voluntary repatriation) are becoming increasingly difficult to achieve. Forced migration disrupts education opportunities which interferes with child development and socialisation, leaves children vulnerable to rights violations, and impedes the education of future peacebuilders (UNHCR, 2019). Limited education impacts on refugee children's preparations to enter the labour market, provide for themselves and their families, participate in the creation of peaceful and just societies, and live fulfilling, independent lives (see chapter 6, section 6.3). As Filippo Grandi, UN High Commissioner for Refugees, states:

> *"Education will prepare refugee children and youth for the world of today and of tomorrow. In turn, it will make that world more resilient, sustainable, and peaceful. And that is not a bad return on our investment" (UNHCR, 2019. Online).*

Despite the evidence on the critical nature of early childhood interventions for children and families in crisis, there is a measurable gap between recommended action and observable implementation (Moving Minds Alliance, 2018). Approximately 250 million children under five years of age are at risk of not achieving their developmental potential due to conflict and exposure to risk factors affecting their nutritional, health, and psychological safety, as well as their relationships with caregivers (Bouchane, Yoshikawa, Murpshy and Lombardi, 2018; Lu, Black and Richter, 2016; Walker, Wachs, Gardner et al, 2007; Walker, Wachs, Grantham-McGregor et al, 2011; Harvard Center on the Developing Child, 2022). In addition, over half of refugee children of school age do not adequately access education (Save the Children, 2016; United Nations, 2019; UNHCR, 2019) and only two per cent of humanitarian financing is spent on education globally, with expenditure on early childhood development interventions comprising a tiny proportion of that (Bouchane et al, 2018). Without adequate early childhood interventions, including early childhood education (ECE) opportunities, children in crisis are often not developmentally ready to transition to school, even where education is provided.

Estimates of global childhood disability prevalence at the time of the research stood at 10.1 per cent of the world's children 0-19 years of age experiencing moderate-severe levels of disability (UNICEF, 2021), over 50 per cent of whom live in sub-Saharan Africa and South-East Asia (Olusanya, Kancherla, Shaheen, et al, 2022). Children who experience disability constitute a large group of out-of-school (OOS) children globally (Male and Wodon, 2017) – indeed 90 per cent are thought to be OOS (Global Partnership on Education, 2016). Refugees who experience disability are also acknowledged to be one of the most at-risk groups of people on earth (UNHCR 2010a; 2011; Women's Refugee Commission (WRC) 2014; 2015), regularly failing to access services, particularly in humanitarian contexts (UNHCR 2011; WRC 2014). Where young children fail to receive the early childhood development and education services they need, their difficulties may become more pronounced, and their likelihood of falling into poverty may increase (World Health Organisation (WHO) and United Nations Children's Fund (UNICEF), 2012). This is, therefore, a high risk for refugee children who experience disability.

Within this group of already at-risk refugee children who experience disability, some children are even more excluded than others – especially those with invisible, misunderstood, and/or or highly stigmatised conditions or impairments, such as those related to communication. (Tanabe, Nagujjag, Rimal, et al, 2015). Although Hussain, Jagoe, Mullen et al, (2018) suggest that up to 20 per cent of the global population will experience CD at some point in their lives, widespread misunderstanding of the causes and nature of CI and associated CD, coupled with poor social status in many contexts, further limits inclusion, participation, and access to support services for refugee children who experience CD and their families (Plan International, 2013).

There is emerging acknowledgement by some humanitarian agencies that refugees with CI may face disabling exclusion from a wide range of services, but also recognition that there is a lack of expertise amongst service providers to address issues effectively (e.g., WRC 2014). Despite a call by the United Nations to include those who experience CD in humanitarian programming, there is a lack of specialist and accessible mainstream service provision for displaced populations, to enable effective inclusion (Barrett and Marshall, 2013; Barrett, Turatsinze and Marshall, 2016; Battle, 2015, McAllister, Wylie, Davidson et al, 2013). This is partly attributable to the paucity of reliable data arising from under-identification and under-enumeration (Tanabe et al, 2015).

1.2.1.2 Recent forced migration and humanitarian response in Rwanda

In 2015, a new influx of refugees from Burundi began to flow into neighbouring Rwanda (see figure 2), due to political instability and civil unrest. Thousands of refugees arrived in a very short time and were relocated near the Tanzanian border by the Government of Rwanda and the UNHCR. This added to the 75,000 plus refugees already seeking refuge from political unrest in DRC.

Figure 2: Map of the Great Lakes Region of east/central Africa

This Photo by Unknown Author is licensed under CC BY-NC-ND

As Burundian refugees began to flow into Rwanda, a new, human-rights based, global agenda - *'Changing Our World: Agenda 2030 for Sustainable Development'* (UNDESA, 2015a) came into being, ratified by the United Nations General Assembly (UNGA). This human rights-based, ambitious, global plan to 'transform our world' over a fifteen-year period (2015-2030), was the new and improved action plan devised following the largely failed Millennium Development Goals (2000-2015), which aimed to halve global poverty by 2015 (United Nations, n.d.). Agenda 2030 focuses on eradicating poverty and equalising opportunities for all, through economic, social, and environmental interventions, operationalised through the application of a set of seventeen Sustainable Development Goals (SDGs - UNDESA, 2015a), with 169 targets.

The conflict in Burundi erupted at the same time as Agenda 2030 was published and as states around the world began to commit to the Sustainable Development Goals, which explicitly refer to the necessity to include marginalised groups and communities, such as displaced populations and those affected by disability, to achieve those goals (UNDESA, 2015a). At this time, the UNHCR in the Rwanda country office conducted a disability scoping review (Lange, 2015), to assess the degree to which refugees who experience disability were participating in social life, accessing services, and realising their rights. Guided by the Convention on the Rights of Persons with Disabilities (United Nations, 2007), several areas of concern were raised by UNHCR regarding refugees with communication impairments (CI), who were potentially experiencing disability related to ineffective service access and participation in community life and failing to fully realise their human rights. Priority areas of concern were identification and registration of this group of refugees, as well as access to effective ECD and education services. UNHCR staff suspected that the former may be a contributor to the latter.

1.2.1.3 Inclusive ECD and education for refugee children in Rwanda

Commitments to global inclusive ECD and education initiatives have been responded to positively by the Government of Rwanda (GoR) since the constitution came into force in 2003 (Government of Rwanda, 2003). Indeed, 97.7 per cent of children are in education (United Nations Rwanda Country Office, 2017b). Equally, the GoR committed to provide education services for refugee children in Rwanda in 2017, documented in the Education Sector Analysis (ESA) report. The introduction of Agenda 2030 (UNDESA, 2015a) was a catalyst for redoubled efforts to ensure all children realise their right to an appropriate education in their local community. In response to Agenda 2030's Sustainable Development Goal (SDG) 4: '*ensure an inclusive and equitable quality education',* and the corresponding Incheon Declaration and Framework for Action (United Nations 2015), the United Nations and the Government of Rwanda committed to supporting inclusive ECD and education services for all children, including refugees and those with disabilities, to promote better life-chances.

As described by Barrett, Marshall and Goldbart (2019: 36):

> *"Education and early-childhood development (ECD) services are now well established. Supported by the Government of Rwanda, UNHCR, and their implementation partners, children attend camp-based or host-community schools, from age six. Children aged 3-6 are encouraged to access ECD services and pregnant women and mothers of young children 0-3, are offered a comprehensive package of early-childhood development support, including nutrition, sanitation, early childhood stimulation and child protection. The majority of children and their families access these services in the camps and surrounding areas. However, there are concerns about the level of access to these services for children who experience disabilities and their families"*.

These concerns are supported by data that illustrate that only 0.75 per cent of primary aged pupils in Rwanda (including refugee children) were documented as experiencing disability (National Institute of Statistics, Rwanda (NISR), 2017). This fell to 0.64 per cent of the primary population registered as experiencing disability in 2021 (NISR, 2021). The United Nations Rwanda Country Office (2017) reported that 57.4 per cent of children who experience disability access school, compared to the 97.7 per cent overall education enrolment rate.

During this research, Rwanda also became a pilot country for the Global Compact on Refugees (GCR: United Nations, 2018), implementing its framework – the Comprehensive Refugee Response Framework (CRRF), set out in the New York Declaration (United Nations, 2016) (see chapter 2, section 2.3) – and committing the GoR to providing state services to refugees, including inclusive ECD and education. Recent evidence suggests that this has, thus far, been successful, insofar as 90 per cent of all refugee children are integrated in Rwanda's schools (UNHCR 2020). However, the Universal Periodic Review (United Nations Human Rights Council (UNHRC), 2021) reiterated that children who experience disability only represent 0.7

per cent of the student population even though, in sub-Saharan Africa, 6.4 per cent of children under 14 years of age experience disability (UNICEF and Education Development Trust, 2016). This suggests that children who experience disability, including in the refugee population, continued to be out of school six years after the commitments to Agenda 2030 – a fact acknowledged by the Rwandan Ministry of Education (MINEDUC, 2018a).

For those children identified as having impairment(s) and/or experiencing disability in Rwanda, *enrolling* in ECD services or school is only the first hurdle. Once enrolled, they face myriad barriers to effective learning and social participation, from physical accessibility barriers for some, to learning barriers for others, exacerbated by social stigma (Karangwa, Miles and Lewis, 2010). The dropout rate, as well as grade repetition rate, for children who experience disability is higher than non-disabled peers, suggesting the education system is not meeting their needs (Thomas, 2005). In response to this, in 2016 the GoR developed an inclusive education training programme, with accompanying guide, to assist mainstream teachers in delivering quality, inclusive education for all children (REB, 2016). This training was planned to be delivered to at least one teacher in each primary school in Rwanda, including those schools with an integrated refugee population. At the time of data construction, this exercise was not complete and ECD centres and schools involved in this study had neither received the guide nor the training.

Operating at the humanitarian-development nexus of short-term crisis relief and longer-term social investment (see chapter 2, section 2.3.), as many Governments and humanitarian organisations now must, has enormous implications for the planning and delivery of ECD and primary education services, as well as the transition between these services, for refugee children. No more so than for those caught up in protracted crises, as is the case for Burundian and Congolese refugee children hosted long-term in Rwanda.

1.2.1.4 Research conceptualisation

At the time of the 2015 Burundi crisis, I was living and working in Rwanda within the inclusive ECD and education space. In a meeting where both UNHCR and I were present, UNHCR approached me to discuss their scoping review results. Upon discussion of my plans to embark upon post-graduate research, we discussed the potential to collaboratively investigate the possible education access challenges and disabling experiences faced by refugee children with communication impairment (CI). I therefore collaborated with the UNHCR Rwanda community-based protection team responsible for disability issues, as well as senior management, to design a research project to meet their need to better understand the factors influencing access to education (including ECD) for this group of children.

UNHCR staff identified that they would benefit from a holistic understanding of the opportunities and barriers to accessing appropriate ECD/education for refugee children with communication impairment (CI), who may be experiencing associated CD (see section 1.5.1. below). UNHCR staff and I decided to consider a) processes of identification and educational inclusion; b) guidelines and policies influencing inclusive practice; and c) the experiences and opinions of service users and service providers, with regards to access to identification, registration, and ECD/education services.

Research planning discussions involving UNHCR Rwanda senior management, community-based protection staff, and me, were held regularly throughout years one and two of the research project, and the requisite permissions and clearances sought from Manchester Metropolitan University (MMU) and University of Rwanda ethics boards, the Rwanda Ministry of Foreign Affairs, the Rwanda Ministry of Education, and the Rwanda Ministry of Disaster Management and Refugee Affairs (MIDIMAR)[1] (appendix 1). A legal data-sharing agreement was signed between MMU and UNHCR Headquarters in Geneva, allowing anonymous refugee data to be

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[1] Now Ministry for Emergency Management (MINEMA)

accessed and analysed, and which set out regulations for the management of confidential data generated during the study (appendix 2).

1.2.2 Research intention

The intention of this research is to support UNHCR Rwanda to understand the opportunities and barriers facing refugee children with CI, who experience CD, in relation to access to ECD and education services, in refugee camp settings. It is envisaged that this increased understanding will support UNHCR and its partners – the implementing organisations (IOs) - to address any identified barriers to educational access and to ensure services are communication accessible and inclusive of children with a range of communication accessibility support requirements, thus increasing their ability to realise their right to inclusive ECD and education. In addition, UNHCR will be able to capitalise on the opportunities available. Ultimately, the findings from this research are envisaged to contribute to UNHCR Rwanda's aims to ensure that every refugee child can realise their right to an inclusive, appropriate education in their local community, and maximise opportunities to achieve independent, productive, and fulfilling lives.

1.3 Research question, aims, and objectives.

The research was conducted in two phases, in response to the research priorities of UNHCR Rwanda, and to answer the question:

'*To what extent do refugee children with communication impairment, who experience communication disability, realise their right to inclusive education in Rwanda?'*

There was one research aim per phase, each addressed through three objectives.

Phase 1: Identification and registration of refugees with communication impairment, who experience communication disability, in Rwanda

The aim of phase one of the research was:

- **A1:** to describe and critically interrogate the current systems, tools and processes used to identify and register refugees with communication impairments, who experience disability, in Rwanda.

I set out to achieve this aim through three research objectives that, together, addressed different but complementary aspects of the research aim:

- **O1a:** to determine the proportion of refugees, including children, registered with communication impairments and/or disability in Rwanda, using current tools and processes.
- **O1b:** to describe and critique the current tools and processes used to identify and register refugees with communication impairments and/or disability in Rwanda.
- **O1c:** to document the self-reported understanding, behaviours, and experience of staff responsible for determining if refugees have a CI and/or experience CD.

Phase 2: Access to inclusive ECD and education services for refugee children, who experience communication disability, in Rwanda.

The aim of phase two of the research was:

- A2: to map the opportunities and barriers to accessing appropriate inclusive ECD and education services, for refugee children with CIs, who experience CD, in Rwanda.

I set out to achieve this aim through the following three research objectives:

- **O2a:** to document the inclusive ECD and education services that are provided to refugee-children in Rwanda and the opportunities for, and barriers to, the educational inclusion of refugee-children with CI, who experience CD.
- **O2b:** to document ECD and education service-providers' views of opportunities and barriers to including refugee-children who experience CD in ECD /education services.

- **O2c:** to document the views of parents/carers of children who experience CD regarding opportunities and barriers to including their children in ECD/education services.

1.4 Thesis structure

The thesis is set out across seven chapters, with supporting appendices. The structure allows for each of the two phases of the research to be described in full, as individual entities, with the final chapter integrating the findings from both phases as an Interpretive Description (ID).

This chapter (chapter one) begins by describing the research, as well as detailing the aims and objectives for each phase. It outlines the thesis structure and then introduces the terminology used throughout the thesis, giving a justification for these choices.

Chapter two contextualises the research with background information. Relevant subject areas to the research, including forced migration, humanitarianism in post/neo colonial contexts, disability and inclusion, and ECD/education, are discussed within a human rights framework and within the global vision of achieving Agenda 2030 (UNDESA, 2015a).

Chapter three presents a semi-systematic review of key literature associated with the research question.

Chapter four presents the methodology for the study, including philosophical guiding principles, research methods, and justification for the choices made.

Chapter five details the research process, including data construction and analytical processes, as well as the results and interpretation, for phase one of the project: identification and registration of refugees with CI/who experience CD. Three data sets are presented, utilising mixed research methods, the results of which are interpreted and discussed.

Chapter six details the research process, including data construction and analysis processes, as well as the results and interpretation, for phase two of the project: access to inclusive ECD and education for refugee children who experience CD. Again, three data sets are presented, which utilise different qualitative methods of data construction and analysis and the results of which are interpreted and discussed.

Chapter seven integrates data from the literature review, phase one, and phase two, with reference to the research question, aims and objectives across both phases of the project. Researcher reflexivity and research challenges and limitations are considered. The chapter presents key findings and implications for addressing issues of exclusion and communication inaccessibility within refugee education services, focusing on the experiences, needs, and wishes of service providers and users.

1.5 Thesis terminology

The terminology I have chosen to use in this thesis reflects the lenses through which I have conducted the research. This section provides a brief overview of some of my choices, to orientate readers to topic-specific terms. More in-depth discussion of the concepts supporting the choice of terminology can be found in chapter two.

1.5.1 Impairment and disability

Disability is an *"ever-evolving concept"* (UNGA, 2006), illustrated by constantly changing language and frameworks. In this thesis, I use the terms impairment and disability as defined within the World Health Organisation's International Classification of Functioning, Disability and Health (ICF – WHO, 2001). Within the ICF framework, which describes functioning and disability in relation to health conditions, impairment relates to 'body function and structure' and the way in which these can be affected by health conditions at anatomical and physiological levels. An impairment may be addressed using medical processes, therapies, and/or pharmaceutical interventions. I use the phrase '*person* *with* *impairment*' to acknowledge the effects on a person's body function(s) or structure(s).

Despite the terms impairment and disability often being used interchangeably, disability does not *only* occur at the level of body function and structure in the way that impairment does. The Convention on the Rights Persons with Disabilities (CRPD: UNGA, 2006) describes a person with disability[2] as someone with *"long-term physical, mental, intellectual or sensory impairments which in interaction with various barriers may hinder their full and effective participation in society on an equal basis with others" (UNGA, 2006: 4).* This description refers to the interaction of the social, physical, legal, and personal context, including barriers and enablers, of an individual with their health condition or impairment, which may (or may not) result in some level of disablement. In the ICF, this translates into limitations on the activities a person can do and restrictions on social participation, creating a unique life experience for each person. This experience is changeable across time and contexts – a person may experience more disability in one (less enabling) context than in another. As such, I use the term '*person who experiences disability'* to refer to a person with a health condition or impairment, whose personal, environmental and/or social context creates limitations on their ability to live life the way they wish to, as appropriate for their age. This term aims to reflect the unique experiences along a continuum of enablement-disablement of every person in their own context(s). I intentionally depart from the CRPD terminology '*person with disabilities',* which implies that disability is integral to the person's body rather than created through the interaction of a set of internal and external conditions and circumstances (see chapter 2, section 2.5 for further discussion).

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[2] 'Person with disability' is the terminology used in the UNCRPD. In this thesis, I use different terminology, as explained in the same paragraph.

1.5.1.1. Communication impairment and communication disability

Reflecting the description provided of ICF-compliant impairment and disability terminology provided above, I use the term communication impairment (CI) to refer to the way in which the body's communication functions or structures may be affected, impacting upon a person's ability to communicate with others effectively, at an individual level. A CI may occur alone (e.g., a voice/language/speech/fluency disorder) or be part of a wider health condition, featuring other impairments (e.g., as may be the case in cerebral palsy). It can be the primary (most significant) impairment, or secondary to others. I use the phrase '*person <u>with</u> communication impairment(s)*' to reflect the effect of the impairment on the body. A person with a CI may have communication access and support needs that need to be met for them to access services and participate in community life on an equal basis with others, as is their right (UNGA, 2006).

I use the term communication disability (CD), however, to refer to the barriers to participation experienced by a person with a communication impairment. The communication impairment itself forms a part of, but is not the sum of, the disability experience. In my use of this terminology, the communication disability experience is the product of a CI in interaction with inaccessible social, legal, and physical environments and personal contexts (e.g., support networks, personal resilience). A person with a CI may, or may not, experience CD and may/may not identify as a person who experiences disability.

In chapter 2, I explain in more detail why I choose to use this terminology, by describing and critiquing the evolution of disability theory, as well as the associated language and its role in shaping how people perceive disability (Andrews, Powell, and Ayres, 2022).

1.5.2 Forced migration and refugeeism

The term 'forced migration' refers to any situation in which a person has been forced to leave their home, for reasons beyond their control, such as the threat of violence or persecution, disaster, or climate change (Stanovich, Ecke, and Wirtz, 2021). Forced migration may result in a person moving within their own country of origin, resulting in the person being internally displaced, or to cross a border to another state, seeking refuge. The term ‘internally displaced person’ (IDP) therefore refers to a person in a situation of forced migration within their own state (Office of the High Commissioner for Human Rights (OHCHR), 2023). The term ‘asylum seeker’ refers to a person who has left their own state and is seeking political refuge in another state (UNHCR, 2023). An asylum seeker can apply for refugee status which, once granted, affords the person refugee rights, including non-refoulement – the right to remain in the country of asylum and not be forcibly returned if likely to be subject to persecution or lack of safety in the person’s home state.

Article 1 of the 1951 Convention on the Status of Refugees (CSR, also known as the Geneva Convention: UNGA, 1951) defines a refugee as a person who:

> *“owing to well-founded fear of being persecuted for reasons of race, religion, nationality, membership of a particular social group or political opinion, is outside the country of his nationality and is unable or, owing to such fear, is unwilling to avail himself of the protection of that country; or who, not having a nationality and being outside the country of his former habitual residence as a result of such events, is unable or, owing to such fear, is unwilling to return to it” (UNGA, 1951: 152).*

Although contested in modern refugee law, due to complex contemporary issues such as climate-related forced migration, this definition as stated in the CSR applies to most refugees from Democratic Republic of Congo (DRC) and Burundi in Rwanda, with whom this research was conducted.

The topic of forced migration can be viewed through several lenses, including from anthropological (Scott-Smith, 2022a), political (Gibney, 2022), and legal (Costello and Briddick, 2022) perspectives – each with their own set of defining features and arguments (see chapter 2, section 2.3). Each lens can illuminate some aspects of forced migration whilst obscuring others. It is therefore critical to understand forced migration through all three lenses to fully appreciate its complexity. In this thesis, I use the term ‘forced migration’ with an understanding of the implications of all three theoretical lenses – the social and cultural impact of human movement, including power relations, through an anthropological lens; political influence and power, including refugee generation and asylum granting, through a political lens; and the implications of international law, through which states cooperate and communicate, through a legal lens. I use the term ‘refugee’ with reference to the CSR (UNGA, 1951) definition stated above.[3]

1.5.3 Humanitarianism and humanitarian action

The meaning of ‘humanitarian’ and ‘humanitarianism’ stems from a moral obligation for humans to help other humans in plight and dates to the beginning of the formation of political communities (e.g., the 1648 treaty of Westphalia establishing sovereignty in central Europe), when people began seeking sanctuary from religious and political persecution (Betts and Collier, 2018). This moral obligation to offer protection to others in need is at the core of the world’s major religions and extends to offering protection from harm, as well as ensuring basic human needs for food, shelter, and safety are met during short-term, exceptional, events. Humanitarian*ism* is a belief system, based on this moral obligation to protect life (with or without a religious grounding), that plays a part in much humanitarian action.

In the last fifty years, the need for humanitarian action has increased exponentially to respond to numerous global crises generated by conflict, natural disaster, and climate change. Traditional (also called classical) humanitarian response is driven by three main components: global reach (Wheeler, 2000), short-term remit (Calhoun, 2010), and universal ethic (Slim, 1997) and is organised around a set of operating principles, namely humanity, independency, neutrality, and impartiality (chapter 2, section 2.3). These principles are considered critical to humanitarian action by some (Rieff, 2002) and as less central to the general idea of a cosmopolitan ethic i.e., that all humans are considered of equal moral worth, by others (Barnett and Weiss, 2008).

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[3] Including the optional protocol of 1967 (UNGA, 1967).

Few disagree that the outcomes of humanitarian action matter more than the motives (Scott-Smith, 2021). Critiques of the humanitarian principles, particularly the practical implementation of impartiality in politically charged contexts such as conflict, exist in scholarly and professional circles (e.g., Slim, 1997, Terry, 2000). Indeed, humanitarian action is acknowledged to be saturated by politics and can be, in itself, considered a form of political action (Scott-Smith, 2022b).

Furthermore, since recent crises (in the last fifty years) have pushed the boundaries of what can be considered 'exceptional' and 'short-term', humanitarian agencies now find themselves operating at the nexus of short term, responsive humanitarian agendas and longer-term, transformational development agendas in protracted situations (see chapter 2, section 2.3). Since the end of the Cold War, refugees have found themselves seeking protection for an average of seventeen years at a time (Betts and Collier, 2017), meaning humanitarian agencies are having to move beyond providing temporary shelter and emergency food rations, to providing semi-permanent settlements, long-term sanitation facilities, social protection, education, health, and livelihoods opportunities. Contemporary human rights approaches clash with classical humanitarianism, as agencies must ensure that rights to health, education, social care, and participation are realised in protracted crises – with or without the support of host states. Agencies intervening in protracted crises occupy a previously unchartered space - those organisations historically involved in development programming are now intervening in protracted crises, and those historically providing humanitarian aid are now involved in rights-based, politically complex, development agendas, with increasingly transformative socio-political goals. Many agencies now describe themselves as 'dual mandate' organisations, operating in humanitarian and development contexts, as well as at the nexus of the two.

The complexities of modern-day humanitarian action render it impossible to use one term to describe a single approach to intervention in forced migration contexts. For clarity, therefore, in this thesis I use the terms 'humanitarian' and 'humanitarianism' to refer to the contemporary approach to intervening in emergency and protracted refugee situations, whereby agencies operate along the humanitarian-development continuum, and, in this research, in collaboration with the Rwandan government.

1.5.3.1 Risk and vulnerability

‘Vulnerability’ is a term used in humanitarian action to describe the factors that place person(s) of concern (POC – a term referring to those under the protection of humanitarian agencies, including refugees, asylum seekers, and internally displaced persons) at greater risk than others. In the case of refugees, all are considered ‘vulnerable’ to one extent or another, having fled their homeland. Other, intersecting, factors can increase the risks facing refugees within a forced migration context, for example unaccompanied children may be at greater risk of exploitation, abuse, malnutrition; women and girls may be targeted for abuse or excluded from livelihoods and education opportunities; refugees who experience disability may be abandoned or fail to reach/access services. These ‘vulnerabilities’ may be cumulative – the more factors attributed to a person, the more ‘vulnerable’ they are considered by humanitarian agencies.

The use of the terms ‘vulnerable’ and ‘vulnerability’ has recently been contested, particularly in relation to feminist and disability theory, and in relation to the individual or a particular group (rather than, for example, situations of vulnerability such as a country’s predisposition to disasters). Freedman (2019) argues that the label ‘vulnerable’ is used in an oversimplified manner, without due consideration of the contextual causes of ‘vulnerability,’ resulting in some groups being (mis)labelled ‘vulnerable’ by virtue of one attribute, e.g., being a woman. This can result in ‘symbolic violence’ (Freedman, 2019: 1), whereby the agency of whole groups of people who may or may not be at risk is reduced by means of mislabelling. Another rationale includes the ‘victim blaming’ culture that has emerged around the concept of ‘vulnerability’ – that the term ‘vulnerable’ implies weakness and that a ‘vulnerable person’ thereby attracts risk (such as abuse) by the very nature of their status – thereby placing the blame on the person of concern (Cuniffe Gilson, 2016). For these reasons, I choose to use terms related to ‘exposure to risk’, rather than ‘vulnerability’.

1.5.4 Majority and minority world

Terminology used to describe a country’s geopolitical position in the world is, like disability and forced migration, complex, with choices of language rooted in geopolitics, economics, colonialism, power disparities and resources. There are strong opinions on which is most appropriate but, essentially, choice is based on purpose and agenda. Table 1 summarises the different terminology in past and current usage.

In this thesis, I choose to use the terms ‘majority world’ and ‘minority world’ to ~~maintain a politically neutral position and to~~ reject negative connotations associated with the country in which my research was conducted. I believe this promotes dignity for the participants from the majority world, whilst also acknowledging that I, as the researcher from the minority world, come to the study with a different experiential lens, through which data will be unavoidably, although transparently, interpreted (see chapter 7, section 7.3.1).

Table 1: Terminology used to describe the geopolitical and economic position of countries in the world.

Term	Description	Critique
First, second and third world	During the cold war, the world was 'divided' into three: the term 'first world' referring to resource-rich, powerful, capitalist nations such as the United States and Western Europe; 'second world' referring to the communist Soviet Union and its allies, and 'third world' referring to all other nations not aligned with either political stance. Although 'third world' countries used the terminology to create unity amongst non-USA or Soviet-aligned nations (Berger, 2004), 'third world' eventually became a term with negative connotations related to being economically unstable, less 'developed', and therefore poor. Schwab (2021) asserts that the unconscious bias created by the use of 'third world' to refer to economically developing countries, has perpetuated the existence of poverty in these regions.	Three world terminology is now considered outdated, and non-applicable since the Soviet Union, and therefore 'second world', no longer exists. Nonetheless, the phrase 'third world' remains common parlance to refer to less economically stable, less powerful, nations in Africa, South America, Asia, and Oceania.
Global north/global south	The terms 'global south' and 'global north' focus on geographical locations as well as geopolitical power relations. Post-independence, former colonies began to recognise that countries of the South often have conflicting interests with those of the industrialised powers located in the North. As stated by Dados & Connell (2012: 13) *"North-South terminology … arose from an allegorical application of categories to name patterns of wealth, privilege, and development across broad regions. The term Global South functions as more than a metaphor for underdevelopment. It references an entire history of*	The terms are not only inaccurate, with some economically 'developed' nations being geographically located south of the equator, and vice versa, but they also lack clarity on which indicators place a county in each category, besides geography. Furthermore, the terms have failed to keep up with geopolitical power shifts and economic development in countries such as Australia, China, and Brazil.

	colonialism, neo-imperialism, and differential economic and social change through which large inequalities in living standards, life expectancy, and access to resources are maintained." These have, therefore, come to 'translate' into 'global south' countries as being less economically developed and geopolitically powerful, and 'global north' countries as being more economically developed and geopolitically powerful.	
Developed/developing nations	The terms developed/developing nation/world uses indicators such as income, education, and service provision and is the preferred term of the United Nations Development Programme (UNDP). UNDP ranks countries from low to very high human development using the Human Development Index (UNDP, 2022) – those with low ranking being less economically stable, with few services, and lower life expectancy of its citizens, and high-ranking countries being labelled 'developed'. The UN also produced a list of 'least developed countries' each year (UNCTAD, 2023)	Although originally welcomed as offering a sense of progress for previously termed 'third world' nations, this terminology is contested due to its paternalistic (and arguably neo-colonial) lens – powerful countries defining other countries as 'lesser' and implying they should follow a set model of western development. Some argue that the divisions between the 'developed' and 'developing' world are no longer definable (Khokhar & Serajuddin, 2015) and that we should classify countries more precisely (Rosling, 2015).
Low/middle/high income countries	In 2016 the World Bank replaced developed/developing nations terminology with a categorisation of the world by region and based on four economic categories: Low-, lower-middle-, middle-, upper middle-, and high-income countries, with a catch-all phrase of 'low- and middle-income countries' (LMICs) (World Economic Forum, 2016).	The use of the catch-all phrase 'LMIC' falls into the same trap as using the term 'developing nations', categorising countries such as South Sudan (low-income, low human development, and 191st on the Human Development Index - HDI) and China (upper middle-income, high human development, and 79th on the HDI, UNDP, 2022) together, despite their vast differences. It is therefore more accurate and meaningful to refer to countries by their specific category, rather than using the term 'LMIC', which can be misleading.

OECD/non-OECD countries	Organisation for Economic Cooperation and Development (OECD) and Non-OECD country terminology divides states by their membership of the OECD. The member states are higher income countries in Europe, Asia, and the Americas, whilst most the world's least economically stable nations are non-members (OECD, 2023).	Defining non-member states by what they are not (implicitly not developed enough to be a member) forces negative connotations upon non-member states, whilst bestowing a sense of superiority on member states. OECD has been criticised for its narrowness of membership and slow response to policy change, in a rapidly changing world (Trade Union Advisory Committee to the OECD (TUAC), 2018)
Fat and lean countries	The terms 'fat' and 'lean' countries (Olopade, 2014) describes how nations use their available resources. Lean nations are resource-limited and so use what they have as efficiently as possible, whilst 'fat' nations, accustomed to plenty, are less concerned with efficiency. Olopade (2014) describes the positive connotations of the term lean, giving an example of individual Africans wasting less, owing less, and having a lower carbon footprint than individuals from 'fat' nations.	This terminology turns typical country categorisation on its head, celebrating the positive contributions to contemporary issues such as climate change, of nations historically ostracised for being 'lesser' than economically and politically powerful nations who, in Olopade's classification, are the ones being critiqued for their wastefulness.
Majority/minority world	In a bid to set aside power relations, negative associations and hierarchy, the terms 'minority world' and 'majority world' are used to describe where the world's population resides (Alam, 2019). 'Majority world' countries are where most of the world's population lives, often with access to the fewest resources, and the eight minority world countries where a small percentage of the world's population lives, with access to the most resources, are termed 'minority world'. The phrases eschew neo-colonial paternalism, reject negative connotations of poverty, and fight back against oppression, by using politically transformative discourse. The term 'majority world'	Although becoming a more popular choice, the terms majority/minority world are not yet universally recognised.

	“defines the community in terms of what it has, rather than what it lacks” (Alam, 2019: 89).	
Western, educated, industrialised, rich, and democratic (WEIRD) and non-WEIRD nations	The term WEIRD was developed to describe the type of researchers dominating the psychology research space (Henrich, Heine and Norenzayan, 2010). Henrich et al (2010) argue that WEIRD societies are some of the most psychologically unusual and that the cultural gap (the differences in the way people understand and perceive the world) between WEIRD and non-WEIRD societies (and even within WEIRD societies themselves) can be substantial. The concept links to majority and minority world terminology as WEIRD societies make up only 12 per cent of the world’s population and are therefore in the minority. The term has, therefore, been used to query the applicability of research conducted in WEIRD societies (and by WEIRD researchers) to non-WEIRD societies.	As with the majority/minority world terminology, the use of the terms WEIRD and non-WEIRD is not common outside of psychological research. It is, however, pertinent to research conducted cross-culturally and can inform a researcher’s reflexive approach.

1.5.5 Inclusive early childhood development and education services

The term 'inclusion' refers to any marginalised or excluded group being able to participate and access mainstream (i.e., not specialist) services on an equal basis with others. It may be used to refer to the inclusion of girls, linguistic and/or ethnic minorities, and/or historically marginalised groups e.g., based on sexuality, religion, or (dis)ability (UNICEF, n.d). The term 'inclusive education' refers to an education system in which every person can attend the same early childhood services, school, and/or a further/higher education institution, and learn – *"all children in the same classrooms, in the same schools" (UNICEF, n.d. Online)* – an interpretation reflected in Agenda 2030 (UNDESA, 2015a), specifically SDG 4 ('*ensure an inclusive and equitable quality education'),* which references the provision of education for children who experience disability. Target 4.5 states: *"By 2030, eliminate gender disparities in education and ensure equal access to all levels of education and vocational training for the vulnerable, including persons with disabilities, indigenous peoples and children in vulnerable situations." (UNDESA, 2015b, online - underlining for emphasis).*

The term 'inclusive education' is, however, most used to refer to the inclusion of persons who experience disability and/or have learning support needs, in community based mainstream ECD and education services, through the adaptation of the physical, sensory, communication, and learning environment to support effective learning. This, by definition, contrasts with segregation practices (such as the provision of 'special education' in dedicated centres or schools), and integration practices, whereby people with physical or learning support needs are present in mainstream facilities but separated as a group for segregated education interventions – an example being 'special classes' within a mainstream school setting. In this thesis, I use the term 'inclusive education' to refer to the practice of including, and providing accessible education experiences for, children with impairments, who experience disability, and/or who have specific learning support needs, in mainstream, community based, ECD and education services.

1.6 Summary

This chapter has provided an overview of the study, including details of its context, aims, objectives, and a brief explanation of key terminology. The structure of the thesis has been presented, to guide readers through the two phases of the research and towards a discussion of overall findings and implications. The next chapter provides a detailed background of the concepts, theories, and frameworks that guided the research development and implementation, influenced research decision making, and to which the research findings are relevant.

Chapter 2: Contextual and theoretical backdrop

2.1 Overview

This chapter provides an overview of the contextual and theoretical foundations of this research project. I describe the socio-political context of the Great Lakes Region of Africa (GLR), including the roots and perpetuators of conflict and forced migration in the region; and an overview of normative frameworks and theory relating to humanitarian action, ECD, education, and disability, all of which have significant implications for disability inclusion for refugees. The chapter also includes an overview of critical disability theory, critical refugee studies, and human rights frameworks - the three key frameworks around which my data were analysed and interpreted. These frameworks are reflected strongly in my philosophical research assumptions, that are described in detail in chapter 4.

2.2 Geographic and socio-political context

2.2.1 Contemporary state of Rwanda and key neighbours

Rwanda is a small, landlocked, mountainous country straddling east-central Africa in, what is termed, the Great Lakes Region (GLR: figure 2, chapter 1) – an area spanning the great Rift Valley from Kenya and Tanzania in the east, through Uganda, Rwanda, and Burundi, and west to Lake Kivu and the Democratic Republic of Congo (DRC) (Mpangala, 2004).[4] With a population of almost 12 million people when this research began in 2016 (Population Pyramid, 2016a), Rwanda is one of the smallest, but most densely populated, nations in sub-Saharan Africa. Its population has historically been understood to comprise three ethnic groups – the Bantu Batutisi and Abahutu, and the indigenous Batwa. However, following the Genocide against the Tutsi in 1994 (see section 2.2.3), ethnicity is no longer commonly referred to. Rwanda is classed as a low-income country reliant on small-scale agriculture, and the export of cash crops

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[4] Mpangala (2004) describes the different perceptions of the countries and areas captured within the GLR – some include the countries bordering the great lakes, including Mozambique, Zambia, Congo-Brazzaville. Others include Ethiopia and Eritrea. The perception mentioned in this thesis is the most common contemporary understanding of the GLR.

and minerals. At the time of this research, Rwanda ranked 159th out of 188 countries on the Human Development Index[5] (HDI), had a per capita gross domestic product of $1882.5 (PPP terms:[6] World Bank, 2017), while 54.4 per cent of the population were deemed to live in multidimensional poverty in 2020 (UNDP, 2020).[7] Although highly reliant upon foreign aid, Rwanda is an ambitious and determined country that aims to attain high-income status by 2050 (Republic of Rwanda, 2015). This agenda sees Rwanda prioritise health, education, and social services, as well as community cohesion strategies, to ensure future generations can enjoy a fair, peaceful, and prosperous nation.

Figure 3: Political map of the Great Lakes Region of Africa

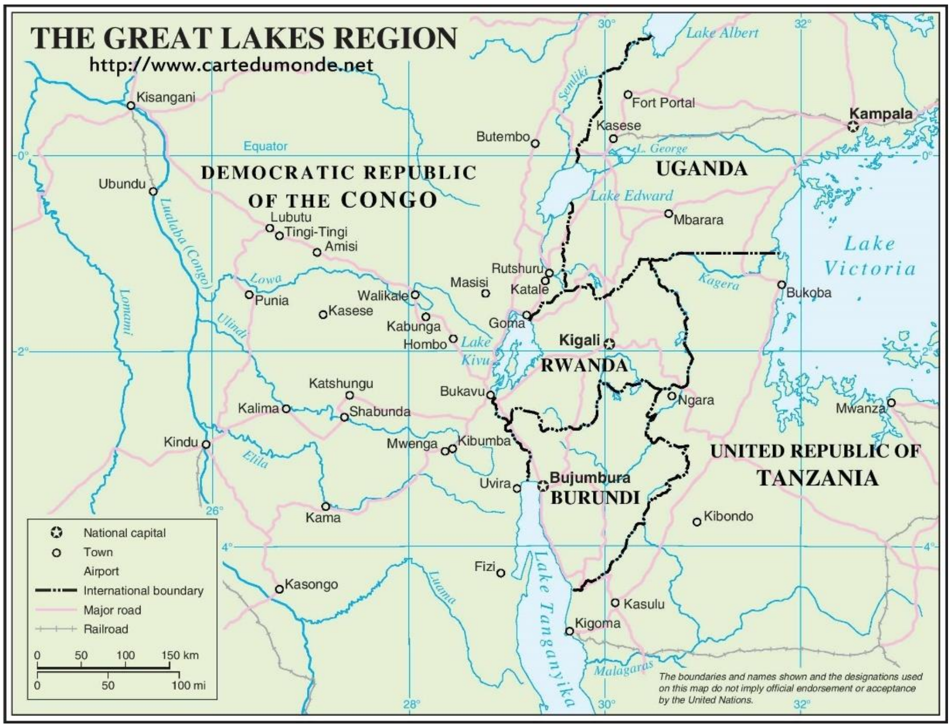

Image credit to: Big World Map Great Lakes Region 1 English continent (theworldmap.net) (accessed 30.6.2023)

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[5] The HDI ranks countries based on human development and is scored using indicators including life expectancy, per capita income, and education levels (One World Nations Online, 2016).

[6] GDP PPP - purchasing power parity - is a measure adjusted to cater for variation in the value of goods and services you can buy with $1 (USD) in a particular country.

[7] Multi-dimensional poverty is a non-monetary assessment of deprivation of basic human rights and needs across numerous indicators, including access to clean water and sanitation, education, healthcare, and decent housing (Alkire and Foster, 2011).

Rwanda is bordered by Democratic Republic of Congo (DRC), Uganda, Burundi, and Tanzania, all also low-income countries with large proportions of their populations affected by multidimensional poverty. Two countries are of particular relevance to this research: Burundi and the Democratic Republic of Congo (DRC).

With a population of almost 10.5 million people in 2016 (Population Pyramid, 2016b), Burundi constitutes another of the smallest, but most densely populated, nations in sub-Saharan Africa. Like Rwanda, Burundi is reliant on small-scale agriculture and export of cash crops and minerals, and 75.1 per cent of the population live in multidimensional poverty (Knoema, 2017). Burundi is comprised of peoples from the same ethnic groups as in Rwanda and, indeed, during the colonial period, Burundi and Rwanda formed a single country (Ruanda-Urundi).

DRC, on the other hand, is the largest country by land mass in sub-Saharan Africa. Occupying most of the central Africa region, its eastern provinces form an integral part of the GLR, bordering Uganda, Burundi, Tanzania, and Rwanda. With a population of nearly 79 million in 2016 (Population Pyramid, 2016c), DRC encompasses the Congo-Nile River basin, and a large swathe of equatorial rainforest that is of global ecological importance. DRC is rich in natural resources, including timber, minerals, precious metals and gemstones, and its equatorial climate and rich soil are highly conducive to the cultivation of cash crops such as cacao and coffee. DRC has endured decades of weakly regulated resource extraction by foreign entities as well as by the Congolese elite and militia groups, while entrenched corruption has ensured that DRC's natural resource wealth rarely benefits its people (Wrong, 2000). However, since the latest Presidential election of 2018, DRC's economy has been growing slowly and certain improvements, such as the introduction of free primary education, various public sector reforms, and renewed emphasis on conflict prevention and stabilisation, are evident (World Bank, 2022).

2.2.2 Colonialism, neocolonialism, and the roots of forced migration in the GLR

Pre-colonisation, the geographical areas spanning modern-day Rwanda, the Kivu region of eastern DRC, southern Uganda, western Tanzania, and Burundi, shared ancestral lands between peoples from different ethnic groups. Ever since the arrival of the Bantu peoples in the region during the 'Great Bantu Expansion' 2500 years ago, Batutsi pastoralists lived alongside, but subjugated, the Abahutu agriculturalists and the indigenous forest dwelling Batwa (Boesten, 2018). The Abahutu were, and remain, the most populous ethnic group in Rwanda/Burundi/Eastern DRC (approximately 85 per cent of the population) and the three groups share a common language (Rwanda-Rundi) split into two dialects – Kinyarwanda and Kirundi. However, prior to the colonial period, intermarriage between the groups was common (Levy Firestone Muse, 2021) and it was possible for Abahutu who owned cattle to 'become' Batutsi, and vice versa.

From the late 1800s to the early 1960s, the GLR experienced widespread colonisation, primarily by Britain (modern-day Kenya, Uganda, and Tanzania), Germany (modern day Tanzania, Rwanda, and Burundi), and Belgium (modern-day Rwanda, Burundi and DRC).[8] Successful colonisation often relied on a strategy of 'divide and rule', whereby colonising nations promoted divisions among ethnic groups to make the population easier to control and govern (Thompson, 1997). With linkages to the wider racist ideologies that was used to rationalise the colonial system, colonisers typically identified a group that they deemed more 'advanced' and granted this group privileges such as access to productive land and employment within the colonial administration. In Rwanda, the Belgian colonial administration introduced identification cards that classified people according to their ethnicity (ethnic profiling was often based on facial features, body characteristics, and church records) and selected the Batutsi to assist in the colonial administration, thereby significantly widening pre-existing socio-economic and political cleavages.

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[8] Following Germany's defeat in World War One, Rwanda and Burundi were handed over to Belgium, who created Ruanda-Urundi.

In the wake of the Cold war, direct and indirect colonial rule collapsed and many countries across the GLR became independent republics. Yet the newly independent nations continued to face challenges associated with the presence of European settler populations and the installation of foreign systems and practices, as well as extensive political interference by their former colonisers (Lange, Mahoney, and Vom Hau, 2006). The support of particular political parties by colonial powers provoked further resentment between the ethnic groups, laying the ground for conflict soon after independence. Indeed, in 1961, the All-African People's Conference held in Cairo, Egypt, identified *neo-colonial* practices as *"the greatest threat to African countries that have newly won their independence or those approaching this status"* (Lange et al, 2006). Neo-colonialist practices increased as independence took place, disrupting progress in the formation of pan-African relationships (The Black Agenda Report, 2022).

In Rwanda, ethnic polarisation and extremism grew throughout the post-war years with regular instances of localised violence. However, in 1959, a series of riots broke out, heralding the start of what is now often referred to as the 'Rwandan Revolution' (Polynational War Memorial, 2018). Sensing that the writing was on the wall for the Tutsi elite and eager to position itself favourably with a likely Hutu-led administration of an independent Rwanda, the Belgian colonial administration arranged a referendum that resulted in the abolishment of the Tutsi monarchy and hastily replaced Tutsi local chiefs with Abahutu. Between 1959 and 1961, more than twenty thousand Abatutsi were killed and over three hundred thousand fled the country over the borders to DRC, Uganda, and Burundi, where they lived as refugees for over three decades (Gourevitch, 1999).

With the exception of a short-lived Tutsi rebellion in 1963, the Abatutsi posed little threat to the Hutu government in Kigali over the next three decades. However, the involvement of Tutsi refugees in rebel campaigns against Idi Amin and Milton Obote in Uganda, where they fought alongside Yoweri Museveni's National Resistance Army (NRA), provided them with critical training and military experience. By October 1990, the Rwandan Patriotic Front (RPF) was capable of invasion and made rapid advances into Rwanda. Although, the RPF were eventually repelled (with assistance from Belgium, France, and Zaire), [9] they gained control over much of northern Rwanda over the next two years. Having reached a stalemate, the Arusha Accords of 1993 provided for a ceasefire and the return of RPF personnel and refugees to Rwanda.

On April 6, 1994, however, a plane carrying the Hutu President of Rwanda, Juvenal Habyarimana, and Burundian President, Cyprien Ntaryamira, was shot down over Kigali, killing everyone on board. Responsibility for this act remains unclear to this day. Organized killing of Batutsi and moderate Abahutu began immediately and, over the next one hundred days, around one million people were massacred by Hutu forces (Levy Firestone Muse, 2021), the Hutu youth militia – the *Interahamwe* – and civilians. In the ensuing chaos, the RPF relaunched their offensive and made rapid progress. Kigali was captured on 4 July and the rest of the country on 18 July, stopping the genocide in the process. In turn, however, up to two million Abahutu (including many genocide perpetrators) fled to Goma in eastern DRC, sparking a humanitarian crisis in the refugee camps (Gordon-Gibson, 2016; Siddique, 1994). The RPF proceeded to form a government of national unity headed by a Hutu president, Pasteur Bizimungu, with Paul Kagame serving as Minister of Defence and Vice-President. However, in 2000 Bizimungu left the government and, two years later, was sentenced to 15 years in prison for stoking ethnic tensions. Paul Kagame was elected President by Parliament in 2000 and embarked on a deliberate process of national reconciliation and development. Over the following two decades, Rwanda gained a reputation for administrative efficiency and good governance and made rapid progress on a wide range of social and economic development indicators.

However, even as Rwanda stabilised and achieved remarkable progress in its national reconciliation and development agenda, ethnic conflicts in neighbouring countries continued to pose a threat. Rwanda's relations with the DRC – which hosts Hutu refugees and militia (such as the Democratic Forces for the Liberation of Rwanda, FDLR) - remained particularly strained. The Rwanda Defence Force (RDF) has

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[9] Now Democratic Republic of Congo

launched incursions into Eastern DRC twice and the Rwandan government has been accused of providing support to the March 23 Movement (known as ‘M23’) Tutsi-led militia which has waged a campaign against the Congolese government and the FDLR since 2012. In November 2022, M23 rebels came close to taking control of the city of Goma, resulting in the displacement of around 180,000 people.

A similar ethno-political conflict has raged in Burundi since independence. The most recent violent episode, in April 2015, led to over 50,000 Burundians fleeing across the Rwandan border. It was at this point that this research was being conceptualised, as a new refugee camp was established for Burundian refugees on the Tanzanian border. Burundi remains unstable today, with frequent violent outbreaks and 50,291 Burundians remain under the protection of the Government of Rwanda and UNHCR (UNHCR, 2022a).

In this context, Rwanda has transitioned from being a refugee producing nation to a refugee receiving nation, accommodating those fleeing violence across its borders as well as Rwandan returnees, creating a complex mixed migration context. Rwanda has now hosted refugees that fled conflict in Eastern DRC for decades, with some of the current refugee population having lived in Rwanda for more than twenty years at the time data construction for this research took place. Some refugees born in the oldest camps now have their own, third generation, children born in a forced migration context, and feel unable to return to their home state. It is this protracted and unfathomably complex and painful context that this research was designed and conducted in three refugee camps managed by GoR and UNHCR in Rwanda. At the time of data construction, Rwanda was host to almost 170,000 refugees and asylum seekers, primarily from Burundi and DRC (UNHCR, 2017a).

2.3. Forced migration and humanitarian theory

2.3.1 Theoretical perspectives on forced migration

Introduced briefly in chapter one, forced migration is a general term used to refer to:

> *"…the movements of refugees and internally displaced people (those displaced by conflicts) as well as people displaced by natural or environmental disasters, chemical or nuclear disasters, famine, or development projects". (International Association for the Study of Forced Migration, 2016. Online)*

Forced migration is a global phenomenon, dating back millennia, with complex, wide-ranging causes. In 2017, when this research was taking place, there were 68.5 million forcibly displaced people in the world because of persecution, conflict, or violence (UNHCR, 2018). Almost twenty million were registered refugees under UNHCR's mandate. However, by 2022, over 100 million had become displaced with 32.5 million registered refugees constituting an unprecedented global crisis. Forty-one per cent of the current global displaced population are children (UNHCR, 2022b) and 74 per cent of refugees are hosted in low- and middle-income countries (UNHCR, 2022b).

The Geneva Convention (UNGA, 1951) replaced informal, duty-based protection mechanisms with a legally binding, rights-based approach to international protection (see section 2.3 below). Despite formalising the rights of displaced populations, the original Geneva Convention excluded some groups from being granted refugee status (see chapter 1 for definition), in a way that informal, duty-based, mechanisms did not. Improved by the 1967 optional protocol (UNGA, 1967), which addressed the previous exclusion of those who became refugees prior to 1st January 1951, refugee status determination remains a topic of ongoing debate, especially in the context of climate change. Shacknove (1985) has long argued that the defining feature of a refugee should be a lack of state protection, not only based on actual or threatened persecution.

In response to specific issues pertaining to refugees not covered by (or requiring expansion upon) the 1951 convention and 1967 protocol, the African Union published the Organisation of African Unity (OAU) Convention Governing the Specific Aspects of Refugee Problems in Africa (African Union, 1969)- a regional complement to the 1951 Convention and 1967 Protocol, brought into force in 1974 and ratified by Rwanda in 1979 (African Union, 2019). It expands on the definition of a refugee, including 'external aggression, occupation, foreign domination or events seriously disturbing public order' (p.6) -as reasons for forced migration and includes reference to environmental events such as drought or famine – a definition that has opened the door to 'prima facie' refugee status determination (applicable in the case of Burundian refugees entering Rwanda included in in this research).

As introduced in chapter one (section 1.5.2), forced migration can be conceptualised using three different frameworks: the anthropological, the political, and the legal perspectives. Here, I expand on the definitions and implications of each one in turn. Each perspective informs the way in which the international community[10] responds to forced migration.

The anthropological perspective primarily focuses on the social and cultural impacts of displacement, theorising that displacement can lead to an erosion of trust in traditional institutions, resulting in rapid social and cultural changes (Scott-Smith, 2022a). Contemporary anthropological perspectives consider the lived experiences of people on the move and their experiences of exile. The anthropological perspective now serves to caution against generalisation of observations about forced migrants, identifying exceptions, telling individual stories and, in modern conceptualisation of the discipline, elevating the voices of migrants through self-portrayed ethnographies. This is now considered a method of decolonising a field of study where, traditionally, white, western anthropologists interpreted and reported on the culture and practices of 'foreign' peoples.[11]

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[10] *"Countries of the world considered or acting together as a group"* (Cambridge Dictionary, 2022. online.)

[11] The term 'decolonising' has taken a new meaning beyond that of former colonised nations gaining independence. It has, more recently, been used to refer to the uprooting of colonial epistemology in fields of practice such as humanitarian aid, education, health, research, and others. It involves re-examining and reframing the colonial lens through which research and practice is often conducted. It challenges hierarchy and moves away from a historically western hegemony. In humanitarian action, it involves placing decision-making in the hands of the people directly impacted by those decision (Byatnal, 2021).

The political perspective identifies and analyses the power relationships affecting situations of forced migration, including domestic and international political competition and policy interventions. Indeed, refugee status can be granted based on persecution due to political opinion (UNGA,1951). As Gibney (2022) states, a political perspective *"helps us to understand why the displaced, despite their legal rights and powerful moral claims, typically find themselves vulnerable and endangered, and indeed why they find themselves displaced in the first place" (Gibney, 2022: 3).*

The legal perspective is of critical importance since international law plays an important role in global forced migration. International law governs the conduct of states, including the management of forced migrants. States can determine whether to ratify international treaties or conventions and whether to translate international law into domestic legislation and policy. *Jus cogens* norms, such as the prohibition of genocide, bind states simply by virtue of their membership of the international community (Costello and Briddick, 2022). In the main, the legal human rights instruments that compel states to assist forced migrants (e.g., the 1951 CSR and 1967 optional protocol) are only applicable to those countries who have chosen to ratify them and domesticate them into local law, thereby absolving some states from providing international assistance. Even where states have ratified international conventions, enforcement mechanisms are typically weak. Forced migrants, therefore, often find themselves embroiled in complex situations of risk, often lacking access to official refugee status and its associated protection, in an unfamiliar state (Costello and Briddick, 2022).

Each perspective can illuminate some issues and obscure others. One must, therefore, consider all three perspectives to truly comprehend the complexity of global forced migration and refugeehood, and how it plays out in different contexts.

2.3.2 Humanitarianism and the global refugee regime

As introduced briefly in chapter 1, humanitarian*ism* is an ideology - a moral duty to protect human welfare. Rieff (2002) considers humanitarian action to be the impartial, neutral, and independent provision of relief to those affected by conflict and natural disaster, whereas Smillie and Minear (2004) argue that humanitarianism is not just a philosophy but is a 'calling' (suggesting religious connotations), *as well as* the delivery of a set of actions. Lacking a universally agreed definition, humanitarianism became the dominant ideology of international assistance in situations of crisis, concerning itself with meeting basic needs and providing human protection (International Association of Professionals in Humanitarian Assistance and Protection: PHAP, 2021).

Traditional (also called classical) humanitarianism is based on four governing principles, established by the UN General Assembly in 1991: Humanity (provision of aid to those in need), neutrality (the responsibility not to choose sides or favour one ideology over another) , impartiality (aid should be provided according to need alone and regardless of gender, race, nationality, ethnicity, class, political party or religious belief), and independency (autonomy from any political or military objective).[12] Plattner (1996) goes further and describes the principle of neutrality as *"a duty to abstain from any act which, in a conflict situation, might be <u>interpreted</u> as furthering the interests of one party to the conflict, or jeopardising those of the other"* (online – underscore for emphasis). Furthermore, some principles are disputed as morally and/or operationally undesirable, as well as unviable in certain practical contexts (Terry, 2002; Scott-Smith, 2016) (table 2). Despite these debates, both the intentions and outcomes of humanitarian action are of principal importance in classical humanitarianism - intervention should do good and reduce suffering. The 'humanitarian paradox' (Terry, 1998; 2002) however, occurs when good intentions do not result in good outcomes, as was the case in Goma, DRC, in 1994/5 following the Genocide against the Tutsi in Rwanda in 1994.

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[12] Pictet (1966) took these principles further, adding unity, universalism, and voluntary service to the list.

Table 2: Classical humanitarian principles: critiques and considerations (based on Scott-Smith, 2022b)

Humanitarian principle	Explanation	Consideration	Critique
Neutrality	Aid agencies do not take sides in hostilities or engage at any time in controversies of a political, racial, religious, or ideological nature. They should not act in a way that advantages one party or another.	External perceptions cannot be controlled – one party may be perceived to be advantaged over another.	Morally undesirable: equalising oppressors and their victims (Terry, 2002)
			Operationally undesirable: Access is granted by the powerful
			Unviable: impossible to be neutral when funding comes through political avenues
Impartiality	Aid should be provided according to need, with no other consideration taken in to account	Impartiality may affect neutrality if one party is more in need than another.	Undesirable: potential to perpetuate a crisis by not addressing structural needs that allow the crisis to continue
			Unviable: humanitarians are humans and are therefore affected by subjective judgement about who is 'deserving'. Funding may direct assistance to some places and not others.

In addition to the guiding humanitarian principles, classical humanitarianism differs from two other, co-existing, approaches to human assistance: a) human rights and b) international development. Classical humanitarian action sets itself apart from human rights and development agendas in several ways (table 3): It is concerned with needs, not rights; it is a matter of voluntary charity, not legal obligation; it focuses on relieving short term suffering in emergency, rather than strengthening institutions; it is paternalistic rather than participatory; and it is ostensibly neutral on political issues (Scott Smith, 2021). It has three main components: a) a global reach (Wheeler, 2000); b) a short-term remit (Calhoun, 2010); and c) a universal ethic (Slim, 1997). In this conceptualisation, where humanitarian intervention ends, development interventions take over – although gaps and overlaps between the two often exist (Hinds, 2015). The definition of contemporary humanitarian action is therefore ever shifting, and new forms are still being identified, including 'minimalist' approaches (in which humanitarian agencies may withdraw or speak out against injustice), [13] 'maximalist' approaches (whereby agencies go beyond classical humanitarian principles and seek to tackle underlying causes of crises)[14] and 'solidarist' approaches whereby classical principles are rejected entirely in favour of supporting particular groups.[15]

Table 3: Humanitarian, human rights, and development approaches to international assistance (based on Scott-Smith, 2021).

Humanitarian	Human rights	International development
Short term	Long term	Long term
Filled with dilemmas and uncertainty	Certain and non-negotiable	Negotiable
Concerned with immediate and basic needs	Concerned with broader rights	Concerned with long-term transformation
Based on voluntary charity	Based on entitlement	Based on governance
Focuses on short term suffering	Focuses on long-term governance	Focuses on long-term transformation
Politically neutral	Politically engaged	Politically engaged
Paternalistic	Participatory	Participatory

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[13] Médicins Sans Frontièrs's withdrawal from Goma, DRC in 1994/5 is a prominent and highly debated case.

[14] e.g., United Nations agencies such as World Food Program and UNICEF.

[15] e.g., Norwegian People's Aid's support for the LGBTQI+ population is a prominent example.

The global refugee regime is responsible for the norms, rules, principles, and decision-making that regulate the behaviour of states (Betts, Loescher and Milner, 2012). The regime, in its current form, emerged out of the League of Nations following the First World War, and was consolidated following the Second World War, with the creation of the United Nations High Commissioner for Refugees (UNHCR). UNHCR became responsible for, and a global expert agency on, international refugee law. Initially responsible for the repatriation and relocation of European refugees, UNHCR's mandate has changed drastically over the seventy-two years of its existence, particularly after the period of independence-granting and following the Cold war. It remains the custodian of the global refugee regime but is now responsible for a wider range of forcibly displaced persons, including refugees, internally displaced persons, and stateless persons, created through a variety of circumstances (Betts et al, 2012).

UNHCR occupies a critical, yet difficult, space in international refugee protection. To function effectively and fulfil its mandate, UNHCR must work with, and influence, states' approaches to displaced persons, as well as implement humanitarian interventions to assist populations of concern (asylum seekers, refugees, and IDPs). Funded by donor states, UNHCR's existence and capacity to operate is determined by wealthy, powerful nations. Relations between donor states, UN General Assembly member states, and refugee producing and hosting states, impact upon how UNHCR is permitted to operate, and it must tread carefully to avoid perceived interference in domestic policy and threats to sovereignty (Barnett and Weiss, 2011).

The UN High Commissioner for Refugees, Felix Schnyder (1960-1965), recognised the growing economic and political problems emerging in post-colonial Africa and that UNHCR's original mandate was inadequate. Not only did he reimagine UNHCR's role in providing emergency and development material assistance in addition to legal protection, but also envisaged a programme of inter-agency cooperation to assist countries with modernisation and development. Thus emerged the coordination function of UNHCR in modern-day refugee response and its position straddling both the humanitarian and development sectors. This position has become more significant in recent years, as protracted crises have seen refugees being displaced for an average of 17 years (Betts and Collier, 2017).

2.3.3 Humanitarian action, development, and Agenda 2030

The humanitarian-development continuum, relief-development continuum (Haider, 2014) or emergency-development continuum encompasses the range of assistance provided to populations in crisis, from provision of life-sustaining basic materials to reconstruction and development activities, including the development of policies, institutions, and services. Linking relief, rehabilitation, and development (LRRD, Hinds, 2015) is a concept that acknowledges the frequent co-occurrence of humanitarian crises, chronic poverty, and state fragility (Otto and Weingärtner, 2013), as well as the need to find effective methods to provide relief at the same time as deliver on a longer-term, preventative and reparative, development agenda. Increasingly, traditional humanitarian organisations find themselves embroiled in development processes, particularly in situations of protracted crisis, while development actors find themselves trying to deliver in the face of emergencies. UNHCR, as custodian of the refugee regime, operates at the intersection of both worlds: coordinator of relief such as food, shelter, and basic health care, as well as negotiator of longer-term provisions for displaced populations, including durable solutions (naturalisation, repatriation, resettlement), integration, and access to/provision of services and livelihoods.

More recently, the humanitarian-development continuum has been reframed as the 'humanitarian-development nexus' (HDN) or humanitarian, development, and peace nexus (HDPN - UNHCR 2022c). This reconceptualization reflects growing acknowledgement of the need for *"humanitarian and development efforts to be more effectively connected, working towards achieving collective outcomes that reduce need, risk and vulnerability, over multiple years"* (UNICEF, 2022. Online). The Global Compact on Refugees (GCR: United Nations, 2018) and its corresponding framework, the Comprehensive Refugee Response Framework (CRRF), responds to the HDPN through a process of burden- and responsibility-sharing and promotion of refugee inclusion within host communities. This altered the way in which UNHCR collaborates with governments in the pursuit of sustainable solutions to the world's protracted refugee crises. Indeed, the GCR and CRRF are also critical to the achievement of Agenda 2030 (UNGA, 2015a) and global poverty reduction goals (UNHCR, 2020), the GCR making explicit the relationship with the SDGs and the 'no-one left behind' agenda:

> *"A spirit of partnership, the primacy of country leadership and ownership, and the mobilization of predictable international responses consistent with national development strategies and aligned with the 2030 Agenda for Sustainable Development, are key to ensuring sustainability that communities affected by a refugee situation are not impaired in making progress towards the Sustainable Development Goals" (United Nations, 2018: Paragraph 65).*

Recognising the need to ease the pressure on host states, as well as ensure dignified futures for refugees, the GCR and the CRRF embody the contemporary definition of humanitarian action in which agencies operate at the nexus of humanitarian relief, human rights, peacebuilding, and development. The GCR encourages refugee self-reliance, access to expanded third-country solutions, and safe and dignified return to countries of origin (United Nations, 2018), demonstrating a global effort to move towards a future where refugees are valued for their capabilities and contributions to society, rather than simply being 'rescued'. This, by default, entails a marked departure from the classical humanitarian principles as it requires significant liaison between humanitarian actors and host states and engagement with political processes.

2.3.4 Critical refugee theory

Critical theories play an important role in the conceptualization and understanding of refugeehood. As described by Kincheloe, McLaren, and Steinberg (2011), critical theories consider thought to be filtered through socially and historically conceived power relationships, such as those created through colonialism and neo-colonialism. Critical researchers *"are committed to challenging constructed social divisions, and* *to acknowledging how structural mechanisms produce inequalities”* (Ballard, Wieling, Solheim et al, 2016: 210).

It is crucial to apply critical theories to research with refugees due to their inherent aim to forefront the stories and voices of marginalised groups. Critical approaches can inform advocacy agendas and strategies for those less heard, ensuring stories of their lived experiences and needs are better understood and their humanhood emphasised, redressing power imbalances between host and refugee communities (Ballard et al, 2016). As further posited by Ballard et al (2016: 210), *“critical researchers actively look for the silent or subjugated voices and seek to facilitate volume”.* There are arguably few groups more silent than refugees with CIs, who experience CD. I describe my critical approach to this research further in chapter 4.

2.4 Early childhood development and education

The right to education is enshrined in the Convention on Human Rights (UNGA, 1948), Convention on the Status of Refugees (United Nations General Assembly (UNGA), 1951), the Convention on the Rights of the Child (UNGA, 1989), and the Convention of the Rights of Persons with Disabilities (UNGA, 2006). Education is also increasingly understood to be key to sustainable, peaceful, and inclusive future societies (Moving Minds Alliance, 2018; United Nations Educational, Scientific and Cultural Organisation (UNESCO), 2022a) – an investment that returns significant social and economic dividends to individuals, communities, and nations (Heckman, 2011).

In recent decades, there has been a rapid acceleration in our understanding of children’s development, leading to greater understanding of risks to, as well as strategies for improving, early child development outcomes and reducing inequities globally. This evidence has galvanized governments and a wide range of stakeholders to prioritize and invest in national and global programmes and policies to promote

ECD (Jeong, Bliznashka, Sullivan et al, 2022). As described by Anderson and Saeed (2022:2):

> *"substantial evidence from neuroscience to economics shows that experiences with severe, prolonged adversity early in life can alter brain development. The result? Negative impacts on health, learning, and behavior across the lifespan. For very young children born into conflict or displacement, the long-term impact can be devastating."*

Without intervention, young children who do not reach their developmental potential become older children who struggle to learn in school and adults who face limitations to their capabilities and opportunities to be productive and self-sufficient citizens (Moving Minds Alliance, 2018; Shonkoff and Garner, 2012). It is now recognised that, unless the ECD needs of young children are met, including children affected by crises, it will be impossible to realise Agenda 2030's (UNGA, 2015) aim to 'leave no-one behind' (UNHCR, 2017b).

In 2018, WHO, UNICEF and the World Bank Group published the *Nurturing Care Framework – A Framework for Helping Children Survive and Thrive to Transform Health and Human Potential* (WHO, UNICEF and WBG, 2018). With five components: good health; adequate nutrition; responsive caregiving; security and safety; and opportunities for early learning, the framework provides a roadmap for service providers to ensure adequate early childhood interventions to mitigate developmental risks. It aims to ensure children not only survive the early years but overcome adversity, thrive, get ready for formal education, and become healthy and productive adults. The framework specifically refers to the importance of early childhood interventions in situations of crisis, and makes four overarching recommendations to support children and families in these contexts:

1. *"Take a holistic approach to families' and children's well-being. That means paying attention to protecting them, so that they survive. But it also means paying attention to mental health, nutrition and opportunities for learning. Families and children feeling the worst adversity and stress may need more intensive services.*

2. *Re-establish security and routines as quickly as possible, as they bring comfort. Do this through early-learning programmes, networks of family support, and other services.*
3. *Rebuild communities' social capital, paying attention to social cohesion and encouraging positive relationships between members of displaced and host communities.*
4. *Research nurturing care – including measurement, implementation, and evaluation – in a way that is sensitive to cultures and contexts. This is vital for informing practice and policy in humanitarian settings" (WHO, UNICEF and WBG, 2018: 11).*

Operating at the humanitarian-development nexus of short-term crisis relief and longer-term social investment (see section 2.3) has enormous implications for the organisations involved in the planning and delivery of ECD and primary education services, as well as the transition between these services, for refugee children – especially those caught up in protracted crises (see chapter 1, section 1.5.2).

2.5 Disability theory

As introduced in chapter 1, disability is an evolving concept that is subject to ongoing debate over definitions and terminology, as well as to the place persons who experience disability occupy in humanity's social and political conscience. To understand contemporary conceptualisations of disability, it is critical to understand the evolution of disability theory over time. Disablement and the disability experience can then be placed within a forced migration context, to facilitate understanding of the intersecting challenges facing people on the move, who experience disabling barriers to inclusion and participation. In this section I therefore describe the evolution of disability theory and its relevance to this study.

2.5.1 Models of disability

Six prevailing models of disability exist, reflecting an ongoing process of evolution of societal understanding of disability and the people who experience it.

1. <u>Divine punishment or test: The religious/moral model</u>.

   This model of disability stems from an understanding of disability as a phenomenon bestowed upon a person or family by a supernatural being, often as a punishment for sin, wrongdoing, or moral failing (Andrews, Powell, and Ayres, 2022). This can result in exclusion and/or even harm to the person and/or their family, based on community understanding that they are cursed, blamed, or 'bad' people (Wilson and Martin, 2018). Alternatively, disability can be seen as a test in life, for which the person or family must seek healing through religious devotion (Andrews et al, 2022). In these circumstances, people who experience disability can be seen as 'special angels' (Stillman, 2006) and passive recipients of care. This can result in paternalism and limitations to autonomy (Casha, 2016) and can motivate (or offer relief to) some people who take on a role as a carer as they believe it is their moral duty and that they will be rewarded in heaven (anecdotal clinical evidence).

   This model of disability is still the dominant way in which some religious groups and cultures understand disability. In my experience of working with people who experience disability in east Africa, this model is of particular significance to this research. It not only affects the way that some communities behave toward people who experience disability and their families, but also how families relate to their children who experience disability, and how service providers respond to service users.

2. <u>Pity the disabled: The charity model.</u>

   Disability viewed through a charity lens sees people who experience disability as objects of pity, with connotations of being broken, deficient, and in need of saving. This model views people who experience disability as being 'sufferers', unable to care for themselves, and results in objectification, underestimation, devaluation, and dehumanisation. It is associated, in some respects, with the religious/moral model described above. Disability language related to this model includes objectifying reference to, for example 'the disabled' – parallels of which can be drawn with similarly charitable models of referencing, for example, 'the deserving poor' (Hindle, 2004) (of which disabled people form part). Through this lens, a human identifier (person/people) is absent from the phraseology.

Although no longer the most prevalent model of disability, it is still widely accepted in some cultures and communities – especially those in which religion plays a major role and where being charitable towards the 'less fortunate' is applauded. In such circumstances, moral accolades are attributed to the giver who is considered by others to be a 'good person'. It is also important to recognise that humanitarianism is rooted in charity and, therefore, response to the needs of people in situations of crisis (including those who experience disability) is often influenced by this model. This is visible in the fundraising campaigns of large humanitarian organisations, such as Save the Children, and UN agencies such as World Food Programme (WFP), United Nations Children's Fund (UNICEF), and UNHCR, who frequently (and controversially – Chance for Childhood, 2022) use pictures and stories of plight to both raise awareness of global crises and as a strategy to raise funds for their aid programmes (Fehrenbach and Rodongo, 2016).

3. A 'problem' to be fixed: The (bio)medical model.

One of the most understood, and globally prevalent, models of disability is the (bio)medical model. This model reduces the lens through which disability is viewed, to the purely biological: Something in the person's body or mind is 'wrong,' 'broken,' 'deviant from the norm,' and requires medical attention (surgery, pharmaceutical management, (re)habilitation) to cure, normalise, and otherwise 'fix' the 'broken part.' No distinction is made between impairment and disability, as in social or biopsychosocial models (see below) – disability is synonymous with impairment and therefore considered inherent to the body or mind – something abnormal that a person 'has' within them. This model creates duality between the 'affected' and 'non affected' and gives power to medical professionals – the gatekeepers of diagnosis (Wilson and Martin, 2018). As such, individuals are disempowered and rendered dependent upon medical science for both diagnosis and cure. Critically, the medical model views disability as resulting directly from a person's medical condition, disregarding any social or environmental barriers to participation (Bickenbach, Chatterji, Badley, and Üstün, 1999).

The medical model is still heavily employed today, encountered frequently in disability data tools such as national censuses and household surveys, and applications for state assistance (e.g., social protection; provision of assistive devices) or reasonable accommodation (e.g., in the education system), despite the evolution of disability conceptualisation. Language related to the medical model persists and veers towards the clinical – e.g., 'the cerebral palsied child' or 'the blind' - phraseology that reduces a person to a diagnostic label, removing their humanhood (Andrews et al, 2022). British disability scholars and activists consider the globally popular terminology 'people/persons with disabilities' to be derived from the medical model, as use of the word *'with'* situates disability as largely inherent to the person, disregarding the role of exogenous factors (e.g., Shakespeare and Watson, 2001; Wilson and Martin, 2018; Barrett, 2021).

British critics of the (bio)medical model (e.g., Union of the Physically Impaired Against Segregation (UPIAS), 1976; Oliver, 1986) claimed that disability is not solely caused by functional limitations to the body and/or mind and is, instead, caused by social and environmental barriers that serve to exclude and oppress people with impairments. This led to the evolution of a new, socio-politically motivated, disability paradigm that was taken in different, although related, directions by British and north American disability scholars and activists (e.g., Oliver, 1986 versus Hahn, 1985)

4. It's not me, it's you: The social/socio-political model

The social/socio-political model of disability developed as early as the 1940s, taking various forms until its popularisation in the 1970s when UPIAS published the 'Fundamental Principles of Disability' (UPIAS 1976). This was soon followed by Disabled People's International's (DPI) distinction between a person's impairment and the loss or limitations of opportunity for participation due to external barriers. This perspective, commonly known as the UPIAS/DPI social model, expounds disability as a social construct, created by the social environment, that serves to oppress disabled people socially and politically – concepts further developed by Michael Oliver (1986). From a social model perspective, people with impairments (affecting body structure and function) are excluded by a society that does not cater to their access needs, resulting in exclusion and oppression. The bedrock of the social model is the explicit differentiation drawn between impairment of the body and/or mind and the disability *experienced* as a result of the social exclusion of those with impairments. As described by Bickenbach et al (1999: 1176):

> *"Disabled people are those with impairments who experience disability as a collection of socially-created restrictions, which are discriminatory because they limit opportunity for full and equal participation" (underlining for emphasis).*

The term 'disabled person/people', preferred by British scholars and activists over 'people/persons *with* disability', is rooted in the social model of disability. It expresses the social model principle that causality lies external to the individual (I am disabled *by* my social and physical environment), rather than internal (*I am* a person *with* disability – it arises within me).

The social model gave permission for disabled people, as an oppressed group, to externalise the creators of their oppression and demand justice through the removal of exclusionary barriers created by societal attitudes and behaviours and environmental inaccessibility (Bickenbach et al, 1999). The social model was emancipatory for disabled people – in both theory and practice - when applied politically within a rights framework. It empowered disabled people to break free from the narrative of deformity and pity and refocus their energies on combatting their oppression (Shakespeare and Watson, 2001).

Publication of the International Classification of Impairment Disease and Handicap (ICIDH) (WHO, 1980) signalled a global acknowledgement of impact of social and environmental barriers faced by people with impairment(s). 'Disability' was reconceptualised as the reduced ability to engage in certain activities that arises from certain conditions, while the disadvantage faced by people with impairments was captured in the term 'handicap'. Nonetheless, ambiguity persisted in the language used to explain the model (Bickenbach et al, 1999).

Various lenses having been applied to the social model, including materialist, feminist, socialist, and psychoanalytic accounts (Shakespeare and Watson, 2001; Tregaskis, 2002). Despite these efforts to refine the model, there is persistent criticism that it remains an overly simplistic paradigm to define a complex and multifaceted disability experience (e.g., Thomas, 2004; Shakespeare and Watson, 2001; Shakespeare, 2018). Like the opponents of the medical model before, critics of the social model lament the lack of acknowledgement of other, inextricable, aspects of the disability experience – in this case the impacts that impairments *do* have on a person's life. Employing either the medical or the social model in isolation became incompatible with contemporary understandings of the lived experience of disability (Shakespeare and Erikson, 2000; Shakespeare and Watson, 2001), and the requirements for emancipation and participation, and led to the evolution of disability theory and the WHO model. This was the dawn of the biopsychosocial conceptualisation of disability.

5. It’s me and you: The biopsychosocial model

The evolution of the World Health Organisation’s (1980) ICIDH into the International Classification of Functioning, Disability, and Health (ICF – figure 6: WHO, 2001) marked another global shift in disability conceptualisation, viewing disability as an embodied ontology, embracing the concept of impairment as a universal human phenomenon (e.g., Sutherland, 1981, cited in Shakespeare and Watson, 2001). The, primarily north American, minority group or civil rights social model conceptualisations of disability, sees systemic devaluation of disabled people as a power play for capitalist gain (reported in Bichenbach et al, 1999). Taking this further, scholars such as Zola (1989) claim that, if impairment is part of the human condition, disability resulting from an interaction between personal, social, and environmental factors requires a lifespan, holistic, approach to ensuring inclusion and equality. As Zola (1989: 20) states:

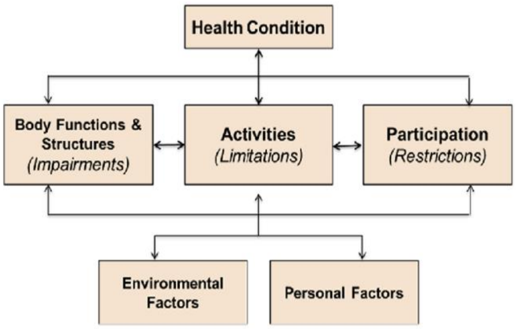
> *“Only when we acknowledge the near universality of disability and that all its dimensions (including the biomedical) are part of the social process by which the meanings of disability are negotiated, will it be possible fully to appreciate how general public policy can affect this issue.”*

This view is supported by contemporary disability theorists with lived experience of disability. Shakespeare and Watson (2001: 20) believe that *“adequate social theory of disability would include all the dimensions of disabled people’s experiences: bodily, psychological, cultural, social, political, rather than claiming that disability is either medical or social”.* Zola also recognises the unintentional rebound towards salient aspects of the medical model created by the minority group conceptualisation of disability whereby, as a minority group, one must be counted. This is done by deciding whether you do or do not ‘have a disability’, based upon impairment-focused information (and is reflected in the north American favoured terminology, ‘people/persons with disabilities’). This, Zola claims, does not make sense when considering the core elements of the social model being external social and environmental impacts upon people. Instead, disability must be understood as a universal phenomenon, affecting individuals in unique ways, through the interaction of their impairment and their social and physical environments (Shakespeare and Erikson, 2000). This conceptualisation accounts for varying experiences of disability across the lifespan and in different contexts – a continuum across which all humans experience ability-disability (Shakespeare, 2006). Disability policy is therefore not for the few but may serve everyone (personally or by proxy) at some point in their lives. Definition of who does and does not experience disability, is therefore made purely on political and economic grounds (Bickenbach et al, 1999).

The ICF (WHO, 2001) was developed in response to these critiques of the medical and social models of disability. Globally accepted as a model for *"framing, describing, recording and measuring functioning and disability"* (ICF Education, 2022, online), it embodies the universalistic principles expounded by scholars such as Zola (1989), Shakespeare and Erikson (2000), and Shakespeare and Watson (2001). In this model, medical, social, environmental, and personal factors are acknowledged as potentially and uniquely impacting upon a person's life and are combined in an interactive framework that makes explicit the multidimensional impacts of impairment and environment (Shakespeare, 2018). These contributing factors can be identified as different components of a single phenomenon: disablement (Bichenbach et al, 1999).

Like in the social model, the ICF defines impairment as affecting body structure and function, which may or may not be associated with a health condition. Impairment can occur in isolation or can be a part of a cluster of impairments,

Figure 4: The International Classification of Functioning, Disability and Health (WHO, 2001)



which may form part of one or more health condition(s). Critically, a person’s impairment(s) may or may not interact dynamically with their social and physical environment, to affect a person’s opportunities to engage in activities of their choice and participate in life the way they wish to. A person with impairment(s) therefore may or may not experience disability, depending on their context (e.g., severity of impairment; availability of medical services and assistive devices; prevailing social attitudes and behaviours; environmental accessibility) and the disability they experience may change over time as features of their impairment and contextual factors shift (e.g., in the case of ageing). Disability is therefore changeable – a continuum – and a deeply personal experience (Goodley, 2017; Shakespeare, 2018a).

This conceptualisation not only illustrates the impact impairment can have on a person’s life, but also offers accountability for the drivers of social oppression encountered by people with impairments, thereby uniting previous models under one holistic paradigm. The ICF can also be used to explain the limitations to human rights realisation (UNGA, 1948) faced by people with impairments that occur at the core of the disability experience. The model illustrates at what level(s) changes need to be made to address barriers to inclusion and participation – be those improvements to medical management of impairment, assistance to overcome activity limitation (e.g., through provision of assistive devices), or changes to the social and/or physical environment (including the legal frameworks governing them) – to ensure inclusion, participation, and emancipation. The model was, however, designed by the World Health Organisation (albeit in consultation with the disability movement) and therefore retains strong ties with the medical world, with all its associated historical (and ongoing) power in the disability space (Krauss de Camargo, 2022). One must, therefore, consider this paradigm with adequate acknowledgement of the potential for medical-model dominance in its implementation.

6. The Convention on the Rights of Persons with Disabilities: The human rights model

Human rights frameworks, such as the Universal Declaration of Human Rights (UN, 1948), Convention on the Status of Refugees (UNGA, 1951), Convention on the Rights of the Child (UNGA, 1989), and Convention on the Rights of Persons with Disability (UNGA, 2006), are the mechanisms by which people who are typically marginalised and excluded, such as refugees and people who experience disability, can attain, and maintain dignified lives (Rioux, Basser and Jones, 2011). They force the conversation beyond mere societal tolerance and integration to a place where people who have historically experienced exclusion become key players in the conceptualisation and realisation of their own futures. Human rights frameworks can also be considered intersectional - facilitating the advancement of critical theories.

The Convention on the Rights of Persons with Disabilities (CRPD: UNGA, 2006) is the key international treaty and framework that assists ratifying governments to create their own national legislation and policies to ensure people who experience disability fulfil their rights and live with dignity. Its global influence is evident by its ratification by 185 of 193 United Nation member states, 100 states also ratifying the optional protocols (as of September 2022). As stated by UNDESA (2022, online):

> *"It takes to a new height the movement from viewing persons with disabilities as "objects" of charity, medical treatment and social protection towards viewing persons with disabilities as "subjects" with rights, who are capable of claiming those rights and making decisions for their lives based on their free and informed consent as well as being active members of society."*

The introduction of the CRPD in 2006 was a significant occasion in human rights history, codifying the human rights model of disability which had been under development for some time (Degener, 2016a). The convention expounds the human rights and freedoms of all *persons with disabilities*,[16] specifying under which circumstances adaptations must be made by states to ensure rights are enjoyed and illustrating circumstances that are considered abusive of those rights. As such, Lawson and Beckett (2021) argue that the human rights model is a model of disability *policy*, providing a roadmap for laws and policies and uniting people in solidarity as humans. They contrast this with the social model of disability which, they assert, supports emancipation of disabled people through solidarity as a distinct and oppressed minority group, but which does not provide guidance on how to do so. The models, they argue, complement each other – an opinion in opposition to human rights model expert, Degener (2016b), who claims the human rights model expounded in the CRPD developed from, and was an improvement upon, the social model.

The human rights approach embraced by the CRPD is considered transformative in its pursuit of equality for *'persons with disabilities'* based on the universalistic principles of scholars such as Zola (1989) and colleagues (Degener, 2016a; Kayess and French, 2008). Conceptual paradigm shifts, their lingering interconnections within the CRPD (such as social model influence, medical model language, and human rights model assertions and recommendations), and a lack of clarity on these issues have, however, been identified as persistent barriers to the CRPD's effective implementation by member states (Degener, 2016b).

In complement to the CRPD, the African Union adopted the Protocol to the African Charter on Human and People's Rights on the Rights of Persons with Disabilities in Africa, in 2018 (African Union, 2018). Signed by Rwanda, the protocol builds on the rights enshrined in the CRPD and UDHR, representing the unique context and concerns of African nations in relation to disability inclusion and human rights realisation. This includes the contextualisation of

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[16] I use the phrase 'persons with disabilities' in italics here to denote its association with the CRPD, rather than it being the terminology that I choose to use in this thesis.

issues including attitudes, beliefs and practices, and the role of communities in ensuring the rights of persons with disabilities are upheld.

This research project draws upon human rights frameworks, as well as critical approaches to disability and refugee theory, to document realities, elevate voices, challenge injustices, and engage with change makers, to contribute to rights realisation for refugee children who experience CD in Rwanda.

2.5.2. Pride and prejudice:[17] Disability language and identity

Disability language is rooted in, and has evolved alongside, models of disability (Shakespeare, 2018). With language comes power: it can liberate and empower as much as it can disenfranchise and subjugate (Andrews et al, 2022; Gernsbacher, 2017; Wilson and Martin, 2018). It can be a source of pride or shame. It is therefore critical to consider the power of language used within global conventions, such as the CRPD, over how people conceptualise disability and how this translates into national policy, programmes, societal perceptions, and represents individual lived experiences.

As discussed, language associated with the medical model situates disability as inherent to the person, with connotations of 'brokenness' and the need to be fixed or cured. Although elements of this language have been reclaimed by disabled communities as a source of identity and pride, their initial conceptualisation was deeply rooted in the medical model. Social model language in Britain, by contrast, extracts impairment from disability, rebalancing power differences so that the person is not considered defective, society is. Language such as 'disabled' is used to reference that the person is disabled by society - its attitudes, behaviours, environments, institutions, and laws. Phrases such as disabled person/people, and a person identifying as 'I am disabled', are rooted in the British social model. By contrast, north American social model proponents continue to use the phrase

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[17] Morris (1991) published on disability through a feminist lens, entitled 'pride against prejudice', inspiring this title.

‘person(s) with disability’. This reflects a different understanding of the social model, one which defines ‘persons with disability’ as a minority group, rather than as socially and politically oppressed, and in which the difference between impairment and disability is not as clearly defined (Shakespeare and Watson, 2001). Despite this rationale, British activists and scholars consider north American terminology to be deeply rooted in the medical model.

Having considered the power of language and connotations associated with medical model and social model phraseology, the language used within the CRPD deserves careful consideration and critique. The CRPD purports to adopt a ‘broad definition’ of those who are considered under the convention and defines *persons with disabilities* to:

> *“…include those who have long-term physical, mental, intellectual or sensory impairments which in interaction with various barriers may hinder their full and effective participation in society on an equal basis with others.” (UNGA, 2006, Article 1).*

Considering the disability language that has evolved along with the conceptualisation of the disability experience over the years, the CRPD can be seen to use, what British disability scholars and activists consider, medical model language in the use of the phrase *‘persons with disabilities’* - a far cry from the UPIAS/DPI social model definitions.

Given that the CRPD codifies the human rights model (Degener, 2016a, 2016b; Kayess and French, 2008), incorporates aspects of the complementary social model, and actively rejects medical model thinking (Lawson and Beckett, 2021), the decision to use the phrase ‘*persons with disabilities*’ in the CRPD is therefore a decision that reflects one or both of two influences:

a) a north American-influenced social model terminology associated with minority group politicisation of disability, which is contradictory to the otherwise universalistic and human rights model principles enshrined in the convention and/or

b) an affiliation with the 'People First' disability movement which aims to 'level the playing field' by putting the 'person' before the 'disability' in grammatical order, in so doing establishing equality and humanity with people without disability and eschewing difference.

Although more in line with universalism, this conceptualisation unequivocally relates to concepts of disability identity: a hugely complex and emotive topic, entwined in ongoing, spirited debate amongst scholars and activists (as described by Gernsbacher, 2017). People first language is contested and, in some cases, vehemently opposed (Forber Pratt, Mueller and Andrews, 2019). It has been criticised for removing disabled identity (Dunn and Andrews, 2015), as well as masking highly stigmatised impairments and conditions, unintentionally *increasing* stigma (see Andrews et al, 2022; Gernsbacher, 2017; Wilson and Martin, 2018). Some people who identify as disabled favour 'identity first' language – embracing disability as central to their identity, often reclaiming terms such as 'crip' with pride (McRuer, 2006; 2018). Others, with chronic health conditions or impairment(s), do not (or do not want to) identify as disabled at all (Shakespeare, 2018).

Even with the (contested) People First argument in mind, using the word 'with' in the phrase '*persons with disabilities*' grammatically places the disability as integral to the person, as does the phrasing 'has' or 'have' a disability (Barrett, 2021). This manifests medical model connotations of individual fault (Oliver, 1986) and is directly counter to the CRPD's recognition of social and environmental contributors to disablement. Crucially, neither influence or rationale for the use of American social model or People First language were explicitly documented by the Ad Hoc Committee (AHC) responsible for drafting the CRPD (Lawson and Beckett, 2021) and it is therefore not easy to understand why this terminology was chosen and who, therefore, feels represented by it (or not). Furthermore, inconsistent use of the terms 'disability' and 'impairment' throughout the CRPD questions the convention's ability to 'say what it means' which, Kayess and French (2008: 21) argue, *"perpetuates and perhaps now* *irrevocably entrenches, the contemporary conceptual confusion between impairment and disability."*

Use of 'include' in the sentence *"persons with disabilities <u>include</u> those who have long-term physical, mental, intellectual or sensory impairments" (UNGA, 2006, Article 1)* furthermore begs the question 'who is *excluded* in this definition?' Although the phrasing here aims to take a broad view of who is included as a 'person with disability', it fails to state, 'but is not limited to', thereby suggesting that only those mentioned are included and others are intentionally excluded. Moreover, it draws attention to some impairments to the exclusion of others. Although most functional limitations may be addressed by 'physical, mental, intellectual or sensory' categories, a glaring omission here is communication impairment, particularly those not arising from those mentioned in the definition (e.g., those associated with a primary communication disorder). As the CRPD definition of '*persons with disability'* is used globally in national policies, within UN agencies, by Organisations of Persons with Disabilities (OPDs)/Disabled Persons' Organisations (DPOs), the omission of communication impairment in the definition may serve to exacerbate the misunderstanding, invisibility, and exclusion, of people with communication impairment in policies and programmes across the world, thereby contributing to their disablement.

It is for people with impairments, who identify as living with the impacts of disability, to choose which language they feel represents them best - their experiences, their community, their wishes, and their rights (Shakespeare, 2018b). This may be, for some, a very individual decision and for others, based on a sense of belonging to a community of disabled people/people with disabilities, or a specific community (e.g., the Deaf community). Either way, it is almost impossible to reach a conclusion on the 'best' way to describe disability, as the 'best' way is a personal decision. In the context of an international convention, 'disability' is also subject to linguistic/translational imperfections (Lawson and Beckett, 2021).

The CRPD was drafted with unprecedented involvement of disabled people from across the globe in the spirit of the ‘nothing about us without us’ movement. It is surprising, therefore, that it is silent on the issue of disability identity and language and offers no explanation for its choice of terminology and the impact this has on the way the CRPD is interpreted and implemented.

2.5.3 Communication impairment and communication disability

Definitions of the terms communication impairments (CI) and communication disability (CD) were introduced in chapter 1. Hartley and Wirz (2002: 1543) state:

> *“The phrase ‘people with communication disabilities’ is used to refer to a population whose ability to communicate is affected by their response to an impairment and/or social and contextual factors, which interrelate with each other and the person themselves, resulting in limited communication skills and ability.”*

This definition is grounded in the ICF’s biopsychosocial model of disability and uses similar terminology - ‘people *with* communication disability’ - as the CRPD.

Using Hartley and Wirz’s ‘communication disability’ terminology, I depart from it at the point of saying a person *has* a communication disability, instead referring to their *experiences* of disablement, for the reasons discussed above. It is not a new idea for disability to be described as an experience – indeed, many scholars and activists, in defining disability, refer to it in this way. Lawson and Beckett (2021), for example, make the distinction between impairment as being something a person ‘has’, that is integral to the body, and disability being something a person ‘experiences’, in saying:

> *“that term [disability] is used to describe the socially created disadvantage and marginalisation experienced by people who have (or are perceived to have) ‘impairments’” (Lawson and Becket, 2021:348. Underlining for emphasis).*

This is supported by other scholars such as Bickenbach et al (1999), as well as scholar-activists with lived experience of disability, such as Shakespeare (2018).

By using the term ‘communication disability’, rather than just ‘disability’, I purposefully highlight the specific role that communication impairment plays in the person’s experience of disability, rather than the impact of other elements of the persons’ health condition or other impairments. That is not to say that I do not acknowledge that other, coexisting, impairments do not influence the person’s experiences, but that I am attempting to bring attention to the specific effects of communication impairment and the related experiences of disablement in this research (e.g., attitudinal, behavioural, environmental, legal exclusion).

Although each person’s experience of disability is unique, evidence suggests that there are some elements of the disability experience that tend to be shared, for example, stigmatisation (Disabled World, 2021). It is therefore important, when considering humanitarian programme design, to identify the shared barriers to inclusion and participation faced by groups of people who experience disability, and to address these as comprehensively as possible. It is, however, also important to recognise specific barriers that individuals, or groups of people, with the same types of impairment, may face to ensure that no-one is excluded in humanitarian action. This is particularly pertinent for people with less ‘visible’ or obvious support needs (such as people who experience CD), or those who have been historically marginalised or with intersecting risk factors.

2.5.4 Critical disability theory[18]

Critical disability theory is considered a research methodology by Shalk (2017) and Minich (2016) due to its commitment to activism in the pursuit of social justice. It seeks to *“analyse disability as a cultural, historical, relative, social and political phenomenon”* (Hall 2019: 1). Although regarded an extension of traditional disability studies by some, critical disability theory represents a marked departure from traditional approaches to studying disability within the social model, instead

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[18] See chapter 4 for a discussion of critical methodologies.

purporting a transformative agenda for social emancipation and justice through social action for, and with, people experiencing stigmatisation of 'body and mind' (Minich, 2016, online), exclusion, and othering (Goodley, Liddiard, and Runswick Cole, 2018; Meekosha and Shuttleworth, 2009). As described by Hall (2019: 2):

> *"[Critical disability] thinkers use the method to both describe the socio-political constructions of disability and track the impacts of these constructions on oppressed persons, including but not limited to those to whom the concept "disability" attaches. Critical disability theory, then, necessarily refers to lived experiences and attempts to transform the circumstances under which oppressed subjects live through critical, intersectional analysis."*

The analysis of ableism is central to critical disability theory. Ableism is an attitude of superiority, based on ability. Moreover, ableism is a process by which people with non-normative bodies and minds are excluded, as ableist attitudes combine with power structures to produce the experience of disability and other forms of experienced exclusions and oppressions (Garland Thompson, 1996; Hall, 2019). This results in stigmatising dis-ableism whereby non-normative bodies and minds are considered, at best, inferior to the social construct of the 'normative' body and mind and, at worst, sub- or non-human.

Critical disability theory is predominantly aligned with phenomenological research methodology which responds to the social origins of meaning, including historical origins, and is therefore inextricably linked to other critical theories including (but not limited to) indigenous and post-colonial theory, and critical refugee theory. Indeed, history and culture play a pivotal role in determining the way in which the disabled body and mind is both experienced and perceived in the world (Merleau-Ponty, 2002). As such, Meekosha and Shuttleworth (2009: 54) *"call for an explicit dialogue with human rights and emancipatory thinking from the diversity of cultures."* In doing so, they reject the importation of 'western' (or minority world) ideals to non-western (or majority world) cultural contexts (Hall, 2019). Further intersectionality with gender, race and ethnicity, sexuality, and other marginalising aspects of embodiment, highlights the multiple oppressions that disabled people may face. In fact, in the case of displaced refugee girl-children who experience disability - even more so CD - caught up in ethno-political conflict, the potential for oppression and exclusion cannot be underestimated.

In this project, I take a critical approach to research design, data analysis, and data interpretation. My philosophical assumptions and rationale are described in more detail in chapter 4.

2.6 Chapter summary

This chapter has provided an explanation and history of forced migration in the GLR, including its colonial and neo-colonial roots and ignitions. I was cognisant of the importance of the socio-political context of the GLR to the research and acutely aware of my positionality within this context. As such, a reflection on this can be found in chapter 7, section 7.3.1. The chapter has also offered a comprehensive overview of humanitarian, education, and disability theory, providing a contextual and theoretical backdrop to this research project.

As introduced in chapter one, this study was conducted within a pragmatist research paradigm and through a critical lens (see chapter 4). This lens necessitates an understanding of critical disability theory, which naturally intersects with critical refugee studies/theory, in this project. Both can be situated within human rights frameworks and together provide the foundation upon which the research is predicated. In combination, they enable the centring of refugee voices and their service providers, in pursuit of dignity and social justice for refugees who experience CD.

Chapter three now presents a literature review, providing a critique on the limited evidence linking the distinct, but interrelated, topics of forced migration, inclusive ECD and education, and communication disability.

Chapter 3: Literature review

3.1 Overview

Literature reviews assist in the identification, summary and/or synthesis, and reporting of the current knowledge base on a given topic using published research or information (Baumeister and Leary, 1997; Tranfield, Denyer, and Smart, 2003). They identify strengths and weakness in available evidence, state what the research evidence does and does not say and conclude on the relevance of the research evidence to a topic of interest (Booth, Sutton, Clowes et al, 2021), providing insights that single research studies are unable to offer. Literature reviews can synthesise sometimes large bodies of literature into a coherent narrative, giving the reader the opportunity to gain an overview of a topic, or a synthesis of topics (Green, Johnson, and Adams, 2006). They can then go beyond presenting available information to offer new conclusions based on novel syntheses and interpretations (Green et al, 2006), facilitating the advancement of existing theories or the development of new theories (Webster and Watson, 2002) and linking findings to future research opportunities.

Literature reviews can also be an effective way of examining information on disparate topics and/or interdisciplinary research (Snyder, 2019), as is required in this project. As Snyder (2019) describes, literature reviews conducted at the intersection of disciplines can uncover where more research may be needed and can therefore become a critical component in the creation of new theoretical frameworks and/or models. The risk of conducting research based on flawed or biased results is, however, a reality if a review is undertaken without careful consideration of methods to ensure transparency and reduce bias. A systematic approach to reviewing literature, with a clear and replicable methodology, can help to minimise this risk (Green et al, 2006).

3.2 Purpose of the literature review

The purpose of this review, therefore, was to identify and critically evaluate the peer-reviewed evidence available on access to inclusive early childhood development (ECD) and education services for refugee children who experience communication disability (CD) in Rwanda. Although it was anticipated that very little literature on this specific topic would exist, literature on forced migration, (communication) disability, and ECD/education, with reference and/or applicability to the Great Lakes Region of Africa (GLR) was sought, identified, and analysed. The overall research question for this project was applied to the literature review:

> *'To what extent do refugee children, who experience communication disability, realise their right to inclusive ECD and education [in Rwanda]?*

Here, brackets are placed around [in Rwanda] as I anticipated that very little literature would be found directly related the situation in Rwanda. Instead, search terms allowed for identification and relevance assessment of global literature with relevance to the Rwandan context.

3.3 Scope of the review

Peer-reviewed journal publications were reviewed with a view to identifying papers most relevant in answering the research question set out above. Documents were critically analysed to evaluate the evidence on access to inclusive ECD and education for refugee children who experience CD.

3.4 Literature review method

A variety of literature review types exist to suit different types of literature. For example, when systematically reviewing quantitative literature, a meta-analysis can facilitate combination of quantitative data, gathered using similar methods, from different studies to produce a strong evidence base to support or refute a theory

(Lau, Ioannidis, and Schmid, 1998). Qualitative systematic review uses a rigorous methodology to search for, identify, and quality assess, literature. The author then summarises findings and critiques the available evidence (Grant and Booth, 2009). The rigorous methodology of a systematic review reduces author bias which poses a higher risk in less rigorous forms of review, such as narrative review. However, for interdisciplinary research, a full systematic methodology may not be possible, or the most effective methodology (Wong, Greenhalgh, Westhorpe et al, 2013). Instead, a semi-systematic review can assist in synthesising perspectives from disparate disciplines (Snyder, 2019), mapping intersections and identifying gaps in evidence in complex research fields. A reduced systematic methodology may increase the risk of author bias but, if counterbalanced with a transparent methodology, can produce more useable results - particularly in under-addressed, new, or innovative areas of research (Wong et al, 2013).

Having considered the relative benefits and challenges associated with different types of literature review (including types beyond the scope of this discussion, such as scoping, mapping, and integrative reviews), I chose a semi-systematic approach to literature identification as the most applicable to this interdisciplinary, novel, area of research. This method is particularly relevant when mapping a field of research (as in my research aims – chapter 1, section 1.3) as well as creating an agenda for future research (Snyder, 2019). A semi-systematic method allowed for the application of a transparent, replicable search strategy, whilst offering the flexibility required to combine searches from various disciplines in the pursuit of understanding interrelationships and research gaps at the nexus of the fields of humanitarian action, ECD/education, and CD. Crucially, it enabled the findings to be linked to the three theoretical frameworks on which the research was based: Human rights, critical disability theory, and critical refugee studies (chapter 2).

3.4.1 Search strategy

Semi-systematic reviews fit well within an Interpretive Description (ID) research methodology (Thorne, 2016), as was used in this research (See chapter 4, section

4.5.2.1). However, for the early career researcher, there are fewer clear steps to follow (Snyder, 2019) and the method requires a broad perspective on how to approach the search strategy to answer the research question effectively.

In this literature review, only peer-reviewed papers were considered for inclusion. Due to the nature of humanitarian service provision through international agencies and local non-governmental organisations, however, it was anticipated that many valuable sources of information would not be in the form of peer reviewed or formally published documents. Documents from humanitarian service providers and global donor sources were therefore identified and analysed using Document Analysis as a research method - the methods, analyses, and results of which are reported in chapter 5, part B, and chapter 6, part A.

Four social science and education databases were searched systematically, using combinations of the search terms listed in table 4. A Google Scholar online search was also conducted for papers specifically relevant to Rwanda, as some local journals are not included in database searches, such as the Rwandan Journal of Education and the Rwandan Journal of Health. Search terms were chosen to encompass the range of terminology used to refer to similar concepts, such as forced migration and refugee status, the various terms to refer to early childhood (education) services, and the terms used (often interchangeably) in relation to disability. Truncated terms were used, and BOOLEAN operators were employed to combine or isolate search strings.

Table 4: Literature review search terms

POPULATION TERMS	DISABILITY TERMS	INCLUSION TERMS	EDUCATION TERMS	ECD TERMS	COMMUNICATI-ON TERMS
Refugee*	Disab*	Inclusive education	Educat*	Early childhood	Speech
Forced migra*	Impair*	Inclusive early childhood	Primary school*	Nursery	Language

Humanitarian	Handicap*	Inclusi*	Elementary school*	ECD Cent*	Communication
	Retard***	Integrat*	School*	Kindergarten*	
	Difficult*			Educat*	
	Disorder*				
	Delay				
	Special*				

***Retardation is a term used, often in American Literature pre-2010 when Rosa's Law was introduced, replacing 'mental retardation' with 'intellectual disability' in the USA. However, as this search covers documents from 2000, the term was included in the search term options, so as not to miss any relevant studies.*

Searching a variety of databases is critical to identifying all relevant material (McFadden, Taylor, Campbell et al, 2012). It also facilitates searching across topic breadth and depth across disciplines (Green et al, 2006). Although the practice of abstract or content searching across all content fields can result in irrelevant material, some important studies may have been missed by searching the title alone. Titles and abstracts were therefore searched for relevant search terms, but full content was not, as an initial 'pilot search' demonstrated that this produced too many results, many of which were irrelevant.

I first conducted a pilot search of the ASSIA database to ascertain which search terms and combinations were most likely to result in identification of appropriate papers (Wafula and Goodman, 2010). This avoided conducting multiple database searches with terms and combinations too broad or too narrow (Green et al, 2006). Due to the limited number of papers identified in the search with GLR terms included, I did not consider them an essential set of terms during the final search. I did, however, make special note of any papers found relevant to the region. Identified papers published between the years 2000 to 2018[19] were included. All data for this study were

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[19] The announcement of the Millennium Development Goals in 2000 marked a shift in the way humanitarian aid and development programmes were conceptualised. This time frame also captures the landmark publication of the CRPD in 2006

collected up to the end of 2018). The identified papers were analysed with regional relevance and/or applicability in mind.

3.4.1.1 Inclusion/exclusion criteria

Following database searching, the abstracts of peer reviewed papers, including intervention studies, observation studies, and commentaries, were reviewed against inclusion criteria (table 5). Articles selected based on these criteria were then read in full. Papers referring to situations of forced migration, even if not specifically to refugee children, were included. Many papers identified focused on mental health amongst refugees or integration in foreign education systems upon resettlement. These papers were excluded unless they included children in forced migration situations who experience disability (including psychosocial disability). Adult-only studies were excluded, unless they focused upon the experiences of families of children in forced migration who experience disability.

Table 5: Literature review inclusion/exclusion criteria

Criteria	Inclusion criteria	Exclusion criteria
Review period	2000-2018	Pre-January 1st 2000 Post-December 31st 2018
Language	English language	Papers not translated into English
Type of document	Peer reviewed paper/article, including intervention studies, observation studies, and commentaries	Book chapters Conference proceedings Full journal editions
Includes **minimum of three** relevant terms from	Population terms ECD/education terms Disability terms Inclusion terms Communication terms	Adult-focused papers, unless including families of children in forced migration, who experience disability. Papers focusing solely on mental health OR

		Papers focusing solely on education in resettlement countries
Terms identified in	Title Abstract	
Publication format	Available electronically through MMU library or open web sourcing	

As suggested by Scior, (2011) and Wafula and Goodman (2010), ancestry searching of included papers only was also employed to identify any articles not detected through database searching.

3.4.1.2 Quality assessment

Due to the limited number of papers meeting inclusion criteria for review, a quality assessment was not applied. All papers reviewed were considered to have the potential to shed some light on ECD/educational access and rights realisation for refugee children who experience communication disability in Rwanda.

3.4.2 Data analysis

Several methods can be employed in the analysis of semi-systematic reviews – many reflecting methods used in qualitative research, such as thematic or content analysis (Snyder, 2019). In the context of limited data availability, and the nature of the papers identified, it was most feasible and appropriate to conduct a broad analysis of service availability, barriers to access, and opportunities for future development of services to improve rights realisation. Content analysis (Hseih and Shannon, 2015 – see chapter 5 section 5.9.1), rather than a more nuanced thematic analysis, was therefore appropriate (Elo and Kyngäs, 2008; Graneheim and Lundman, 2004; Hseih and Shannon, 2005).

I followed a method for data extraction and interpretation most recently described by Popenoe, Langius-Eklöf, Stenwell, et al (2021), similar to directed content analysis described by Hsieh and Shannon, (2005). This involved analysing the content of each paper for information relevant to the research question, coding excerpts using both a priori codes generated from the research questions and codes identified from the data and grouping data by category and sub-category. This method allowed for flexibility of approach to data analysis based on combinations of search terms, not all of which overlapped, but served to address the research question.

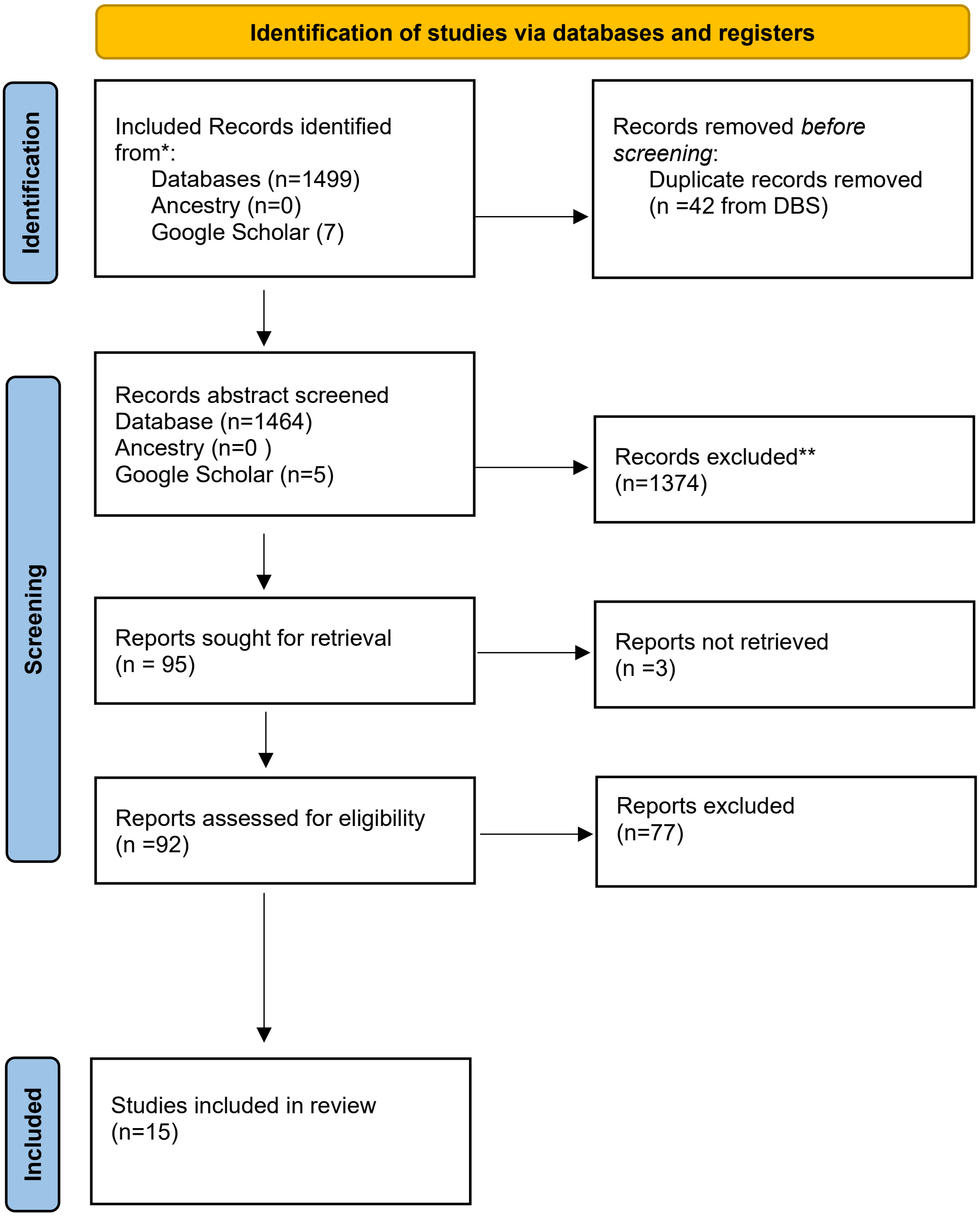
Computer Assisted Qualitative Data Analysis Software (CAQDAS), NVivo version 10, was used to assist data extraction and sorting. The analysis of the literature enabled mapping of the evidence on ECD and educational rights realisation for refugee children who experience CD [in Rwanda] and was mainly descriptive (reflecting the nature of the papers identified). A critical analysis was, however, conducted as far as possible by analysing the data with reference to the frameworks of critical disability, critical refugee theory, as well as human rights (see chapter 2).

3.5 Results

A summary of the search results is presented in figure 5, using the Preferred Reporting Items for Systematic Reviews and Meta-Analyses (PRISMA 2020) flow diagram (Page, McKenzie, Bossuyt et al, 2021). The PRISMA 2020 statement reflects advancements in methodology and terminology since its original statement, made in 2009, and incorporates updated checklists and diagrams. Although this research employs a semi-systematic review methodology, the PRISMA 2020 flow diagram provides a clear and transparent representation of the data identification and appraisal process.

Following analysis of the data as described in section 3.4.2, data were coded and sorted into sub-categories, and categories of information, then related to the research questions – see table 7 (for full table, including codes, see appendix 4).

Figure 5: PRISMA (2020) flow diagram for systematic reviews: Summary of included papers at each stage



(Template from Page et al, 2021)

The final papers included in the review are listed table 6 appendix 3.

Table 6: Papers included in the literature review

Code	**Reference**	**Geographical focus**	**Thematic focus**	**Design**
LR1	Alborz, A., Slee, R., and Miles, S. (2013).	Iraq	Inclusive education Conflict	Mixed methods: Household survey, semi-structured interviews, FGDs
LR2	Ayazi, T., Swartz, L., Eide, A.H., Lien, L., and Hauff, E. (2015).	South Sudan	Mental health and functional impairment Conflict	Cross sectional community survey
LR3	Battle, D. (2015).	Global	Communication disability Conflict	Opinion paper
LR4	Grover, S. (2007).	Global	Education rights	Opinion paper
LR5	Karangwa, E. (2014).	Rwanda	Inclusive education	Opinion paper
LR6	Karangwa, E., Miles, S., and Lewis, I. (2010).	Rwanda	Disability and education	Community-based ethnographic study: in-depth interviews, FGDs, observations
LR7	Krupar, A. (2016).	Kenya	Parent empowerment Childhood disability Refugee context	Ethnographic study: video-recorded observations, interviews
LR8	Marshall, J., Barrett, H., and Ebengo, A. (2015).	Rwanda	Communication disability Refugee context Sexual and gender-based violence	Qualitative study: FGDs, interviews
LR9	Miles, S. (2013).	Iraq	Education	Literature review

			Disability Conflict	
LR10	Njelesani, J., Siegel, J., and Ullrich, E. (2018).	Rwanda	Disability rights	Scoping review
LR11	Pinnock, H., and Hodgkin, M. (2010).	Global	Education for all Displacement	Opinion paper
LR12	Rose, R., and Shevlin, M. (2004).	UK	Education Marginalised groups (including refugees and children experiencing disability)	Various youth engagement approaches, including interviews (other approaches not specified)
LR13	Sagahutu, J.B., Tuyizere, M., and Struthers, P. (2013).	Rwanda	School attendance Childhood disability	Quantitative, cross sectional, descriptive study
LR14	Talley, L., and Brintnell, S.E. (2016)	Rwanda	Inclusive education	Scoping review
LR15	Trani, J.F., Kett, M., Bakhshi, P., and Bailey, N. (2011).	Global	Education Childhood disability Conflict	Summary of several survey studies.

Table 7: Categories identified in the literature review

Sub-category	Category
SC1. Individual-level barriers to inclusive education access	**LRC1. BARRIERS TO ACCESSING INCLUSIVE ECD/EDUCATION**
SC2. Family-level barriers to inclusive education access	
SC.3 Community-level barriers to inclusive education access	
SC4. Environmental barriers to inclusive education access	
SC5. Policy and service-level barriers to inclusive education access	
SC6. Additional challenges	
SC7. Human rights infringements	**LRC2. IMPLICATIONS OF ECD/EDUCATIONAL EXCLUSION**
SC8. Reduced potential for nation-building	
SC9. Policy and guidance	**LRC3. EXISTING POLICIES AND PRACTICES**
SC10. Existing practices	
SC11. Commitment	**LRC4. WHAT IS NEEDED FOR BETTER INCLUSION?**
SC12. Investment	
SC13. Listening and learning	
SC14. Collaboration	**LRC5. OPPORTUNITIES FOR INCLUSION**
SC15. Crisis-related opportunities	

The papers included in the review reported on quantitative, qualitative, and mixed-method studies, as well as reviews of the literature. Four commentary pieces were also included. No studies were found to address issues directly related to educational rights (encompassing ECD) realisation for refugee children who experience communication disability as their primary focus, revealing a gap in the literature at the intersection of forced migration, inclusive education, communication disability, and human rights. Several studies addressed inclusive education in situations of crisis and/or forced migration. Others discussed issues of CD and exclusion within refugee communities either directly, or as part of a wider discussion on disability rights or inclusion. Six studies addressed issues of disability rights and/or inclusion specifically in Rwanda but were not directly related to refugee children. The results are presented with reference to critical disability theory, critical refugee theory, and human rights frameworks, to address the research question:

> *'To what extent do refugee children, who experience communication disability, realise their right to inclusive ECD and education [in Rwanda]?'*

3.5.1 Category LRC1: Barriers to accessing inclusive education

The literature documented numerous barriers to inclusive education access for children who experience disability in crises and/or situations of forced migration, as well as children in the Rwandan education system (which includes integrated refugee children). These barriers were found to exist at multiple and intersecting levels (figure 6) and are reported here, by sub-category.

SC1: Individual barriers to inclusive education access

Limitations at an individual level were reported to affect a child's personal capacity to interact with others, hindering access to education. Communication limitations were cited by Karangwa et al, 2010, Njelesani, Siegel, and Ullrich (2018), and Sagahutu, Tuyizere, and Struthers (2013) as notable barriers to attending school and being able to learn effectively once in school.

SC2: Family barriers to inclusive education access

Within the family, barriers to accessing inclusive education were found to exist due to contextual and cultural factors, as well as practical considerations, such as safe passage to school (Krupar, 2016; Pinnock and Hodgkin, 2010; Trani, Kett, Bakhshi, et al, 2011). In contexts of crisis and/or forced migration, prioritisation of meeting basic needs for the whole family were found to sometimes take precedence over considerations about the relative benefits of education for all children, not just those with impairments (Krupar, 2016). Synergies between prioritisation of needs and resources and family financial constraints could be made as, even in countries where education is ostensibly free, there are costs associated with going to school such as books, uniform, food, and transport, that families must meet (Karangwa et al, 2010; Pinnock and Hodgkin, 2010; Trani et al, 2011).

Trani et al, 2011 found that cultural and contextual understandings about the capabilities and rights of children with impairments, who experience disability, may further influence a family's decision not to send a child to school (Alborz, Slee, and Miles, 2013; Sagahutu et al, 2013). It is possible that perceptions of reduced capability may intersect with financial prioritisations, meaning families choose not to invest in their child with impairment(s) (Pinnock and Hodgkin, 2010). Exacerbating these decisions are the role conflicts experienced by women in some circumstances, where their traditional role of caregiver to children may conflict with their need to carry out tasks or do paid work when school-aged children remain at home. Taking their children with impairment(s) to/from school if they cannot travel alone, interferes with time needed to be spent elsewhere (Trani et al, 2011). Further conflicts with the, often externally imposed, women-focused projects implemented by humanitarian agencies means that women are both expected to occupy traditional roles, whilst seeking empowerment through humanitarian agencies' 'enlightenment projects' whereby they are expected to challenge the status quo. As Krupar, 2016 explains, *"women are targeted in empowerment programming and must navigate between traditional or conservative values, and the enlightenment projects in which they participate" (Krupar 2016: 106).* Sending their child with impairment(s) to school, potentially contrary to community and cultural expectations, may occupy the space between humanitarian agency-envisaged empowerment and the role that the mother is expected to play in the community and family (Battle, 2015; Krupar, 2016). There may also be conflicts with how much engagement the parent is expected to have in the child's educational life. For example, Battle (2015: 237) describes how *"the required parental involvement in the education decisions for a child with a disability may conflict with the cultural perception of the role of parents in the education of the child."*

Finally, in situations of displacement, families may simply not be aware of the educational opportunities available for their children, and may assume inclusive services are not available, based on their previous experiences (Karangwa et al, 2010; Krupar, 2016).

SC3: Community-level barriers to inclusive education access

Barriers to inclusive education were also found to exist in the community. It must be acknowledged that families and service providers are part of communities, and therefore I consider the findings and observations in the papers reviewed to reflect this wider understanding of 'community'. Identified barriers primarily took the form of discriminatory attitudes and behaviours, including stigmatisation, sometimes stemming from understandings of impairment as a curse or punishment (Talley and Brintnell, 2016). Children may be hidden (Pinnock and Hodgkin, 2010) but, in stark contrast to the common view that this is simply because of families' shame, can be understood from both historically influenced and protective perspectives. As described by Karangwa et al (2010: 274), in Rwanda:

> *"most families in income-poor contexts show great love and concern for their family members with disabilities, and that if children are hidden this should be seen in a wider historical and developmental context, and not condemned by outsiders."*

Some understandings of impairment and disability may stem from linguistically influenced conceptualisations. For example, some of the more nuanced meanings behind different terminology, such as 'inclusive education' cannot be directly translated into languages such as Kinyarwanda (Karangwa et al, 2010). Indeed, Karangwa et al (2010) describe how different impairments are named by a prefix of 'lacking' in the Kinyarwanda language. They turn references to people into references to objects and are *"therefore dehumanising" (Karangwa et al, 2010: 272).* Although possibly stemming from a place of compassion for some:

> *"derogatory terms are often used in an affectionate way and they are rarely challenged. The continued use of dehumanising language to describe people with disabilities clearly needs to be challenged at the community level and the national level" (Karangwa et al, 2010: 273).*

Despite these nuanced understandings of the root causes of disabling stigma and discrimination towards people with impairment(s), they remain rife in some communities, including in Rwanda (Karangwa et al, 2010; Njelesani et al, 2015; Talley and Britnell, 2016). Devaluation and underestimation of their ability to learn, and later contribute meaningful to society, results from, and reinforces, deficit-focused (rather than biopsychosocial) understandings of disability. This affects the type of services offered, and the access afforded to, children who require inclusive services (Alborz et al, 2013; Miles, 2013; Rose and Shevlin, 2004; Trani et al, 2011).

SC4: Environmental barriers to inclusive education access

Environmental barriers were one of the most cited reasons for children with impairments not attending, or dropping out of, school. Primarily related to physical barriers to access, such as schools being too far away or in unsafe territory and latrines and classrooms being physically inaccessible (e.g., steps, rough terrain, narrow doorways) (Alborz et al, 2013; Battle, 2015; Karangwa et al, 2010; Pinnock and Hodgkin, 2010; Rose and Shevlin, 2004; Sagahutu et al, Talley and Brintnell, 2016; Trani et al, 2011), the learning environment was also described as an additional barrier to accessing education, affected by both social and pedagogical challenges, including oversubscribed classes (Trani et al, 2011), stigmatising and discriminatory learning environments (Battle, 2015; Karangwa et al, 2010; Njelesani et al, 2018; Pinnock and Hodgkin, 2010), and under-resourced services, such as a lack of teaching materials and support for teachers (Karangwa et al, 2010). In situations of crisis, the prevailing circumstances also mean that education may simply not be the priority for governments coping with war, mass destruction, and population displacement (Alborz et al, 2013; Battle, 2015; Miles, 2013; Trani et al, 2011). Moreover, and in contrast, the opportunities provided by crisis to ‘build back better’ also present the opportunity for exploitation or misappropriation of scarce resources so that the most in need of support to access services are often the last to benefit (Miles, 2013).

SC5: Policy and service-level barriers to inclusive education access

Service-level barriers to inclusive education encompass everything from the humanitarian and host-state policy environment that influences service funding, design, and implementation, through to the attitudes and behaviours of educators towards children with impairment. The barriers identified in the literature can be summarised as external service provider influence, the policy-implementation gap, and the temporary nature of crisis responsive service planning.

External service providers in crisis situations are often humanitarian agencies, implementing an external, donor-driven, agenda (Karangwa et al, 2010; Krupar, 2016). This has been identified as a major factor impeding effective inclusive practice because it may bypass local policy, as well as the potential of local community support mechanisms, knowledge, and understanding (reported in Talley and Brintnell, 2016). It also frequently excludes service users with lived experience of disability and/or displacement (Rose and Shevlin, 2004) in service planning. As Krupar (2016) describes, effectiveness of interventions may be threatened by a clash of perceptions and understandings:

> *"It was assumed that the typology from the West could explain disability in Dadaab, regardless of local knowledge of customs around disability. This presumption that the information from the West was superior has roots in SGC's* relationship to UN enlightenment projects, as well as reluctance to embrace local knowledge about disability" (Krupar, 2016: 117).*
> **fictitious NGO, used for anonymisation purposes*

Externally driven and/or provided services can result in service user dependency, where families do not have choices about their child's educational options (Krupar, 2016). In situations of crisis, families can be wholly dependent upon humanitarian agencies for support. This system is described by Krupar (2016: 115) as *"a system in flux"* – responding to external policies and efforts to return refugees to their place of origin and so instilling a sense of lack of permanence. Families may therefore have reservations about the sustainability or trajectory of services, and the impact of temporary, or unreliable, services on their child, affecting their decision about whether to enrol their child in ECD or school services:

> *"from the parents' perspective: "for children with special needs, if he's [the SGC teacher] the only person who's teaching our children, if he goes away, will we get another person?" (Krupar,*

> *2016: 115).*

The assumed temporary nature of services in crisis is a further barrier to establishing, implementing, and sustaining, inclusive education services for children affected by displacement, as are the funding cycles to which agencies must respond (Krupar, 2016; Miles, 2013). Moreover, a moral dilemma related to initiating services that cannot or will not be sustained upon repatriation is faced by humanitarian budget holders (Miles, 2013). High turnover of staff in international agencies further affects commitment to agendas for longer-term social change (Miles, 2013).

The result of these challenges is a vast policy-implementation gap, explicitly identified in most of the literature reviewed: inclusion is mandatory on paper, it is limited in practice. In response to global, human rights-based, agendas such as the CRPD, CRC, and SDGs (and formerly the MDGs), humanitarian and national policies have, in many cases, responded by incorporating a rights-based approach to inclusive education within them (Karangwa et al, 2010; Njelaesani et al, 2018; Sagahutu et al, 2013; Talley and Brintnell, 2016).

The notion of educational provision in emergencies is relatively new (Trani et al, 2011) and the concept of inclusive education even more so within humanitarian action. Despite inclusive humanitarian education policies and guidance, such as the Inter-Agency Network for Education in Emergencies (INEE) guidance (see Miles, 2013), displaced persons with impairments are known to be subjected to disabling exclusion (Miles, 2013) and placed low down on the list of priorities for emergency response (Miles, 2013; Trani et al, 2011). Indeed, in 2010, UNHCR was considered an agency behind the curve in terms of disability awareness, inclusion policy and practice, and was identified to actively discriminate on the grounds of disability (reported in Miles, 2013). Within the vast numbers of persons of concern, persons who experience disability have been just one of many potentially at-risk groups to whom humanitarian agencies are mandated to respond (Trani et al, 2011). Moreover, attention has primarily been paid to those acquiring impairments through combat, rather than to young people with developmental or acquired impairments affecting their education (Miles, 2013). Despite existing policies, practice (including budgetary allocation: Njelesani et al, 2018), interventions continue to respond to the needs of the majority, inherently excluding those who require support to access services effectively (Battle, 2015; Karangwa, 2014), and in the absence of effective disability-inclusive accountability processes and monitoring (Miles, 2013; Trani et al, 2011).

The policy-implementation gap widens when the population of concern is under-identified. In the case of persons who experience disability, this is tied up with cultural beliefs, attitudes, and practices (such as stigmatising disability), as well as with insufficient attention to the population of concern by service providers (Battle, 2015; Karangwa et al, 2010; Krupar, 2016; Marshall et al, 2017; Miles, 2013). Furthermore, narrow and misguided views of inclusion (Alborz et al, 2013; Krupar, 2016; Miles, 2013; Rose and Shevlin, 2004) a feeling that inclusion is 'too difficult' (Miles, 2013; Pinnock and Hodgkin, 2010), and limited understanding, knowledge, and skills to address needs, limit the effectiveness of any efforts towards inclusive service provision (Battle, 2015; Karangwa et al, 2010; Marshall et al, 2017; Njelesani et al, 2018; Talley and Brintnell, 2016). As described by Karangwa et al, 2010 (p.272):

> *"the majority of teachers expressed fear and disapproval of teaching classes in which children with challenging or profound disabilities were included, 'We only admit those who were acceptable in our classes, … those with mild impairments who do not disrupt lessons are tolerated'" (Karangwa, 2006: 143).*

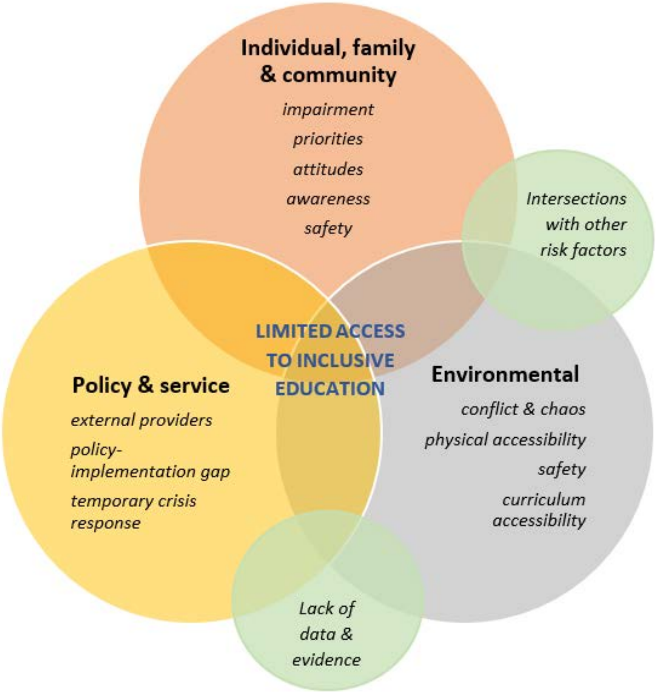
SC6: Additional challenges

Additional challenges to inclusive education access were identified in the literature, including the impact of intersectionality of disability with other factors increasing a person's exposure to risk and/or exclusion, such as their experience of conflict; refugee status, age, gender, mental health status, and family needs (Battle, 2015; Krupar, 2016; Rose and Shevlin, 2004; Trani et al, 2011). As described by Rose and Shevlin (2004: 155):

> *"Many young people have been excluded both from education and participation in everyday activities simply as a result of having a label with negative connotations attached to them."*

Further exacerbating the policy-implementation gap described above is a lack of robust evidence on the number of refugees who experience disability (e.g., Marshall and Barrett, 2017; Trani et al, 2011) as well as what works in situations of crisis and post-emergency inclusive education service provision. Miles (2013), in describing the results of her literature review, states that "*this search provided strong evidence that academic research on the inclusion of disabled children in education in the context of conflict and emergencies is virtually non-existent" (Miles, 2013: 802).* Several more papers cited a great need for further research to progress inclusive agendas in humanitarian and/or low-resource contexts (e.g., Njelesani et al, 2018; Talley and Brintnell, 2016), whilst others refer to conflicting evidence (Krupar, 2016) on some of the reasons why children who experience disability fail to access, or progress through, education systems (e.g., what affects parental decision-making). In essence, there is a concern that humanitarian agencies both implement practices for which there is a lack of evidence of effectiveness, whilst also failing to evaluate and document the practice-based evidence that they, themselves, produce, in a robust manner (Miles, 2013). Scholars therefore call for more research on inclusive education processes and practices in low resource and emergency contexts, to learn from challenges and successes, and to inform the future development of effective inclusive services (Karangwa et al, 2010; Miles, 2013; Rose and Shevlin. 2004; Talley and Brintnell, 2016; Trani et al, 2011).

Figure 6: Intersecting barriers to educational rights realisation for displaced children who experience disability, as identified in the literature.



3.5.2 Category LRC2: Implications of educational exclusion

In making the case for inclusive education in humanitarian and/or low-resource contexts, two common threads are evident in the literature: that exclusion from education constitutes a human rights infringement, and that exclusion in education limits opportunities for nation building in recovery and reconstruction. Whilst highlighting the scale of the problem by documenting the sheer number of children who experience disability and who are out-of-school, the literature calls out service providers for not responding to clear global policy and guidance on inclusive education in an effective manner.

SC7: Human rights infringements

Access to education is a right enshrined in the UDHR, CRC, and CRPD, as well as many national government policies (reported in most papers reviewed). Despite this, evidence suggests that children who experience disability are far less likely to attend, and/or complete, primary education in resource limited and/or humanitarian contexts (Alborz et al, 2013; Battle, 2015; Karangwa, 2014; Krupar, 2016; Miles, 2013; Njelesani et al, 2018; Sagahutu et al, 2013; Trani et al, 2011). Indeed, Sagahutu et al, 2013 reported that up to 98 per cent of children who experience disability in 'developing countries'[20] do not attend school. In crisis response contexts, this can be assumed to increase as *"displaced persons with disabilities are effectively deprived of the humanitarian aid and services they need"* (Battle, 2015: 238). For children with CIs, Sagahutu et al (2013: 12) found *"a significant association between speaking difficulties and never attending school"* in Rwanda, during their primary quantitative research.

The wider opportunities and services afforded to children and their families through ECD and education services, including safe spaces, nutrition services, public health messaging, and sexual and reproductive health education, play a vital role in child development, child protection, health promotion, and social participation. Education services protect children's and families' mental health (Grover, 2007), providing a routine for children and vital time for families to engage in livelihoods activities. In excluding children who experience disability from these opportunities, governments and service providers increase children's risk of exposure to violence, malnutrition, poor health, sexual exploitation, and continuing social exclusion from their peer group (Krupar, 2016; Marshall et al, 2017; Pinnock and Hodgkin, 2010; Trani et al, 2011). This constitutes multiple human rights infringements to protection, food, and healthcare, as well as education. Moreover, exclusion from education can impact upon children's very survival (Krupar, 2016; Miles 2013), as well as their future potential to engage in economic activity and care for themselves (Karangwa, 2014; Krupar, 2016; Sagahutu et al, 2013; Trani et al, 2011).

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[20] This terminology is used by Sagahutu et al (2013). In this thesis I choose to use the term 'majority world' – see chapter 1, section 1.5.4 for further explanation.

SC8: Reduced opportunity for nation building

Much of the literature referred to the wider benefits of inclusive education beyond academic achievement, including its contribution to creating socially cohesive and inclusive societies. Ensuring children learn together means they also learn to value each other, which they take with them as they grow into adults. As Grover (2007) states, when citing The Committee on the Rights of the Child: *"children are capable of playing a unique role in bridging many of the differences that have historically separated groups of people from one another" (Grover, 2007: 62).* This is reinforced by Alborz et al (2013), who report that education systems have the potential to either reinforce existing patterns, or create new patterns, of social inclusion or exclusion.

The social and economic cost of excluding children who experience disability from education is described as 'incalculable' by Karangwa (2014: 57). A calculation *can,* however, be made for inclusion – with inclusive services purported to be much more cost effective than segregated education, not least because it is an opportunity to consolidate resources following a crisis (Alborz et al, 2013). Without educational inclusion, refugee children who experience disability are *"further marginalised from their mainstream peers"* (Rose and Shevlin, 2004: 160), which reinforces negative stereotypes within communities. In childhood, families bear the brunt of exclusion, often needing to stay at home to care for their child rather than engaging in economic activities to support the family (Alborz et al, 2013; Miles, 2013; Trani et al, 2011), which can subsequently affect their mental health and coping abilities in crisis situations (Ayazi, Swartz, Eide, et al, 2015). As children grow into adults themselves, those excluded from education are limited in their ability to participate in their communities and engage in economic activity to care for themselves and their families (Alborz et al, 2013; Karangwa, 2014). They become *"passive, dependent citizens"* (Karangwa, 2014: 54, citing Stubbs, 2002) that the state is responsible for, their lack of participation undermining their very citizenship (Alborz et al, 2013). As Trani et al (2011: 1188) articulate:

> *"As well as the protective function, research shows that including children living in conflict-affected areas in educational activities*

> *has positive and incremental effects on future economic growth, health indices and infant mortality rates, peace and security, and paves the way for good governance and active engaged citizenship….. Inclusive education promulgates broader values than education as a means to an end (skills acquisition, employment); it also highlights issues of social justice…. This has enormous potential for peace-building benefits in Conflict Affected States."*

It goes without saying that the impact of *exclusion* is considered to be socially and economically devastating for the futures of nations recovering from conflict, disasters, and emergencies.

3.5.3 Category LRC3: Existing policies and practices

Although inclusive education in humanitarian action is a relatively new endeavour, it is directed by global, humanitarian, and national policy and guidance. This is beginning to translate into the development of inclusive practices in some contexts, some of which are reported in the literature. Much work carried out by humanitarian agencies, however, remains outside the public domain, and much less is conceptualised as research that reaches peer reviewed journals (Miles, 2013).

SC9: Policy and guidance

The literature reports on the global policy and guidance on inclusion that exists within a human rights framework, from the UDHR (UNGA, 1948) through to the CRC (UNGA, 1989), and the CRPD (UNGA, 2006) (reported in Alborz et al, 2013; Battle, 2015; Krupar, 2016; Miles, 2013; Njelesani et al, 2018; Rose and Shevlin, 2004; Sagahutu et al, 2013; Trani et al, 2011). Krupar (2016) reports that the Additional Protocol II to the Geneva Convention specifically calls for access to education for all children (United Nations, 2004). Further global endeavours to clarify and promote the right to inclusive education have been made through global statements and commitments, such as through the Salamanca Statement (UNESCO, 1994), the Millennium Development Goals (United Nations, n.d.), and the more recent

Sustainable Development Goals (UNGA, 2015a, reflected in the associated Incheon Declaration and Framework for Action, United Nations, 2015) and are reported in Alborz et al (2013); Battle (2015), Krupar (2016), Miles (2013), Njelesani et al (2018), Rose and Shevlin (2004), Sagahutu et al (2013), and Trani et al (2011).

Humanitarian organisations, in their position as implementers in ever more protracted crises, have begun to incorporate the right to inclusive education into their guidance. As reported by Miles, (2013: 808):

> *"the moral imperative to provide all children of primary age with an education of good quality, combined with the raising of the profile of disability through the UNCRPD, has led to some high-level discussions about the need to include disabled children in educational opportunities, including in conflict and post-conflict contexts."*

In response to both the moral imperative and human rights frameworks, the Inter-Agency Network for Education in Emergences (INEE) developed minimum standards for inclusive education in crises. The INEE guidance is *"an official companion to the Sphere Project's Minimum Standards in Disaster Response Handbook"* (Pinnock and Hodgkin, 2010: 34) – the Sphere Standards constituting the most comprehensive and globally accepted standards for emergency response. The INEE standards set out why, and more importantly how, to incorporate inclusive education programming into emergency responses.

In addition, Battle (2015) reports on the development of UNHCR's education strategy 2012-2015, stating that the strategy:

> *"aims to develop skills and knowledge to enable refugees with disabilities to live healthy and productive lives. The first goal of this strategy is to improve education access and learning achievement among refugee children, focusing on the learning environment, teaching quality, and early childhood development and accelerated learning programs" (Battle, 2015: 236).*

This demonstrates clear commitment amongst humanitarian organisations to implement inclusive education, grounded in human rights.

Beyond global and humanitarian guidance, it is most important to evaluate if and how national governments translate this into national policy and practice, be they governments experiencing crises within their own borders, or extending protection to refugees from other countries. Karangwa (2014), Karangwa et al (2010), Njelesani et al (2018), and Sagahutu et al (2013), report on the Rwandan government's translation of global guidance into local policy, including stipulating provision of education for people experiencing disability in Article 40 of the constitution, and ensuring nine years of fee-free basic education for all, illustrating their commitment to human rights agendas and vision for an inclusive future. Trani et al (2011) report that the government of Sudan has committed to free education for children who experience disability, and the government of Sierra Leone to education legislation referencing 'children with disabilities' and 'special needs education', though falling short of committing to inclusive educational for all.

Despite these national commitments to children who experience disability and, in some cases, extending this to refugees, the policy-implementation gap with regards to inclusive education exists in all crisis-affected countries represented in the literature (see SC5 above).

SC10: Existing practices

The literature reports on a small variety of existing inclusive education practices in humanitarian contexts, including in refugee host states in the GLR. Current practice is reported to centre around the commitments made to enact human rights-based approaches to service provision, including inclusive education. In some contexts, this is in collaboration with (host) governments (Miles, 2013), but often occurs in isolation from state systems in crisis situations. Consultation and collaboration with affected communities, including families, appears to be a common method of engaging people in sensitisation activities, often targeted at attitudinal and behavioural change (e.g., Krupar, 2016). Empowerment of families, particularly women, is also a strategy employed to encourage parents to send their children to school. Empowerment projects include training on why, but not often how, to increase their child's participation in their family and local community, including school (Krupar, 2016).

Involving local communities in decision-making and implementation of inclusive education projects has been found to be effective. For example, Pinnock and Hodgkin (2010) report on the effective use of local education councils to identify out-of-school children and to encourage families to send their children who experience disability to school. Karangwa (2014) also discusses the importance of local ownership of inclusive education initiatives in ensuring their success.

Commitment to, and resourcing of, inclusive education services is also described in the literature. Investing in qualified staff (Krupar, 2016), training educators, families, and communities on disability-inclusive education (Alborz et al, 2013; Krupar, 2016), and establishing task forces to monitor inclusive practice and effectiveness (Karangwa, 2014; Talley and Brintnell, 2016) were reported. There was, however, a paucity of robust evaluation of inclusive education interventions for refugee children who experience disability, in the peer-reviewed literature. To combat this, research is becoming an increasingly recognised need and is beginning to take place in crisis contexts (Alborz et al, 2013; Miles, 2013). It does, however, take more careful planning and is associated with higher risk than research in peaceful contexts (Alborz et al, 2013), which may affect how much research takes place.

3.5.4 Category LRC4: What is needed for better inclusion?

Much of the literature identified challenges with current inclusive education provision in low-resource and/or crisis contexts. Many authors also went on to suggest what might be needed to depart from the inertia in implementing inclusive education policy reported in the scant research to date. This included recommendations around commitment, investment, and listening and learning.

SC11: Commitment

Evidence suggests that a clear commitment to making inclusive education a reality by all service funders, designers, and implementers, is required. This commitment means that inclusive principles, grounded in human rights, should inform all humanitarian work in accordance with contemporary global and humanitarian inclusive guidance (Battle, 2015; Miles, 2013; Pinnock and Hodgkin, 2010). Challenging discriminatory perceptions, attitudes and beliefs that interfere with inclusive education implementation is a crucial step to ensuring that, not only do children who experience disability (Alborz et al, 2013) attend school and access learning opportunities appropriately, but that teachers and peers welcome them, and parents of non-affected children appreciate the value of inclusive education. As described by Alborz et al (2013: 979):

> *"the wider community of parents [must] become comfortable with the notion of co-education of disabled and non-disabled children. This may impact on the reluctance of head teachers to accept disabled children into school due to concerns that parents of non-disabled children may complain, or at worst, withdraw their child."*

In addition to improving implementation of inclusive education services themselves, improvement in inclusive systems, tools, and processes to enable service providers to identify children who would benefit from support to access education effectively, is required (Alborz et al, 2013; Marshall et al, 2017). This is especially important for children with impairments and/or learning support needs that are less visible, such as CIs, and requires commitment to improving the knowledge, understanding and skills of humanitarian staff across service sectors (Marshall et al, 2017). Finally, the establishment of robust monitoring, evaluation and learning systems are crucial to the development of effective inclusive education services, not only for accountability for inclusive practice but to facilitate knowledge sharing, innovation exchange, and to avoid repeating the same mistakes (Pinnock and Hodgkin, 2010).

SC12: Investment

One of the major policy-implementation gaps identified in the literature, was the under-resourcing of inclusive services. Inclusive practice can never become a reality if adequate budgeting and resourcing does not follow on from the creation of inclusive policy and guidance. This includes: resourcing universal design[21] during infrastructure (re)development (Alborz et al, 2013; Sagahutu et al, 2013); financing attitudinal and behavioural change activities amongst communities and educators (Alborz et al, 2013; Battle, 2015; Miles, 2013; Trani et al, 2011); investing in human capacity development (including numbers and skills of educators) (Talley and Brintnell, 2016); resourcing time for humanitarian staff and educators to understand and respond to the needs of service users (Krupar, 2016; Pinnock and Hodgkin, 2010); and ensuring flexibility in budgeting to respond to needs as they arise (Alborz et al, 2013; Pinnock and Hodgkin, 2010).

SC13: Listening and learning

The literature highlighted the imperative for services to be responsive to need. This can only occur when the needs of the affected population are identified from lived experience, necessitating consultation and collaboration with service users. It is sometimes the case that what service providers assume are high priority needs, are not for individuals. For example, until very recently, education was not perceived to be an immediate need in emergency situations in comparison to things like food, shelter, and livelihoods opportunities. Ayazi et al (2015), however, demonstrated that, in South Sudan, children accessing education was a significant perceived need for parents and a lack of access negatively affected parental mental health, potentially affecting their ability to care for their children effectively at home and impacting upon other areas of life, such as economic productivity. Without listening

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[21] Universal design is a process whereby systems, buildings and programmes are designed to be accessible by all, rather than designing specialist features for some, or retrofitting something designed for the majority (The Universal Design Project, 2023). An example might be installing more windows in classrooms to make it easier for children with low vision to see the teacher or work, or for deaf children to see a sign language partner. In reality, all children benefit from more natural light in the classroom.

to families, damaging assumptions may have continued to have been made about people's priorities.

Pinnock and Hodgkin (2010) specifically discuss the need for humanitarian actors to avoid making assumptions about the population of concern. Indeed, they give examples of misinterpretation of situations such as parents not wanting to send their child to school in Pakistan. Originally assumed to be due to prevailing negative attitudes and beliefs about disability, parents were, in fact, fearful for the safety of their child on an unsafe route to school and therefore kept their child at home. Once the problem was identified and addressed, children began accessing school.

Imposition of external knowledge and constructions of complex notions such as disability can also work counterproductively with local communities. As illustrated by Krupar (2016), assumptions about knowledge needs in Sudan meant that humanitarian agency staff training families imposed external notions of disability that did not make sense in the context. Families explained that they have their own ways of knowing and understanding disability, and that the trainers should work with them from that starting point to ensure everything from thereon in would be contextualised appropriately, and therefore meaningful.

Research has a critical role to play in exploring and documenting the needs of families of children who experience disability in low-resource and/or humanitarian contexts. There is a particular call for participatory action research, led by local communities (Karangwa et al, 2010). Involving stakeholders including policy makers and service providers, as well as service users, has been highlighted as important to ensure plans to meet needs are met with realistic capacity to deliver (Miles, 2013; Talley and Brintnell, 2016). Generating evidence about the reasons for exclusion, the barriers and opportunities that facilitate or impede effective inclusive education access, and the outcomes of inclusive humanitarian interventions, is key to ensuring future humanitarian services respond to human rights agendas, meet service user and service provider needs, and provide evidence for what works, now and in the future

(Trani et al, 2011). Evidence can be used to make arguments for or against certain practices, highlight gaps in provision, and advocate for resources (Miles, 2013).

3.5.5 Category LRC5: Opportunities for inclusion

Although there is plenty evidence in the literature of the shortfalls in access to inclusive education for refugee children who experience disability, authors also identify several opportunities that governments and humanitarian agencies can capitalise upon to improve the current situation.

SC14: Collaboration

According to the literature, a significant opportunity to promote and support access to inclusive education for refugee children appears to be collaboration with the local community. Surprisingly, and despite evidence suggesting disability-related discriminatory attitudes and behaviours are rife in some communities, there is evidence that there can be strong community support for inclusion (Pinnock and Hodgkin, 2010) and both the necessity and desire for inclusion to contribute to community cohesion (Alborz et al, 2013).

Karangwa (2014) and Karangwa et al (2010) refer to the concept of ‘ubumwe’ in Rwanda. Translating as ‘unity’, it is a practice of community solidarity that supports every member, but particularly disadvantaged groups and individuals. Talley and Brintnell (2016) describe another study by Karangwa, Ghesquire and Devlieger (2007) in which they state that:

> *“local cohesiveness, or ‘Ubumwe’, fostered the inclusion of children with disabilities as community members. Their evidence indicated that solidarity and inclusion was more evident in rural impoverished areas than in urban, affluent families” (Talley and Brintnell, 2016: 371)*

Community support for inclusion was also evident in the work of Alborz et al (2013), Krupar (2016) and Njelesani et al (2018), the importance of which is reflected in the need for community consultation and collaboration reported in LRC4 above. Further taking advantage of the opportunity for community support, is the potential to engage with community members, children, and families, in planning inclusive services. Through dialogue, misunderstandings can be addressed (Pinnock and Hodgkin, 2010), discriminatory attitudes and behaviours challenged (Karangwa et al, 2010), challenges tackled in innovative and contextually appropriate ways (Pinnock and Hodgkin, 2010), and local ownership can be taken for the development of socially cohesive interventions (Karangwa, 2014).

Collaboration with key stakeholders, including (host) governments and service providers such as educators, also presents opportunities to develop services with policy, budgetary, resource, and practical delivery implications in mind (Alborz et al, 2013; Karangwa, 2014; Karangwa et al, 2010; Miles, 2013). Listening to what families want and need, in the absence of listening to what service providers need to respond to those wishes, is considered a grave mistake. Indeed, Grover (2007: 61) cautions that *"a strong state commitment to human rights in every domain and reflected in practice is a prerequisite if educational integration at any level is to become a viable reality."*

SC15: Crisis-related opportunities

Finally, crisis is considered to present the opportunity to 'build back better'[22] (reported in Miles, 2013). The phrase has become popular in the humanitarian sector, referring to the opportunity to reconceptualise policies, systems, infrastructure and capitalise upon, or re-sculpt, cohesive community practices. 'Build back better' can be conceptualised as capitalising upon the need to rebuild systems and infrastructure post-crisis and using this as an opportunity to change exclusionary attitudes and practices (Alborz et al, 2013; Pinnock and Hodgkin, 2010; Trani et al, 2011). As Miles (2013: 801) states:

> *"The destruction of schools and related infrastructure is*

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[22] A phrase coined by President Clinton during the Hurricane Katrina response in America in 2005.

> *traumatic for all those affected, but it also interrupts the status quo. It is this interruption that can be seen as an opportunity to rebuild an education system which is more inclusive than the one that was damaged or destroyed."*

A combination of building on what positive aspects of attitudes, behaviours and practices that already exist (such as ubumwe, as described above – Karangwa, 2014; Karangwa et al, 2010) with using the post-crisis opportunities to pilot new and innovative ways of working (Miles, 2013), has the potential to contribute to a 'build back better' strategy of increased inclusivity in education systems and services. Examples of using educator training post-crisis as an opportunity to include inclusive education training, is provided by Miles (2013) and Pinnock and Hodgkin (2010).

3.6 Discussion and implications

The peer reviewed literature connecting refugee children, CD, and access to inclusive ECD/education is scarce. Fifteen papers were identified that connected some, but not all, of the issues and were analysed using a process of content analysis to produce a semi-systematic review.

The scarcity of evidence on the educational inclusion of refugee children who experience CD illustrates the invisibility of this population. Communication disability amongst the refugee population was the focus of only one paper (Marshall et al, 2017). Evidence on inclusive education services, barriers, and opportunities for displaced children (including refugees) who experience disability more broadly, was more abundant but still in scant supply. In these papers, amongst some examples of good practice, was a clear message that policy and guidance towards inclusive education for children who experience disability, and towards refugee education, is necessary but not sufficient in the pursuit of educational rights realisation for all children. Barriers to implementation of these policies are wide-ranging and exist within the policies themselves, within the environment, within communities, and within organisations and services. It is therefore almost impossible to make fundamental and sustainable changes to inclusive education access for refugee children who experience (communication) disability without addressing each one of those barriers to at least some degree.

When considering the results of the review within a human rights framework, there are clear indications that displaced children with impairments experience disabling exclusion from educational opportunities that constitutes a violation of their human, child, refugee, and disability rights. The global normative frameworks of the UDHR, CRC, CSR (and optional protocols), and CRPD articulate very clearly the right to education for *all* children, without exception. For children in low-resource and/or humanitarian contexts, the right to education is a conduit for the realisation of other human rights, such as protection from violence, adequate healthcare, access to nutritious food, and being accepted as a valued citizen with a right to participate in society and be heard. More broadly, inclusive education is considered key to the creation of peaceful, fair, and just societies, free from discrimination, in which citizens are capable of human capital development and nation-building. Despite wide recognition that exclusion from education violates several fundamental rights, governments, humanitarian agencies, and educators are complicit in these infringements through the perpetuation of exclusionary attitudes, behaviours, and practices. This is particularly potent for children who experience intersecting risks affecting their current and future wellbeing.

The needs and opportunities identified for improvement of the current situation depend entirely upon understanding the context of exclusion in a holistic manner. This involves analysing the policy environment, including political will and capacity to deliver on political promises; the physical environment, including existing and required infrastructure; the social environment, including prevailing beliefs, attitudes, and behaviours; the fiscal space for inclusion; and the knowledge, skills, and resources required to deliver on effective disability identification, needs assessment, and educational support. Miles (2013) describes the opportunity to ‘build back better’ with reference to education *systems.* In so doing, she cites Oh and van der Stouwe (2008) who raise concerns that humanitarian organisations frequently implement ‘ad hoc’ and ‘fragmented’ inclusive education projects that fail to change anything at a systemic level - a sentiment echoed by Somali mothers in Kruper’s (2016) study in Dadaab refugee camp, Kenya.

The paucity of data on children who experience disabling exclusion from education, combined with the lack of robust evidence of strengths, weaknesses, challenges, opportunities of current inclusive education systems in contexts of forced displacement, means that humanitarian actors are left floundering, not knowing where to start with changing the way that they currently implement education services. Evidence suggests that current services exclude, and infringe upon the rights of, children who experience disability. It further highlights the inertia in commitment, resourcing, and accountability for inclusion in difficult contexts, such as during crises. Children who experience disability in forced displacement are particularly at risk of remaining undetected when communities break down, survival is the priority, and no-one is held accountable for their identification, protection, and rights fulfilment. Placed in the hands of humanitarian actors, for whom operating at the nexus of crisis response and development in protracted crises is a new endeavour (see chapter 2, section 2.3), realisation of their right to inclusive education in their local community appears to be an aspiration, rather than a reality.

From critical disability and critical refugee theory perspectives, this review illustrates just some of the ableism and social injustices endured by refugee children with impairments, who experience disabling exclusion from education. When disability is considered as a “*cultural, historical, relative, social and political phenomenon”* (Hall 2019: 1), oppressive policies, attitudes, behaviours, and practices can be seen to combine with low prioritisation and under-resourcing in times of crisis, excluding children with impairments from educational opportunities and future life opportunities. The relatively recent consideration of refugees who experience disability as an at-risk group, and their relative low prioritisation in terms of service provision and access, suggests that normative bodies and minds continue to be considered superior to non-normative bodies and minds (Garland Thompson, 1996), despite a global disability rights agenda being firmly in place since 2006. This oppression not only limits children’s current educational experiences but exposes them to a high risk of living in poverty, poor health, and exposed to violence, now and in the future.

When disability intersects with other marginalising aspects of embodiment (see chapter 4, section 4.5.2.2), such as refugee status, gender, race, ethnicity and/or sexuality, multiple oppressions may be experienced. The literature particularly illustrates the intersectionality of refugeehood and disability with reference to refugee children in host nations and resettlement nations, describing the discrimination and marginalisation that children face on both grounds and amplifying their risk of exclusion and its sequalae. A distinct lack of opportunity for the voices of marginalised persons to be heard in these contexts exemplifies the power imbalance between (often outsider) [23] service providers and service users, as well as between those given opportunity to advocate for themselves, and those suppressed from doing so.

3.7 Conclusion

The scant literature available addressing the issue of educational rights realisation for refugee children who experience communication disability [in Rwanda] suggests that this group of children are systematically excluded from appropriate educational opportunities affecting their safety, mental health, physical health, potential to build their own human capital and, ultimately, violating their rights. Beyond the individual, communities miss out on opportunities to build cohesive, inclusive, and peaceful societies that can work together to build a strong and prosperous nation – essential in post-conflict reconstruction.

The literature on refugee children who experience communication disability is extremely scarce. That which does exist, however, suggests that, in humanitarian contexts, children with communication impairments are more marginalised and less able to access education than other displaced children with more visible or

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[23] An ‘outsider’ is a person who is not a member of a particular group. Insider or outsider status (and the overlap and movement between) has implications for interactions with study participants (Limaputtong, 2011). See chapter 7, section 7.3 for a reflexive account.

understood impairments, such as physical or sensory impairments (visual/hearing), resulting in exclusion, oppression, and disability. That said, displaced children with all forms of impairment are acknowledged to experience disabling exclusion due to a web of barriers spanning political, personal, social, structural, and organisational domains. Education *services* are only one part of the problem – education *systems* in emergencies and protracted crises appear to require a fundamental reconceptualisation to facilitate a rights-based response to inclusion for all children in situations of forced displacement.

Without this fundamental shift across humanitarian (sometimes host-state supported) education systems, including establishing robust accountability mechanisms for inclusive practice, refugee children with impairments will continue to experience disabling exclusion, alterity, marginalisation, and oppression. This constitutes a violation of their fundamental human rights, and places states and organisations charged with ensuring rights realisation in contravention of their own policies and guidance.

3.8 Chapter summary

This chapter has presented a semi-systematic review of academic literature on the intersections of CD, forced migration, and access to ECD/education. It has provided integrated evidence from across disciplines to place this research project within a global context, thereby providing a broader and deeper understanding of the issues from a range of perspectives. The chapter concluded with a discussion of findings, applicable to the findings presented in chapters five and six and is integrated into the thesis discussion in chapter seven.

Chapter four now presents a discussion of, and rationale for, the philosophy underpinning this research, as well as the methodology applied to phases one and two of the project.

Chapter 4: Methodology

4.1 Overview

This chapter presents an in-depth discussion of the theoretical underpinnings of this research project. A discussion on research design, encompassing the relationships between research philosophy, strategies of enquiry, and methods of data construction[24] and analysis, precedes a presentation of the choices made in this project, and their rationale (section 4.5).

The philosophical underpinning of a research design is not always clear (Killam, 2013), described by Crotty (1998 p.1) as presented to early career researchers *"more as a maze than as pathways to orderly research".* Researchers choose different terminology to describe their epistemological (theory of knowledge) and ontological (nature of reality) stances (Crotty, 1998), their philosophical worldview (Crotty, 1998; Creswell, 2009), or research paradigm (Killam, 2013; Lincoln and Guba, 2000; McAllister and Lyons, 2019) – terms which are described in more detail throughout this chapter. Some researchers may describe an ontology, whilst others claim the same to be a theoretical perspective (Killam, 2013 versus Crotty, 1998, for example) or approach (Robson, 2002). This can be further complicated by discussion of research designs, methodologies, and strategies (McAllister and Lyons, 2019), sometimes viewed through a particular lens, that may lend themselves to a particular research method or methods. In summary, despite many authors' attempts to produce a logical representation of research philosophy, there is no definitive approach to categorising the philosophical influences on a researcher's approach to a study. The 'box and arrow' style logical progression diagram that early career researchers so desire is, by its philosophical and highly debated nature, impossible to produce.

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[24] Thorne (2016) uses the term 'data construction' in preference to data collection or generation, reflecting the social constructionist influences on her interpretive description methodology (see section 4.5.2.1).

In this chapter I will, however, attempt to provide some clarity on each of the philosophical concepts applicable to this research and provide a rationale for the study's theoretical underpinnings. These influenced the decisions made about the overall research design, including methodology and methods employed to address the research question, aims, and objectives of my research (see chapter 1, section 1.3).

The aims and objectives of each phase of the research reflect my desire to understand the multi-faceted issues relating to the identification of communication impairment (CI) and communication disability (CD) and access to inclusive early childhood development (ECD) and education services amongst refugee children in Rwanda. As the study was conducted in two distinct phases, my chosen research methods are discussed broadly in this chapter and then with more specificity in the relevant chapters (chapter 5 for phase 1 and chapter 6 for phase 2), along with the procedures for data construction and analysis for each phase.

4.2 The research paradigm

McAllister and Lyons (2019: 4), describe a research paradigm as *"an overarching framework for the research"* and Guba (1990: 17) as *"a basic set of beliefs that guide action".* Killam (2013) defines a paradigm as a framework that guides what a researcher does, drawing an analogy between the lenses on a pair of spectacles that change the way you see the world, while Guba and Lincoln (2005) include not only ontology and epistemology, but also methodology, under their paradigm definition. Kuhn (1996, cited in Morgan, 2014: 5) defines a paradigm as *"shared beliefs within a community of researchers who share a consensus about which questions are most meaningful and which methods are most appropriate for answering those questions."* McAllister and Lyons (2019) acknowledge that the term 'paradigm' is used by some researchers with reference to ontological and epistemological perspectives, whilst others use it to describe methods of data collection. They go on to describe the two prevailing research paradigms as *qualitative* and *quantitative*, whilst others describe paradigms in more ontological than methodological terms, such as the '*positivist paradigm*' (Park, Konge and Artino, 2020). In this chapter, I will use the term 'research paradigm' with reference to the influences of a researcher's philosophical worldview, incorporating what some term ontological and epistemological perspectives, on their choice of research methodology and methods.

A researcher's philosophical worldview stems from their beliefs and theoretical assumptions about the world and how reality is constructed (Creswell, 2007; 2009). This guides a researcher's decision-making and determines the direction a piece of research will follow (Guba, 1990; Crotty, 1998). Indeed, a researcher may conduct their research in a particular way *because of* their philosophical position (Crotty, 1998). However, it is also conceivable that a researcher's worldview may evolve over time, influenced by prior experience and the topic of research itself, which may demand that the researcher adopt a particular paradigm to address a research question effectively. My views on this align with those of Robson (2002), who suggests that our worldview is shaped by our experience: the subject we study; our beliefs; and our past experiences. I believe that, as our research interests develop, new experiences demand that we continually question and amend our views of the world which, in turn, may mean that our worldview evolves or that we view a topic, question or challenge through different lenses at different times depending on context and experience. This will then influence the paradigm we choose to adopt. Indeed, Crotty (1998) asserts that we do not usually approach research from an unshakeable epistemological perspective, but that our research questions guide us to use methodologies and methods that align with an epistemology. Nevertheless, we are likely to be interested in phenomena and specific research questions based on our worldview.

Crotty (1998) delineates the relationship between epistemology, theoretical perspective, methodology, and methods, through the creation of a philosophical framework. Although Crotty is clear that the relationships are not absolute, he describes the common philosophical alignments between the elements. Although he does not use the phrase 'paradigm', I consider his framework to comprise the fundamental aspects of a paradigm, as conceptualised by Guba and Lincoln (1994), Killam (2013) and McAllister and Lyons (2019). As such, I use Crotty's framework as a basis to discuss the core features of key epistemologies, theoretical perspectives, and methodologies. Following Crotty's framework is not to say that the writings of other theoretical researchers are to be cast aside – indeed, I endeavour to critique my own research choices in light of their work – but referencing one framework serves to provide clarity in the conceptual quagmire that is research philosophy.

Looking beyond Crotty's framework, I present pragmatism as a paradigm (section 4.2.3) that sets itself aside from traditional metaphysical constraints and the qualitative/quantitative paradigmatic dualism described by McAllister and Lyons (2019). Pragmatism is not discussed by Crotty in detail, other than in relation to interpretivism, but is considered by others to occupy an important space in contemporary social research (Adelaine, 2015; Kaushik and Walsh, 2019; Morgan, 2014).

4.2.1 Theoretical perspective

Although Crotty (1998) asserts that epistemology and ontology 'sit beside each other' in his model of research design (Crotty, 1998: 10), he uses the term 'theoretical perspective' to describe what some researchers would refer to as ontology (e.g. positivism, realism, relativism, interpretivism, critical inquiry) and that others encompass within their understanding of a researcher's 'worldview' (Creswell, 2009) or 'research paradigm' (McAllister and Lyons, 2019). He describes a theoretical perspective as *"a way of looking at the world and making sense of it"* (Crotty, 1998: 8) which also incorporates what others may term a theoretical lens, or research approach, such as the feminist approach (Creswell, 2009; Robson, 2002). It is through describing our theoretical perspective that we elucidate our assumptions about the world and their bearing on the methodology and methods we choose to employ. As Crotty (1998: 66) states, *"different ways of viewing the world shape different ways of researching the world"*. As such, transparency about research philosophy is considered a critical component in any research reporting (Creswell, 2009) as it allows the reader to consider findings against the assumptions made during the design of the study and assess their bearing upon the research perspective and process. Moreover, clarifying the philosophy through which the research process was developed constitutes an important part of a researcher's reflexive process, compelling them to consider why they made the choices they did, what impact their theoretical perspective had upon the way they approached the research questions and tackled challenges, and what role(s) they themselves played in the study and the direction it took.

Although there are many theoretical perspectives (or semantic equivalents), it is beyond the scope of this chapter to describe them all. Using Crotty's chosen terms, I will briefly describe five key perspectives that influenced my decision making: Positivism; relativism; realism; interpretivism; and critical inquiry.

4.2.1.1 The positivist perspective

The positivist perspective contends that that there is one universal truth that can be observed through scientific enquiry (Crotty, 1998; Park et al, 2020; Robson, 2002) – that this truth exists independently of human interpretation. *People* assign meaning subjectively, whilst *science* ascribes no meaning, but seeks to discover the meaning or truth that already exists inherently in objects (aligning with an objectivist epistemology) (Crotty, 1998).

Post-positivism emerged through evolution of the positivist stance, continuing to value the scientific method, but asserting that there is no *absolute* truth, but only the absence of disproof. By the early 1990s, Paul Feyerabend was controversially professing the 'anarchy' of science and the unavoidable cultural and socio-political influences on it, dividing some researchers firmly into the positivist camp, encouraging some towards a more constructionist epistemology, and convincing the remainder to occupy the emerging middle ground of post-positivism.

4.2.1.2 The relativist perspective

The relativist perspective sits in stark contrast to positivism, professing that there is no objective reality as reality is constructed by a participant in interaction with an object (Robson, 2002), i.e., there are multiple realities (Guba and Lincoln, 1994). Moderate relativists claim that meaningful reality exists as a product of human action and that the same phenomena can be experienced differently by different people, at different times, and in different places, in part due to the cultural lens through which we experience the world (Crotty, 1998). As such, a relativist perspective assumes a qualitative research paradigm (McAllister and Lyons, 2019).

4.2.1.3 The realist perspective

The realist perspective has evolved over time from what has been termed 'naïve realism' to more modern forms of 'critical realism' (also known as fallibilistic realism, subtle realism, transcendental realism, and scientific realism – Robson, 2002). Realism considers facts to exist alongside the context in which those facts occur – i.e., there are no facts that are 'beyond dispute' (Robson, 2002: 22). Considered to be a sensible approach to 'real world' research as it finds its way between puritanical positivist and relativist approaches, critical realism *"criticises the social practices that it studies"* (Robson, 2002: 41). In essence, realism allows objectivism and subjectivism to co-occur within the same sphere and is the reason for which Crotty (1998) states that the social constructionist epistemology has its roots in both realist and relativist ontologies.

4.2.1.4 The interpretivist perspective

The interpretivist perspective stands in contrast to a positivist approach to research and is closely associated with a social constructionist epistemology (Mertens, 1998). It is concerned with the interpretation of the social world according to cultural and historical lens of the individual. Although Robson (2002) subsumes interpretivism as a form of relativism, Crotty (1998) describes the intricacies of three different interpretivist approaches: symbolic interactionism, hermeneutics, and phenomenology – each with their own interpretation of the influence of culture upon the construction of meaning. Interpretivism is considered an important research perspective within the qualitative research paradigm and guides much applied social research design (Ritchie, Lewis, McNaughton, et al, 2014).

4.2.1.5 Critical inquiry

Critical inquiry is a theoretical perspective that stands in contrast to interpretivism, which Crotty (1998) claims to be an inherently uncritical perspective. Also known as *critical theory* (see Crotty, 1998; Ritchie et al, 2014), critical perspectives bridge the gap between objectivism and subjectivism and recognise *"the unity between subjectivity and objectivity in the act of knowing"* (Crotty, 1998: 151). In this sense, critical inquiry has obvious synergies with social constructionism and critical realism but can also be considered to take a rather pragmatic approach to research. Critical researchers go beyond social constructionism and critical realism by focusing on action as empowerment of 'the oppressed' (Freire, 1970). Critical theorists therefore frequently adopt an advocacy, emancipatory, or transformative research lens (Robson, 2002), elevating or centring the voices of the marginalised. As described by Noel (2016), emancipatory research recognises power imbalances in the research process and aims to empower those to whom the research refers, applies and/or impacts upon. Similarly, transformative research aims for empowerment of the historically marginalised, but goes further than emancipatory research by using research findings to promote social change (Mertens, 2010). Some researchers consider critically oriented transformative methodologies or lenses to be, by default, emancipatory (Ntanyoma, 2022).

Ostensibly emerging from Marxist ideology through scholars of the Frankfurt School, critical inquiry underwent a complex evolution through the works of Horkheimer, Adolfo, Habermas, and Freire. The work of Paolo Freire (1970) led to contemporary critical theory, in which:

> *"Critical forms of research call current ideology into question, and initiate action, in the cause of social justice. In the type of inquiry spawned by the critical spirit, researchers find themselves interrogating commonly held values and assumptions, challenging conventional social structures, and engaging in social action."* (Crotty, 1998: 157).

Critical approaches to research seek to break down power relations between the researcher and the researched, ensuring meaningful research agendas are addressed through collaboration in the pursuit of social justice (Ritchie et al, 2014). Critical inquiry is an overarching term for specific critical movements, drawing on feminist, disability, race, and queer research agendas (Ritchie et al, 2014), empowering members of historically oppressed or marginalised groups to take action to change their current situation. Researchers, who may not themselves be members of the group that they are researching, position themselves within the research as a learner, participant, facilitator, and/or advocate.

4.2.1.6: Theoretical perspective considerations in this study

As a speech and language therapist I am familiar with the (post) positivist, quantitative, research that has historically dominated within the profession, related to its roots in medically focused practice. I value its unique contribution to the development and evaluation of efficacious treatment programmes and to evidence-based practice. I do not, however, believe that only one objective reality exists or that quantitative research is the only way to answer respond to professionally relevant research problems, especially in complex contexts.

The theoretical perspective of critical realism, as described by Ritchie et al (2014), supports my understanding of reality: that reality does exist independently of the human conscious, but that it is accessed and attributed meaning through human interaction and experience. As such, individual experience and interpretation of reality varies and cannot be absolute. Critical realism has been adopted by critical disability theorists for its ability to explore the multifaceted experiences of impairment and disablement (Roulstone, Thomas, and Watson, 2012). Similarly, I believe that critical realism can illustrate the complex facets of reality and contribute to human understanding of the natural and social world (Ritchie et al. 2014; Robson, 2002). I also appreciate aspects of the interpretivist perspective, valuing individual experience in different contexts and the use of both inductive and deductive research techniques to place research within existing theory whilst exploring individual experience. As described by McAllister and Lyons (2019), qualitative research in speech and language therapy is usually interpretive in some way.

Despite philosophical agreements with elements of both critical realism and interpretivism, my theoretical perspective also aligns with critical inquiry. The aims of critical inquiry are to understand why power inequities exist and to link them to meaningful emancipatory action (Robson, 2002). People with CIs, who experience barriers to social participation, are often limited in their ability to advocate for themselves (Barrett and Marshall, 2017). As Paterson (2012) argues, social communication norms can be oppressive to people with communication limitations. Roulstone, Thomas and Watson (2012: 6) validate this by stating that *"it is difficult for people with speech impairment to acquire and sustain the physical and cultural capital necessary to participate in everyday social encounters."* Working with people who experience CD, and their families, to evidence their challenges, opportunities, needs and wishes, inherently involves an element of advocacy. My overall perspective would therefore be best described by Creswell (2009) as an advocacy worldview, which fits well with critical research approaches.

4.2.2 Epistemology and ontology

Epistemology and ontology are the foundations upon which research is built. Epistemology refers to the beliefs we hold about the nature, or theory, of knowledge (Teddlie and Tashakkori, 2010) – *"how we know what we know"* (Crotty, 1998, p. 8). The direction a study will take will be influenced by a researcher's epistemological view and its associated ontology (the nature of reality, being or existence - understanding *"what is"* Crotty, 1998 p.10) and axiology (the role of values or ethics, Killam, 2013; Teddlie and Tashakkori, 2010). However, some researchers, including

Crotty (1998), Creswell (2009), and Teddlie and Tashakkori (2010) choose to set discussion about ontology aside, reasoning that epistemological and ontological issues converge and are difficult to delineate, but that both epistemology and ontology influence a researcher's theoretical perspective. Indeed, in Crotty's (1998) framework, ontology is described as 'sitting alongside' (p.10) epistemology in a logical flow of research design from epistemology through theoretical perspectives, methodology and methods.

Crotty (1998) describes three overarching epistemologies upon which researchers frame their assumptions about the acquisition of knowledge:

a) Objectivism
b) Constructionism and
c) Subjectivism

Objectivists postulate that meaning exists independently of consciousness, meaningful actors, or experience – that objects themselves hold meaning that can be uncovered through scientific enquiry (Crotty, 1998). As such, an objectivist epistemology aligns with a positivist ontological or theoretical perspective, whereby positivist researchers believe that the world is 'value free', factual, universal, and objective (Park et al, 2020; Robson, 2002) – that the results of scientific enquiry will not vary if repeated under the same conditions, across time or across cultures (Crotty, 1998). Positivism and post-positivism, and therefore objectivism, align most closely (although not exclusively) with quantitative methodologies of enquiry and associated methods of data collection[25] and analysis. Typically, these methodologies value numerical data, statistical analysis (Braun and Clarke, 2013), and the proof or disproof of a specific hypothesis – in the case of post-positivism, until proven otherwise.

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[25] I use 'collection', rather than 'construction' here purposefully, as positivists/post positivists consider data to already exist and not to be socially constructed.

Constructionists posit that there is no objective truth and that meaning only arises through human interaction with our world– that it does not 'exist' but is 'constructed' within social contexts and within the historical and social perspectives related to culture[26] (Crotty, 1998). Constructionists assert that meaning is neither objective nor subjective but occurs through interaction of the object and the human mind: consciousness coming to 'know' the object and the object being *"shaped by consciousness"* (Crotty, 1998: 44). Social constructionism acknowledges the existence of the natural world that is brought to meaning by the human conscious and asserts that social reality exists only through a culturally interpreted lens. This accounts for the difference in interpretation of the same phenomena by different people across time and cultures and enables constructivism to occupy a middle ground between the poles of objectivism (meaning exists) and subjectivism (meaning can only exist when it is created) (Crotty, 1998).

The social constructionist epistemology arguably forms the basis of the qualitative research paradigm, with its ontological roots in both realism - the understanding that something exists in and of itself (with or without meaning), and relativism (Crotty, 1998) – the understanding that, if people construct their own reality, one single reality therefore cannot exist to be 'discovered' (Guba and Lincoln, 1994). In contrast, although McAllister and Lyons (2019) agree that the qualitative paradigm assumes a relativist ontology, they suggest that it inhabits a more of a subjectivist than constructionist, epistemology. This conundrum is acknowledged by Crotty (1998) who explains that many researchers who claim to be to be constructionists, are actually subjectivists as their epistemological view is more that objects themselves do not have meaning and can only be claimed to do so when meaning is *imposed* upon them by the onlooker – that *"meaning is created out of nothing"* (Crotty, 1998: 9). Indeed, the interpretivist theoretical perspective (or ontology) with which the subjectivist epistemology aligns most closely, acknowledges the cultural and historical *interpretations* of phenomena and the meanings made of them.

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[26] Geertz (1973) defines 'culture' as a *"system of significant symbols"* in his description of constructionism and the impact of 'culture' upon the human conscious and our construction of meaning.

Aligning with Robson's (2002: 23) critiques of the 'standard view' of science in relation to social research, I reject a pure objectivist epistemology and, instead, favour that of social constructionism: that the existence of the natural world is brought to meaning by the human consciousness, and that *social* reality exists only through a culturally interpreted lens. This, for me, explains the difference in interpretation of the same phenomena by different people across time and cultures (reflected in Crotty, 1998).

4.2.3 Pragmatism: An alternative paradigm

Pragmatism emerged as a research philosophy in the late nineteenth century through the works of Charles Sanders Peirce (1839-1914), William James (1842-1910), John Dewey (1859-1952), and James Herbert Mead (1863-1931), amongst other American academics (Adelaine, 2015; Crotty, 1998; Kaushik and Walsh, 2019). Peirce originally developed the term 'pragmatism' to embody the Kantian theory of connectedness between knowledge and action and the consequences of action on the construction of meaning, which endures to this day (Adelaine, 2015). However, as pragmatism developed through the work of James and Dewey, it took a turn away from Peirce's original ideology becoming, what he considered, uncritical, to the point of Peirce abandoning the 'new' form of pragmatism and renaming his ideology, 'pragmaticism' (Crotty, 1998).

Deweyan pragmatism rebuffed the concept of a single, abstract notion of how we access reality, instead turning its attention to the human experience and its central role in the development of knowledge. For Dewey, *"experience creates meaning by bringing beliefs and actions in contact with each other"* (Morgan, 2014a: 2). Culture, experience and context, or environment, are key to the pragmatist understanding of knowledge development. In this way, pragmatists assert that reality is changeable, that there is no single reality to be discovered or experienced, only what is experienced within a given context.

Although Deweyan pragmatists believe that multiple realities exist, that is not to say that their views are bound by constructionist principles. On the contrary, pragmatism embraces the principles of both multiple- and single-reality philosophies (Creswell and Plano Clark, 2011) as "*social contexts for inquiry as a form of social action, rather than as abstract philosophical systems"* (Morgan, 2014: 5). Indeed, pragmatism sought to dissolve the polar realism/idealism debate, instead considering them both necessary to understand human experience in the context of a single reality existing, but being situated within an environment that can only be *"encountered through human experience"* (Kaushik and Walsh, 2019: 3). Breaking down metaphysical polarity constituted a momentous paradigm shift in research philosophy. In doing so, Dewey was considered to have created a new research paradigm that broke free from the traditional theoretical constraints of the polarised traditional ontologies and epistemologies (Hall, 2013; Morgan, 2014).

4.2.3.1 Deweyan inquiry: Experience, emotion, and fallibility

Human experience is a central tenet of Deweyan pragmatism. The sources of human belief and the meaning of human action are considered inseparable and cyclical. As Morgan (2014: 2) states, *"beliefs must be interpreted to generate action, and action must be interpreted to generate beliefs."* 'Inquiry' occurs when we employ a detailed process of decision-making. Dewey considered research *"a form of inquiry that is performed more carefully and more self-consciously than most other responses to problematic situations"* (Morgan, 2014: 3). In other words, research is simply one form of inquiry and inquiry is one form of experience (Morgan, 2014).

Dewey also considered emotions to link beliefs and actions. He refuted the idea that inquiry is linear, moving from problem identification to problem resolution, but posited that inquiry involves continuous cycles of movement between beliefs and actions, giving rise to, and being influenced by, emotions before a resolution can be established (Morgan, 2014). According to Dewey, human feelings affect every aspect of inquiry. As such, reflection upon decisions made throughout the process of inquiry is critical to the pragmatist approach to research. Indeed, pragmatism is a deeply reflective practice: one which locates the researcher, with their own experience, culture, history, emotions, and agency, as central to the inquiry.

In Deweyan pragmatism, an ongoing cycle of action and reflection is inherent throughout the inquiry process. This illustrates Dewey's assertion that reality is not fixed and that every person has individual agency to act on their environment according to their experience and to experience the environment according to their actions (Adelaine, 2015). Indeed, if the world comprises both physical and social realities, pragmatists believe that we cannot separate the two in the same way that Dewey asserted that the 'knower and the known' cannot be separated (Bentley and Dewey, 1949).

The concept of fallibility comes into play when considering the changing nature of human circumstance. When environment and experience are subjected to human interpretation in differing contexts, knowledge can be nothing *but* fallible and changeable. As such, pragmatist inquiry is not concerned only with *what* researchers do, but *why* they do it in the way they do (Morgan, 2014). They consider how outcomes would be different if other methodologies were to be employed, and what this would mean in terms of understanding of the human experience.

4.2.3.2 Pragmatism in social research: Towards social justice, emancipation, and transformation

In rejecting the metaphysical contrasts between ontology, epistemology and methodology, the pragmatic paradigm offers the researcher freedom to place the research question at the fore, and the theoretical aside. Although criticised for avoiding the epistemological question (Lincoln, 2010), Dewey called for traditionalists to move on from the unsolvable debates. In doing so, researchers become untied from a single metaphysical pole and are encouraged to select the best research methodology to produce the best answer to the research question(s) (Miles, Huberman and Saldaña, 2020). As Morgan (2014: 6) highlights, *"pragmatism emphasizes that all aspects of research inherently involve decisions about which goals* *are most meaningful and which methods are most appropriate"*. Pragmatism is therefore an inherently solution-focused and pluralistic worldview (Patton, 1990; Robson, 2002) that permits researchers to employ a range, and sometimes combination of, research methodologies that traditionally fell within one or the other of the polarised quantitative and qualitative paradigms: the aim being to describe the nature of human experience (Morgan, 2014).

An increased adoption of pragmatism by proponents of mixed methods research (MMR – see section 4.3.1.4) caused some concern amongst pragmatists, who worried that some MMR researchers reduced it to a merely practical, methodological approach to inquiry that was seen to let the researcher 'off the philosophical hook' (Morgan, 2014). The concern was that some proponents of MMR emphasised 'how' to address a research problem, whilst neglecting the other half of the pragmatist approach – the *why* of research that goes beyond problem solving as a means to an end (Morgan, 2014). This crude reduction to the practical also served to diminish pragmatism's credibility as a research philosophy in some academic circles and illustrates the great importance of philosophical transparency in any MMR research project.

Despite this, the applicability of pragmatism to contemporary social science research cannot be overstated. Questions of social inequality, power and politics are common features of pragmatist inquiry (Collins, 2017), with a view to creating an agenda for social change. Pragmatism's focus on experience and context is also a critical element of research conducted with a postmodernist lens – that with an agenda for disruption of the status quo (¡Ntgrty, 2016), or social and political advancement (Creswell, 2009).

The philosophical underpinnings of pragmatism include axiological considerations: the researcher is aware of their personal values and the effects of their objective and subjective interpretations on the design of research and the way in which results are interpreted (Hesse-Bieber, 2012). As Morgan (2014: 6) explains:

> *“ethical questions are questions about what to do and about the difference it would make to act one way versus another, and, as such, they fall directly within Dewey’s philosophical emphasis on human experience”*.

The ‘freedom of inquiry’ that Dewey assigns to the pragmatist approach enables people to define which problems are most meaningful to them (Dewey, 1954) and hence provides a natural segue to transformative and emancipatory research approaches, such as research with a critical feminist (Morgan, 2014) or disability (Robson, 2002) lens, where the traditional power relations between the researcher and the researched are reduced or dissolved (Robson, 2002). As Kaushik and Walsh (2019: 12.) articulate, *“[pragmatism] sets an inclusive framework of inquiry that supports interdisciplinary and cooperative research about social justice”.*

~~Central to my professional engagements across the GLR is the understanding that history, culture, and experience play crucial roles in people’s understanding of their world, and that experienced reality is a deeply personal phenomenon. Cross-cultural engagement in research brings with it a plethora of challenges related to how the different parties understand the research process. Although I have attempted to clarify the research philosophy underpinning my worldview, I find it challenging to classify complex, cross-cultural social research in absolute terms, as demonstrated by my appreciation of aspects of critical realism, interpretivism and critical inquiry. I have concluded that it is not possible to pigeonhole cross-cultural social research into one philosophical framework or another. I therefore consider that my research is conducted within a pragmatist paradigm moving away from staunch metaphysical debates, classifications, and rule-bound limitations, and towards a philosophy of freedom of inquiry to conduct research in the best way to answer the research questions. Pragmatism’s focus on the influence of history and culture, coupled with its emancipatory ideology, fits well with the combination of critical realist, interpretivist, critical inquiry, and advocacy perspectives that I value and that influenced my research. The quest for social justice overlaps both pragmatism and critical inquiry. I suggest that a critical inquiry with a disability focus can be considered a lens through which research is conducted under a pragmatist paradigm.~~

~~As advocated by Ritchie et al (2014) and Thorne et al (1997; 2004), quality of research is based on choosing the most appropriate tools for the job, rather than adhering to a particular research tradition, and I agree that applied, real-world, research necessitates this perspective.~~

4.3 Methodology

As research philosophy suffers from a lack of consensus on terminology and categorisation, research methodology is similarly subject to semantic ambiguity. Returning to Crotty (1998), methodology is described as a *strategy* that incorporates the type of research being carried out, alongside a description of the way(s) in which it will be conducted. The methodology chosen is informed by a researcher's theoretical perspective. Crotty also suggests that the methodology should account for any specific lens or approach that may be utilised within a particular strategy. He does not, however, discuss quantitative, qualitative, or mixed method research as methodology. Instead, these are embedded within the research design without explicit mention.

Although McAllister and Lyons (2019) refer explicitly to qualitative and quantitative research *paradigms*, their understanding of methodology aligns with that of Crotty (1998), as being research choices about *how* to explore phenomena (also reflected in Silverman, 2013). In contrast, Glogowska (2011) refers to qualitative and quantitative *methodologies* and, in further juxtaposition, Creswell (2009) considers qualitative, quantitative, and mixed-method *research designs*. Creswell's (2009) *strategies of inquiry* are types of design that are related more to procedural direction within the research – that which Crotty (1998) and McAllister and Lyons (2019) consider methodology.

Whichever terminology a researcher favours, it is imperative that the decisions made as to the overall design of the study are transparent, and that the researcher offers a sound rationale for their choices, aligned with their philosophical worldview.

Moving away from Crotty’s (1998) framework, I describe quantitative, qualitative, and mixed method designs as defined by Creswell (2009), to ensure clarity of terminology, incorporating my thoughts on the appropriateness of each to this study. I will then return to Crotty (1988) and McAllister and Lyons’ (2019) definition of methodology.

4.3.1 Quantitative, qualitative, and mixed method designs

Although research designs traditionally fell into two categories that roughly aligned with the opposing positivist-relativist ontologies or theoretical perspectives, as research philosophy evolved so did its corresponding methodological considerations. Creswell (2009) warns against viewing quantitative and qualitative designs as dichotomies, instead suggesting they are two ends of a continuum along which research can be positioned, based on a researcher’s underlying philosophical assumptions.

4.3.1.1 Quantitative research design

Quantitative design is primarily concerned with measurement, the relationship between variables, and the proving or disproving of a priori hypotheses using deductive methods (Creswell, 2009). It focuses on the use of numerical data and their statistical analysis. Experimental design and the ability to generalise or replicate findings aligns closely with an objectivist epistemology and positivist ontology. As post-positivism emerged, quantitative research methodology evolved to incorporate quasi-experimental designs, descriptive studies, and survey research, for example (Robson, 2002).

4.3.1.2 Qualitative research design

Qualitative design has traditionally stood at the opposite end of the spectrum to quantitative research, concerned with understanding human behaviour. As such, it aligns most closely with the constructionist/subjectivist epistemologies and interpretivist theoretical perspective. Qualitative research *"uses words as data"* (Braun and Clarke, 2013: 3). Theory tends to be generated from data within a more flexible research design that typically favours an inductive style of inquiry and appreciates the complexity of situations involving human interactions (Creswell, 2009).

4.3.1.3 Multiple method research design

Multiple method design is considered by some researchers to constitute the use of multiple methods of data collection and analysis under one qualitative *or* quantitative paradigm (e.g., Creswell and Plano-Clark, 2007). However, this definition is contested, and multiple method research is defined by others as the use of more than one qualitative *and/or* quantitative data generation and analysis procedure (e.g., Mills, Durepos and Wiebe, 2010; Morse, 2003). In the latter sense, *mixed* methods research (see 4.3.1.4 below) is therefore one type of multiple method research whereby more than one method of data collection and analysis has been utilised. Indeed, Fetters and Molina-Azorin, (2017: 5) state:

> *"Multiple methods research refers to all the various combinations of methods that include in a substantive way more than one data collection procedure. Multiple methods research can include two or more exclusively qualitative approaches, Qual plus Qual, two or more quantitative approaches, Quan plus Quan, or a combination of qualitative and quantitative approaches, Qual plus Quan, hence mixed methods research. In our view, mixed methods is one category of multimethods or multiple methods research"*

4.3.1.4 Mixed-methods research (MMR)

As discussed, MMR is one form of multiple method research and commonly combines elements of both quantitative and qualitative research. It can therefore be considered to align well with the pragmatist research paradigm that rejects traditional theoretical dichotomies, and with which this study aligns. Criticised by steadfast metaphysicians from the positivist and interpretivist camps for avoiding epistemological and ontological debates (see Lincoln, 2010) and for attempting to combine philosophically incompatible methodologies (Glogowska, 2011), MMR has also come under criticism from pragmatists themselves who believe that some MMR practitioners use solution-focused research design in the absence of accountability to the underpinning philosophy upon which pragmatism is built (Morgan, 2014). MMR has nonetheless experienced a surge in popularity in recent years and has gained credibility as a sound research methodology. Moreover, Creswell (2013) and Creswell and Plano Clark (2007) assert that MMR is not simply the sum of two research parts. Indeed, MMR utilises both approaches to strengthen research *beyond* the sum of those parts: ‘crystallisation’ (Richardson, 2000) or ‘integration’ (Fetters, Curry, and Creswell, 2013)[27] playing a key role in constructing rigorous, credible interpretations of synthesised data.

MMR is acknowledged to have made a significant contribution to research in global health and education, with applicability to complex research realities in low and middle-income countries (LMICs) (Adelaine, 2015; Abdullahi and Farouk, 2014; Ozawa and Pongpirul, 2014). It is also becoming a more accepted research design for health professions such as speech and language therapy (Glogowska, 2011) which have been historically dominated by quantitative research (McAllister and Lyons, 2019).

Within MMR designs the order in which data are constructed,[24] and the weight they are given in relation to other parts of the study, is based upon its purpose within the research. Creswell (2009) presents four important aspects of mixed method procedure which determine how the data are used. These include timing (when the data will be generated in relation to other data); weighting (the priority given to certain data based upon the purpose of the study); mixing (when to mix qual/quant data, and how), and theorising (how a theoretical perspective or lens shapes the research).

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[27] Also referred to as triangulation (e.g., Denzin, 2012; Lincoln and Guba, 1985; Noble and Heale, 2019; Tariq and Woodman, 2013). However, this terminology is contested as it suggests a precise answer can be reached, which is contra to the ethos of qualitative research (Fetters and Molina-Azorin, 2017; Clarke, 2022).

Creswell (2009: 209-216) describes six major mixed methods designs,[28] including:

- Sequential explanatory strategy
- Sequential exploratory strategy
- Sequential transformative strategy
- Concurrent triangulation strategy
- Concurrent embedded strategy and
- Concurrent transformative strategy

Creswell (2009) urges researchers to be explicit about their design choices, including influences such as any theoretical lens, or practical limitations such as time and resources. As such, the results of the research process can be considered against the overall research design, including its strengths and limitations (see section 4.5 for an explanation of my choices for this research).

Quantitative research design is common in medical and allied health research, including in speech and language therapy. Its contribution to change and impact measurement is undoubtedly valuable. Quantitative methods alone, however, are seldom able to elucidate the reasons why change may occur, or the impact that change may have on people’s lives. For this, qualitative research methods offer the opportunity to explore human experiences and opinions in depth.

As this study is grounded in my own experiences and beliefs as a speech and language therapist, I see the professional value of combining both quantitative and qualitative methodologies in a mixed (and multiple) methods approach in health and education research. In this study, I aimed to understand a situation from multiple perspectives – both what ‘exists’ in terms of numerical data, as well as peoples' experiences, in a complex context, as well as to understand what could be done to change the situation and why. I felt that the meaning of these phenomena could not be

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[28] Each design is visually represented using a system of mixed-methods notation whereby capitalisation implies weight, ‘->’ implies sequential data collection, ‘+’ implies concurrent data collection, and a system of boxes denotes how and when data will be mixed.

understood sufficiently by taking only one methodological approach. Supporting Creswell and Creswell and Plano-Clarkes' assertions that MMR brings more to research than the sum of its parts, I believe that MMR facilitated the judicious use of multiple methods to answer my research question in the best way possible – from a 360° perspective.

4.3.2 Crotty's definition of methodology

Returning to Crotty (1998), a methodology should guide the researcher to choose their methods with which to conduct the research, informed by their theoretical perspective. Similarly, McAllister and Lyons (2019), suggest that the methodology of choice is influenced by underlying philosophical assumption, and influences approaches to data collection and analysis, thus occupying a crucial position in the research process.

Below I discuss three qualitative methodologies that influenced my decision-making on the approach I chose for this study: Ethnography, grounded theory (GT), and phenomenology. My choice of quantitative methodology is described in section 4.5.2.3.

4.3.2.1 Ethnography

Ethnography is an anthropological methodology, characterised by long-term, physical, social, and cultural immersion of the researcher in the lives of the researched. Multiple qualitative methods such as participant observation, open-ended interviewing, and the collection of artefacts are employed to construct data.[24] The documentation of the experiences and observations made, along with the generation of explanations of *"the cultural constructions, in which we live"* (Hoey, n.d., online), generate rich information about peoples and cultures from an insider's perspective. Contemporary ethnographers have combined ethnographic strategies with other methodologies, such as case-study research (Parthasarathy, 2008) to produce hybrid methodologies more suited to application in a wider range of fields, including health care.

Although in-depth ethnography would be an appropriate research methodology for the qualitative elements of this study, in terms of understanding more about the challenges and opportunities affecting refugee children who experience CD, it was not possible to take this approach for practical reasons. This included the restricted access time I was granted to visit the refugee camps, the time available for data collection overall, and the fact that the study took place across three locations. There are also considerations related to the colonial/outsider elements of ethnography (stemming from its roots in the observation of 'primitive' cultures by white westerners) that were of significance to this study. Interpretive Description is, however, influenced by ethnography and incorporates elements of it into its approach to data construction and analysis.

4.3.2.2 Grounded theory (GT)

Grounded theory was developed by Glaser and Strauss (1976), becoming a methodology for theory generation 'grounded' in data that are collected and analysed in a systematic fashion (Noble and Mitchell, 2016). GT follows a strict methodological process of theoretical sampling, data coding, and analysis, which results in novel theory of social process and explanation of social behaviours related to the topic of investigation. Not without controversy, the architects of GT themselves took the methodology in different directions throughout the 1970s and '80s (Charmaz, 1994). Indeed, what was originally conceived on positivistic foundations has, over time, been appreciated and implemented from a more constructivist perspective (Charmaz, 1994), Moreover, the evolution of modern qualitative research has witnessed studies being undertaken using methodologies based on the principles of GT, rather than using GT in its pure form. Charmaz (1994: 509) describes how *"researchers have claimed the use of these methods to legitimate their research."* This can be regarded as both damaging to the reputation of the methodology as rigorous and valid, whilst simultaneously leading modern researchers toward new and innovative research techniques better suited to complex contemporary research agendas, particularly in applied fields – a case in point being the evolution of traditional qualitative methodologies into approaches such as Interpretive Description, as employed in this study (e.g., Thorne, Reimer Kirkham, and MacDonald-Emes, 1997; Thorne, Reimer Kirkham, and O'Flynn-Magee, 2004).

Although aspects of grounded theory could be very applicable to this study, I aimed to document and describe human experience, and understand intersections and influences, rather than to generate theory. The elements of grounded theory utilised within Interpretive Description, such as systematic coding and staying 'close' to the data are, however, employed and described in chapters 5 and 6.

4.3.2.3 Phenomenology

Phenomenology emerged in the early 20th century. Based on the notion that truth can be ascertained through the understanding of human experience (Burch, 1989), it is concerned with 'entering the lifeworld' of research participants (Finlay, 2011; van Manen, 1990) to explore and describe social phenomena, rather than explain them (MacKenzie, McAllister, Hudson, et al, 2019). It invites us to "*explore and perceive in order to understand as we journey with our participants*" (MacKenzie et al, 2019: 193).

The phenomenological research perspective was influenced by the works of interpretivist thinkers such as Brentano, Husserl, Heidegger, Gadamer, Arendt, Levinas, Sartre, Merleau-Ponty and Derrida (Moran, 2000). Although early phenomenologists such as Husserl believed that researchers should leave aside their own prejudices and biases when approaching the research task in a process known as 'epoché' or 'bracketing', more contemporary thinkers, such as Heidegger, considered bracketing impossible and instead proposed a form of hermeneutic phenomenology that embraced the pre-existing experiences of researchers and brought them to the research experience (MacKenzie et al, 2019).

Hermeneutic phenomenology looks for meaning beyond words. It seeks to interpret the data considering the author's history, culture, and other social and environmental influences (MacKenzie et al, 2019). Gadamer (2013) developed this concept further through his metaphor of a 'fusion of horizons' between the researcher and the participant whereby each brings their own pre-existing prejudices to the experience and, whilst maybe not agreeing with each other, are able to come to an understanding of each other. The hermeneutic phenomenological approach to researcher-participant engagement arguably facilitates the equalisation of power that is also central to more critical approaches to research and is therefore most applicable to the philosophical underpinnings of this study.

The concept of the double hermeneutic refers to the *"dialogical relationship between research and researcher"* (Mills, Durepos, and Wiebe, 2012: 323). Hermeneutic phenomenology is particularly suited to communication disability research in many ways (MacKenzie et al, 2019; Paterson, 2012). It appeals to a therapist's desire to interact with clients openly and to 'journey' with them, whilst also bringing their experiences to the interaction – a process Rogers (1951) terms listening with 'congruence'.

Of the three qualitative methodologies described, hermeneutic phenomenology aligned most with what I was aiming to achieve in this study and the way in which I felt I could best approach the qualitative aspects of the research to address the research question. The concept of the double hermeneutic aligned with both the study's pragmatist philosophical grounding, as well as the critical approach I aimed for. It also addressed aspects of cross-cultural research challenges, such as researching as an 'outsider' of a cultural and/or linguistic group and the ability to bring myself to the research processes, whilst acknowledging the impact this may have on the findings.

4.4 Research methods

Research methods form the final section of Crotty's (1998) framework of the research process. Methods of data construction[24] and analysis stem from the methodology chosen, influenced by a researcher's philosophical assumptions. As such, they can be considered the techniques, or tools, used by the researcher to gather the information required to answer the research questions, or construct theory grounded in the data. Research methods constitute the *how* of the research process. Crotty (1998) therefore urges researchers to be specific when describing not only what methods we choose, but how we use them and to what end, thus conducting a critical appraisal of our own research design process.

As there are numerous methodologies and methods at the researcher's disposal, it is beyond the scope of this chapter to discuss them all in detail. Instead, I will explain and justify my choice of methodology and methods, and the rationale for my decisions, in section 4.5 below, and in chapters 5 and 6.

4.5 This research project's design and rationale

In this section I apply the philosophical and methodological theory discussed above, to this study. Some of the choices I made, along with the rationale for doing so, have been introduced in the above sections. Here I bring this together in summary. A summary infographic of the study design is provided in chapter 1, figure 1.

Transparency regarding research philosophy is critical to ensuring that the research audience can judge the relevance of outcomes and interpretations against the assumptions inherent in the research design (Creswell, 2009), as well as to the assessment of research quality (see section 4.6). By the very nature of research philosophy, it is difficult to pinpoint whether my worldview guided my choice of research topic and questions, or whether my interest in the topic developed my understanding of my own philosophical outlook. On reflection, I believe that both processes occurred simultaneously.

4.5.1 Research philosophy

As discussed above, I describe my understanding of research philosophy as a theoretical perspective. Influenced by alignments of my perspective with elements of social constructionism, critical realism, interpretivism, and critical inquiry, I find it challenging to classify complex, cross-cultural social research in absolute terms. Pragmatism's focus on the influence of history and culture, coupled with its emancipatory ideology, therefore fits well with the combination of perspectives that I value and that influenced my research.

The quest for social justice overlaps both pragmatism and critical inquiry. I suggest that a critical inquiry with a disability focus, can be considered a lens through which this research is conducted under a pragmatist paradigm. As advocated by Ritchie et al (2014) and Thorne et al (1997; 2004), quality of research is based on choosing the most appropriate tools for the job, rather than adhering to a particular research tradition, and I agree that applied, real-world, research necessitates this perspective.

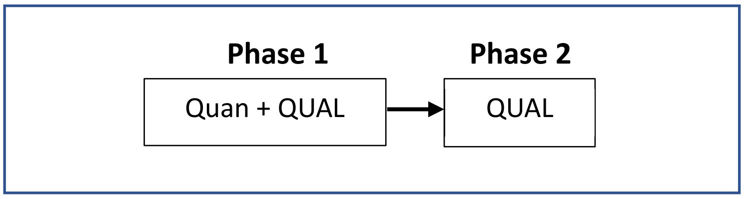
4.5.2 Methodology

As is the case with much pragmatist research, this study followed a multiple methods research design**.** The study was in two phases with different, but connected, aims and objectives (chapter 1). Phase one was concerned with the identification and registration of refugees with CI, who experience CD, as a precursor to understanding the experiences of providing and accessing inclusive ECD and education services in refugee camps in Rwanda (phase 2). Multiple (in phase one, mixed) methods were therefore chosen to provide distinct, yet complementary, approaches to the research objectives.

Within each phase, a range of methods were used to construct data.[24] Therefore, the overall design of the study was mixed quantitative-qualitative design in phase one, and a multiple qualitative design in phase two. This enabled me to understand the different perspectives of a range of participants and sources, whilst situating quantitative information in a real-world context. (Writepass, 2017).

A two-phase sequential transformative research design (Creswell, 2009 – figure 7) describes the way in which the research was conceptualised. Research was conducted through a critical disability lens and data were collected sequentially: Phase one data first, followed by phase two data. Phase one analysis informed, but was not necessary for the completion of, phase two. In this study, the quantitative data informed, but were not necessary for, the analysis of the qualitative data.

Figure 7: Sequential transformative research strategy



As described by Creswell (2009: 213):

> *"The purpose of the sequential transformative strategy is to best serve the theoretical perspective of the researcher. By using two phases, a sequential transformative researcher may be able to give voice to diverse perspectives, to better advocate for participants, or to better understand a phenomenon or process that is changing as a result of being studied."*

This design not only reflects the two-phase nature of this study, but also allows for any changes across the research that are due to the research being undertaken (e.g., potential increase in knowledge and understanding of CD amongst participants through wider engagement on the topic in their professional life).

The pragmatist approach to this research, conducted through a critical disability lens, did not lend itself wholly to any one of the established research traditions. Instead, elements of each were relevant to the study, but the complex, cross-discipline, cross-cultural, practice-based nature of the research aims and objectives dictated that no single research tradition was fully applicable. Keen as I was for the findings of this research to address real-world issues of rights realisation and social exclusion and make tangible changes for refugee-children who experience CD, I was frustrated by the criticisms levied against researchers who are perceived to 'tinker' with the methodological traditions to fit their own research agendas, ostensibly diluting the methodologies. As I investigated further, I was reassured to find other contemporary applied practitioners (e.g., Thorne, 2016) had experienced the same frustrations.

4.5.2.1 Interpretive description (ID)

Interpretive Description is a qualitative research methodology that originally developed within the field of nursing (Thorne, et al, 1997) and has since been applied more broadly across the health sciences, including in speech and language therapy (e.g., Brewer, Harwood, McCann et al, 2014). Its roots are grounded in traditional qualitative research traditions, drawing on phenomenological, ethnographic, and grounded theory methodologies (Brewer et al, 2014), yet depart from them since none are considered *"compatible with the pragmatic demands of the applied disciplines"* (Thorne, 2016: 35).

ID emerged from nursing science research being conducted to respond to research needs specific to the profession, but which could not be categorised as following a specific methodological tradition. This, arguably innovative and responsive research, would therefore usually be classified as of 'generic qualitative design' (e.g., Bradbury-Jones, Breckenridge, Clark, et al, 2017) or 'non-categorical' design (Thorne, et al, 1997). Unperturbed by criticism that this generic research was ill-conceived, 'sloppy' (Morse, 1989), or mediocre (Stern, 1994), Sally Thorne and her colleagues insisted that it was instead crucial to the development of clinical knowledge and insight within their discipline. Indeed, Thorne (2016: 11) describes how research in the applied disciplines is:

> *"fundamentally complex and messy, often representing the kinds of wicked problems that defy whole or coherent theorizing and demand instead a multiplicity of insights, perspectives, and approaches, used intersectionally together within increasingly dynamic contexts."*

As such, she and her colleagues sought to attribute credibility and gravitas to this style of flexible and responsive research by grounding it firmly in nursing's epistemological and practical mandates (Thorne et al 1997; 2004). The result was the classification of ID as a rigorous, epistemologically explicit, accepted methodology for high quality qualitative research.

ID seeks to elucidate commonalities and divergences within a topic of concern. Brewer et al (2014: 1290) describe how ID researchers:

- *"value the clinical insight gained from subjective and experiential knowledge;*
- *pay attention to the context in which the research occurs, although the issues being researched are not unique to one context;*
- *acknowledge the inseparability between the knower and known, and the way the researcher and participant influence each other.*
- *acknowledge that human experience is socially constructed and can involve many contradictory realities; and*
- *are attentive to the participants' ethical rights and comfort and undertake research in the most naturalistic setting possible."*

A researcher will naturally sway towards (even if not completely buy into) a philosophical ideology and the proponent of ID is no exception. Although ostensibly 'atheoretical' (Thorne, 2016), ID is broadly interpretivist[29] in its acknowledgement of the constructed and contextual nature of health experience (Thorne et al, 1997), and is of a social constructionist epistemological persuasion. However, the overall philosophically unbound nature of ID[30] (Brewer et al, 2014) sits comfortably within a pragmatist paradigm that addresses the issues at hand in the best possible way. Indeed, proponents explicitly refer to the concept of the *"inseparability of the knower and the known"* (Brewer et al, 2014: 1290) - a clear link to Deweyan philosophy (see section 4.2.3.1). Moreover, both ID and pragmatism value the applied nature of exploratory research in developing findings that are relevant to action, with a critical

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[29] Indeed, Sandelowski (2016) refers to the influence of Thorne's symbolic interactionist understanding on research methods in ID.

[30] Thorne (2016) does not claim that ID comes from one philosophical stance or another.

lens (Thorne, 2016). In the case of ID, this was conceived as clinical action – changes to improve clinical service delivery. In the case of this study, it was not *clinical* action per se (although with reference to a clinical *population* in people who experience CD), but instead related to *humanitarian* action (as reflected in Hunt, 2010) based on the lived experiences of refugee children who experience CD, their families, and their service providers.

4.5.2.2 ID through a critical disability lens

ID is an inherently critical methodology, and its proponents actively encourage researchers to develop such a critical lens (Thorne, 2016). Mladenov's (2016) critical approach to the exploration of 'existential-ontological aspects of disability' (Mladenov, 2016: 3) and the notion of 'dis/ableism' (Mladenov, 2016: 4) is rooted in Heideggian and Merleau-Pontian phenomenology. Merleau-Ponty (2002), through his phenomenological theory of embodiment, posits that humans engage with the world around them through their bodies, rather than just their consciousness (Weiss, 2015). MacKenzie et al (2019: 196) describe this as the human lived body being *"a self which is a both thinking entity in a physical manifestation and a physical entity with an intellect."* Merleau-Ponty's concern with how the lived body is used in the perception of reality has been central to the development of a significant body of research in the health sciences. Moreover, although criticised by many critical theorists for the lack of attention to gender, race, and disability issues, Meleau-Ponty's theory of embodiment has played an undeniable role in the evolution of critical inquiry in feminism, race, and disability research. Indeed, Weiss (2015: 77) describes:

> *"specific feminist philosophers, critical race scholars, and disability theorists who creatively utilize Merleau-Pontian insights to illustrate, and ultimately combat, the insidious ways in which sexism, racism, and ''compulsory able-bodiedness'' (McRuer, 2006) ….. impoverish the lived experience of both oppressors and the oppressed, largely by predetermining the meaning of their bodily interactions in accordance with institutionalized cultural expectations and norms."*

As people who experience CD frequently communicate in ways contrary to 'cultural expectations and norms', it is important to understand the way in which they experience their reality through the interaction of their body and mind with society, viewed through the lens of CD and any intersection with other features considered to contribute to oppression (e.g., gender, sexuality, race/ethnicity). In support of this, ID methodology has been combined with critical approaches in cross cultural CD research (Brewer et al, 2014). Brewer et al's (2014) critical approach to cross-cultural research, combining ID and Kaupapa Māori Research (KMR) methodologies, raises and tackles important ethical and moral issues related to ownership and power in cross-cultural research within an ID framework – issues that were central to my own study (see chapter 7, section 7.3.1). The synthesis of KMR and ID in Brewer et als' work resulted in a shared outcome of culturally relevant, ethically sound, participant-owned piece of research, which was, in tandem, emancipatory for the Māori participants who experienced CD and clinically transformative for the SLT profession in Aotearoa (New Zealand).

My study employed an ID methodology, incorporating a critical disability lens, to describe the experiences of refugees who experience CD, their families, and their service providers in Rwanda. ID afforded me the opportunity to conduct research within a broadly pragmatist paradigm, whilst establishing *"relevant and meaningful disciplinary logic"* (Thorne, 2016: 39), methodological rigour (see section 4.6), and credibility. It also allowed for a multiple qualitative methods approach to most of the study and statistical analysis of secondary numerical data in phase one. Indeed, Thorne and colleagues consider that *"the judicious application of a range of data sources can add considerable strength to the usual data sources of interviews and observations for the purposes of generating practice knowledge"* (Thorne et al, 1997: 174) within ID methodology. Furthermore, ID enabled me to locate the research within existing theory and knowledge, to appreciate emerging knowledge and understanding, and to expound its practical applications to the field context. Crucially, I was able to bring myself to the research as a participant in the interaction, acknowledging my experiences, biases and prejudices and their influences on the study in a cycle of participation and reflection. I consider this opportunity for reflexivity an essential component of cross-cultural, cross-contextual, cross-linguistic, research (see chapter 7, section 7.3).

Viewing ID methodology through a critical disability lens enabled me to design a piece of research directly responsive to UNHCR's observations of, and concerns related to, exclusion of persons of concern (POC) – refugees who experience CD. The ID methodology supported the generation of both service-relevant (in this case registration, ECD and education services for refugees) and socially relevant findings, with the voices of POC at the core. In analysing the data and presenting findings to UNHCR and their partners, the opinions of the excluded and their service providers can be brought to the fore, fulfilling an advocacy function culminating in a call for social action.

4.5.2.3 Methods: data construction

Interpretive description is based on a broadly symbolic interactionist (interpretivist) understanding of research methods: that *"they become what they are in the hands of the users"* (Sandelowski, 2016: 21). The unique flexibility of research design allows a range of methods to be used to best address the research aims and objectives. Within this, Thorne (2016) also describes how data generation construction and analysis using different methods are often unexpectedly interdependent. Indeed, as a researcher gathers qualitative data, they are actively making decisions as to what is relevant or peripheral, adding or rejecting new forms of information, and subtly adjusting lines of enquiry. Therefore, rather than referring to data collection, or generation (e.g., Graue and Walsh, 1998; Clarke, 2022), Thorne refers to data *construction* to describe this inductive and evolving process. This conceptualisation is supported by Clarke (2022), who takes a similar approach to understanding qualitative data analysis. Clarke argues that data are co-constructed by the researcher, through their own participation in the research process: *"There is no research without the researcher. They are not mere witnesses – they are the research"* (Clarke, 2022. Online.).

Thorne (2016) describes how, when using an ID methodology, the researcher must be accountable for the methods chosen, demonstrating critical appraisal of the rationale for their selection and transparency in their execution. Strengths and limitations should be clearly elucidated, from selection of methods through to analysis and interpretation. This is of relevance when integrating data from a range of sources, to ensure each data construction and analysis method is transparent and their combined strengths contribute to cumulative academic rigour (see section 4.6).

The methods employed in phases one and two of this study are described below, with the rationale for their selection. However, the detailed procedures for carrying out each method and for analysing data are detailed in chapters 5 and 6 (parts A, B, and C respectively).

1. *Statistical analysis of secondary numerical data*

   As discussed in section 4.3.1.1, quantitative methodology aligns most naturally with positivist and post-positivist research paradigms (see section 4.2.1.1), except when employed within an MMR study (with fundamentally different philosophical roots) as a method for integration with qualitative methods. In this research project, quantitative methods were chosen to analyse secondary numerical data, generated by UNHCR Rwanda, to better understand the (documented) prevalence of CI/CD amongst the refugee population. This information was utilised alongside primary qualitative data to enrich understanding of participant stories. Not only was it not possible to generate numerical data myself due to the size of the refugee population and complexities associate with access but using secondary UNHCR data also enabled comparison of Rwanda data to regional and global data from the same source. Moreover, and as stated by MacInnes (2020, online), *"Secondary analysis promotes transparency, reproducibility, and replication in research and facilitates the cumulative growth of knowledge."*

   Two common methods of data analysis and presentation were possible:

   a. Descriptive statistics

These aim to describe raw data using summaries, graphs, tables, and other visual displays. They enable the researcher and their audience to understand data quickly and easily and can be used to summarise large sets of data into a small number of (or single) figures. Measures such as central tendency, or measures of dispersion, are used to identify and display centres of data convergence and dispersion patterns. Graphs and tables can be used to visually display data (Wheelan, 2014). Descriptive statistics are concerned with describing a context, and not necessarily generalising results to broader or large contexts.

b. Inferential statistics

These aim to use smaller data samples to make predictions or assumptions about larger data sets from the same population/origin. Issues of representation of the sample are important in inferential statistical analysis, to avoid any skew in interpretation that may be rendered meaningless in application to a larger population (e.g., over/under-representation according to age/sex/gender/location). As such, the sample characteristics should, as far as possible, match the characteristics of the wider population about which the inferences are being made, to ensure generalisability of findings is possible. Common inferential methods include hypothesis testing, use of confidence intervals to measure certainty of an assertion, and regression analysis to understand the relationship between variables (Wheelan, 2014).

For this research, I chose to use descriptive statistical analysis. This was due to utilising population data sets (not samples), as well as the assumption that the data available may not be representative of the population of refugees with impairments, who experience disability (the premise upon which the research was conducted).

2. Document analysis (DA)

Heffernan (n.d, online) describes document (or documentary) analysis (DA) as "*various procedures involved in analyzing and interpreting data generated from the examination of documents and records relevant to a particular study*." Citing Atkinson and Coffrey (1997), both Heffernan (n.d.) and Bowen (2009) describe documents as 'social facts' that have been socially generated and fulfil socially mediated functions, produced within the multiple realities of its creators (Schütz, 1962). During DA, materials (including, but not limited to hard or soft-copy documents; reports; letters; minutes; journals; artefacts; pictures; film; or other electronic media) are typically, although not exclusively, analysed using qualitative methods to enable the researcher to *"elicit meaning, gain understanding, and develop empirical knowledge"* (Bowen, 2009: 27). Broad 'first pass' (Bowen, 2009) content analysis (see chapter 5, section 5.4.2) is generally employed to extract the data from written sources, before thematic analysis (see chapter 5, section 5.4.2) facilitates more in-depth interpretation (Bowen, 2009). A priori criteria may be utilised in the initial stages to guide the analysis, whilst it may be later guided by data that are constructed through familiarisation with the documents (Heffernan, online). In this way, both deductive and inductive strategies can be used in tandem to determine existing, and construct new, categories and major themes. Quantitative strategies, such as identifying number and frequency, may be used to augment qualitative analysis, and follow up interviews, observations, or other qualitative methods of inquiry may be employed to further investigate and provide a deeper understanding of, or explanation for, findings from the DA (Bowen, 2009; Heffernan, online).

DA is considered an important method in both multiple-method qualitative and mixed-methods data crystallisation - a post-modernist reconceptualisation of the notion of triangulation – (Richardson, 2000).[31] Its

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[31] Triangulation (Denzin, 1978) uses a variety of research methods to 'validate' research findings. This term is deeply rooted in positivist philosophy (and therefore mainly quantitative methodology) and is therefore contested when applied to qualitative inquiry as it suggests a precise answer can be reached, which is contra to the ethos of qualitative research (Fetters and Moline-Azorin, 2017; Clarke, 2022). The preferred term in multiple-method and qualitative inquiry is 'crystallisation'

unobtrusive, non-reactive, nature (Bowen, 2009; Robson, 2002) allows the researcher to engage with material without personal influence or reaction from participants. As such, it provides information unaffected by (a lack of) reflexivity (Bowen, 2009). However, when analysing documents qualitatively, it is important to not only review content, but to also consider the nature of the document: its purpose, audience, author, and authenticity (Bowen, 2009; Robson, 2002). A document may paint a false picture in the absence of due consideration to important 'unwitting' (those the author did not intend to impart) features (Robson, 2002). The role of DA in integration is generally as a secondary method in a multiple-method study, providing further evidence of *"convergence and corroboration"* (Bowen, 2009: 28). Nevertheless, it is also possible that evidence from one source may contradict another, providing the impetus for investigation into the reasons for such contradictions (Bowen, 2009). For all its advantages as a complementary qualitative research method, DA is not advisable as a standalone method of data construction (Bowen, 2009).

I chose DA as one qualitative method in my multiple methods study, in both phases one and two. As numerous researchers agree (Bowen, 2009; Heffernan, n.d; Robson, 2002; Yin, 1994), DA can be combined with interviews and observations to increase understanding of the topic of inquiry thereby increasing methodological rigour. It adds to the richness of data, providing context and historical orientation that can both guide the direction of subsequent interviews and observations and corroborate or contradict findings from those interviews or observations. Moreover, the process has the potential to highlight where *"certain matters have been given little attention or … certain voices have not been heard".* (Bowen, 2009. p. 3).

(Richardson, 2000), which encompasses a post-modernist deconstruction of the notion of, and requirement for, research validity as a measure of research rigour (Richardson, 2000. Also see section 4.6).

The processes and procedures utilised to gather documents and analyse their content are described in chapter 5, part B, and chapter 6, part A.

3. *Interviews*

Interviewing is considered *"one of the most common and powerful ways in which we try to understand our fellow human beings"* (Fontana and Frey, 2000: 645) and is a popular choice for qualitative researchers aiming to access subjective knowledge (Thorne, 2016). When used as a qualitative research tool, it enables the researcher to construct data ranging from the superficial to the deeply personal and gain anything from a rudimentary to a rich description of the interviewee's perspectives.

Interviews are, by their nature, interactions. Semi-structured interviews (SSIs) and unstructured interviews produce data that can confirm or refute commonly held assumptions or create new knowledge and understanding of lived experiences (McIntosh and Morse, 2015). Interview data are the product of interactions between two or more parties, meaning the interviewer's and interviewee's combined contributions lead to *"negotiated, contextually based results"* (Fontana and Frey, 2000: 646), as supported by Clarke (2022). Not only is the SSI a popular tool in qualitative research, but its association with a range of philosophical assumptions has aligned it with a pragmatist research perspective, making it an appropriate choice for MMR (Bryman, 2006; McIntosh and Morse, 2015) within an ID methodology (Thorne, 2016).

SSIs allow the participant to become the focus of the research (Braun and Clarke, 2013), whilst being guided in the direction that the research needs to take to address the research questions or aims. It also allows for follow up of issues and for the researcher to probe or explore different avenues in more depth. As such, SSIs retain something of their founding ethnographic flavour, whilst simultaneously engaging principles of phenomenology.[32] This resonates with the multidimensional characteristics of an ID research methodology. Thorne (2016), however, cautions against using interviewing as an ‘easy’ method of data construction, advising that researchers acknowledge the limitations interviewing brings to ID research, such as the difficulty in reconciling the *“either/or position on subjective and objective knowledge in relation to … complex human issues”* (Thorne, 2016: 138).

Face-to-face SSIs were chosen as a method of data construction for several reasons. This included the opportunity for me to:

a) Become an active participant in the discussions (as per the pragmatist paradigm upon which the research was based).
b) Read facial expressions and body language to adjust my speed or line of questioning - essential when working cross-linguistically.
c) Employ live translation from English to Kinyarwanda, and vice-versa, checking understanding as the interviews progressed.

In addition, I chose SSI for this study due to its familiarity to participants and application to practical field research. In this case, humanitarians and health professionals alike are familiar with SSIs. They were therefore likely meaningful to them, and they were likely able to understand the significance of having employed SSIs as one method of constructing data. Crucially, SSIs aligned with my pragmatist approach to the research and, as they are considered a method for advocating for participants in political activism (Fontana and Frey, 2008), aligned with my advocacy world view.

Despite these advantages, one must be aware that interviews, as social constructions and negotiated texts, are influenced by many factors, including language, culture, time, and space (Thorne, 2016) and are therefore unique contributions to the research arena that defy the positivist notion of

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[32] Creeley (2011) and Erfanian, Latifnejad Roudsari, Heydari et al (2019) give examples of ethno-phenomenological research.

‘generalisability’ in considering research quality (Clarke, 2022; see sections 4.6 and 7.4.3). Disadvantages similar to those noted by McIntosh and Morse (2015) were also considered, including ‘unwanted’ interviewer effects brought on by age, race, gender or affiliation with organisations perceived as powerful (e.g., UNHCR, implementing organisations, university). This, however, is considered in light of Clarke’s (2022) assertions that all of what a researcher brings to the research *is* the research and is the reason why it is unique. In response to this, reflexive practice was central to data construction and analysis (see chapter 7, section 7.3).

4. *Focus group discussions (FGDs)*

Coined by Merton, Fiske, and Kendall in 1956, the term ‘focus group discussion’ refers to a form of group interview for which participants are recruited based on pre-determined criteria. These criteria can include, for example, age, gender, experience of a given phenomenon, or any other factors relevant to the research topic. They can be chosen to be homogenous or heterogeneous and a variety of sampling techniques used to identify and recruit participants, depending on the aims of the research. A similar process to the SSI can be applied, whereby a researcher develops a topic guide based on prior knowledge or experience and participants are guided through a discussion, but with the freedom to personalise their responses.

Not only are FGDs a more resource-efficient option than one-to-one interviews, but they offer a range of advantages over asking people the same questions one by one. Instead, the FGD *“capitalises on communication between research participants in order to generate data”* (Kitzinger, 1995: 299) and harnesses shared beliefs, attitudes, and behaviours (Hennick, 2007; Liamputtong, 2010; Onwuegbuzie, Dickinson, Leech et al, 2009), producing complex and rich information. The group context can give confidence to respondents who may, in a one-to-one situation, feel ill at ease, encourage recall, and spark new ways of thinking about a topic or experience (Fontana and Frey, 2000). This is particularly likely when groups are homogenous in terms of race, gender, socioeconomic group, ethnic culture, and language (Liamputtong, 2010; Madriz, 2000).

FGDs are considered an important research method in the study of marginalised and under-represented groups. They empower participants to share information amongst people they identify with, which can, under the right conditions, have important decolonising effects[11] on the researcher-group dynamic in cross-cultural research (Madriz, 2000). Reducing the amount of vertical interaction with the researcher and capitalising on the horizontal interactions between participants can validate respondent voices and contribute to *"shattering a colonizing discourse in which images of research subjects as the Other are constantly reproduced"* (Madriz, 2000: 840). Furthermore, FGDs can be considered a tool for the advancement of social justice, potentially leading to *"the participants' involvement as change agents in the affairs that affect their neighbourhoods and communities"* (Madriz, 2000: 848).

FGDs using topic guides were chosen as the primary method of collecting qualitative field data in this study for several reasons, from the philosophical to the practical. FGDs fit well as a research method within an ID methodology, with their application to pragmatism, critical theory, and an advocacy worldview. Hearing and validating collective professional and lived experiences was central to being able to understand challenges and desired solutions to exclusionary practices, and the interactional aspect of the data, including contradictions, validations, and storytelling, was sought to shed light on real life engagement with the issues discussed. Additionally, the practical benefits of conducting FGDs cannot be overlooked. They enabled me to talk to a much greater number of participants from a wider range of organisations and groups. This suited my time, financial and research assistant availability, and enabled generation of a broader range of data than would have been possible using only one-to-one interviews.

5. *Observations*

Naturalistic observations are the cornerstone of ethnographic research methods (Werner and Shoepfle, 1987) but with an incontrovertibly unnatural colonial history – traditionally, the voice of the ethnographer described the social characteristics of 'primitive' cultures (Gupta and Ferguson, 1996). The theory that the ethnographer does not impact upon the observed is now refuted, 'observer effects' being well recognised (Angrosino and Mays de Perez, 2000). This is particularly the case in observations where the researcher plays an active role in the environment or activity under observation. Contemporary observations therefore give great credence to researcher reflexivity in the interpretation of data and may employ methods of data corroboration, such as participant reflections (Clarke, 2022) by the observed.

Descriptive, focused, or selective, observations will have different outcomes for the researcher (Angrosino et al 2000) and require differing levels of engagement. A focused observation, for example, deems some information irrelevant to the research topic and the researcher therefore employs 'filters' to the situation. Selective observations dictate that the researcher concentrates on certain attributes of the environment or activity. Utilised as a standalone method of data construction, observation can only elucidate what is happening, and cannot explain why something is happening. Thus, observation is commonly used in data integration, enhancement, and verification when using an ID methodology (Thorne, 2016). Researchers must acknowledge the reactive nature of observational study and potential observer effects that may be at play. Less of an issue in the past when covert observation was utilised, reactivity is of the utmost significance in contemporary, ethically bound, observational practice, when observation is typically (but not always) overt and has involved a thorough consent process with those under observation.

Classroom observation was chosen as a method to contribute to data integration in phase two (chapter 6, section 6.5), after interviews with humanitarian service provider staff, but before interviews with teachers were conducted. The observations were selective to enable me to place the information about the mainstream ECD and education environments in the camps that I had gathered during FGDs/interviews with service providers and gain an understanding of the classroom environment and teaching strategies used with the whole class and with children who experience CD. This prompted me to think carefully about the probes I could use in the interview with the teacher following the observation. I was acutely aware of the possibility of observer effects and that a degree of 'performance' may occur with my presence. It was therefore necessary to reflect upon this in my field notes and journal.

4.6 Methodological rigour and research quality

It is critical for all research to be of the highest quality possible. This is particularly important for applied research involving, and potentially impacting upon, the lives of people. The historical dominance of positivist, quantitative, research has resulted in concerns such as how 'reliable'[33] and 'valid'[34] a piece of research is. Generalisability refers to the extent to which the results of a piece of research can be applied to another population or context. Further indicators, such as objectivity[35] are also commonly used to assess the rigour and quality of research. These terms, however, reflect a positivist research paradigm – that a single truth exists and can be sought through tightly controlled scientific inquiry. It is, by default, therefore less applicable to qualitative or mixed methodologies, with ontological and epistemological foundations that reflect multiple, different and/or socially derived, 'truths' and that may be openly influenced by researcher engagement, experience, and position.

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[33] Reliability is concerned with replicability: the extent to which a piece of research can be reproduced by another researcher.

[34] Validity reflects 'accuracy' (Braun and Clarke, 2013).

[35] The removal, or minimisation, of any human subjective interpretation.

Qualitative inquiry has, in the past, been considered less rigorous and of lower scientific quality than quantitative, positivist-driven, research (Robson, 2002). More recently, however, qualitative researchers have sought to establish their methodologies as scientifically robust, rigorous, and high quality, generating evidence on social phenomena of great significance to the understanding and development of humankind. Instead of considering the reliability, validity, objectivity and generalisability of qualitative research, Lincoln and Guba (1985) propose that the ‘trustworthiness’ of research is judged against markers of:

a. credibility (does the research capture the reality of its subject?)
b. transferability (are the findings useful in other contexts?)
c. dependability (can the study be repeated and achieve similar findings?) and
d. confirmability (are the results bias-free?)

– a concept supported by Yonge and Stewin (1998) and Sandelowski (1986).

Morse (2015: 1212), however, critiques Lincoln and Guba’s work and observes that the *“where, why and how to use these strategies have not been developed.”* Morse, therefore, suggests quality assessment of qualitative research against the markers of:

a. prolonged engagement
b. persistent observation
c. thick, rich description
d. inter-rater reliability
e. negative case analysis
f. peer review or debriefing
g. clarifying researcher bias
h. member checking
i. external audits and
j. triangulation (in this thesis referred to as ‘integration’)

many of which are critiqued by Clarke (2022), who disputes the concepts of research bias, member checking, and triangulation, in application to qualitative inquiry, as contrary to the very essence of its philosophical foundations.

As described by Reinhardt, Kreiner, Gioia, et al (2018: 519):

> *"qualitative research is not rigorous just because it follows a structured, rigid protocol for data collection and analysis; it is rigorous if it is transparent about the unexpected, surprising observations that led you to reorient your focus, the twists and turns your project took as your observations challenged initial research interests and working assumptions."*

Reinhardt et al (2018) go on to describe rigour in qualitative research as something that emerges from the transparency of a researcher's process of moving from data through to interpretation and theory. They suggest that rigour can be demonstrated by:

a. Fostering credibility (providing an in-depth description of the research context)
b. Enhancing verisimilitude (elevating the voices of participants) and
c. Allowing for auditability (providing a transparent account of the analytical process)

-qualities that resonate more with a pragmatic research paradigm.

4.6.1 Research quality in mixed methods research

As described in section 4.3.1.4, MMR utilises quantitative and qualitative approaches together to strengthen research *beyond* the sum of each of its parts and is recognised as increasingly valuable in international and cross-cultural research (Hennick, 2007). It has, however, a different philosophical underpinning to that of either quantitative or qualitative paradigms. In MMR, the philosophy on which the research is grounded, which often takes a pragmatist approach (see section 4.2.3), must influence the way in which methodological rigour is ensured and reported. Bryman (2006) describes how mixed method research quality can be made explicit through the judicious application of one of several processes including the use of:

a. Convergent criteria, which uses the same quality criteria for all components of the research,

b. Separate criteria for quantitative and qualitative research, and
c. Bespoke criteria, in which new quality criteria are created for mixed methods.

In MMR, crystallisation (Richardson, 2000) of different data sources plays a key role in constructing rigorous, credible interpretations of integrated data. These terms refer to the process of assimilating data constructed using different methodologies to corroborate, differentiate, and substantiate the results of a study, increasing research transparency and rigour.

4.6.2 Research credibility in interpretive description

In addition to the suggestions for ensuring quality in MMR described above, Thorne et al (1997), in the development of ID, sought to develop a methodology to:

> *"address what had been identified as an epistemological confusion within the qualitative health research field that appeared in the form of weak or ambiguous methodology resulting from an incomplete shift from a quantitative to a qualitative philosophical orientation" (Thorne, 2016: 231).*

They identified that quality assessments traditionally designed for use within quantitative paradigms (and their associated epistemologies) were being inappropriately applied to qualitative paradigms. They therefore sought to attribute credibility and gravitas to the style of flexible and responsive research required in real-world clinical settings, by grounding it firmly in nursing's epistemological and practical mandates (Thorne et al 1997; 2004), informed by naturalistic enquiry (Lincoln and Guba, 1985). The result was the classification of ID as a rigorous, epistemologically explicit, accepted methodology for high quality qualitative research (see section 4.5.2.1) - a representation of both the *"artistry and science"* (Thorne, 2016: 232) of using multiple (and sometimes mixed) methods to answer complex research questions.

Given the responsibility of researchers in the applied sciences to service users for their findings to be of practical benefit, credibility of applied research extends beyond compliance to methodological 'rules' and more towards the meaning that can be made from research findings (Harley and Cornellison, 2022; Thorne, 2016). As this is more difficult to define and measure, Thorne (2016: 233-235) proposes nine quality evaluation criteria for interpretive descriptions, namely:

1. Epistemological integrity

   The research clearly illustrates reasoning for decision-making throughout the research, from philosophical underpinnings to methodological processes. Findings will only be considered credible if the research question is consistent with epistemology and a logical interpretive strategy (as advocated by Koch, 1995; Simmons, 1995).

2. Representative credibility

   Theoretical claims must be consistent with the manner in which data were constructed and analysed. Research involving prolonged engagement (as advocated by Lincoln and Guba, 1985), will be considered more credible that that which has involved superficial engagement. Triangulation[36] (or crystallisation, Richardson, 2000) of data sources (again, as supported by Lincoln and Guba, 1985) enhances rigour, as does recognising knowledge from different angles and perspectives.

3. Analytic logic

   Researcher decision-making and reasoning is made explicit throughout and is evidenced throughout reporting, so that the reader can accept or reject analytic credibility (supported by Burns, 1989; Miles and Huberman, 1994; Morse, 1994). Typically, processes are auditable and replicable (as advocated by Carcary, 2009). Interpretations are grounded in verbatim data examples and illustrate context (supported by Ponterotto, 2006).

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[36] Thorne's (2016) chosen term.

4. Interpretive authority

   Interpretations of data should be fair, representative, and unbiased. They should account for researcher reactivity and be explicit in the knowledge the researcher has chosen to present. Explicit researcher reflexivity contributes to this.

5. Moral defensibility

   Research must be explicit in why it is necessary to gather information from participants who have or may experience suffering or harm (especially applicable in health sciences and, in this case, humanitarian contexts). It must be explicit about the potential benefits and possible uses of findings, even before the research has begun (as supported by Hays and Singh, 2012).

6. Disciplinary relevance

   Interpretive Description was developed as a methodology for use within applied disciplines. It is therefore critical that the outcomes of ID research have disciplinary relevance (Thorne, 2001) and contribute to the understanding and advancement of an applied field of (clinical) practice.

7. Pragmatic obligation

   This relates to a pragmatic research paradigm in which research in applied fields appreciates the individuality of participants, whilst aiming to be practically relevant to a wider audience. As such, no new idea should be understood as purely theoretical – it should always be considered as having the potential to be applied in practice.

8. Contextual awareness

   Qualitative research largely locates knowledge within the society in which it is constructed, including the influences of the researcher themselves upon research decision-making, process, and outcome. Research findings must therefore be presented as contextual, recognising that *"the issues being* *researched are not unique to one context, but she or he recognises the context in which the research occurs" (Brewer et al, 2014: 1294).* A reflexive research process is consequently critical to this quality measurement.

9. Probable truth

   In relation to research validity, Thorne (2016: 238) describes how *"no set of standards against which we measure our [qualitative] procedures and products can fully account for the notions of truth or even representativeness within the real world."* Researchers must understand truth to be fallible, altered by new evidence further down the line.

Against these recommendations, Thorne (2016), however, cautions that rigid adherence to guidelines and checklists within qualitative research will not necessarily produce research of high quality – a sentiment echoed by Harley and Cornellissen (2022) and Morse (2015). Instead, Thorne advocates for a focus on purpose, process, and context to achieve research quality within an ID methodology.

4.6.3 Quality assessment in cross cultural research

Mill and Ogilvie (2003) report that there is little guidance on how to ensure methodological rigour in international research. Reflecting on their experiences in conducting cross-cultural health research in Ghana, they state that:

> *"research methods may require adaptation to overcome barriers in language. Approaches to data collection must be adjusted to ensure that local beliefs and practices are considered and respected. Additional steps are required during data analysis to ensure that interpretation and meaning have not been altered during translation. In order to overcome these challenges, patience, flexibility and sensitivity are required of the researcher" (Mill and Ogilvie, 2003: 80).*

Jakobsen (2012) similarly reflects on her experiences researching in Tanzania and describes the challenges to methodological rigour that exist when researching cross culturally, especially in cross minority-majority world contexts (see chapter 1, section 1.5.4). She identifies that challenges commonly relate to issues of positionality and power, ostensibly mitigated using some research methods, such as FGDs, which have scope to address power imbalances. It is, however, important to acknowledge that methods, and discussions of their quality, primarily evolved in the minority, and have been applied to majority, world contexts – sometimes with insufficient attention to applicability of assumptions (Jakobsen 2012).

Jakobsen (2012) also identifies researcher positionality as a threat to the quality of, for example, FGD-generated data. This reflects the importance of applying Thorne's (2016) quality criteria of contextual awareness (see above) insofar as it acknowledges the significance of the researcher potentially holding multiple positionalities and navigating these in cross cultural research (especially for those straddling insider-outside identities (Liamputtong, 2010)). Researchers in a position of relative power compared to participants (particularly within less participatory methodologies) pose a threat to data quality as they will, inevitably, interpret the data through their own, potentially very different, cultural, and experiential lenses. It is crucial, therefore, that this is not only acknowledged by the researcher but that the audience understands the impact of this aspect of the research process on the outcomes.

4.6.4 Quality of data construction methods

In addition to assessing the quality of a research project, each research method in multiple method research has its own strengths and challenges. Here I address each method used in this project (see section 4.5) in turn, and discuss issues related specifically to research rigour and quality.

1. Secondary statistical data gathering

   Secondary data have been gathered by a different researcher or organisation and/or for a different reason than the study they are being used for. MacInnes (2020) states that secondary analysis encourages research transparency and reproducibility, as well as enhancing replicability – all measures of research rigour within a quantitative paradigm.

Threats to rigour occur if/when the data gathering and analysis process fails to be transparent, is non-replicable, and/or fails to be classed as high quality against data quality checklists (Claydon, 2015). Although Thorne (2016) and Harley and Cornellissen (2022) caution against the use of rigid quality checklists within a qualitative paradigm, they are more applicable to research carried out with a positivist epistemology. In this research project, secondary statistical analysis is used as one method within a mixed methods design.

2. Document analysis

Document analysis is also a form of secondary data analysis. Kayesa and Shung-King (2021) consider that, for DA to be considered rigorous and of high quality, it is important that:

   a. There is an initial clear alignment of the research method to research question(s)
   b. The search strategy is applied and reported clearly
   c. Documents are sourced, organised, and stored systematically
   d. Robust data coding and analysis is carried out and adequately documented, and
   e. Documents are clearly linked to the research findings and conclusions.

This transparency of process and method ensures *“authenticity, representativeness, and credibility of data” (Kayesa and Shung-King, 2021: 2).*

They also caution, however that it is important to balance the methodological rigor of robust search strategy against the reality that, particularly in low- and middle-income country contexts, the availability and quality of documents may be smaller than in high-income country contexts. Rigour of document selection against strict criteria may therefore result in a quality threat through loss of useful information in documents that may not meet inclusion criteria.

In this research project, I endeavour to ensure a transparent and rigorous application of DA methods, reporting on these clearly to maximise the quality of the analysis and the application of the results (see chapter 5, section 5.4 and chapter 6, section 6.3). I also endeavour to make a judgement on inclusion of documents in the DAs for each phase of the research, based on sourcing, availability of information, and previous professional knowledge and understanding of the sector in which I conduct the analysis. In such circumstances, the judgement to include a document which may not meet all inclusion criteria but is deemed to be of value to the analysis, is reported transparently and with rationale for the decision.

3. Individual interviews

   When conducting individual, semi structured, interviews, the quality of resultant data largely relies upon interviewer skill and experience (DeJonckheere and Vaughn, 2019). Although methodological rigour is undoubtedly important, interpretive rigour (Lincoln and Guba, 2000), is of critical significance in quality assessment. With this comes a trust value attributed by the reader – can the results be trusted to represent important social or human issues (DeJonckheere and Vaughn, 2019)? A consideration in judging the quality of data resulting from interviews is the way in which the researcher reports on their positionality. How the researcher relates their approach to underlying research philosophy must also be transparent (Wimpenny and Gass, 2000).

   In this research project I aim to be epistemologically and methodologically transparent (see section 4.5), as well as reflexive (see chapter 7, section 7.3), ensuring maximum insight into my decision-making.

4. Focus group discussions (FGDs)

   The benefits of using FGDs in international, cross-cultural, research, are described above in section 4.5.2.3. The limitations to using FGDs in international contexts are summarised by Hennick (2007) as being influenced by researcher skill, group dynamics, and data construction and analysis processes.

There is little guidance on quality assessment criteria in FGDs, beyond transparency of method and analysis. Onwuegbuzie et al (2009), however, describe how transcript-based analysis of FGD data may be the most rigorous and time-intensive mode of analysing data. This involves the transcription of videotapes and/or audiotapes, in comparison to tape-based analysis which creates an abridged transcript, or memory-based analysis which relies on researcher recollection.

In this research project I endeavour to ensure rigorous application of the FGD method, a transcript-based analysis, and a reflexive approach to analysing my positionality within the process (see chapter 7, section 7.3). I also aim to be transparent with regards to design, implementation, analysis, interpretation, and reporting of the research process (see chapters 5 and 6).

4.6.5 Research ethics

Research ethics are a set of principles, guided by morals to do ‘the right thing’ and prevent harm to research participants. Research institutions such as universities, therefore, tend to have ethical guidelines in place to guide and regulate ethical research practice. Ethical dilemmas, however, exist in all research, especially that which involves people, and therefore requires consideration of relational ethics as well as compliance with regulatory ethical practices (Aellah, Chantler, and Geissler, 2016). Relational ethics considers the relationships between researchers, participants, donors, government, and any other stakeholder in the research conceptualisation, process, and outcomes. They are complex, unpredictable, idiosyncratic, and, in the case of international research, often conducted across historical power differentials and inequalities (Aellah et al, 2016; see chapter 2).

4.6.5.1 Ethical approval

Ethical approval for this study was granted by Manchester Metropolitan University (MMU) and by the University of Rwanda in November 2016. The study was also approved by the Rwanda Ministry of Education (MINEDUC) in December 2016 (see appendix 1). Reflections on ethical dilemmas associated with conducting cross-cultural research are presented in chapter 5, section 5.14 and chapter 7 section 7.4.

4.6.5.2 Confidentiality and the right to withdraw

Data shared by UNHCR were handled according to the data sharing agreement signed between the legal departments of UNHCR and MMU (see appendix 5). Participants were recruited using non-coercive practices and the right to withdraw their participation at any time and without consequence, was made explicit throughout (see chapter 5 section 5.13.3). Participant confidentiality was ensured throughout the study by a process of immediate anonymisation of data. RAs were contractually bound to abide by UNHCR's employee confidentiality policies. All electronic data (including confidential information such as names and refugee registration numbers) were stored in encrypted files in password protected folders. Audio data were e-shredded as soon as anonymous transcriptions were created. All hard-copy data were stored in a locked safe in a private location and will be destroyed after the research outcomes have been shared with participants.

4.6.6 Section summary

Considering rigour during the research design phase helped me to plan a high-quality project. In chapter 7, section 7.2.2.4, I evaluate, and reflect on, the research choices I made and their implications and limitations, considering Thorne's (2016) quality guidance for interpretive descriptions.

4.7 Chapter summary

This chapter has described the philosophical, methodological, and practical considerations and choices related to this research project. It is crucial for a researcher to be explicit about the basis upon which their research is built, so that the audience can understand the assumptions underpinning the methodological, analytical, and interpretative decisions made, and judge the quality and outcomes of the research in light of those assumptions and choices (Creswell, 2009).

The paradigm to which this study is aligned is that of pragmatism. Although not allied to any one epistemology or theoretical perspective, my natural tendency towards a social constructionist epistemology and critical inquiry perspective, lends itself towards the aspects of pragmatism associated with advocacy for social change through a critical disability lens. The application of this practical, applied, critical approach to research is embodied within an interpretive description methodology which encourages the use of multiple research methods and forms of data analysis and interpretation, to address my research aims and objectives (see figure 9). A detailed discussion of the methods chosen for each phase of the research can be found in chapters 5 and 6.

Chapter 5: Phase 1

5.1 Overview

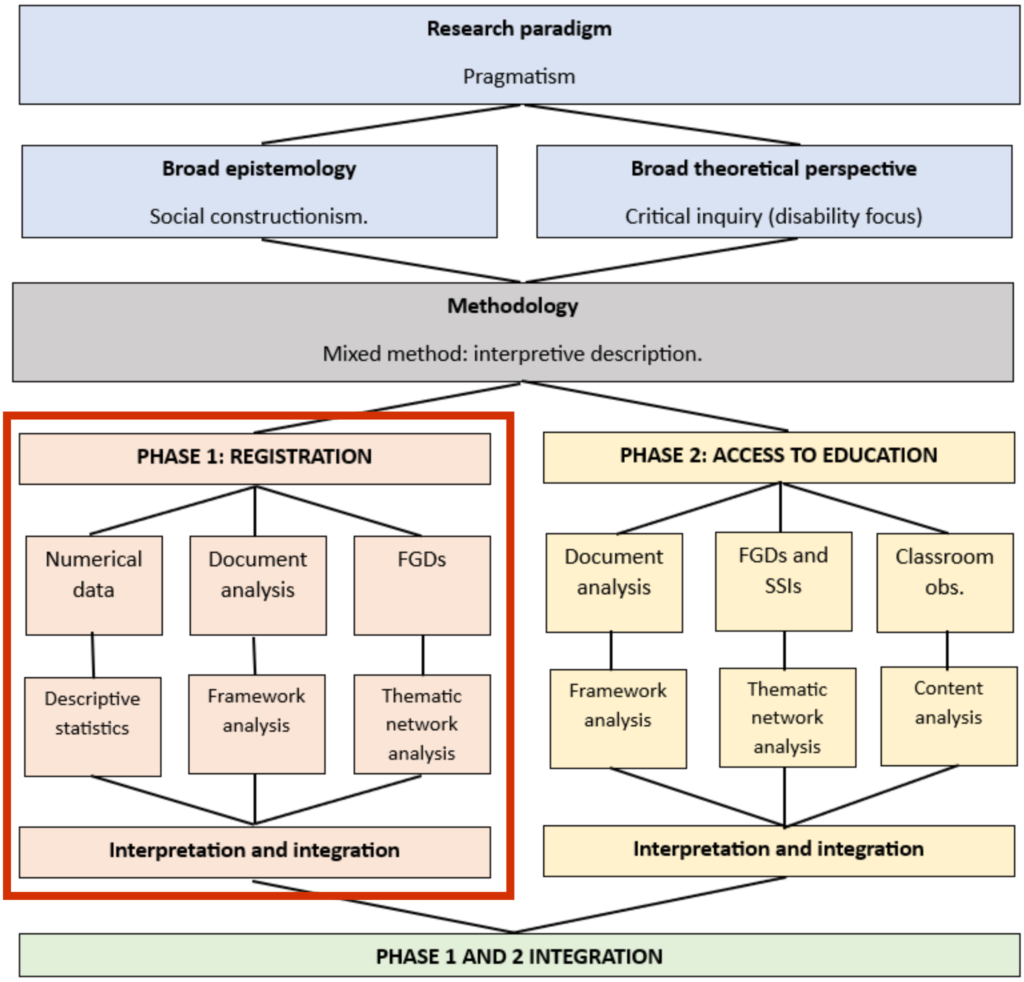
The 2015 UNHCR Rwanda country office disability scoping review (Lange, 2015) discussed in chapter 1, identified that some groups of refugees with impairments were potentially experiencing more significant levels of exclusion than others. Of particular concern were those with communication impairment (CI) who were noted to be under-represented at community consultations and who struggled to access education services. To facilitate understanding of the opportunities and barriers facing refugee children with CI, who experience communication disability (CD) when accessing education, UNHCR staff first considered it to be necessary to understand whether, and how, these children are identified for support. Phase one of the research therefore focused on the issues of identification and registration of CI and CD amongst the refugee population.

A mixed methods approach to data construction and analysis was employed for this phase of the research project (figure 8). In this chapter I report on three data sets which were constructed independently. Each data set is presented as a sub-chapter of this chapter:

- **PART A: Data set 1:** Secondary UNHCR refugee registration data, analysed using descriptive statistics.
- **PART B: Data set 2:** Documentary analysis of guiding documents, relevant to refugee registration process and procedure, analysed using the Framework method.
- **PART C: Data set 3:** Focus Group Discussions (FGDs) with service providers, analysed using Thematic Network Analysis (TNA).

For each data set, I present the data construction methods, analysis, and results, followed by a discussion of the findings. At the end of the chapter, I integrate the results of all three data sets and discuss overall findings.

Figure 8: Phase 1 – registration: chapter structure



5.2 Phase 1 aims and objectives

The aim of phase one of the research was:

> *A1: To describe and critically interrogate the current systems, tools and processes used to identify and register refugees with communication impairments, who experience disability, in Rwanda.*

I set out to achieve this through three research objectives that, together, addressed different but complementary aspects of the research aim (see table 8).

Table 8: Phase 1 objectives and methods

	OBJECTIVE	DATA COLLECTION METHOD	DATA ANALYSIS METHOD
O1a	To determine the proportion of refugees, including children, registered with communication impairments and/or disability in Rwanda, using current tools and processes.	• Secondary population data, including disability registration data, from UNHCR Rwanda and UNHCR headquarters	• Descriptive statistics
O1b	To describe and critique the current systems, tools and processes used to identify and register refugees with communication impairments and/or disability, in Rwanda.	• Document analysis • FGDs	• Framework analysis • Thematic Network Analysis
O1c	To document the self-reported understanding, behaviours, and experience of staff responsible for determining if refugees have a communication impairment and/or experience communication disability.	• FGDs	• Thematic Network Analysis

PART A:

PHASE 1, DATA SET 1

SECONDARY REFUGEE REGISTRATION DATA

5.3 Introduction

Part A reports on the statistical analysis of existing UNHCR refugee registration data, shared by UNHCR headquarters and the Rwanda country office. Here I report on data sharing, construction and analysis, results, and end with a discussion of the findings and implications.

5.4 Data construction: Sources and procedures

A legal data sharing agreement was drawn up between UNHCR and MMU, stating which types of data could be accessed for this research and how they could be used and stored (appendix 5). The following data were sourced (see table 9):

Table 9: Phase 1 data sub-sets and source information

Data sub-set	Data type	Date	Source	Notes
1	Global data	August 2017	UNHCR Headquarters	
2	Regional (East and Horn of Africa) data	August 2017	UNHCR Headquarters	
3	Rwanda data	April 2017	UNHCR Rwanda	Pre-disability mapping exercise
4	Rwanda data	September 2017	UNHCR Rwanda	Post-disability mapping exercise
5	Rwanda data	January 2020	UNHCR Rwanda	Post verification, with CD

				screening tool (see figure 9) in one study location.

Existing numerical data on global and regional refugee registration (data sub-sets 1 and 2) were shared by UNHCR Headquarters in Geneva for data generated in August 2017. The data include age and any recorded impairments/disability. Rwanda country-level data were shared by UNHCR Rwanda for three points in time: a) April 2017 (data sub-set 3), b) September 2017 (data sub-set 4), and c) January 2020 (data sub-set 5). These dates correspond to a) before and b) after a disability-mapping activity was undertaken across all refugee locations in the country and c) following a verification activity re-registering all refugees in the country. Unfortunately, the CD screening tool mentioned in table 9 above, and described in figure 9, was not used in all research locations and the information shared included data from some locations in which the CD screening tool was utilised, but that were not study locations for other parts of this research project. I therefore report the data from locations not included in other parts of this research project, solely to illustrate trends and data changes before and after the tool was used.

Refugee registration data were requested to be shared, by age group, for refugees under 12 years old and over 12 years old.[37] I combined these to obtain overall population data. Data were also requested to be shared by disability 'specific needs codes', or 'SNCs' (UNHCR's data term) relevant to communication impairment and disability (henceforth referred to as communication-related impairment/disability, or CRID[38] - see table 10). Information was all anonymous and shared electronically, although not all information requested was available.

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[37] In Rwanda, ECD services are provided for children 0-6 years old, and primary education is for children aged 6-12. I therefore requested data to be disaggregated for under 12s, as applicable to the population of refugee children in ECD and primary education in this research project.

[38] Communication Related Impairment and/or Disability (CRID) SNC codes for impairments/disability are those that are associated with a high possibility of communication impairment and/or disability. This includes codes DS-DF (hearing impairment and deafness), DS-MM (Mental disability-moderate), DS-MS (Mental disability – severe) and DS-SD (speech impairment/disability). Although a person with physical impairment, or visual impairment could also have a communication impairment, many may not and so those codes were not included in the analysis. It can therefore be assumed that the CRID data still under-represent the total number of persons with communication impairments, who may experience communication disability, in the refugee population.

Table 10: UNHCR Communication-Related Impairment and Disability (CRID) specific needs codes

UNHCR Specific Needs Code	Expansion
DS	Disability
DS-DF	Disability – hearing impairment and deafness
DS-MM	Disability – mental disability moderate
DS-MS	Disability – mental disability severe
DS-SD	Disability – speech impairment/disability

5.4.1 Processes and tools used for UNHCR refugee data generation and management.

UNHCR utilises a global database – ProGres[39] to record all country-level information on refugee registration.[40] Data are collected upon initial registration as a refugee with the host country and UNHCR and updated regularly through a process of verification (usually every four years), whereby all refugees in a country are called to re-register to update their details. Refugees may also request amendments to their registration information at any time, through a system of ongoing registration.

Data in ProGres are collected via a structured questionnaire that is delivered verbally to refugees in a face-to-face interview upon initial registration (and again during verification), in either one or two stages. Stage one involves the collection of biodata and basic family information (e.g., age, gender, country of origin, family members etc) from each person, with adults providing information about any children in their care. Household information is also collected (i.e., which individuals together constitute a household). No disability-specific questions are asked at this stage but, if any specific needs are identified or suspected by the registrar through observation or unsolicited self-reporting, individuals are referred to the Community Services Desk (CSD) for further registration of any 'specific need(s)', such as disability, that may increase a person's exposure to protection risk.[41] If the registrar does not refer a

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[39] At the time of data analysis, UNHCR Rwanda was using ProGres3

[40] Not every country uses the ProGres system. Global data reported here is therefore only for countries using the ProGres database.

[41] E.g., Being an unaccompanied child/ person with impairment(s), who experiences disability/ older person.

person to the CSD at this point, their challenges and support requirements may go unregistered and unrecognised.

The CSD is usually staffed by a member of the UNHCR community-based protection team, trained in working with refugees with, what UNHCR consider, ‘specific needs.’ Upon referral to the CSD, refugees attend a second face-to-face interview to allow them to explain their challenges and support requirements in more detail. The CSD staff then records this under the relevant section in ProGres, which has a dedicated section for each ‘specific need’. The system employs a tick box system for categorisation of issue(s) and features a free-text box where comments on an individual’s circumstances or needs can be recorded.

In addition to the ProGres database held by UNHCR, information on refugee ‘specific needs’ is collected on an ongoing basis by their partner Implementing Organisations (IOs), according to their mandate. Each IO across sectors reports to UNHCR with regular updates and this information should be updated in ProGres should there be any change in circumstance of any registered refugees.

On occasion, a mapping exercise may be conducted to update information and/or gather more detailed information about a particular specific need or group. In 2016, a mapping exercise of ‘refugees with disability’ was conducted by the International Non-Governmental Organisation (INGO) Humanity and Inclusion, and the results recorded in ProGres as an update (see data sub-set 4).

Figure 9: Verification and the piloting of a communication disability screening tool

Following ongoing professional engagements on CD with UNHCR Rwanda, in September 2016 I was asked to design a simple tool to be used during the upcoming verification exercise, to help data clerks and Community Service Desk staff to identify CD more accurately and to record this in the ProGres database. I did so in my capacity as an independent consultant, and this overlapped with the period during which I was conducting my PhD research.

The tool specifications dictated that the tool must be a maximum of one side of A4 and must a) alert clerks to who may need referral to the Community Service Desk and b) assist Community Service Desk staff to identify CD and the impacts upon a person's life. The tool had to fit with the existing ProGres system as it was not possible to change a global system to accommodate a pilot project (UNCHR, 2009). It was agreed that the Community Service Desk staff would complete the tool in a Microsoft Word document, then copy and paste the answers in to the free-text box of the disability section of ProGres. The tool was developed in the style of the globally accepted Washington Group Short Set of Questions (Washington Group on Disability Statistics, 2020), focusing on functioning and levels of independence in communication (quite different to the existing questions in ProGres 3).

A one-hour training programme was developed for registrars and Community Service Desk staff. Data clerks were hired to move from location to location throughout the verification process, so all 35 clerks were trained during one session, along with Kigali-based Community Service Desk staff. Community Service Desk staff from field offices were trained in their own location. Staff in Kibuye field office, responsible for one camp in the West of the country, were not trained due to security concerns in the area at the time.

5.4.2 Inclusion criteria for data

Data were requested as per the data sharing agreement and in accordance with the following criteria:

1. Data must be held by UNHCR and shared in an anonymous format.
2. Data must have been collected between January 2017 and January 2020.
3. Data must relate to numbers, location, and disability status of refugees registered with UNHCR.

The criteria ensured that the data were relevant to addressing objective O1a and had already been anonymised for protection purposes, in accordance with the data sharing agreement.

5.4.3 Data analysis: methods and process

I chose descriptive statistics (see chapter 4, section 4.5.2.3) to summarise and display the data related to registration of refugees with impairment, who may experience associated disabilities - specifically those with CIs, who may experience CD.

Descriptive statistics enabled me to address objective O1a by determining if UNHCR's initial assumption that refugees with CI and/or who experience CD were under-registered, was correct. To do this I compared their country-level data to regional and global refugee and non-refugee populations. This then influenced the design of the semi-structured interviews with service providers and service users related to identification and registration of refugees with CI, who experience CD, in Rwanda (see phase 1, data set 3; phase 2, data set 2). It also served as a foundation upon which to base UNHCR'S assumption that few children with CI, who experience CD, are accessing inclusive ECD and education services in Rwanda, and to further investigate why this may be.

I chose not to use inferential statistics for this data set (see chapter 4, section 4.5.2.4), preferring to investigate the reasons why data may have represented phenomena through in-depth qualitative inquiry rather than inferring reason from the numerical data. Indeed, I was open to the possibility that qualitative inquiry may reveal contradictions to phenomena suggested by the numerical data.

5.5 Results

5.5.1 Data sub-set 1: Global refugee registration data, August 2017. (Source: UNHCR Headquarters, Geneva)

This data sub-set (table 11) details the number of children under 12 years old who held asylum seeker or refugee status across the globe in August 2017. It is presented by registered disability status. Unfortunately, not all data requested were available, including data for all ages and data by disability specific needs code.

Table 11: Global refugee registration data for children under 12 years old, August 2017

Description	Number
Registered refugees <12 years old	2,587,256
Refugees registered with a disability specific needs code <12 years old	22,630 (0.87% of refugee children <12 years old)

5.5.2 Data sub-set 2: Regional refugee registration data, August 2017. (Source: UNHCR Headquarters, Geneva).

This data sub-set (table 12) details the number of children under 12 years old who currently hold asylum seeker or refugee status in the East and Horn of Africa region and is ~~disaggregated~~ presented by registered disability status. Data ~~disaggregated~~ by disability specific needs code (as per ProGres database) were not available.

Table 12: Regional refugee registration data for children under 12 years old, August 2017.

Host country	Country of origin	# Registered refugees <12 years old	# Refugees registered with disability specific needs code <12 years old
Tanzania	Burundi, D.R.C, Kenya, Rwanda, Sudan	116,214	587 (0.51% of refugees <12)
Kenya	Burundi, DRC, Eritrea, Ethiopia, Nigeria, Rwanda, Somalia, South Sudan, Sudan, Tanzania, Uganda	194,885	1743 (0.89% of refugees <12)
Uganda	No data available	No data available	No data available
Burundi	DRC, Rwanda, Somalia	26,124	326 (1.25% of refugees <12)
DRC	Angola, Burundi, Central African Republic, Republic of the Congo, Rwanda, South Sudan, Sudan	75,004	186 (0.25% of refugees <12)
Ethiopia	Burundi, DRC, Eritrea, Kenya, Somalia, South Sudan, Sudan, Yemen	325,724	1293 (0.40% of refugees <12)
Eritrea	Somalia	991	4 (0.40% of refugees <12)
TOTALS		**738,942**	**4193 (0.57% of refugees <12)**

5.5.3 Data sub-set 3: Rwanda refugee registration data: Pre-mapping, April 2017. (Source: UNHCR Rwanda).

The data shared in this sub-set were correct at the time of request in April 2017, before data from a disability mapping exercise that took place across refugee communities in Rwanda were available. This data sub-set (table 13) details the number of refugees/asylum seekers in the country and is ~~disaggregated~~ presented by age (under 12 years old/ total population) and by registered disability status. It also details the number of refugees by study location as well as numbers of refugees in Rwanda by disability category (Code DS), as per the ProGres database in which they are registered. Each category is given a code. The only specific needs code used to register people with all forms of communication impairment and associated disability, is DS-SD (speech disability/impairment). Here I also report on Communication-Related Impairment/Disability (CRID) specific needs codes.[38]

Table 13: Rwanda refugee registration data, by research location and age: Pre-mapping, April 2017

AGE		**NUMBER OF <12S REGISTERED**				**NUMBER OF TOTAL POPULATION REGISTERED**			
RESEARCH LOCATION		**A**	**B**	**C**	**ALL RWANDA**	**A**	**B**	**C**	**ALL RWANDA**
REFUGEE POPULATION		-	-	-	54,928	52,634	19,491	12,686	159,349
CRID SNCs*	**DS-DF**	3	2	0	13 (0.02%)	29	51	57	318 (0.20%)
	DS-MM	7	2	1	16 (0.03%)	45	19	22	207 (0.13%)
	DS-MS	7	9	1	40 (0.07%)	28	29	37	216 (0.14%)
	DS-SD	2	3	3	17 (0.03%)	11	28	22	135 (0.08%)
	Total CRID	19	16	5	86 (0.16%)	113	61	138	876 (0.55%)
Non-CRID		22	18	15	142 (0.26%)	240	327	261	1884 (1.18%)
TOTAL DS		41	34	20	228 (0.42%)	353	388	399	2760 (1.73%)

**DS – disability, DS-DF – hearing impairment/deafness; DS-MM – mental disability moderate; DS-MS - mental disability severe; DS-SD - speech impairment/disability; CRID – communication-related impairment/disability*

5.5.4 Data sub-set 4: Rwanda refugee registration data: Post-mapping, September 2017. (Source: UNHCR Rwanda)

This data sub-set details the number of refugees/asylum seekers in the country and is ~~disaggregated~~ presented by age (under 12 years old/ total population) and by disability specific needs code (table 14). It also details the number of refugees by study location and the number of refugees registered with CRID/ non-CRID SNCs, by age category (under 12 years old, over 12 years old).

Table 14: Rwanda refugee registration data, by research location and age: Post-mapping, September 2017

AGE		**NUMBER OF <12S REGISTERED**				**NUMBER OF TOTAL POPULATION REGISTERED**			
LOCATION		**A**	**B**	**C**	**ALL RWANDA**	**A**	**B**	**C**	**ALL RWANDA**
REFUGEE POPULATION		-	-	-	56,127	-	-	-	161,958
CRID SNCs *	**DS-DF**	9	2	0	19 (0.03%)	66	51	63	365 (0.23%)
	DS-MM	14	2	1	36 (0.06%)	103	19	23	309 (0.19%)
	DS-MS	41	9	2	80 (0.14%)	85	29	50	299 (0.18%)
	DS-SD	7	3	4	25 (0.04%)	25	28	23	157 (0.10%)
	Total CRID	71	16	7	160 (0.29%)	279	127	159	1,130 (0.70%)
Non-CRID		159	14	26	319 (0.57%)	669	192	283	2,188 (1.35%)
TOTAL DS		230	30	33	479 (0.85%)	948	319	442	3,318 (2.05%)

** DS – disability; DS-DF – hearing impairment/deafness; DS-MM – mental disability moderate; DS-MS - mental disability severe; DS-SD - speech impairment/disability; CRID – communication-related impairment/disability.*

5.5.6 Data sub-set 5: Rwanda refugee registration data: Post-verification, January 2020. (Source: UNHCR Rwanda).

The data in this sub-set represent the refugee population in Rwanda after a national verification (re-registration) exercise took place across all refugee communities in the country. This exercise incorporated the use of the pilot communication disability (CD) screening tool (figure 9) in some communities (camp and urban locations).

This data sub-set details the number of refugees/asylum seekers in the country and is presented ~~disaggregated~~ by age (under 12 years old/ total population) and by disability SNC (table 15). It also details the number of refugees by research location and the number of refugees registered with CRID SNCs by age category (under 12 years old, total population). The sub-set is not complete for all locations or categories.

Table 15: Rwanda refugee registration data, by research location and age: Post-verification, January 2020

AGE		**NUMBER OF <12S REGISTERED**				**NUMBER OF TOTAL POPULATION REGISTERED**			
LOCATION		**A**	**B**	**C**	**ALL RWANDA**	**A**	**B**	**C**	**ALL RWANDA**
REFUGEE POPULATION		-	-	-	57,390	62,259	21,130	12,249	150,574
CRID SNCs*	**DS-DF**	14	2	3	29 (0.05%)	92	75	61	428 (0.28%)
	DS-MM	87	7	3	113 (0.20%)	355	38	34	570 (0.38%)
	DS-MS	NR	NR	NR	NR	NR	NR	NR	NR
	DS-SD	8	6	4	31 (0.05%)	33	162	34	210 (0.14%)
	Total CRID	109	15	10	173 (0.30%)	480	275	129	1208 (0.80%)
Non-CRID		205	54	28	429 (0.75%)	1005	442	364	3283 (2.18%)
TOTAL DS		314	69	38	602 (1.05%)	1485	717	493	4491 (2.98%)

** DS – disability, DS-DF – hearing impairment/deafness; DS-MM – mental disability moderate; DS-MS - mental disability severe; DS-SD - speech impairment/disability; CRID – communication-related impairment/disability.*

The CD verification screening tool (see figure 9 and appendix 5) was implemented in only three locations – two of which were not research locations. Nonetheless, these data were made available and are reported below (table 16). Percentage change in registration using the DS-SD code in these three locations demonstrated a +162.5% increase in DS-SD registration across the three locations (see table 20). The most significant increase was in location D, where the data collection clerk training was originally held, and several UNHCR community-based protection and administrative support staff received direct training from the researcher on CI, CD, and the use of the tool. This +162.5% increase in CD screening tool locations compares to a +40.00% increase in DS-SD registration across the total population, including in locations where the CD screening tool was not used. This may indicate that use of the CD screening tool may be useful in identifying, and/or more accurately registering, CI and/or CD, under the DS-SD code, if found to generate valid and reliable outcomes upon further testing and evaluation.

Table 16: Number of refugees (all ages) registered under SNC code DS-SD (speech impairment/disability) before and after use of communication disability screening tool at verification.

Location	**Population**		**Number DS-SD**		**% change Pre-verification to post-verification**
	Pre-veri	Post-veri	pre-verification	post verification	
C (research location)	12,686	12,249	23 (0.18% of total population)	34 (0.28% of total population)	+55.56%
D* (non-research urban location)	30,314	11,249	9 (0.03% of total population)	21 (0.19% of total population)	+533.00%
E** (non-research camp location)	14,502	14,416	14 (0.10% of total population)	23 (0.16% of total population)	+60.00%
TOTAL	57,202	37,914	46 (0.08% of total population of locations C, D and E combined)	78 (0.21% of total population of locations C, D and E combined)	+162.5%

**Population data taken from UNHCR (2017a)*

***Population data taken from UNHCR (2021)*

5.5.7 Data comparison

See appendix 6 for data summary tables comparing pre-mapping (April 2017), post-mapping (September 2017) and post-verification data for all age groups and for children under 12 years of age.

5.5.8 Disaggregation by research location (camp A, B, C)

Data on population of each camp were made available in April 2017 (data sub-set 3) and January 2020 (data sub-set 5) but were not available for September 2017 (data sub-set 4). This means that changes in disability registration as a proportion of the refugee population was only measurable from pre-mapping (April 2017, data sub-set 3) to post-verification (January 2020, data sub-set 5) without being able to measure if the interim mapping exercise (September 2017- data sub-set 4) may have been associated with any change in identification of refugees with impairments and/or who experience disability.[42]

Population data by camp were only reported in data sub-sets 3 and 5, for the total refugee population, and were not available ~~disaggregated~~ by age group. It was therefore not possible to ascertain if the mapping and verification exercises may have been associated with changes in identifying refugee children of compulsory school age with impairments, who may experience disability.

The tables below detail numbers of refugees registered in camps A (table 17), B (table 18) and C (table 19) before disability mapping (April 2017 – data sub-set 3), and after verification (January 2020 - data sub-set 5). They also detail the proportion of refugees registered with disability related SNCs as a percentage of the camp population, and the percentage change in the proportion of refugees registered with those SNCs codes over time, following the verification activity.

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[42] Since the UNHCR ProGres code is 'speech impairment/disability' I have referred to both here.

Table 17: Camp A - pre-mapping and post-verification data comparison (all ages)

		Pre-mapping: April 2017 *(Data set 3)*		**Post verification: January 2020 *(Data set 5)***		**% Change April 2017 -> Jan 2020 *(Data set 3 -> 5)***
TOTAL REFUGEE POPULATION		52,634		62,259		+18.29%
		Number of refugees registered	**% of population registered**	**Number of refugees registered**	**% of population registered**	
CRID SNCs*	**DS-DF**	29	0.06%	92	0.15%	+150.00%
	DS-MM	45	0.09%	355	0.58%	+544.44%
	DS-MS	28	0.05%	-	-	-
	DS-SD	11	0.02%	33	0.05%	+150.00%
TOTAL CRID		113	0.21%	480	0.78%	+271.43%
NON-CRID		240	0.46%	1005	1.61%	+250.00%
TOTAL DS		353	0.67%	1485	2.39%	+256.71%

** DS - disability; DS-DF – hearing impairment/deafness; DS-MM – mental disability moderate; DS-MS - mental disability severe; DS-SD - speech impairment/disability; CRID – communication-related impairment/disability*

Table 18: Table X: Camp B - pre-mapping and post-verification data comparison (all ages)

		Pre-mapping: April 2017 *(Data set 3)*		**Post verification: January 2020 *(Data set 5)***		**% Change April 2017 -> Jan 2020 *(Data set 3 -> 5)***
TOTAL REFUGEE POPULATION		19,491		21,130		+8.41%
		Number of refugees registered	**% of population registered**	**Number of refugees registered**	**% of population registered**	
CRID SNCs*	**DS-DF**	51	0.26%	75	0.35%	+34.62%
	DS-MM	19	0.10%	38	0.18%	+80.00%
	DS-MS	29	0.15%	-	-	-
	DS-SD	28	0.14%	162	0.77%	+450.00%
TOTAL CRID		61	0.31%	275	1.30%	+319.35%
NON-CRID		327	1.68%	364	1.72%	+2.38%
TOTAL DS		388	2.00%	493	2.33%	+16.5%

** DS - disability; DS-DF – hearing impairment/deafness; DS-MM – mental disability moderate; DS-MS - mental disability severe; DS-SD - speech impairment/disability; CRID – communication-related impairment/disability*

Table 19: Camp C - pre-mapping and post-verification data comparison (all ages)

		Pre-mapping: April 2017 ***(Data set 3)***		**Post verification: January 2020** ***(Data set 5)***		**% Change April 2017 -> Jan 2020** ***(Data set 3 -> 5)***
TOTAL REFUGEE POPULATION		12,686		12,249		-3.45%
		Number of refugees registered	**% of population registered**	**Number of refugees registered**	**% of population registered**	
CRID SNCs*	**DS-DF**	57	0.45%	61	0.50%	+11.11%
	DS-MM	23	0.18%	34	0.28%	+55.56%
	DS-MS	37	0.29%	-	-	-
	DS-SD	22	0.18%	34	0.28%	+64.70%
TOTAL CRID		138	1.09%	129	1.05%	-3.67%
NON-CRID		261	2.06%	364	2.97%	+44.17%
TOTAL DS		399	3.15%	493	4.02%	+27.61%

** DS - disability; DS-DF – hearing impairment/deafness; DS-MM – mental disability moderate; DS-MS - mental disability severe; DS-SD - speech impairment/disability; CRID – communication-related impairment/disability*

5.6 Discussion ~~and summary of findings~~

In response to objective 01a, *'To determine the proportion of refugees, including children, registered with communication impairments and/or who experience communication disability in Rwanda, using current tools and processes',* analysis of the data shared by UNHCR headquarters, and the Rwanda country office, has facilitated understanding of the current registration status of refugees with CI/who experience CD, including the registration status of children under twelve years old (compulsory primary school age in Rwanda at the time of data collection).

It is well recognised that global disability prevalence data are far from accurate, affected by issues including the definition of disability itself, along with resource capacity to collect accurate data (much reduced in situations of conflict, for example), the tools and methods used to collect the data, and the complex nature of health conditions and impairments that contribute to disabling experiences (Mont, 2007; WHO and WBG, 2011). With this in mind, global estimates of disability stand at approximately 15-16 percent of any population (WHO and WBG, 2011; WHO, 2023) and many countries' data are roughly in line with this (Wylie, McAllister, Davidson, et al, 2013), although often generated from incomparable data sets. Analysis of refugee data has illustrated that a very small percentage of refugees were registered with a disability SNC in Rwanda at the times of data collection (1.73% April 2017 – 2.98% January 2020), compared to global estimates of disability prevalence. These figures are, however, in excess of regional refugee disability data (data sub-set 2 – only available for children under 12 years old). It must be noted, however, that the UNHCR tools used to collect the data reported here (UNHCR, 2006a) did not incorporate Washington Group (WG) questions on functional ability (Washington Group on Disability Statistics, 2020) and so may result in quite different data from those used to reach a global disability prevalence estimate of 16% (e.g., WHO, 2023) – many of which now utilise the WG short-set of questions. The UNHCR tools also did not incorporate any threshold in defining who was considered to have an impairment and/or experience disability.

5.6.1 Disability registration (specific needs code 'DS')

Data for the total refugee population in Rwanda illustrated an increase in disability specific needs code registration after both mapping (data sub-set 4) and verification (data sub-set 5) exercises took place, accounting for population change. Percentage registration rose from 1.73% of the total refugee population registered with a disability specific needs code before mapping (data sub-set 3), to 2.05% of the population after mapping (data sub-set 4), and 2.98% of the population after verification (data sub-set 5). Despite the overall low disability specific needs code registration rates for refugees in Rwanda compared to global prevalence estimates, the disability mapping exercise that took place in September 2017 (data sub-set 4) may have contributed to a +102.38% increase in registration of disability across the whole refugee community, considered against a population increase of only +2.18%

in that time. In January 2020 (data sub-set 5), the refugee population decreased in comparison to the population in September 2017 (data sub-set 4), yet overall disability registration increased by +45.37%. This suggests that targeted disability mapping exercises may be a useful continuous registration mechanism and 'safety net' for registration of people who experience disability who may fail to register, or have their needs accurately captured, at initial registration – especially if SNC codes are also updated to enable more accurate data collection and documentation.

Although data on childhood disability prevalence are equally scarce, global estimates of disability prevalence for children (aged under 12 years) stand at between 10% (WHO and WBG, 2011) and 11.2 % (Olusanya, Wright, Nair, et al, 2020). Despite this, in 2017 refugee child registration of disability globally stood at 0.87% (data sub-set 1). Regional child refugee disability registration stood at only 0.57% (data sub-set 2) and in Rwanda only 0.9% to 1.05% of refugee children under 12 years of age were registered with a disability specific needs code - a stark contrast to global prevalence estimates. [43]

Despite low registration of disability for refugee children in Rwanda in comparison to global estimates, data illustrate an increase in disability registration after the disability mapping exercise (September 2017, data sub-set 4), as well as after the verification exercise (January 2020, data sub-set 5), accounting for population change. The percentage of children under age 12 registered with a disability specific needs code rose from 0.42% of the under 12 population before mapping (data sub-set 3) to 0.85% after mapping (data sub-set 4) and 1.05% after verification (data sub-set 5). Interestingly, although child disability registration increased by +102.38% overall, between April and September 2017, with a +53.85% increase in registration in moderate intellectual impairment (DS-MM) and a +28.57% increase in severe intellectual impairment (DS-MS), there was no increase in the number of children registered as having 'special educational support needs' (CR-SE). A range of factors may have been affecting registration, including the possibility that: a) families were

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[43] Noting the previous discussion on frequent incomparability of data due to different definitions, tools, methods and thresholds used during data collection.

not reporting 'special educational support needs' (or were unaware of the needs their child might have); b) clerks were unaware of how to register 'special educational needs' during the mapping exercise, c) children with 'special educational needs' were not going to school, d) data updates from schools were not being uploaded into ProGres, or e) all of the above. Data from data sub-set 2 (see section 5.4) and sub-set 3 (see section 5.5) may help to explain these possibilities further.

Despite the acknowledgement that refugees who experience disability are one of the most at-risk groups in society (Lange, 2015; UNHCR 2010a; 2011; WRC, 2014), this analysis demonstrates that registration of disability amongst refugees, including refugee children globally, regionally, and in Rwanda, likely falls far short of what would be expected given global and regional estimates. This reflects the findings of other disability researchers in humanitarian contexts (Smith Khan, Crock, Saul et al, 2014; Tanabe et al, 2015).[44] If refugees with impairments, who experience disability, are frequently unregistered this may (at least in part), explain why they fail to access the humanitarian support they need (UNHCR, 2011; WRC, 2014).

5.6.2 Communication impairment/disability registration – codes 'DS-SD' and 'CRID'

Data analysis illustrates that registration of speech impairment/disability (DS-SD) was reported for 0.08% of the total refugee population in Rwanda in April 2017 (data sub-set 3), rising to 0.10% by September 2017 (data sub-set 4) – an increase of +33.33% following the disability mapping exercise. At first glance, this suggests that targeted disability mapping may be a useful process to identify refugees with CIs, who may experience CD, who may have missed, or experienced inaccurate, initial disability

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[44] This observation should, of course, be balanced against factors such as the ability to flee a crisis, as some people who experience disability may be limited in their resources, capacity, or support to do so and may be left behind, potentially reducing the expected numbers of people registered with a disability SNC in refugee populations (Mednick, 2022; Mirza, 2011). Conversely, crisis situations are recognised to increase the proportion of people who experience disability, often as a consequence of the interaction of injury or trauma with environmental barriers (Mirza, 2011). In the Rwandan context, however, many refugees have protracted refugee status (PRS) and have been residing in Rwanda for over twenty years, or may have been born as a second-generation refugee, so reduced ability to flee may not be as relevant to a portion of the PRS population and will less affect the population of children under 12 years of age amongst refugees with PRS, many of whom have been born in the Rwandan camps.

registration (especially if SNC codes are updated to capture disability data more accurately). When considering other disability specific needs registration codes that could involve aspects of CI (reported as CRID codes),[38] 34.06% of the population registered with a disability SNC post-mapping would have been recognised as potentially having a CI/experiencing CD, following the disability mapping exercise (data sub-set 4). Although CRID registration also increased by +81.25% after the mapping exercise, of the 1130 refugees registered under a CRID code post-mapping, only 157 of them (13.89%) were recorded as having a communication impairment (DS-SD), leaving the potential communication support needs of up to 86.11% of refugees undocumented and therefore 'invisible' in the registration data.

Although during the verification exercise (data sub-set 5) the CD screening tool was only used in three refugee locations out of eight (including one research location), 4.68% of the refugee population registered with code DS-SD after the verification exercise- an increase in registration of CI/CD of +40.00% from September 2017 (data sub-set 4). A much higher increase in DS-SD registration of +162.5% was noted in the three locations in which the CD screening tool was used. This tool (see appendix 5) incorporated Washington Group-style questions based on functional ability, as well as impacts on participation, which may have been more sensitive to CD than the existing ProGres 3 questions. The threshold for issuing a DS-SD code when using this tool was set to 'some difficulty' which, although a subjective judgement', may have also been lower than would have been considered using ProGres 3 alone (and which included no threshold guidance), and the tool instructed users to register *all* disability categories (e.g., DS-SD and DS-MM), thus resulting in higher levels of registration using code DS-SD.

When considering all the specific needs codes that are likely to include elements of CI and/or CD (CRID specific needs codes, including speech impairment/disability, hearing impairment, and intellectual impairment – moderate and severe), overall registration of CRID across the country increased from 0.70% of the population registered with a CRID specific needs code to 0.80% – an increase in registration of +14.29% between September 2017 (data sub-set 4) and January 2020 (data sub-set

5). Critically, despite the 40% increase in DS-SD registration overall, this still only amounted to 17.38% of refugees with a CRID specific needs code having their communication impairment/disability explicitly recorded, leaving 82.62% of potential communication impairment remaining undocumented.

The above analysis suggests that, despite increases in registration of CI/CD, it continues to remain under-registered under the DS-SD SNC, and that refugees who experience CD within a wider condition or set of impairments, may not have their communication support needs recognised when registered solely with another disability SNC. This may be because refugees may only have their primary impairments recorded with one SNC, despite the directive that all specific needs should be recorded separately (UNHCR, 2006), and despite the potential for a person to have multiple health conditions and/or impairments. This may leave secondary or additional CI neglected and masked by registration under another SNC. The creation of CRID codes in this study highlights that a much higher proportion of refugees who potentially experience disability could be registered, but that their CIs and associated experiences may not be captured. This could have significant implications for service design and provision since services are designed based on data to meet needs. Moreover, data also suggest that the introduction of the CD screening tool (figure 9, appendix 5) based on functional ability and participation, in three locations (which included staff training on identifying and recording CD, as well as recording multiple disability experiences using several codes) may be useful in identifying and more accurately registering CD.

For refugee children in Rwanda, only 0.03% of those under 12 years old were registered with a communication-related impairment or disability under the DS-SD specific needs code in April 2017 (data sub-set 3), rising to 0.05% of refugee children by January 2020 (data sub-set 5). This compares to 8.3% of children in the USA estimated to have a speech and language disorder (age 3-17 – NIDCD, 2016) and 25% of children who experience disability in one province of Ghana reporting CD (Biritwum, Devres, Ofosu-Amaah, et al, 2001). When considering potential communication impairment/disability within CRID specific needs codes, still only

0.16% (April 2017, data sub-set 3), increasing to 0.30% (January 2020, data sub-set 5), of the refugee population under 12 years old were registered with a CRID code.

For the population of refugee children under 12 years of age registered with a disability specific needs code in Rwanda, 7.46% were registered with a DS-SD code in April 2017, dropping to 5.15% of this population by January 2020. However, 37.72% were registered with a CRID specific needs code in April 2017 so may have had a CI and experienced some forms of CD. Of those registered with a CRID code, only 17.92% had their CI/CD explicitly documented with a DS-SD specific needs code (comparable to the 17.37% for all ages reported above), suggesting 82.08% of those registered with a CRID code may have their communication support needs masked by a primary or other 'visible' disability registration code. By January 2020, the proportion of the disability-registered child refugee population with a CRID code had fallen to 28.78%.

5.6.3 Analysis by research location

Analysis of the data ~~disaggregated~~ presented by research location (A, B, C) revealed that overall disability registration, as a proportion of the population, increased in all three camps between April 2017 and January 2020. This was notable in camp A, where disability registration increased by +256.71%, resulting in 2.39% of camp A's refugee population being registered with a disability specific needs code. The overall increases in disability registration were smaller in camps B (+16.5%) and C (+27.61%) but constituted 2.33% and 4.02% of the refugee population being registered with a disability specific needs code respectively. This suggests that the capacity to identify and register refugees with impairments, who experience disability, and/or the willingness of refugees to come forward to register their impairments/disability, increased over time. This may, in part, be related to staff training and community sensitisation activities that took place in the camps. Camp A was the focus of much attention from IOs, due to the ongoing emergency status of the camp and influx of refugees. It therefore may have received more focused, intense, and/or targeted inputs and support from the disability IO than other camps at the time.

Despite this positive step forward in disability registration across the three research locations, the proportion of the refugee population registered with a disability specific need code in each camp continued to be less than global disability prevalence estimates of 15-16 per cent of a population (WHO and WBG, 2011; WHO, 2023).

Registration of CI/CD under the specific needs code 'Speech impairment/disability' (DS-SD), as a proportion of the refugee population in each camp, increased by +150% in camp A, +450% in camp B, and +64.70% in camp C between April 2017 (data sub-set 3) and January 2020 (data sub-set 5). This represented 2.22% (camp A), 23.86% (camp B) and 6.9% (camp C) of the population of refugees registered with a disability specific needs code in each camp being registered under the DS-SD specific needs code after verification (data sub-set 5).

As a proportion of those registered with a CRID code in camp A, only 9.73% had their CI/CD registered under the DS-SD code in April 2017, dropping to 6.88% by January 2020. This means that over 90% of refugees registered with a CRID code (i.e., who may have communication support needs related to a CI), did not have them explicitly documented. In camp B, 45.90% of those registered with a CRID code had their CI/CD registered under a DS-SD code in April 2017 (data sub-set 3), rising to 58.9% in January 2020 (data sub-set 5), potentially leaving 41.1% of CI/CD undocumented. In camp C, 15.94% of those registered with a CRID code had their CI/CD registered with a DS-SD code in April 2017 (data sub-set 3), rising to 26.36% in January 2020 (data set 5), yet still leaving a potential 73.64% of CI/CD undocumented.

5.7 Implications of the findings from the statistical analysis

The data presented suggest that refugees with CI, who may experience CD, could be under-identified and under-registered in Rwanda. This is the case for all age groups, including the population of compulsory school-age children under 12 years of age. Although the percentage of the refugee population registered with a disability specific needs code registration increased over time, registration of CI/CD increased only marginally, and sometimes decreased.

The common practice of registration of impairment/disability using one single specific needs code[45] means that refugees registered with, for example, ‘severe mental disability’ (DS-MS), may have a CI and experience CD, but not have that captured in the data. Their possible communication support needs may therefore go unrecognised, and the prevalence of CI and CD may be under-represented. This potentially masks the communication support needs of up to 90% of refugees who experience disability registered with a CRID specific needs code (ProGres codes ‘hearing impairment/deafness’: DS-DF; mental disability’: DS-MM/DS-MS; ‘speech impairment/disability’: DS-SD) who do not have their CI or experiences of CD formally recognised in the registration system. One can therefore assume the estimate of those with CI, who experience CD, excluded from registration with a DS-SD code, may be higher than these analyses suggest.

Although the data from locations in which the CD screening tool was used at verification (figure 9, appendix 5) are incomplete, preventing analysis of potential effectiveness, all locations in which the tool was used documented a notable increase in DS-SD registration (+162.5% across the three locations). This compares to an increase in overall DS-SD registration of +40.00% across all refugee locations in Rwanda, suggesting a possibility that the training given to verification clerks and UNHCR community-based protection staff, as well as the CD screening tool itself, may have contributed to an increase in registration of CD under code DS-SD. These observations should be considered against changes in the population demographics, and an overall increase in disability awareness training and staff capacity building through the disability IO, since 2015. The increase in DS-SD registration code utilisation cannot be directly, or solely, attributed to CD training and screening tool use at this stage. Further national piloting of the screen is now required to enable assessment of whether it may be an effective addition to the ProGres data tools, to

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[45] The common practice of registering only one SNC per section was discussed by registration clerks during training for using the CD verification tool.

increase identification of a previously ‘invisible’ and excluded group of refugees. Evaluation of its validity and reliability is crucial to this decision-making.

Key findings from this data set analysis include:

1. Refugees with CIs, who experience CD, are likely to have their communication support needs under-identified and under-registered.
2. Registration codes are insufficiently sensitive.
3. Recording of multiple impairments and disability experiences is not catered for.

When considering developments in disability research since 2006, and the advent of data collection tools such as the UN Washington Group on Disability Statistics (2020) questions, now in global operation and in use in some humanitarian programming (O’Reilly, Jagoe, Brahmbhatt et al, 2022), it is possible that the ProGres tool and related database in use at the time of data analysis was insufficient to register communication impairment and disability accurately. The tool used in Rwanda has since been updated to ProGres 4, which uses Washington Group-style questions on functional ability. An analysis of registration data since the implementation of ProGres 4 would now be prudent to analyse whether it has effected change in CD identification and registration.

PART B

PHASE 1, DATA SET 2

DOCUMENT ANALYSIS

5.8 Introduction

This section reports on the document analysis (DA) of refugee registration policies and guidance, sourced through direct requests and online searching, to achieve objective O1b: *To describe and critique the current systems, tools and processes used to identify and register refugees with communication impairment and/or who experience communication disability, in Rwanda.*

For a discussion of DA as a method, see chapter 4, section 4.5.2.3. Here I report on data construction, data analysis, results of the analysis, and end with a discussion of the key findings.

5.9 Data construction: Sources and procedures

As described in chapter 4, section 4.5.2.3, DA was chosen to give context to the process of identification and registration of refugees who experience disability – specifically CD. It was employed to facilitate deeper understanding of the processes and procedures that UNHCR and implementing organisation staff are expected to follow and to elucidate opportunities and potential gaps for equitable service provision at both global and country levels. Themes identified in the DA were further explored through FGDs (data set 3, part B). Documents providing both top-down (e.g., global UNHCR and humanitarian directives) and bottom-up (from refugees in Rwanda e.g., consultation reports) information were sought to identify similarities and disparities between expected and experienced contexts. In response to objective O1b, documents referring to the process of identification and registration of refugees were sought through several channels. The search strategy is detailed in appendix 7.

Searches were conducted at the beginning of the search window (January 2016) and repeated monthly throughout the search window time frame (January 2016-June 2018) to identify any missed, new, or updated documents. Academic databases were not used in this document search as I was primarily seeking to analyse guidelines and policy directly applicable to humanitarian action, rather than theory or research. Search terms for open web searching are listed in table 20 below.

Table 20: Phase 1 document analysis search terms

Refugee terms	Registration and identification terms	Disability terms	Inclusion terms
Refugee*	Registration	Disab*	Inclusion
Forced migration	Identification	Impair*	Integration
	Verification	Handicap*	Participation
	Rapid assessment	Special needs	Consultation
	Best interest assessment	Specific needs	

**stem words*

Once documents were identified for potential inclusion, basic information about each document was extracted and entered into a Microsoft Excel spreadsheet (see appendix 7) according to the following categories:

- Document ID
- Document title
- Document type
- Year of publication
- Country the document refers to
- Language
- Author
- Source
- Format
- Purpose
- Audience

Each document was then read in full and inclusion/exclusion criteria applied as per appendix 7. An initial title/abstract/executive summary search was not conducted, as this may have led to critical documents being excluded early in the review process since not all documents explicitly mentioned disability identification/registration in their titles or featured abstracts/executive summaries. Documents focusing on refugee registration of CI and CD specifically were not sought at this point, as previous experience demonstrated that few documents focusing on this under-recognised issue would be available. Instead, documents discussing disability registration more broadly were searched for content referring to CI and CD.

5.9.1 Data analysis: methods and process

In this section I discuss some of the options available for data analysis, before describing and providing a rationale for using the Framework method of analysis.

As Bowen (2009) discusses, the process for carrying out DA is often lacking in description and detail in publications. Indeed, there is no ‘correct’ way to conduct a DA. It often combines elements of both qualitative content analysis and thematic analysis, for example, and the processes employed can depend upon the research questions, the research philosophy upon which it is grounded, and individual researcher preference. DA commonly involves an initial process of *“skimming (superficial examination), reading (thorough examination), and interpretation”* (Bowen, 2009: 32), common to both content and thematic analysis, followed by a more in-depth review of the data to identify themes and interpret meaning (Bowen, 2009).

Content analysis (Hsieh and Shannon, 2005) tends to focus on the content and context of the documents analysed, according to the central research question (Krippendorff, 2004; Spencer, Ritchie, Ormston, et al, 2014). Many of the techniques used in qualitative content analysis (such as reduction of data, inductive and deductive coding choices/combinations, and identification of categories or themes) overlap with other qualitative research techniques, such as thematic analysis (TA).

Indeed, Braun and Clarke conceptualise CA as a form of TA, even though it is generally more limited in scope (Braun and Clarke 2021a, 2021b). TA is a broad term given to a flexible analytical tool during which patterns and themes are identified within the data and, in some cases, meaning interpreted by the researcher (Braun and Clarke, 2006; Spencer, Ritchie, Ormston, et al, 2014), often leading towards theory validation or generation (Boyatzis, 1998; Braun and Clarke, 2006). Braun and Clarke have, more recently, evolved their thinking on TA, now describing their inductive method of TA as ‘reflexive thematic analysis’ (Braun and Clarke, 2019a).

TA is applicable to a range of qualitative inquiries and claims theoretical flexibility, facilitating its application across a range of epistemological and ontological research foundations (Braun and Clarke, 2006). The process of categorising data and generating themes within it means it lends itself equally well to researchers wishing to apply predefined *a priori* concepts arising from existing theory or literature, *in vivo* concepts grounded in the data, and/or *emergent* concepts grounded in the data but interpreted by the researcher (Spencer, Richie, Ormston et al, 2014), depending on the research question and the researcher’s epistemological stance, as well as the data being analysed. Braun and Clarke (2021a, 2021b) advocate for researchers to carefully consider the kind of TA that would be most applicable to their research, ensuring their epistemological stance is clear throughout the analysis. Some forms of TA take a more post-positivist orientation (such as classical grounded theory), whilst others are far more experiential (critical realist or contextualist) or critical (relativist or constructionist), in orientation, for example, reflexive TA (Braun and Clarke, 2021b).

The ‘Framework’ method of analysis (Ritchie and Spencer, 1994) is considered to reside under the umbrella of TA by some researchers (e.g., Serrano-Fuentes, 2021), but this is contested by others who feel it is sufficiently unique to be considered a standalone method of analysis (Green and Thorogood, 2018). Braun and Clarke (2021a, 2021b), classify the Framework method as a form of ‘codebook TA’, bridging the gap between qualitative content analysis, and reflexive TA. This method was first developed in the 1980s (Ritchie and Spencer, 1994) and has since been successfully employed within a broad range of disciplines, including multi-disciplinary health research (Gale, Heath, Cameron, et al, 2013). Framework provides a guided method of substantive (capturing what that text says, rather than what it does), cross-sectional (a set of labels applied across a set of data) qualitative data analysis that stays close to the data whilst facilitating data abstraction (Spencer, Ritchie, O'Connor, et al, 2014). A central tenet of the Framework method is the production of data summaries and displays, in the form of matrices, enabling analysis of key themes across whole data sets, whilst retaining the ability to compare data within an individual case or document (Gale et al, 2013) and "*increasing confidence that analysis adequately represents the whole dataset"* (O'Donnell, 2021, online).

Critically, the Framework method creates a transparent, systematic, and auditable research trail, from initial data sorting, through levels of data extraction and abstraction, increasing the rigour and validity of the results (Gale et al, 2013; Smith and Firth, 2011; Ritchie and Spencer, 1994; Spencer, Ritchie, O'Connor, et al, 2014). I therefore considered the Framework method to be a suitable method for analysing the data in this DA. Moreover, Framework aligns well with the philosophical assumptions underlying the research project as a whole (see chapter 4), in terms of its flexibility of approach (e.g., a priori and in vivo coding) to answer the research question and objectives.

5.9.1.1 Applying the Framework method to the data.

Application of the Framework method to the documents identified for this DA enabled me to not only gather information about registration tools and processes, but also later contextualise their meaning in relation to the stakeholders' experiences analysed in data set 3 (see part C). As such, the DA formed a critical part of the data integration process.

Following identification of the documents for inclusion in the analysis, I followed the five key stages of the Framework method of data management (Spencer, Ritchie, Ormston et al, 2014).[46] This involved:

1. Familiarisation: Immersion in the data gaining an overview of the body of data as a whole.
2. Identifying and constructing a thematic framework: Identification of key issues and construction of initial themes and subthemes into which data can be sorted, some of which may be a priori and others in vivo or emergent concepts.
3. Indexing and sorting: The initial framework is applied to the data and labels are added to the text (this is not always necessary for 'well ordered' texts).
4. Reviewing data extracts: Considering whether the frameworks are coherent or need refinement.
5. Data summary and display: construction of matrices summarising the data. (Spencer, Ritchie, Ormston, et al 2014).

Labelling and coding of the data began with several *a priori* codes derived from the research aim and objective O1b, including codes directly derived from my familiarity with the processes of refugee identification and registration.

For documents that included reference to identification and registration processes and procedures, but also included other areas of humanitarian action (such as sector-specific guidance),[47] only the sections on identification and registration (including identification and registration for specific types of service access) were extracted and coded. Further familiarisation and labelling led me to refine the *a priori* codes and identify new, *in vivo*, codes within the data that related to the research aim and objective. Codes were then grouped into themes and sub-themes. Absence of

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[46] These were further refined in Spencer, Ritchie, Ormston et al, 2014, since publication of the stages in Ritchie and Spencer (1994).

[47] Sectors within humanitarian action include (but are not limited to) (child) protection; water, sanitation and hygiene (WASH); shelter; livelihoods; education; food and non-food distribution (including cash and voucher assistance); health; education; resettlement.

information was also noted as relevant in some documents and was documented in research notes.

Cross tabulation of document against code and theme at each stage facilitated intra and inter-document comparison and was initially carried out manually and then by entering the information into computer assisted qualitative data analysis software (CAQDAS) NVIVO-12 as I became more familiar with the data.

5.10 Results

Forty-five documents were identified for potential inclusion in the analysis. Twenty-nine documents were excluded for not meeting inclusion criteria (see appendix 7), and sixteen documents were analysed in full. Each document was given a code from S1.01 through S1.45 (see appendix 8).

Documents are produced as ‘social facts’ (Atkinson and Coffrey, 1997) and, when analysing them, their author, purpose, and intended audience must be considered to ensure a full understanding of their content and application. The purpose of most documents was to support humanitarian actors to implement effective identification and registration activities (n=11). Some were produced to address the specific issue of disability and inclusion in humanitarian service planning and delivery (n=3) and others were produced as reports documenting the situation faced by refugees who experience disability, including children, and gave suggestions to make services more inclusive (n=3).[48] These documents tended to be produced by NGOs with specific rights agendas, including UNICEF and Women’s Refugee Commission (WRC). Guidance documents were more likely to be produced by UNHCR and other humanitarian agencies or consortia and documented organisational expectations. As per the inclusion criteria (appendix 7), the documents analysed were, by and large, produced by and for humanitarian actors and therefore represented a relatively unified perspective.

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[48] Some documents covered more than one type of issue.

The documents included were all relevant to global humanitarian action, including in Rwanda, and were analysed to produce a descriptive summary of their content and application. Analysis generated forty-two codes (appendix 9) that were subsequently grouped into eight sub-themes and four themes that described the essence of the documents' content and meaning (table 21).

Table 21: Phase 1 DA sub-themes and themes

Sub-theme	Theme
1 Identification and registration processes, procedures, and safety nets	1 IDENTIFICATION AND REGISTRATION IS A REFUGEE'S RIGHT
2 Disability identification and registration	
3 Disability rights	2 RIGHTS ARE THREATENED
4 Violations of, and threats to, rights realisation	
5 Barriers to inclusion	3 EXCLUSION CONTRIBUTES TO PROTECTION RISK
6 Heightened protection risk	
7 Refugee-focused responses	4 THE NEED FOR MULTI-FACETED SUPPORT MECHANISMS
8 Service provider focused responses	

5.10.1 Theme 1: Identification and registration is a refugee's right.

Incorporating sub-themes 1 and 2 (see table 21 and appendix 10).

This theme describes the rights-based framework that governs identification and registration services for all refugees, including those with impairments and who experience disability.

Disability rights enshrined in the CRPD (UNGA, 2006), and adopted in most documents, are inextricably interwoven with the refugee right to identification and registration. Realisation of both rights should result in equitable access to services for refugees who experience disability. Accurate documentation of disability 'status' and support needs are therefore acknowledged as crucial to ensuring service providers understand what accommodations and provisions may be required to provide accessible services.

Despite the documented commitment to identify and register refugees who experience disability by coordinating bodies, service evaluations highlight exclusionary practices that suggest refugees who experience disability may not be identified at all or may be unable to realise their right to accurate specific needs registration, impacting upon their access to protection services.

> *"Children and adolescents with disabilities are rarely included in assessments and other data collection exercises. Thus, humanitarian programmes may inadequately document and consider their needs" (S1.34: UNICEF, 2017: 15).*

5.10.2 Theme 2: Rights are threatened.

Incorporating subthemes 3 and 4 (see table 21 and appendix 10).

> *"Exclusion of persons with disabilities during displacement can be inadvertent or purposeful: in either case, nevertheless, it is discriminatory"* (UNHCR and Handicap International, 2011: 4).

It is critical that, in situations of forced migration, refugee rights (UN General Assembly, 1951) and disability rights (UN General Assembly, 2006) are amalgamated. This principle is upheld in print by UNHCR and supporting humanitarian organisations.

Documents suggest that, at the intersection of being a refugee and being a person who experiences disability, lies elevated exposure to risks due to passive and active discrimination. This impacts upon the ability to realise refugee, disability, and human rights, including the right to accurate and timely registration.

5.10.3 Theme 3: Exclusion contributes to protection risk.

Incorporating sub-themes 5 and 6 (see table 21 and appendix 10)

Documents describe how refugees who experience disability face a multitude of attitudinal, environmental, and institutional barriers to inclusion and participation.

This contributes to elevated exposure to protection risk - the antithesis of the protective and rights-based global humanitarian agenda.

5.10.4 Theme 4: The need for multi-faceted support mechanisms.

Incorporating sub-themes 7 and 8 (see table 21 and appendix 10)

Having identified the protection risks and rights infringements that refugees who experience disabilities face, several documents make recommendations for both meeting their specific support needs and enhancing inclusive practice. These recommendations follow the popular ’twin-track’ approach (Department for International Development (DFID), 2000) whereby a split focus on providing specialist support, alongside empowerment strategies and improving access to mainstream services, is advised to enhance participation whilst ensuring individual support needs are addressed. The need to address the participation support needs of refugees who experience disability through both targeted responses to individuals and groups, as well as through service provider focused responses, demonstrates commitment to delivering a holistic approach to inclusion.

5.11 Implications of the findings from the document analysis

DA facilitated the identification and analysis of sixteen documents, producing four overarching themes and eight sub-themes (appendix 10) related to the refugee identification and registration processes and their application to refugees with impairments, who experience disability.

Results[49] indicate that the refugee registration policy and guidance landscapes recognise that a rights-based framework governs identification and registration services for refugees who experience disability, meaning that they are a refugee’s right in international refugee law. For refugees who experience disability, rights

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[49] Including data from sub-themes detailed in appendix 10.

stipulated in the CRPD (UN General Assembly, 2006) also apply and are adopted in most documents produced after its publication.

Despite adoption of the CRPD human rights framework to guide its disability interventions, the UNHCR categorisation system used to register 'disability', at the time of data construction, was framed upon an impairment-based model. This means data that were intended to identify disability, actually often captured impairment data, and was not consistent with a rights-based framework, which focuses on participation. This is highlighted by information in the data collection tools (document S1.12 – see appendix 8), which collects information on 'speech impairment/disability' and 'hearing impairment/deafness' (UNCHR, 2006a), in the absence of collecting information on a person's functional capacity (as is captured by the Washington Group Questions, Washington Group on Disability Statistics, 2020), experience of barriers to participation, and their communication access needs. The refugee registration labels use the word 'disability', but the registration document and database only allow for documentation of one aspect of the disability experience (impairment) in the absence of information on the interaction of impairment with the social and physical environment (WHO, 2001). This information, therefore, does not accurately inform services of the needs of service users. In addition, there is no explicit instruction within the disability section for enumerators to record all impairments or support needs, potentially giving the impression that only one can be registered. This is confusing in the face of complex health conditions and multiple impairments which may involve aspects of CI, even if it is not the primary impairment.

Analysis of these data further highlights that refugees with impairments are recognised to be disabled by numerous barriers to inclusion and participation, heightening their exposure to protection risk. Indeed, realisation of the right to registration (and subsequent service access) is threatened by the existing prejudices of communities and service providers (UNHCR and Handicap International, 2011). Refugees' disability rights are considered to be realised in part but recognised to be threatened by active and passive discrimination, resulting in ongoing rights violations (UNHCR and Handicap International, 2011).

Service provider organisations acknowledge that ensuring inclusion and participation of refugees with impairments, who experience disability, in registration requires both service user and service provider focused support mechanisms. There are some recommendations for *what* to do to move towards more inclusive practices, but with relative lack of information of *how* to operationalise those recommendations, potentially leading to stagnation of progress.

In summary, key findings from this document analysis are listed below:

1. **Use of disability terminology is inconsistent across guiding humanitarian registration documents.**
   This creates a juxtaposition of rights-based and medical models of disability, impeding accurate identification, registration, and data disaggregation.

2. **Refugees with CI are at risk of disabling exclusion from registration of specific needs.**
   This risks infringement of refugee rights and has ramifications for service design and provision, service access, and community participation.

3. **Refugees with CI experience heightened protection risk.**
   This directly contradicts UNHCR's mission: *"UNHCR's primary purpose is to safeguard the rights and well-being of refugees"* (UNHCR, 2007).

4. **There is a disconnect between commitment and reality.**
   Inclusive registration expectations are clearly documented, whilst evaluative evidence demonstrates that these expectations are not always effectively operationalised.

PART C

PHASE 1, DATA SET 3

FOCUS GROUP DISCUSSIONS (FGDs)

5.12 Introduction

This section reports on data constructed from FGDs with service provider stakeholders, including implementing organisations (GoR, UNHCR, NGOs), community volunteers, educators, and refugee committee members, to achieve objectives O1b and O1c:

- *Objective 1b: To describe and critique the current systems, tools and processes used to identify and register refugees with communication impairment and/or who experience communication disability, in Rwanda.*

- *Objective 1c: To document the self-reported understanding, behaviours, and experience of staff responsible for determining if refugees have a CI and/or experience CD.*

I report on data construction, data analysis, results of the analysis, and end with a discussion.

5.13 Data construction procedure

This section reports on the data construction process, including the selection and training of research assistants (RAs), and participant identification and recruitment.

5.13.1 Preparation for participant identification and recruitment: Gatekeeper and Research Assistant (RA) selection and training

FGDs were chosen as the most effective method of data collection to address objectives O1b and O1c (chapter 4, section 4.5.2.3). To ensure the highest standards of ethical research practice (see chapter 4, section 4.6), I planned to recruit participants through a staged process, utilising first gatekeepers and then research assistants (RAs).

Gatekeepers are intermediaries, used to ease access to study settings and participants that may otherwise be difficult to reach (Andoh-Arthur, 2019). They are often connected to a research population in some way (membership of a community or working relationship (Andoh-Arthur, 2019). They are utilised to both identify potential participants (typically when fulfilling their usual job role) and reduce the risk of coercion of potential participants to take part as they represent a 'middle ground' between potential participant and research team. The initial plan was for gatekeepers to be selected, in conjunction with UNHCR, from implementing organisation staff who were in contact with potential participants as part of their usual job role. Instead, UNHCR considered it acceptable for the RAs to also act as gatekeepers in this study.

RAs are a common feature of cross-cultural research and are typically recruited from the local community in which research is taking place. They can fulfil a range of functions, including gatekeeper, translator (Stevano and Deane, 2019), and cultural broker, to facilitate research implementation. Their involvement, however, inevitably has implications for how the research process occurs, and the quality of the research design and results (Ozano and Khatri, 2018; Stevano and Deane, 2019 – see chapter 7, section 7.3.3 for a reflection on using RAs in this study).

RAs were carefully selected and trained to ensure they understood a) the purpose of the research b) the identification, recruitment, and data construction methods, and c) communication impairments and associated disability. One RA per location was selected (total 3), with the assistance of the UNHCR Rwanda country office, based on experience working with refugees who experience disability, and interest in the role. According to Ozano and Khatri (2018: 202) *"the employment of more than one RA further helped [them] with communication, reflexivity, confidence and challenging an outside researcher perspective."* Community-based protection officers responsible for disability issues were selected to be most appropriate.

A one and a half day interactive training package was delivered to all RAs (see appendix 11 for training schedule) in each research location between November 2016 and January 2017. It covered CI and CD, research methods for the study, research ethics, roles and responsibilities, the consent process, translation versus interpretation, timeframes and documentation, and logistics.

5.13.2 Participant identification.

Participants were required to meet the inclusion criteria for the study to take part (see table 22). The criteria were designed to ensure participant safety, relevance to the aims and objectives, and ability to participate.

Although 'sampling' is a term commonly used when describing the process of identifying potential participants for research, Clarke's (2022) understanding of this has evolved somewhat, related to the progression of scholarship on research quality and rigour in qualitative and mixed-method inquiry (see chapter 4, section 4.6). Clarke (2022) states:

> *"Another term I've used in the past but now avoid is sample - as that does seem inherently linked to the notion of sampling from a population for the purposes of statistical generalisability" (Clarke, 2022: Online).*

The way in which potential participants were identified for this data set is more traditionally described as using a process of 'a priori sampling' (Gentles, Charles, Ploeg, et al, 2015; Gentles and Vilches, 2017). This involves making identification decisions before data construction begins, to identify participants who would be able to contribute to discussions in pursuit of the research aim and objectives. A priori sampling is arguably a form of purposive sampling (Gentles et al 2015; Gentles and Vilches, 2017), in which participants are selected based on *"the researcher's judgement as to typicality or interest"* (Robson, 2002 p.265). From a pragmatic paradigm perspective, participants for this research were identified and selected based on their potential to be best able to provide different, but relevant, perspectives on the research question, aims and objectives.

Potential professional participant organisations and volunteer groups were selected, based on involvement in the identification/registration of refugees with impairments experiencing associated disability, in any capacity. A target of eight participants per stakeholder group FGD was considered ideal, based on guidelines by Overseas Development Institute (2009). One FGD per group, per camp, was planned (see table 22). Each group consisted of one 'type' of participant, based on their formal professional or formalised volunteer (officially recognised by GoR and UNHCR) role.

Table 22: Number of participants by professional group for phase 1

Participant population (stakeholder groups)	Target number per camp	Total number (3 camps)
Implementing organisations (GoR, UNHCR, and (I)NGO partners)	8	24
Educators (ECD caregivers and teachers)	8	24
Community volunteers (health workers and disability mobilisers)	8	24
Refugee disability committee (RDC)	8	24
TOTALS	**32**	**80**

5.13.3 Participant recruitment

For implementing organisations (IOs) and educators, RAs approached the field office heads of the groups identified above to ask them if they would be willing to allow (an) appropriate member(s) of staff to participate in the research, according to the inclusion criteria (table 23). Participant information sheets (PIS) were given to each potential participant, via the office head. Community volunteers and the refugee disability committee (RDC) were approached directly by an RA during the normal course of their community work and given the research documentation for their consideration. After a full verbal and written explanation of the research,[50] the RA gave potential participants a chance to ask questions, and then obtained full, written, informed consent to participate, if the person was willing (figure 10). Anonymity and the right to withdraw at any time and without reason or consequence, was explained carefully and repeatedly throughout the recruitment process. Details of the FGDs/interview were communicated by telephone in advance, and a telephone reminder given on the day. Approach and consent processes were staged to reduce the chance of coercion.

Any person who did not meet the inclusion criteria in full was excluded from being approached to take part in the study from the outset. If initially approached and it later became evident that they did not meet one or more of the criteria for inclusion, they were thanked for their interest and no longer involved in the research.

Table 23: Inclusion criteria for phase 1 FGDs

INCLUSION CRITERIA
Over 18 years of age at time of recruitment
Fluent in at least one of: Spoken or signed Kinyarwanda, French, or English language
Involved in a formal capacity in the identification and/or registration of refugees with impairments and disabilities
Has capacity to give full, voluntary, informed consent as per the PIS and consent procedure
Able to attend *either* a FGD *or* individual interview at a time when the researcher would visit the camp for data collection

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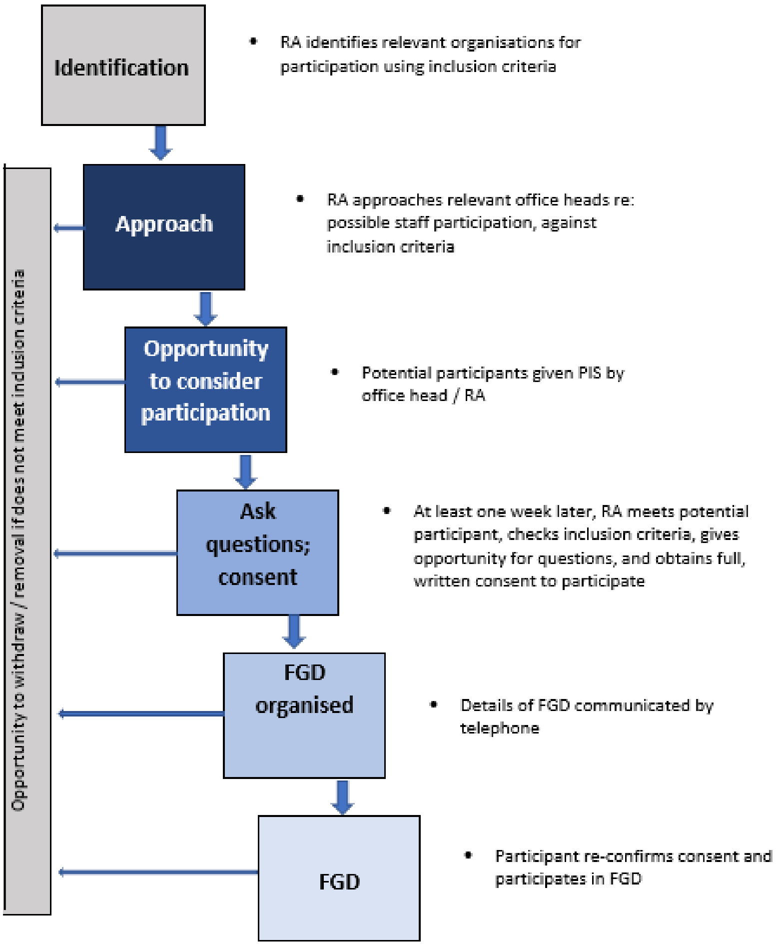
[50] Full written, plain language, or symbol supported PIS and consent form in English, French or Kinyarwanda – see appendix 12 for examples.

Figure 10: Participant recruitment process for stage 1 FGDs



5.13.3.1 Participants

The final participant groups involved seventy-three participants in total. Demographic information on gender identity and age, along with years of professional experience, is provided (appendix 13). The final composition of the participant groups was necessarily influenced by the identification/sampling process (e.g., using existing data and personal connections of the RA and community volunteers they work with). It was also influenced by the recruitment process and factors out of my control (Gentles and Vilches, 2017), such as exactly how the participants were identified and approached, as the process was carried out by RAs when I was not present.

5.13.4 Conducting the Focus Group Discussions (FGDs)

Arrangements were made for the FGD in each location, according to the clearance granted by the Government for me to enter the camps at specific times. The data were collected in the same sequence in each of the three assigned camps (A, B, C) between January–March 2018.

Participants were asked to attend the relevant FGD according to their stakeholder group (1: implementing organisations (IOs), 2: community volunteers, 3: educators, 4: refugee disability committee) to ensure the conversation would be relevant to their experiences and that they would feel comfortable talking with each other. The FGDs were held in locations chosen to be familiar, neutral, and to offer as much privacy as possible. This was usually the UNHCR camp-based office buildings or the community centre.

Upon arrival at the FGD, participants were welcomed, two copies of their consent forms (see appendix 14) checked and counter-signed by the researcher or RA, and their continued willingness to participate confirmed verbally. Water was provided throughout the discussions, and snacks and soda at the end, in appreciation of participants' time.

If all participants agreed, each FGD was audio-recorded using a digital multiple-microphone Dictaphone. The data storage and anonymisation process was explained clearly to all participants verbally, any questions answered, and their verbal agreement to proceed sought. If any participant declined to be audio recorded, contemporaneous notes were made, digitised, and stored securely. Each FGD lasted approximately one hour. Participants were assured at the outset that if they had any other concerns or things to discuss not related to the research, they would be given time at the end to discuss these or offered an appointment with the relevant staff at UNHCR.

FGDs followed the same format, according to a topic guide of open-ended questions and conversation stimulators. The topic guide (appendix 15) was developed in advance of the discussion based on the research aims and objectives for phase 1, to help focus the conversation whilst being flexible enough to allow participants to incorporate information they believed to be of relevance to the discussion. Participants were encouraged to talk to each other, elaborate on each other's responses, contribute other relevant information, and discuss experiences with each other throughout, and the guide was flexible enough to allow follow up on interesting avenues for discussion. The topic guide was adapted iteratively for future FGDs (as in Berkowitz, 1997; Srivastava and Hopwood, 2009).

The discussions were led by me as principal investigator, in English, and translated both ways by the RA into/from French/Kinyarwanda, as necessary (see chapter 7, section 7.3.3 for a reflexive account of this). Conversations were sometimes conducted in multiple languages. At the end of each FGD, the conversation ended, the audio-recorder was switched off, and the participants thanked.

5.13.5 Data storage and management

Audio data were transferred to a password protected computer at the end of each FGD. Later, recordings were backed up to a memory card which was kept in a safe in a locked room. Each file was given a code. At this point the data were deleted from the audio recorder. Upon transcription of the files into written form, individual identifying information was anonymised, and transcripts were saved on a secure computer, and locked hard drive, with a coded file name. Audio files were then deleted from the computer and hard drive using data shredding software 'Wise Care 365'.

5.14 Ethical considerations and reflexivity

This section details some specific ethical considerations that were made before carrying out FGDs, as a well some reflections on how the process occurred during the data construction window. For further discussion of ethical considerations and reflexivity, see chapter 7, sections 7.3 and 7.4.

5.14.1 Consenting process.

Consent is a construct upon which cultural understanding, values and practices have a significant impact. In minority world academic circles, the definitions, understanding and practices of giving consent, ongoing consent, and withdrawal of consent, are well established, and understood, albeit continuously evolving (Byrne, 2001). However, when conducting cross-cultural research, the construct of consent in other contexts may be vastly different to that upon which minority world ethical approvals have been granted.

Although bound by the ethical standards of both MMU and University of Rwanda, that full, written informed consent should be sought from participants at least forty-eight hours before a FGD or interview, RAs and participants were sceptical of this, sometimes unfamiliar, process and were confused about the ‘formal’ approach taken to the organisation of the kinds of FGDs that they were familiar with. The use of gatekeepers, PIS, and formal written consent was viewed as ‘heavy handed’ and unnecessary in that context. Although I felt unable to change the approach too radically, due to ethical requirements of the supporting Universities, I did explain this as openly as possible to participants, ensuring they understood that the process was for their own protection and to ensure I acted in their best interests at all times.

5.14.2 Trust, rapport, and credibility.

I made efforts to familiarise myself with each camp before data construction began. These efforts to ‘be there and be seen’ are acknowledged to be essential to build rapport, trust, and credibility amongst potential participants, which must then be maintained throughout the research process (Sixsmith, Bonham and Goldring, 2003). My experience living in Rwanda taught me that people tend not to divulge much information until you are considered ‘known’. This can take quite some time and involve revelation of personal information, including about one's family, to build trust and rapport. As such, I used my experience of working with communities in East Africa as an entry point to build rapport and credibility. My experience living in Rwanda also taught me that greeting people in Kinyarwanda and establishing a personal connection with them was also highly appreciated. Being able to understand and use some words and phrases, such as greetings and thanks, served to 'break the ice' during discussions.

Rwanda has a hierarchical society in which power and rank are upheld and respected. To establish credibility with Government officials and high-ranking staff, there was a need, as a white, British, 'outsider' female, to balance my presentation as a competent and knowledgeable professional, whilst complying with, and maintaining respect for, power and hierarchy in my engagements. My familiarity with cultural routines was helpful to establish myself as culturally knowledgeable and aware. During negotiations with Government officials about the way in which the research could be carried out, I was careful to be clear about my research purpose and plans, whilst respectfully exploring any reason for concerns.

During the research, my direct association with UNHCR possibly enhanced my credibility with participants, who are thought to value UNHCR and its work. As a member of staff explained:

> *"When you are with UNHCR you are OK. They trust us because they know that we work for them"* (UNHCR, Camp A).

This, however, also had implications for my positionality and the power dynamics at play during interviews and FGDs (see chapter 7, section 7.3.1).

5.14.3 Conducting FGDs across cultural and linguistic difference.

FGDs have the potential to generate high quality data on perceptions and social norms, through interactive group discussions. As discussed by Jakobsen (2012), however, it is not unusual in cross cultural research for participants to find this unconventional and for FGDs to morph into a form of group interview. In this situation, interactions centre around the researcher taking the lead in asking questions which are answered by a ‘spokesperson’ or one by one by each participant, often looking to each other for group consensus, or to the researcher to make sure they are giving the ‘right’ answer. This can affect the quality of data, since the researcher’s position may be such that the group perceives they should answer ‘as one’, avoiding disagreement and dissonance (See chapter 4 for further discussion on research rigour, and chapter 7 for further reflection on this). Indeed, responses may be externally motivated to be ‘socially desirable’ (see chapter 7, section 7.4.2.7), depending on who the group perceives the researcher to be, and what power or position they perceive them to hold (e.g., access to funds, services, or goods). Responses may be more factual than opinion-driven, thereby negating the very purpose of the FGD (Jakobsen, 2012).

To mitigate these issues, I ensured that, following introductions and explanations of what would happen during the FGD, I let the Rwandan RA take the discussions forward in the preferred language of the participants. Although (not ideally) the RA translated live into English for the purpose of the recording (see chapter 7, section 7.4.3), participants were encouraged to discuss topics amongst themselves, rather than directing answers to me or the RA. This was more successful in some groups than others, possibly related, in part, to the power, rank and/or positionality of the participants in that group (e.g., government officials versus refugee volunteers), since the RA was a UNHCR member of staff, with their own perceived position, power, and rank. FGD results must therefore be considered with the potential effects of this on data quality.

5.14.4 Compensation and tokens of appreciation.

It was critical from the outset to ensure that no element of the recruitment or participation process was coercive in any way. However, I believed it important to balance this with appreciation for participants' input in a context where humanitarian staff are very stretched for time and resources, and refugees live hard lives in harsh and under-resourced environments.

Although RAs advised against cash compensation, they agreed that thanking participants in some way for their efforts would be polite. They deemed it most appropriate to thank participants by providing food and drink at the end of the discussion. For transparency, the PIS (see appendix 12) explained that refreshments would be provided, so that participants were fully aware of what to expect from the discussions.

5.15 Data analysis: methods and process

This section details the methods and processes used in data preparation and analysis.

5.15.1 Data preparation.

The English content of the audio recordings were transcribed and anonymised by me as soon as possible after the FGDs had taken place. Express Scribe and FastFox Text Expander software were used with Microsoft Office 365, to assist with accurate and efficient transcription, transfer, and storage of anonymised, transcribed data. Contemporaneous notes were formatted in the style of an orthographic transcription as far as possible.

As the recordings were audio-only, and of group conversation, they were transcribed verbatim, in an orthographic style (Guendouzi and Müller, 2006). I considered this the most appropriate style of transcription for the purpose as a) it was difficult to know exactly which participant was speaking in the group when audio-only content was available; b) it was not possible to read facial expression or gesture from audio-only content; c) live translation of content from and into English/Kinyarwanda/French meant the English version may have not been exactly what the participant said; and d) the supra-lingual features of what was said were lost upon translation. Orthographic transcription is, however, considered to be at the core of analysis of connected spoken language and requires consistency and careful attention to detail (Guendouzi and Muller, 2006).

5.15.2 Data analysis: method.

As described in section 5.15.2, thematic analysis (TA) is useful for its theoretical flexibility and application to a range of disciplines (Braun and Clarke, 2006; 2019a) and is described by Braun and Clarke (2006: 6) as *"a method for identifying, analysing, and reporting patterns (themes) within data."* Although Spencer, Ritchie, Ormston, et al (2014) describe thematic analysis as a 'generic approach' rather than a 'method' (a sentiment shared by Boyatzis, 1998; Ryan and Bernard, 2000; Vaismoradi, Turunen and Bondas, 2013), Braun and Clarke (2006; 2019a; 2021a) posit that TA encompasses a range of analytical techniques and that each *is* a method(ology) in its own right. They claim that different types of TA (including grounded theory, discourse analysis, interpretative phenomenological analysis, and reflexive TA), although similar in many ways, are sufficiently distinct in one or more domains of epistemological grounding, process, values, and/or outcomes, to warrant their own classification as distinct methods/methodologies (Braun and Clarke, 2021a; 2021b). Furthermore, they claim that specific forms of TA do have their own paradigmatic and epistemological assumptions about knowledge production and are therefore *"more or less constrained"* (Braun and Clarke 2019a: 592), challenging the common assumption that TA is completely atheoretical.

The interpretive nature of what Braun and Clarke term *reflexive* TA (2019a; 2019b; 2021a; 2021b) (see section 5.15.2), with its appreciation for researcher experiences in the interpretive process, positions it as an analytically sound method for use in research conducted within a pragmatic research paradigm and ID methodology -

listening to the voices of underrepresented groups and interpreting their stories through the experiential and philosophical lens of the researcher (Braun and Clarke, 2019a; 2021a; 2021b). Braun and Clarke (2021a: 38) describe how reflexive TA unavoidably becomes *"infused with theoretical assumptions when enacted in a particular study"* and how researchers must be explicit about their theoretical assumptions when applying the method to their research.[51]

Thematic Network Analysis is a means of transparently conducting and displaying a TA. Although its proponent, Attride-Stirling (2001), is not explicit about which form of TA can or should be used in conjunction with thematic networks, her work was published before the seminal work of Braun and Clarke in 2006, and their iterations over a decade later. Attride-Stirling stated that:

> *"Applying thematic networks is simply a way of organizing a thematic analysis of qualitative data…. What thematic networks offers is the web-like network as an organizing principle and a representational means, and it makes explicit the procedures that may be employed in going from text to interpretation." (Attride-Stirling, 2001: 387-8)*

On reviewing the potential application of TNA to the various forms of TA described by Braun and Clarke (2021a; 2021b), I considered TNA to be aligned with their reflexive form of TA, based on several factors, including: the level of rich data exploration and interpretation; the centralisation of researcher experience in the analysis; the interconnectedness of themes in a non-hierarchical structure, essential to the 'story-telling' so core to reflexive TA (Braun and Clarke, 2021a); and the focus on epistemological and procedural clarity. Indeed, Braun and Clarke (2006) cite Attride-Stirling's (2001) work as a positive example of demonstrating transparency when describing the 'how' of (reflexive) TA. One difference is their understanding of how themes 'come to be' – Attride-Stirling (2001) describing themes as being 'unearthed from' the data (p. 388), and Braun and Clarke (2019a: 591) staunchly rejecting the notion that themes reside 'within the data' at all (hinting at a *"whiff of positivism"* (p. 591) with roots in grounded theory), instead taking a strong stance

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[51] I explain my theoretical assumptions for this research in chapter 4.

that themes are generated by the researcher, at the intersection of *"data, analytic process, and subjectivity"* (Braun and Clarke, 2019a: 594). Despite these differences of opinion, TNA aligns well with a reflexive approach and can be used as a means of organising and displaying the data generated[52] in this way.

The clear, staged approach to performing TNA, described by Attride-Stirling (2001), lends itself to ensuring the methodological clarity when both carrying out and reporting the process of thematic data analysis, as applauded by Braun and Clarke (2006). This level of transparency then contributes to methodological rigour (see chapter 4, section 4.6).

5.15.3 Data analysis: Procedure.

Attride-Stirling (2001: 390-394) describes a 6-step process for TNA:

1. *Coding the material*

   The first step in TNA is to reduce data into more manageable chunks, through a process of coding. This has synergies with Braun and Clarke's (2021b: 331) description of 'systematic data coding.'

   Having transcribed my own audio recordings, I then read and re-read my transcripts to get to know the data (Thorne 2016). After some consideration, I decided to analyse the data by stakeholder group, across the three research locations. I imported the transcripts into NVivo 12 by stakeholder group. Each transcript was individually re-read, and codes created as they corresponded to the data. The initial set of codes were then reviewed against the transcripts, by stakeholder group, and collapsed into a smaller number of codes where repetition or linked concepts were identified.

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[52] Here I use the term 'data generation' in discussion of Braun and Clarke's work. I, however, choose to describe a process of 'data construction', aligning with Thorne's (2016) interpretive description terminology.

2. *Identifying themes*

   The second step is to construct themes from the coded data, as patterns are identified. A continuous process of refinement is required and reflects Braun and Clarke's (2021b: 331) 'generating initial themes from coded and collated data.' This resulted in a coherent set of 'basic themes' which remained close to the data in content and became the basis for further levels of abstraction and meaning making, through my epistemological and experiential lens.

3. *Constructing the networks*

   Attride-Stirling (2001) describes this stage of the process in 6 sub-steps that result in the creation of three thematic levels: basic themes (those constructed in step 2 above); organising themes (groups of basic themes that focus on a common issue or theory); and global themes (an overarching message about what the network describes). More than one network can be created from a data set if distinct 'stories' begin to take form. This stage of TNA reflects Braun and Clarke's (2021b: 331) steps of 'developing and reviewing themes' and 'refining, defining, and naming themes.'

   During this stage of the data analysis, I found myself reworking the basic themes as I began to understand how they worked together to form organising themes. This, at times, required rearrangement of the codes and basic themes as the process unfolded and I could understand the data from different perspectives. Although there are differing opinions about how many times a data excerpt can be used to create a code, I agreed with Cruz-Cardenas (2018), that one data excerpt can belong to several codes, and therefore themes – indeed that *"it can be an indication of connection between themes, which in qualitative research can lead to unexpected findings"* (Cruz-Cardenas, 2018, online). As such, I felt able to stay close to the data without having to make decisions about 'which story' was being told too early in the analytical process.

4. *Describe and explore the thematic networks*

   Once the networks have been constructed and illustrated, the researcher must return to the data to interpret it using the networks. This involves reading the transcripts through the identified themes, and a level of abstraction more detailed than that undertaken thus far.

5. *Summarise the thematic network*

   Attride-Stirling (2001) encourages researchers to summarize their networks with supporting illustrations, in a similar way to Braun and Clarke's (2021b) advice to produce a 'thematic map' (p. 345). Attride-Stirling (2001) argues that presenting the data succinctly and making explicit the patterns constructed during the analysis *"makes the interpretation more compelling"* (Attride-Stirling, 2001: 394). I therefore illustrated thematic networks for each global theme and for each of the four groups.

6. *Interpret patterns*

   At this stage, the researcher must summarise all the networks and describe the overarching conclusions drawn in relation to the original research aims. I was able to look at all the global themes together, from all four groups of participants, and identify synchronicities and differences between their stories.

Attride-Stirling's TNA process has been traditionally applied to single-groups, single location, research (Mano, 2017). The challenge of using TNA to synthesise interpretations of multiple data sets was experienced and described by Mano (2017) who, similarly, collected data from four distinct groups of participants in six locations. In her 2017 paper, Mano described how she felt that the six-step TNA process fell short of being able to provide a full interpretation of the data when they are derived from the perspectives of more than one group of participants. When I considered my own global themes from four groups, I too felt that Attride-Stirling's (2001) six-step TNA did not enable me to complete the analytical process, and that a new level of interpretation was required to fully understand the realities being described by participants.

Mano's (2017) approach to this challenge was to advance Attride-Stirling's (2001) six steps, adding another step that she labelled 'supra-global themes', applicable specifically to data constructed from multiple groups across multiple sites. Mano treats each global theme from each data set in the same way as a second level of 'organising theme', from which a supra-global theme is constructed, integrating the global themes from all four groups of participants, and exploring their relationships. As Mano (2017: 47) attests, *"the new supra-global theme not only successfully encapsulated the perspectives of all groups but retained the significance of the contributions made by each group of participants."*

I decided to apply Mano's advancement to my own analyses and realised almost immediately that there were, indeed, themes than encapsulated all group global themes but that I had, up to that point, been unable to articulate. Moreover, unlike Mano, I felt unable to synthesise everything the participants had said into one supra-global theme, since the participants in the study told two quite distinct stories. I therefore created two networks to illustrate this phenomenon, each illustrating the stories told between groups and across research locations.

5.16 Results

This sections details results of the data analysis by stakeholder group.

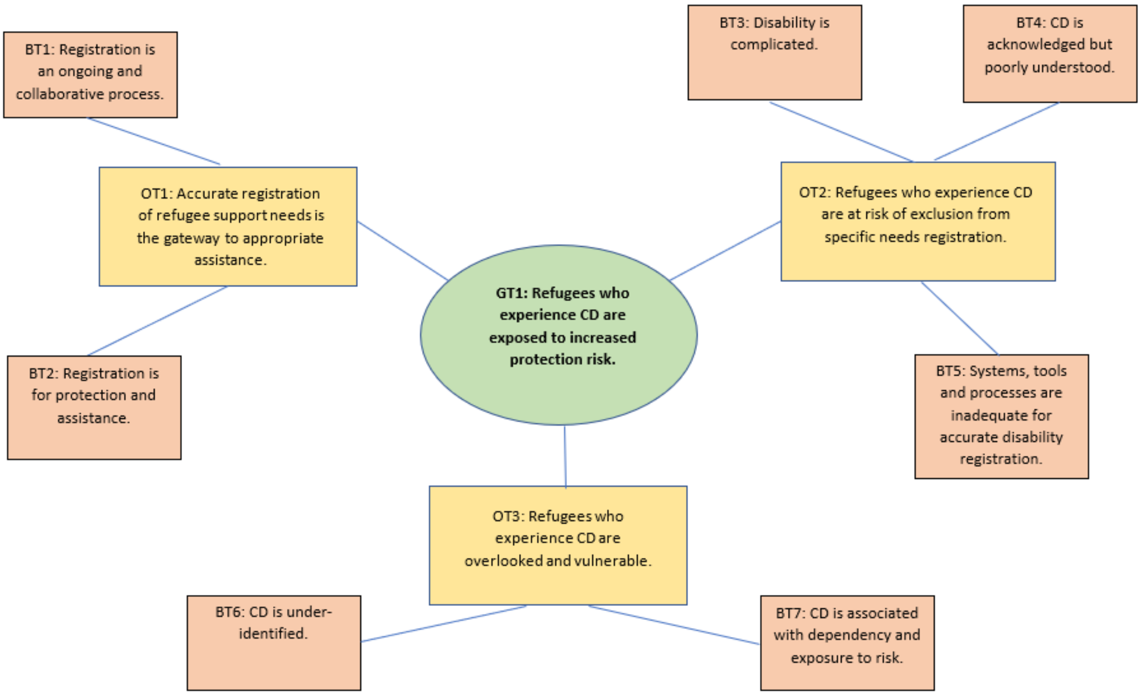
5.16.1 Stakeholder group 1 (G1): Implementing Organisations (UNHCR, Government officials, NGOs).

Analysis of this data sub-set resulted in the construction of 51 codes**.** As the analysis progressed, these codes facilitated the construction of 13 basic themes, 5 organising themes, and 2 global themes. The themes are represented as visual thematic networks (figures 11 and 12), which aided further analysis. A full table of codes and all themes is available in appendix 16.

Group 1 (Implementing Organisations), global theme 1 (G1-GT1): Refugees who experience CD are exposed to increased protection risk.

This theme encompasses understandings of the systems, tools, and processes (STPs) that constitute refugee registration services, and the roles implementing organisations (IOs) play within them, in relation to refugees who experience CD. The systemic barriers within this system, that IOs identify as contributing to exclusion from identification and registration services, have wide ranging impacts on every aspect of the lives of refugees who experience CD. IO staff feel the weight of exclusion that they know exists, but feel unable to respond to effectively, come to bear on their role as custodians of protection services for refugees. This creates feelings of discomfort. The space in the system that IOs occupy is simply one of many affecting the STPs that apply to refugee registration. This means that conflicting feelings of being able to act to improve the situation in one area, and yet being unable to address all the exclusionary factors at play, make IO staff feel that the problem is too big to tackle. Exclusion from identification and registration systems for refugees who experience CD, is therefore reluctantly accepted. IOs recognise that the consequence of this exclusion is exposure to increased protection risk for refugees who experience CD.

Figure 11: Thematic network group 1, global theme 1 (G1-GT1) – implementing organisations (camps A, B, and C)



<u>Group 1 (implementing organisations), organising theme 1 (G1-OT1): Accurate registration of refugee support needs is the gateway to appropriate assistance.</u>

Incorporating:

- *Basic theme G1-BT1: Registration is an ongoing and collaborative process.*
- *Basic theme G1-BT2: Registration is for protection and assistance.*

Registration is viewed as an essential process without which refugees with specific needs would remain unidentified and would therefore fail to receive the support they need, increasing protection risk and infringing upon refugee rights.

> *C1G1: "Whenever you are assessing disability and vulnerability, …. it is for the sake of assistance. Now, when you want to assist, you want to assist vulnerable people."*

Different routes to registration, as well as the collaboration between IOs and community structures, create a 'safety net' system with a strong focus on people whose needs may not have been captured at initial registration, or whose circumstances and/or needs change over time. This system of official process, combined with community-based safety nets, is designed so that most people with specific needs are identified and registered appropriately, granting them access to life-sustaining and life-promoting services.

> *B1G1: "The role of the community then is also to refer the case..... There is a referral pathway, and everyone knows that when he met a case of disability, he have to do a referral to the partner in charge".*

Group 1 (implementing organisations), organising theme 2 (G1-OT2): Refugees who experience CD are at risk of exclusion from specific needs registration.

Incorporating:

- *Basic theme 3 (G1-BT3): Disability is complicated.*
- *Basic theme 4 (G1-BT4): CD is acknowledged but poorly understood.*
- *Basic theme 5 (G1-BT5): Systems, tools, and processes are inadequate for accurate disability registration.*

Disability is perceived to be a complicated issue and that STPs, including individual understanding, skills, attitudes, and behaviours, can exclude some groups of refugees from accurate registration of support needs, for example those with communication impairments.

> B1G1: *"In ProGres [53] we have limit. It is only speech impairment and deaf and there is no details for those who cannot speak clearly. They are not included. It is only either you talk, or you don't talk".*

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[53] ProGres is the UNHCR refugee database – see chapter 5.

Tools are thought to lack nuance, which contributes to the potential for registration of specific needs to be inaccurate. Additionally, individual IOs have their own STPs that feed into UNHCR/Government data collection processes and systems, each subject to individual interpretation of how to record information, and which may not transfer directly to UNHCR/Government databases. As such, excluded refugees may be unable to access necessary assistance (see OT1 above). Examples of different approaches to data recording are illustrated below:

> *A1G1: "<u>Choose one.</u> Because if we register the one child in different case we can, er, we can got different numbers".*

In contrast with:

> *A1G1: "For us what we do, we register that person with disability that he has multiple disability. <u>We don't choose one."</u>*

IO staff believe that most refugees who experience CD need to access services using sign-language, suggesting a misunderstanding that all refugees who experience CD can use and understand this medium.

> *B1G1: "The family members must come with them and the person who knows sign languages to help us to register them."*

<u>*Group 1 (implementing organisations), organising theme 3 (G1-OT3): Refugees who experience CD are overlooked and vulnerable*</u>[54]

Incorporating:

- *Basic theme 6 (G1-BT6): CD is under-identified.*

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[54] The term 'vulnerable' was used by participants and is reported as such, although it is not my choice of terminology (see chapter 1, section 1.5.3.1).

- *Basic theme 7 (G1-BT7): CD is associated with dependency and exposure to risk.*

Implementing organisation staff believe that refugees who experience CD are under-identified and therefore under-registered. They attribute this, in part, to a lack of understanding about the causes and nature of CIs (beyond hearing impairment, which is more recognised) and the impacts of disabling attitudes, behaviours and environments.

Furthermore, forced dependency on others to communicate on their behalf leads refugees who experience CD to experience reduced autonomy and under- or misrepresentation of challenges and needs, as well as reduced capacity to participate in community life.

> *A1G1: "sometimes even the ones who are living together with them, they may interpret instead themselves, instead of the person who has the problem."*

As a result, refugees with CIs are at risk of disabling exclusion from services across the board. This exclusion increases their protection risk (also expressed as 'vulnerability') considerably.

> *B1G1: "because don't know how to express myself you get a bad service because they don't well catch your problem and they don't really respond you properly because of speech problem."*

Stigma, shame, and misunderstanding also play a large part in exclusion from community participation and service access, despite efforts for IOs to sensitise communities to disability rights issues. The sense is that some progress is being made in reducing stigma and misunderstanding around disability, but that it is still deeply ingrained at community level and within families, particularly when related to communication.

> *A1G1: "It's a shame. It will not be productive. She will not be productive, or he will not be productive, then they fail to send him to school."*

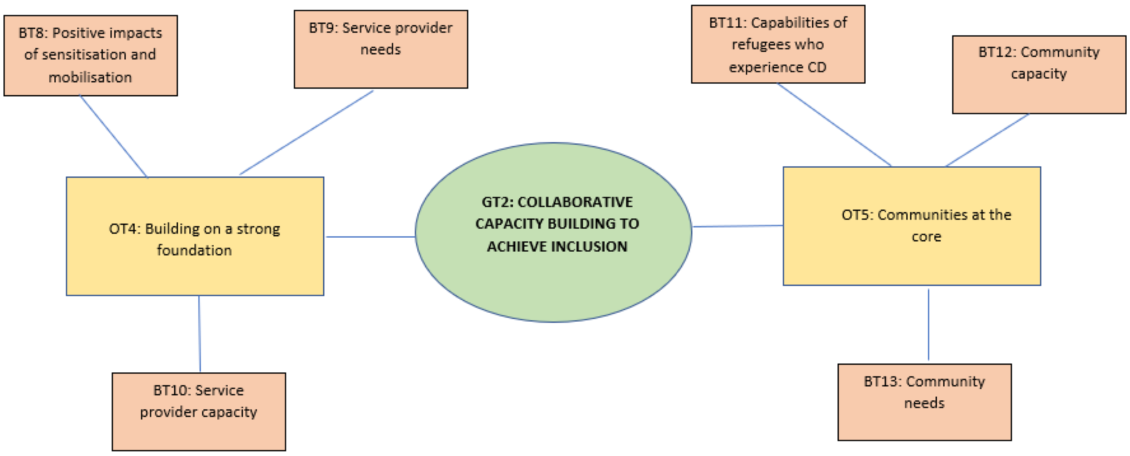
Group 1 (implementing organisations), Global theme 2 (G1-GT2): Collaborative capacity building to achieve inclusion.

This theme encompasses understandings of possible ways forward towards inclusion within refugee communities, to enhance participation of refugees who experience CD. Alongside the 'beast is too big' sentiment documented in G1-GT1, IO staff do also feel the responsibility to improve the experiences of refugees, and reduce protection risk, particularly for marginalised or excluded groups. The widely accepted practice of humanitarian collaboration to increase efficiency and maximise resource use (Janz, Soi and Russell, 2009) bolsters the belief that a firm collaborative foundation has already been laid, upon which improvements can be made to ensure more effective inclusion of refugees who experience CD.

> *A1G1: "Putting our effort together, as we are many agencies working with UNHCR, we can reach some result."*

The identified need to work together both celebrates the achievements being made in disability inclusion within the camps, whilst recognising there is some way to go to achieve full inclusion and participation. Collaboration centring community structures, relationships, and trust, embodies community understanding and importance of communal support and the culturally significant concept of 'ubuntu'– *'I am, because we are'* - in eastern and central African communities. This bridges the divide between individuals and services.

Figure 12: Thematic network group 1, global theme 2 (G1-GT2) – implementing organisations (camps A, B, and C)



Group 1 (implementing organisations), organising theme 4 (G1-OT4): Building on a strong foundation.

Incorporating:

- *Basic theme 8 (G1-BT8): Positive impacts of sensitisation and mobilisation*
- *Basic theme 9 (G1-BT9): Service provider needs*
- *Basic theme 10 (G1-BT10): Service provider capacity*

Implementing organisations recognise the cross-sectoral[47] gaps in service provision and access for refugees who experience CD and that they need additional capacity in terms of knowledge, understanding, skills and resources, to meet the needs of those currently excluded from identification and registration services. The ongoing perception is that staff need to learn how to use sign language to meet the needs of refugees who experience CD.

> *A1G1: "If you knew sign language you feel your job would be easier in communication with people with a communication disability if you had those skills."*

It is important to note that some participants reject the idea that some groups of refugees who experience disability are more marginalised and excluded than others, and that services do not meet their needs. This may be because it threatens their credibility within their professional role. IO staff also recognise, however, the progress that has been made since 2015 in changing attitudes and behaviours towards refugees who experience disability and that there are some strong foundations upon which to build better, more inclusive, services and communities for refugees who experience CD. Much of this stems from effective community sensitisation and engagement, as well as building upon the skills they have developed over several years in their line of work.

> *A1G1: "For me it's above one year that I work in the CBR programme. When you take that time with them you know how to communicate with them."*

Group 1 (implementing organisations), organising theme 5 (G1-OT-5): Communities at the core.

Incorporating:

- *Basic theme 11 (G1-BT11): Capabilities of refugees who experience CD*
- *Basic theme 12 (G1-BT12): Community capacity*
- *Basic theme 13 (G1-BT13): Community needs*

Implementing organisation staff consider refugees who experience CD as capable of participation in their community.

> A1G1: *"There are many and they can talk, they can discuss, they can ask, they can [pause] everything."*

In addition, communities, including families and formal structures such as refugee committees, are understood to play a key role in identification, registration, and support to participate in the community, for refugees who experience CD.

> *B1G1: "That committee is in charge of identifying in the community a person with that. So we train them, they have skills, they have special skills of assessing a person with difficulties or they can see in the community a person with specific needs so that they can do for themselves the advocacy so that we can be able to assess. This is a very good channel."*

IO staff value community structures for their ability to operate in a formal capacity, but with personal reach to individuals and families. As such, IO staff believe that community capacity building and engagement is key to the improvement of identification and registration STPs, for refugees who experience CD. Moreover, there is a recognition that, if service improvement is not community-led, top-down redesign of services is futile.

> A1G1: *"I think we should strengthen the community. We should adopt the community-based approach …. once the community is not strengthened, you might miss some cases – it's normal. And then once they go in the camp there, they are forgotten."*

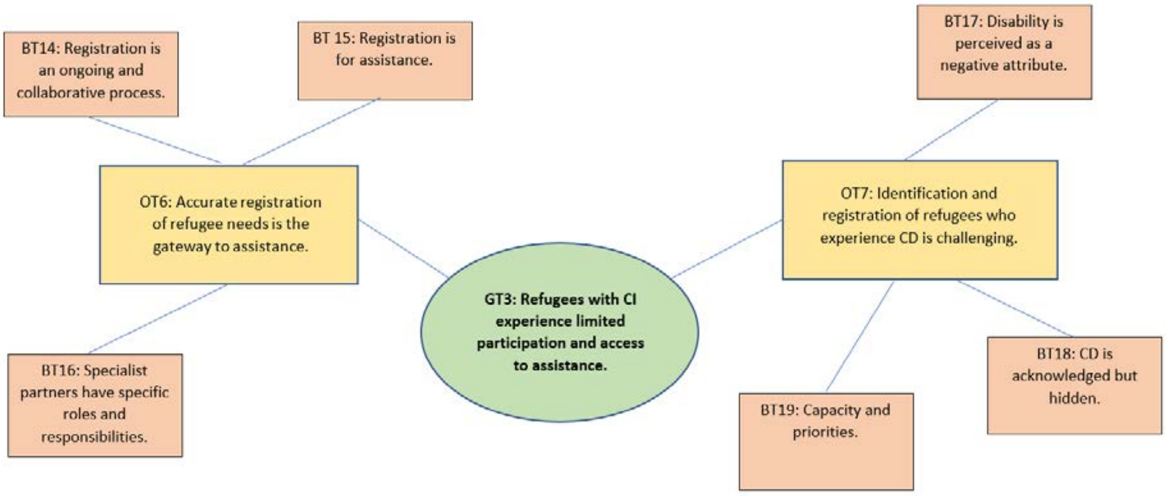
5.16.2 Stakeholder Group 2 (G2): Community volunteers (community mobilisers and community health workers)

Analysis of this data sub-set resulted in the construction of thirty-eight codes. As the analysis progressed, these codes facilitated the construction of eleven basic themes, four organising themes, and two global themes. The themes are represented as visual thematic networks (figures 13 and 14), which aided further analysis. A full table of codes and all themes is available in appendix 16.

Group 2 (community volunteers), global theme 3 (G2-GT3): Refugees with CI experience limited participation and access to assistance.

This theme encompasses understandings of the disabling consequences of exclusionary attitudes, behaviours, and practices, for refugees with CI. Like IO staff, community volunteers consider refugees with CI to experience disabling exclusion from critical identification and registration services, impacting upon their ability to access assistance and protection. A widespread misunderstanding of the causes, nature, and impacts of CI and CD, results in taboo and stigma within communities, causing shame and concealment. Furthermore, a lack of capacity to identify and support refugees with CI, who experience CD, at all levels of service provision, affects everything from community participation to service access. These experiences are acknowledged, but not accepted, by community volunteers who, as members of the community themselves, are able to understand the situation from a multitude of perspectives. They can identify barriers to inclusion in both community systems and implementing organisations, and those affecting the entire identification and registration system.

Figure 13: Thematic network group 2 (community volunteers), global theme 3 (G2-GT3) – community volunteers (camps A, B, and C)



Group 2 (community volunteers), organising theme 6 (G2-OT6): Accurate registration of refugee needs is the gateway to assistance.

Incorporating:

- *Basic theme 14 (G2-BT14): Registration is an ongoing and collaborative process.*
- *Basic theme 15 (G2-BT15): Registration is for assistance.*
- *Basic theme 16 (G2-BT16): Specialist partners have specific roles and responsibilities.*

Community volunteers consider themselves a valuable resource in bridging the gap between communities and implementing organisations. As community members themselves, they can collaborate with individuals, families, and community structures, such as refugee committees, to facilitate refugees to realise their right to registration and access the assistance to which they are entitled.

Community volunteers consider identification and registration of specific needs to be of great importance. They agree with implementing organisation staff (G1-OT1) that, without accurate registration of need, refugees are at risk of exclusion from support mechanisms. As such, efforts are made to ensure people whose specific needs may not have been captured at initial registration are identified through the community-based 'safety net' (G1, BT1) and that they are referred to specialist services.

> *B1G2: "You know that disability can come any time so what we do is continuous follow-up. We identify new cases and we take them to the staff of Humanity and Inclusion."*

This involves service provider-community collaboration, as well as additional processes, such as sensitisation and mobilisation campaigns (captured within BT14 and BT16) to ensure no-one is left behind. Some participants consider that all refugees with specific needs are identified and registered through these processes (as in G1-OT4), but this is contested by others in the group.

> *B1G2: "Everyone [who] has disability was called to come and they were verified and registered in the machine and their details, address, names, type of disability were registered so through that data that we got we know that everyone is identified."*

Group 2 (community volunteers), organising theme 7 (G2-OT7): Identification and registration of refugees who experience CD is challenging.

Incorporating:

- *Basic theme 17 (G2-BT17): Disability is perceived as a negative attribute.*
- *Basic theme 18 (GS-BT18): CD is acknowledged but hidden.*
- *Basic theme 19 (G2-BT19): Capacity and priorities.*

Community volunteers recognise that refugees 'with communication disability' (their words in translation) experience exclusion from identification, registration, and support services. They attribute this partly to a lack of understanding about communication impairment and disability, including the causes, nature, and impacts, that contributes to stigma and taboo within the community (see G1-OT3).

> *C1G2: "When you deliver a child with mental disability you don't want anyone to find out. Even when you're in public you feel ashamed. When you breast feed, you hide yourself. These mothers, they sometimes isolate themselves because of the children they delivered."*

Indeed, individuals with significant CI may not self-identify, or be identified as, 'disabled', or may actively avoid being labelled as such. As a result, their support needs remain unidentified, unregistered and they do not receive the assistance they need or to which they are entitled. For example, a refugee who has a severe stammer may not consider themselves (or be considered to be) disabled, even if they experience disabling exclusion, public shaming, and failure to access services.

> *C1G2: "when themselves they don't consider themselves as person with disabilities, so it's difficult to register a person because it's something you create for them. A disability it's not something to be proud of, so if you tell that person they have a disability it can be difficult."*

Compounding this issue is the fact that refugees in the camps live hard lives and struggle to meet their basic needs which may be prioritised over the desire for some services and/or community participation. Community volunteers belong to the same communities and understand the struggles.

> *B1G2: "Another challenge that we have is that us as community mobilisers, when we go to visit people at their home we go empty hand and sometime it is not what they need from us."*

Furthermore, community volunteers feel that they lack capacity to fulfil their support role with refugees who experience CD and recognise that, even if referred, specialist service providers are similarly ill-equipped to support them. As such, they concede that refugees with communication support needs also experience disabling exclusion from these specialist provisions. This exemplifies how the 'twin track' approach to disability inclusion (targeted support, plus mainstream access) is not working.

> *C1G2: "We had training from Humanity and Inclusion and the issue was not mentioned as one of the types of disabilities."*

This feeds into the feeling that change is impossible:

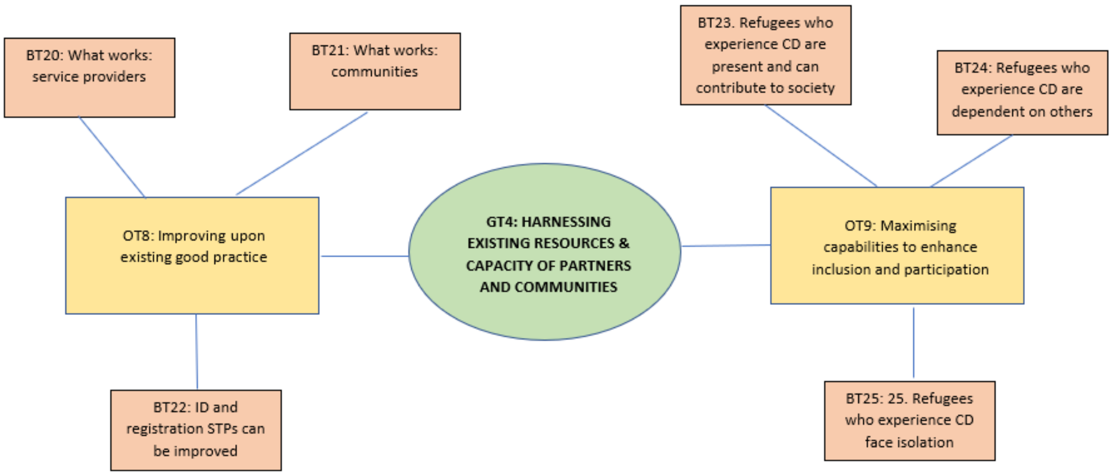
> *C1G2: "If the specialists do not know, what hope do we have here now?"*

<u>Group 2 (community volunteers), global theme 4 (G2-GT4): Harnessing existing resources and capacity of partners and communities.</u>

This theme captures how community volunteers conceptualise a way forward to enhance the inclusion and participation of refugees who experience CD, reducing exposure to protection risk.

The progress that has been made in identification, registration, and support service provision (mainstream and specialist), for refugees who experience disability since 2015, is considered to have laid a firm foundation for expansion to groups of refugees who have historically 'fallen through the net'. Nevertheless, there is recognition that refugees who experience CD have been neglected thus far, in part due to misunderstanding of who they are, the barriers they face, and the lack of autonomy that they endure.

Figure 14: Thematic network group 2 (community volunteers), global theme 4 (G2-GT4) – community volunteers (camps A, B, and C)



<u>Group 2 (community volunteers), organising theme 8 (G2-OT8): Improving upon existing good practice.</u>

Incorporating:

- *Basic theme 20 (G2-BT20): What works - service providers.*
- *Basic theme 21 (G2-BT21): What works – communities.*

- *Basic theme 22 (G2-BT22): ID and registration STPs can be improved.*

Although acknowledged as necessary, current STPs are considered inadequate for the accurate identification and registration of refugees with CI, who experience CD, as are strategies for their inclusion in mainstream service provision. Considering service providers as part of the 'system', community volunteers believe that refugees who experience CD will be better served if the individuals involved in registration services are more knowledgeable of, and skilled in, recognising their unique challenges and offering support.

> *C1G2: "It's more about referral and what we are supposed to do is to advocate for them but also what we could do is to guide them after the identification what they should be doing."*

Additionally, existing community-based sensitisation and mobilisation campaigns are considered to be effective in changing attitudes and behaviours towards people who experience disability and to have potential to be further enhanced, with a focus on communication.

> *C1G2: "Usually when a mother or parent try to hide a child it's because of ignorance or lack of knowledge of what they can benefit, for example, when we do CBR session, we had a low number but with sensitisation campaigns the number is increasing."*

Future campaigns have the potential to focus on educating communities about CI and their impacts, as well as how to interact with people who experience CD. Inclusion in community-based services could also be a way to encourage the participation of a wide range of people (including those who experience disability) in community life, and in supporting each other.

> *C1G2: "If they are able to be integrated, others who do not opt to reveal the disability they have they will come up and express themselves."*

Community volunteers consider that humanitarian service providers have some knowledge and skill related to CD, primarily in the domain of sign language, to support refugees who experience CD to access services. Using this as a starting point, further training in sign language is the most desired response amongst community volunteers. There is, however, little recognition of the continued exclusion this would expose refugees who cannot use sign language to.

Group 2 (community volunteers), organising theme 9 (G2-OT9): Maximising capabilities to enhance inclusion and participation.

Incorporating:

- *Basic theme 23 (G2-BT23): Refugees who experience CD are present and can contribute to society.*
- *Basic theme 24 (G2-BT24): Refugees who experience CD are dependent on others.*
- *Basic theme 25 (G2-BT25): Refugees who experience CD face isolation.*

Community volunteers recognise and appreciate that refugees who experience CD can participate and contribute to society, if given the opportunity, but that their potential is limited by their communication abilities within their social context and the abilities of others to support their participation. As such, there is a recognised conflict between a person's potential and their capacity in their current context, that causes some discomfort amongst community volunteers, whose job it is to support refugees who experience disability within the community. Community volunteers are aware of their own limitations (skills, time) in supporting people that it is their job to assist, and aware that these limitations contribute to discrimination, exclusion, and disablement - albeit unintentional.

> *C1G2: "We are supposed to go to the community to provide messages [about community consultations etc]. If we can take 2 minutes, that person with stammer can take 5 minutes so it will be difficult for that person to be recruited [to community consultations]"*

This exclusion is acknowledged to create isolation, communication dependency, as well as a burden of care for families.

> C1G2: *"The first challenge is for the person. It's a shame because they try to communicate but when they try and it doesn't work they need to pass through someone to pass a message so it creates a kind of shame for them to express what they think or their opinion."*

Recognition and registration of support needs, as well as appreciation of capability and maximisation of opportunities for engagement, could offer a way forward towards independence as well as inclusion, participation, and social connection. This may ultimately reduce protection risk and maximise autonomy, improving realisation of rights and enhancing wellbeing amongst refugees who experience CD.

> *A1G2: "Put them together in association which can generate income. This also can help them to bring them closer to other people and feel included among the community."*

5.16.3 Stakeholder group 3: Educators (ECD caregivers and teachers).

Analysis of this data sub-set resulted in the construction of twenty-nine codes. Some of these codes overlap with those constructed in G1 and G2 but were maintained within the G3 analysis at this stage, to maintain the integrity of this group's story. As the analysis progressed, these codes facilitated the construction of nine basic themes, four organising themes, and two global themes. The themes are represented as visual thematic networks (figures 15 and 16), which aided further analysis. A full table of codes and all themes is available in appendix 16.

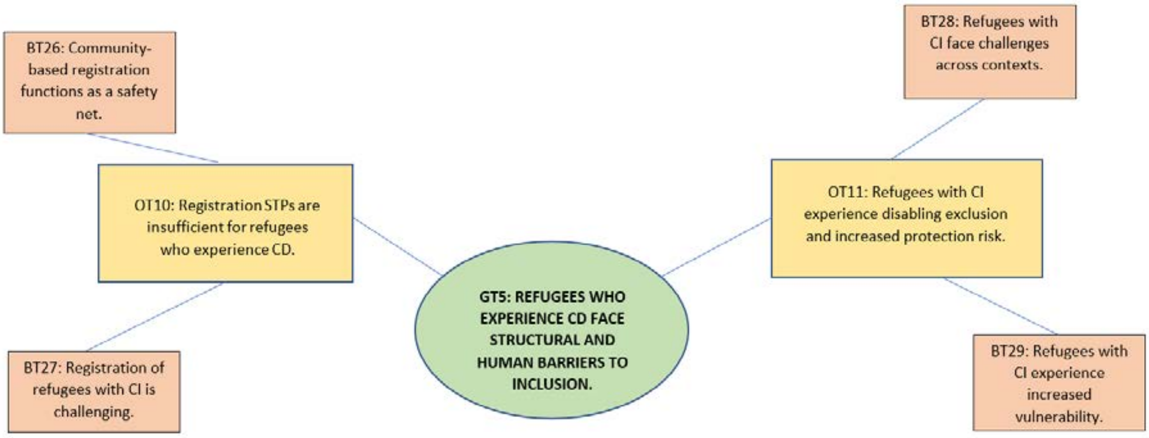
Group 3 (educators), global theme 5 (G3-GT5): Refugees who experience CD face structural and human barriers to inclusion.

This theme embodies educators' stories of the way in which refugees with CIs face disabling exclusion through an inextricable web of attitudinal, behavioural, and structural (including physical, environmental, and legal), barriers to inclusion.

Educators consider that the barriers encountered by refugees who experience CD not only preclude access to essential services to meet basic needs, such as health care, but also access to life-promoting services, such as education and livelihoods, that foster independence, dignity, and wellbeing. Limited participation in family and community life leads to social isolation, dependence, and increased risk of abuse and neglect. The combination of structural and human barriers to inclusion across contexts has the potential to create a spiral of deprivation whereby refugees who experience CD face lack of access to services, possibly resulting in negative impacts upon their future.

Educators recognise the disabling gaps in specialist service provision and mainstream service access for refugees with CI and lament their part in this. Their stories tell of the focus on enrolment of children in school that masks the exclusion from learning within the classroom when teachers cannot meet children's communication support needs. They understand the elevated risk that children with CIs face when encountering disabling exclusion from accessible education, and they advocate for change.

Figure 15: Thematic network Group 3 (educators), global theme 5 (G3-GT5) – educators (camps A, B, and C)



Group 3 (educators), organising theme 10 (G3-OT10): Registration systems, tools, and processes are insufficient for refugees who experience CD.

Incorporating:

- *Basic theme 26 (G3-BT26): Community-based registration functions as a 'safety net'.*
- *Basic theme 27 (G3-BT27): Registration of refugees with CI is challenging.*

Registering refugees who experience CD is known to be challenging and, as described by G2, community-based identification and registration processes are considered essential 'safety nets' in identifying children with communication support needs, particularly upon ECD/school entry.

> *C1G3: "Handicap [Humanity and Inclusion] works closely with the school because when they do home visits and they come across with such children who are not attending school, so they refer those children to the school so they are being enrolled."*

Despite processes such as home visiting and school registration being considered effective for identification, there are concerns that STPs beyond the ECD centre/school level are not sensitive enough to capture the CIs and support needs of children. Educators record what they think are the children's main challenges, but struggle with 'categorisation' of impairment and disability. They do not know why the children do not receive assistance and assume this is because they are not fully registered with a disability specific needs code in the ProGres database, possibly because families are also unsure of what to report.

> *A1G3: "When I identify the child as having the communication issue, but some time I am not sure of what is the problem, I call the parents for at least they explain to me what happened since the birth until the age. But at the time they are not also sure of what is there."*

This is reflected in the lack of response teaching staff see from supporting agencies and in the data captured in the ProGres database (see data set 1, section 5.3 above) – one participant reported twenty-five children with communication support needs in their ECD services, whilst only seven were registered in ProGres age 0-12, in the entire camp, at the time of the FGD. A participant from camp A described how, despite reporting data to UNHCR/MIDIMAR, they do not know if it is ever entered into the ProGres database, as they don't see any special assistance being offered to the children, as would be expected if a child were appropriately registered.

> *A1G3*: *"For us we register them, although we don't have enough to do for them, and it is important, but we don't see too much because we don't see how it comes out as the assistance to them."*

Group 3 (educators), organising theme 11 (G3-OT11): Refugees with CI experience disabling exclusion and increased protection risk.

Incorporating:

- *Basic theme 28 (G3-BT28): Refugees with CI face challenges across contexts.*

- *Basic theme 29 (G3-BT29): Refugees with CI experience increased vulnerability.*

Educators know that life as a refugee is challenging, but even more so if unable to access basic services and participate in community and family life autonomously. Mainstream service providers lack the knowledge and skills to support refugees with CI, resulting in disabling exclusion and/or poor outcomes, especially in education.

> *A1G3: "These children are not er, cared for as well as others because others at least they are assisted - those with physical, er, impairment, they are assisted, but those with speech and hearing impairment, they are behind, they are not looked for, they are not cared for because they are not learning as very well as others, the skills to teach them we don't have, we see that they are somehow neglected."*

Specialist disability services do not provide (re)habilitation or support to those with CI who cannot or do not use sign language. This results in frustration on the part of educators, who feel powerless to help, as well as increased exposure to risk for those who cannot access the support they need.

> *A1G3: "How can we teach these people and help them while we cannot communicate with them? The life of this person became lonely because she's there saying I cannot be assisted by any, I cannot communicate my issue to any, then my life is life useless because of my disability".*

Stigmatisation, abuse, and neglect are a real risk, whilst preventative and responsive services are insufficient. As a result, families often bear a burden of care whilst also struggling to communicate with their family member.

> A1G3: *"The teacher is assisting the children when they are at school, but when they are at home, they have this*

> *issue of communication. They have problems but they don't know how to address them.”*

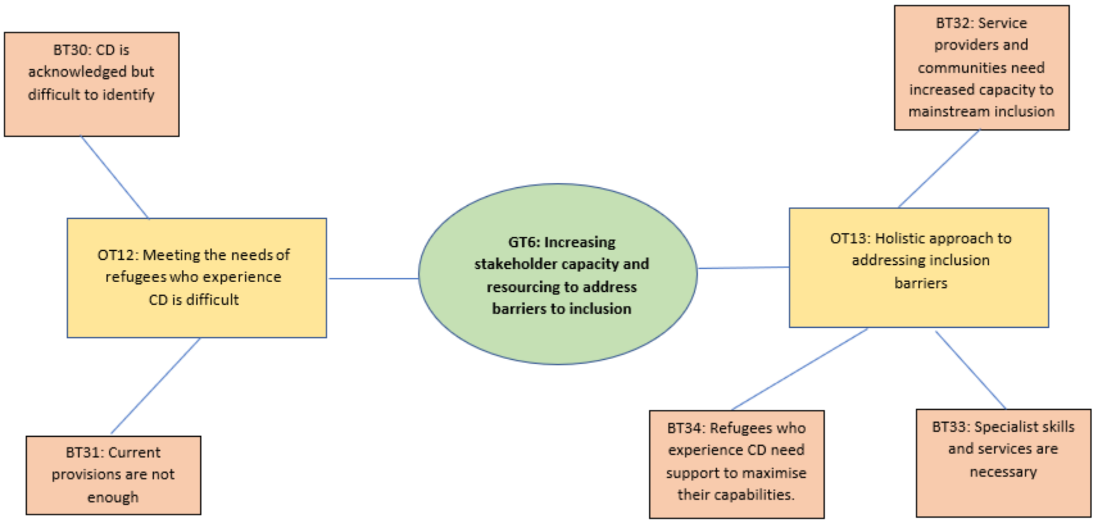
Group 3 (educators), global theme 6 (G3-GT6): Increasing stakeholder capacity and resourcing to address barriers to inclusion.

This theme captures the perceived barriers faced by refugees who experience CD, as well as the potential for solutions, from the perspective of educators. Educators recognise that refugees who experience CD are under-identified and under-served, and attribute this to a combination of: limited CI and CD-related knowledge and skills amongst service providers to deliver accessible mainstream services; insufficient availability of specialist support services; as well as functional limitations on the part of the refugees who experience CD themselves. This reflects an understanding of the intersectional nature of the biopsychosocial model of disability (WHO, 2001).

Although the importance of accurate identification and registration of specific needs as a gateway to service eligibility is recognised, there remains a concern that mainstream services remain inaccessible and CI/CD specialist knowledge and support is unavailable. This means that, even if identified, refugees with CIs will continue to face disabling exclusion.

Increasing knowledge, understanding and skills related to CI and CD amongst service providers and community members is, in alignment with implementing organisations and community volunteers, considered to be the best course of action to tackle exclusion. This, in combination with a programme of social and environmental change, and provision of a specialist service provider as a focal point, is thought to have the potential to ensure accessible mainstream services with specialist support where necessary. Appreciating refugees who experience CD as capable, and as stakeholders themselves, could contribute to ensuring a holistic approach to addressing the inclusion barriers they currently face.

Figure 16: Thematic network group 3 (educators), global theme 6 (G3-GT6) – educators (camps A, B, and C)



Group 3 (educators), organising theme 12 (G3-OT12): Meeting the needs of refugees who experience CD is difficult.

Incorporating:

- *Basic theme 30 (G3-BT30): CD is acknowledged but difficult to identify.*
- *Basic theme 31 (G3-BT31): Current provisions are not enough.*

Educators know that there are refugees who experience CD in their camps and believe they are not all formally registered as having specific support needs. Despite this, they strive to provide accessible services to all, to ensure that nobody is excluded, but feel limited by their skill level and resource availability, including time.

> *A1G3: "How can we teach these people and help them while we cannot communicate with them?"*

Service provision is limited to basic-level Rwandan sign language training for a small number of service providers, although educators acknowledge that many refugees themselves do not know any sign language (Rwandan, or that of their home state) and themselves require training.

> *A1G3: "You know that we include these children with speech and hearing impairment, it means also themselves need this sign language and even those without speech and hearing impairment but, we do have only 3 teachers in all the school hosting children about 20-something thousand of students".*

Educators find the signs they do know do not meet more than the basic needs of the children they teach, and they do not have any other knowledge or skills to draw upon.

> *A1G3*: *"They tried to train the teachers, but it was a short time, like one week, in sign language."*

As such, they believe refugees who experience CD, particularly children, do not have their needs met and that more should be done to ensure their inclusion and protection.

> *C1G3: "It's difficult and discouraging for those in ECD who want even to be registered at school because they are observing there is no support or extra attention to them because they have some needs, so it's difficult."*

Group 3 (educators), organising theme 13 (G3-OT13): Holistic approach to addressing inclusion barriers.

Incorporating:

- *Basic theme 32 (G3-BT32): Service providers and communities need increased capacity*[55] *to mainstream inclusion.*
- *Basic theme 33 (G3-BT33): Specialist skills and services are necessary.*

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[55] 'Capacity' here encompasses increased knowledge and skills, as well as physical and human resources.

- *Basic theme 34 (G3-BT34): Refugees who experience CD need support to maximise their capabilities.*

Educators recognise the current gap in capacity, spanning knowledge and skills, as well as physical and human resources, that contributes to the disabling exclusion of refugees with CI from identification, registration, and support services, as well as community participation. This gap is known to exist across services and contexts and educators believe it requires a cross-sectoral, systemic, approach to improving access and participation, spanning services, communities, families, and individuals. It also and demands a holistic approach to inclusion for refugees who experience CD.

Educators implicitly describe CD in terms of the biopsychosocial model of disability: interactions between body, environment (social and physical) and person, and suggest direct support to maximise capabilities, as well as indirect support to enhance inclusion, for refugees with CIs who experience CD.

> *A1G3: "This [sign language training] is not enough solution but what we have to add as a solution is that we teach the community, we mobilise the community to accept these people as they are."*

A recognition of the need for an approach incorporating accessible mainstream services as well as specialist provisions, further reinforces the need for accurate registration of specific needs so that an understanding of communication support needs can be developed by service planners, and individuals can be identified for appropriate assistance.

> *A1G1: "We need among partners working here, let's one of them focus on this specific group and that they care for them, for that they hear what is the problem of them, and what services they need. That will be helping too much. Even for us we will be able to address these issues by working closely to that specific partner."*

5.16.4 Stakeholder group 4: Refugee Disability Committee (RDC).

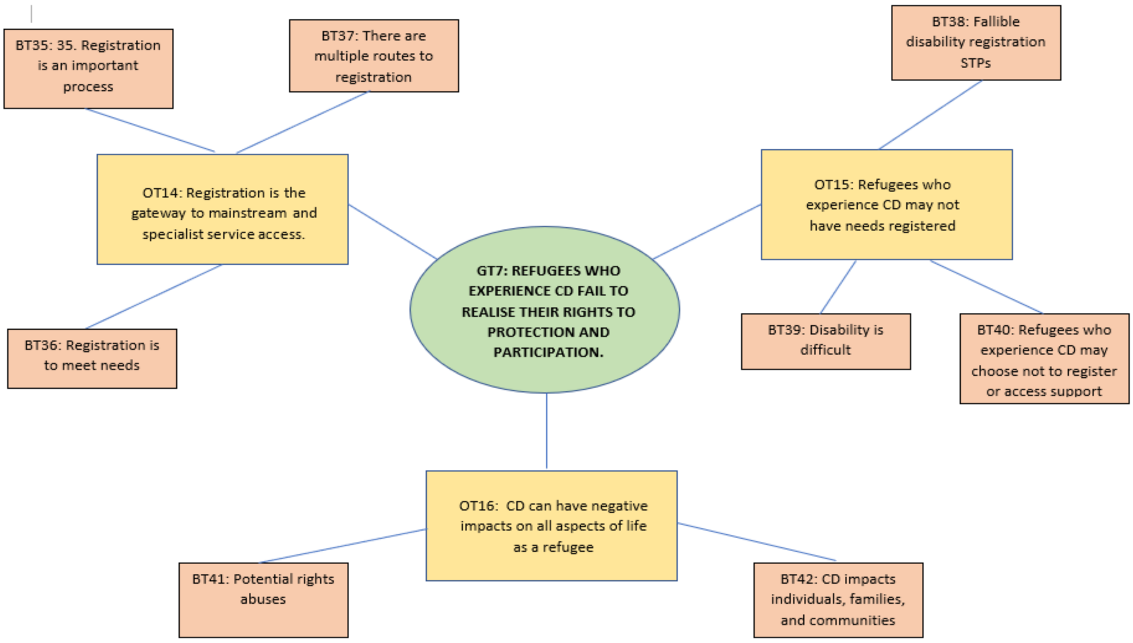
Thirty-nine codes were constructed during the analysis of group 4 data. As the analysis progressed, these codes generated twelve basic themes, five organising themes, and two global themes. Themes are represented as a table (appendix 16) and as visual thematic networks (figures 17 and 18), which aided further analysis.

Group 4 (Refugee Disability Committee), global theme 7 (G4-GT7): Refugees who experience CD fail to realise their rights to protection and participation.

This theme captures RDC member stories of how refugees who experience CD face systemic discrimination and exclusion from community life and services. At the core of their experience is the interaction of individual communication limitations with social and environmental barriers to participation and inclusion. This increases the potential for infringements on rights and protection, as well as impacting upon mental health and wellbeing, and community cohesion. The impact of exclusion upon individuals, families, and communities, cannot be underestimated.

> A1G4: *"The person came to there and communication is broken, tomorrow the same, then the person get angry and tired and say I will never come back again to ask services. This is the way their lives orienting themselves."*

Figure 17: Thematic network group 4, global theme 7 (G4-GT7) – refugee disability committee (camps A, B, and C)



<u>*Group 4 (Refugee Disability Committee), organising theme 14 (G4-OT14): Registration is the gateway to mainstream and specialist service access.*</u>

Incorporating:

- *Basic theme 35 (G4-BT35): Registration is an important process.*
- *Basic theme 36 (G4-BT36): Registration is to meet needs.*
- *Basic theme 37 (G4-BT37): There are multiple routes to registration.*

As other groups attest, registration is an essential process in granting eligibility and access to life-protecting and life-promoting services. Similarly, initial registration is acknowledged to be imperfect and may miss some important information. Continuous and ongoing registration is therefore essential - the community acts as a safety net in this regard and advocates, refers, and reports on registration updates to agencies and to MIDIMAR and UNHCR. The RDC applauds this as a valuable mechanism to ensure no one is left behind.

> A1G4: *"This is hierarchy process. It is done from village. Village to quartier, quartier to camp committee. Then camp committee report to MIDIMAR at the same to partners in charge then they share the data to UNHCR to update the ProGres."*

Group 4 (Refugee Disability Committee), organising theme 15 (G4-OT-15): Refugees who experience CD may not have needs registered accurately, or at all.

Incorporating:

- *Basic theme 38 (G4-BT38): Fallible disability registration STPs.*
- *Basic theme 39 (G4-BT39): Disability is difficult.*
- *Basic theme 40 (G4-BT40): Refugees who experience CD may choose not to register or access support.*

A combination of insufficiently sensitive registration STPs and competing personal priorities means that refugees who experience CD may not have their specific needs registered accurately, or at all. The complex nature of CD is compounded by a lack of capacity to support refugees who experience communication challenges, both at community level and throughout services. Families are relied upon as interpreters, reducing the autonomy of the individual.

> *C1G4: "Sometimes it's even difficult like for those who are registering are not even themselves able to communicate with these people. Many times these children are being accompanied with the parents and the parents, when they explain, they may add or like remove, change, information - you never know."*

Moreover, individuals and families are affected by stigma and discrimination, potentially influencing their decision-making when it comes to reporting disability.

> *A1G4: "People feel like as if it is calamity fallen upon them to bear a child with disability …. they don't want to show out these disabilities in their family."*

Alongside these experiences, individuals and families may have other priorities or pressing needs that may delay or deter them from registering CD. Life is hard in the camp and basic needs may take priority.

> *A1G4: "People are living here for almost three years and because they survive on the assistance only … and the life is not easy."*

Additionally, a lack of transparency regarding what happens to reported information leaves RDC members feeling unable to further advocate for refugees who experience CD and their families, as they are not involved beyond reporting in the hierarchical system of service provision. This leaves some feeling despondent – unable to follow up to ensure the protection of their community members.

> *C1G4: "[We] can't know like from Humanity and Inclusion how they do communicate or like information sharing with UNHCR so [we] are not involved."*

Group 4 (refugee disability committee), organising theme 16 (G4-OT16): CD can have negative impacts on all aspects of life as a refugee.

Incorporating:

- *Basic theme 41 (G4-BT41): Potential rights abuses.*
- *Basic theme 42 (G4-BT42): CD impacts individuals, families, and communities.*

The RDC members know that life as a refugee who experiences disability is hard but recognise that it must be even more challenging if faced with disabling exclusion related to communication. The interaction of individual communication limitations along with stigma, othering, and service exclusion, leads to risk of infringement of human rights as well as impacting upon mental health and wellbeing and productive and independent livelihoods. For children, inadequate opportunities for appropriate education may lead to social exclusion and limited potential for independent futures.

> *A1G4: "It needs more service about communication, communication disability, identification, in order that at least the counselling is given because people are despairing, they don't know what next".*

Individuals, families, and communities are affected – all frustrated by a lack of capacity to interact and facilitate inclusion.

> *B1G4: "They get sad very easily and we are also sad that we cannot communicate with them."*

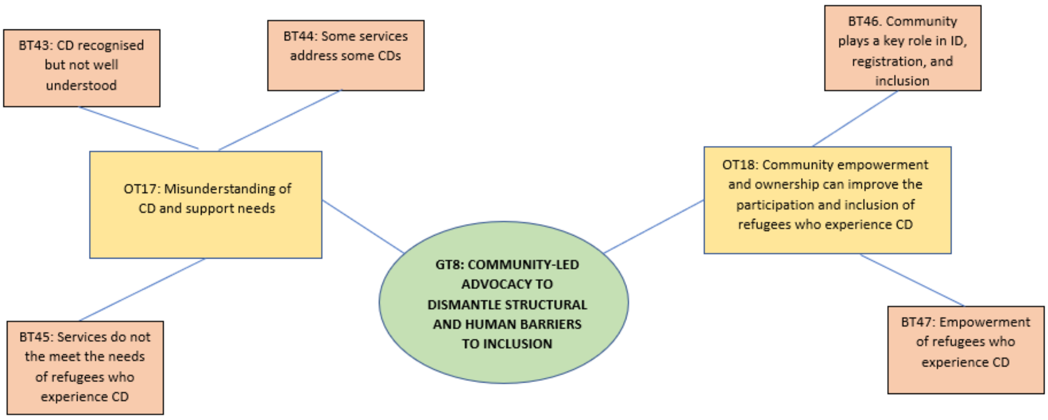
Group 4 (refugee disability committee), global theme 8 (G4-GT8): Community-led advocacy to dismantle structural and human barriers to inclusion.

This theme captures the significance of communities taking the lead in decreasing stigma around, increasing understanding of, and achieving equity and inclusion for, refugees who experience CD.

A cycle of marginalisation, grounded in discrimination, occurs for refugees who experience CD. The discrimination is founded upon a basic misunderstanding of the challenges and needs associated with different types of CI and the resulting disabilities that people face and leads to a small number of people with a specific type of CI being served, this service masking the exclusion of others.

Current community capacity means that refugees who experience CD may be 'known', but their support needs are little understood, leading to frustrating interactions on both sides. Community capacity building and empowerment to identify and support refugees who experience CD, have the potential to reach excluded individuals and families in their homes, enhancing advocacy for their service needs at the highest levels of camp coordination. Improved identification and registration could lead to service providers better understanding the needs of service users, therefore enabling them to plan more responsive, accessible, and inclusive services, ensuring rights realisation for all.

Figure 18: Thematic network group 4, global theme 8 (G4-GT8) – refugee disability committee (camps A, B, and C)



<u>Group 4 (refugee disability committee), organising theme 17 (G4-OT17): Misunderstanding of CD and support needs.</u>

Incorporating:

- *Basic theme 43 (G4-BT43): CD is recognised but not well understood.*
- *Basic theme 44 (G4-BT44): Some services address some elements of CD.*
- *Basic theme 45 (G4-BT45): Services do not the meet the needs of refugees who experience CD.*

There is consensus across all groups that CD is known to exist but is poorly understood by communities and service providers. Only stammering, psychological trauma, and hearing impairment were described as contributing to CD during the discussions.

> *A1G4*: *“Sometime the persons of his place were killed and persons were killed when he was there observing and some other time this other person fled from his properties and went away and this bring the person to depression because he compare the former life and the present life and there is too much.”*

However, people with hearing impairment or who identify as D/deaf are more likely to be identified and registered, as the impairment is more known and understood. Some people with CI, who are not hearing impaired or D/deaf, may be falsely registered and therefore be offered unsuitable support.

> *B1G4: “When they talk about communication disability we understand it concern a person who cannot interact to whom you cannot talk and they cannot talk to you. When you talk they cannot hear you and he cannot talk to you.”*

Despite this misunderstanding, participants recognise that the limited availability of sign language training and interpretation services fails to meet the needs of even those who would benefit from them. Moreover, refugees who cannot or do not use sign language are further marginalised as there is little else available to facilitate their participation and service access. Indirect discrimination (Tobler, 2008) therefore leaves many refugees who experience CD unsupported, marginalised, and exposed to risks such as sexual and gender-based violence.

RDC members identify a conundrum insofar as service providers do not know the prevalence of CI or CD and therefore do not know that services are needed, whilst refugees with CI experience disabling exclusion from registration services because support is not provided. This leaves them unsure about their right to access support and feeling despondent and neglected.

> *A1G4: "We suggested even that you increase the services for this communication disability in order that those people know that they have right to come out because they are in the community, they don't know whether their problem is a problem which is concerning the services provided."*

Group 4 (refugee disability committee), organising theme 18 (G4-OT18): Community empowerment and ownership can improve participation and inclusion for refugees who experience CD.

Incorporating:

- *Basic theme 46 (G4-BT46): Community plays a key role in identification, registration, and inclusion.*
- *Basic theme 47 (G4-BT47): Refugees who experience CD need to be known.*

The community plays a key role in supporting and advocating for its members. Community leaders know individuals and families and the challenges they face. They are locally elected, well trusted, and therefore have the potential to be effective educators and sensitisers on CD at community level, whilst being able to advocate at the highest levels through camp leadership hierarchies.

> *B1G4: "One of our other important role[s] is to know where the people with disabilities live so that when they have a problem we can reach them easily. If they have a problem we can speak out, bring the… guide people who are coming to help them, because we know where they live in our different quarters."*

There is a perception that refugees who experience CD are currently unidentified and need to be ‘known’ so that people can understand their needs and they can be served effectively. Community leaders can play a key role in sensitising members to reduce disability related stigma and mobilising individuals and families to ‘come forward’ and make their support needs known. This is thought to have the potential to improve visibility, acceptance, and, potentially, inclusion.

> *B1G4: “Another thing that we do for them is to educate them, especially to make them to understand that they are people like others, and we like to make them groups, in association, so when they are together, they feel they can help each other, and we make also parents together so that they can accept their children.”*

RDC members, however, feel ill-equipped to offer effective assistance. To better serve their communities, they would like increased knowledge, skills, and resources, to identify and communicate with refugees who experience CD, so that they can support them locally and advocate for equitable service access on their behalf.

5.16.5 Supra-global themes.

I combined data from each camp by stakeholder group, resulting in four sub-sets of data for analysis (G1-G4). I chose not to combine the four sets of data together as one in the first instance, as I aimed to take an emic perspective (Sue and Sue, 2015, Willis and Jost, 2007) of the experiences of different expert groups. Although some resulting themes are similar, or overlap, in concept, the codes and data excerpts in which those themes are grounded differ and offer unique perspectives on the issues. The overlaps in basic and organising themes also demonstrate similarity of understanding of some issues across groups, whilst differences highlight unique understandings and perspectives.

Following analysis of each of the four sub-sets of data (i.e., by stakeholder group), I then combined the global themes and further analysed the results together. From this analysis I constructed two supra-global themes (SGT1, SGT2). Although differing from Mano (2017) who reached one SGT, my data clearly illustrate two quite distinct stories about identification and registration: one relates to identification and registration of challenges and needs, and the other to addressing those challenges (see table 24, figures 19 and 20).

Table 24: Phase 1 supra-global themes

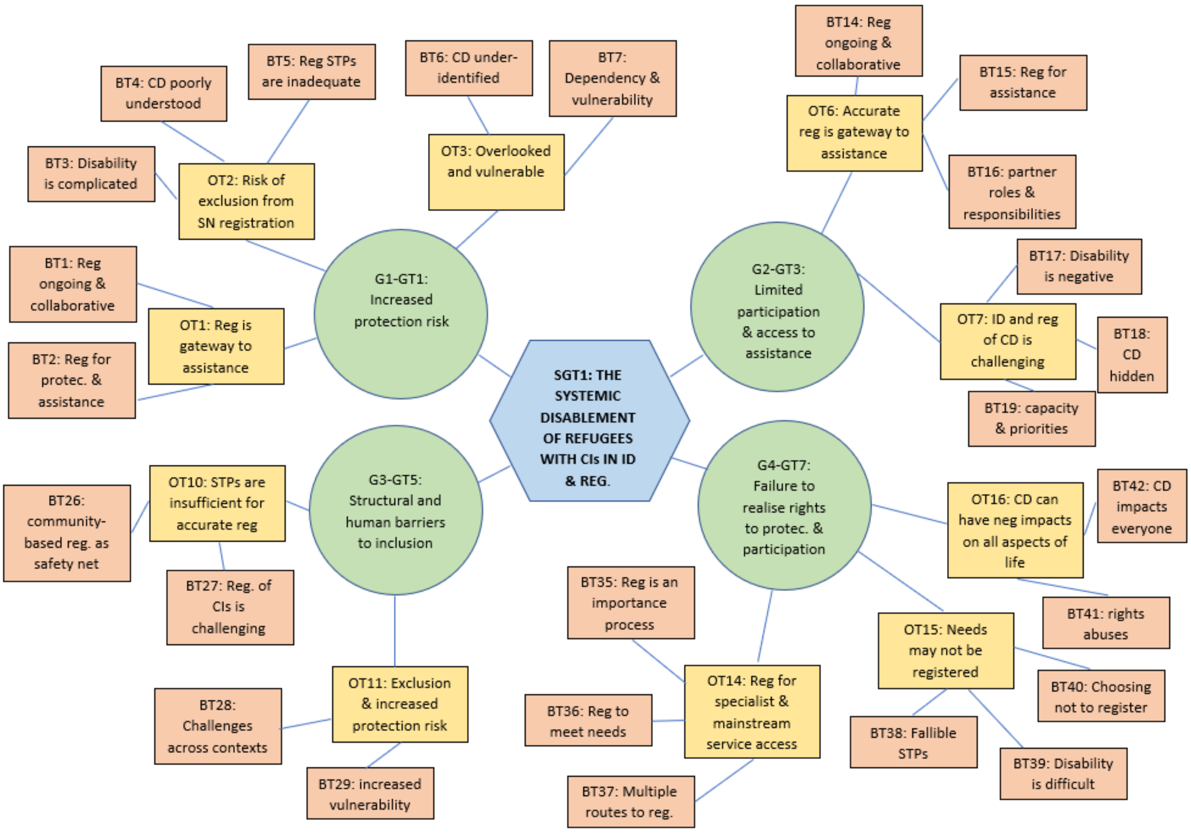
GLOBAL THEMES	SUPRA-GLOBAL THEMES
G1-GT1: Refugees who experience CD are exposed to increased protection risk	SGT1. THE SYSTEMIC DISABLEMENT OF REFUGEES WITH COMMUNICATION IMPAIRMENTS IN IDENTIFICATION AND REGISTRATION
G2-GT3: Refugees who experience CD experience limited participation and access to assistance	
G3-GT5: Refugees who experience CD face structural and human barriers to inclusion	
G4-GT7: Refugees who experience CD fail to realise their rights to protection and participation	
G1-GT2: Collaborative capacity building to achieve inclusion	SGT2. A HOLISTIC APPROACH TO ACHIEVING INCLUSIVE REGISTRATION STPS
G2-GT4: Harnessing existing resources and capacity of partners and communities	
G3-GT6: Increasing stakeholder capacity and resourcing to address barriers to inclusion.	
G4-GT8: Community-led advocacy to dismantle structural and human barriers to inclusion	

Supra-global theme 1 (SGT1): The systemic disablement of refugees with communication impairments in identification and registration

Incorporating:

- *G1-GT1: Refugees who experience CD are exposed to increased protection risk.*
- *G2-GT3: Refugees who experience CD experience limited participation and access to assistance.*
- *G3-GT5: Refugees who experience CD face structural and human barriers to inclusion.*
- *G4-GT7: Refugees who experience cd fail to realise their rights to protection and participation.*

figure 19: Thematic Network, supra global theme 1 (SGT1): All stakeholder groups



Key:

Blue: Supra-global theme *Green: Global theme*

Yellow: Organising theme *Orange: Basic theme*

This supra-global theme tells the story of the barriers to identification and registration faced by refugees who experience CD, and their consequences, as told by a range of service providers, from government staff to refugee volunteers.

Analysis of the experiences of all four stakeholder groups (G1-G4) leads to the understanding that the systems (including people who are part of those systems), tools (including data collection, storage, and analysis tools), and processes (including specific registration exercises, as well as continuous and community-based registration processes) used to identify and register refugees with CI, who may experience CD, are inadequate. Misunderstanding amongst staff and community members (including volunteers with formalised responsibilities) of the causes, nature, and impact of CI and CD; insufficiently sensitive data collection tools; and limitations in process (such as lack of time at registration, differing interpretations of how to collect and record data amongst partners; reporting bottlenecks; and lack of staff and volunteer capacity to cater for the communication support needs of refugees with CIs), combine to create pervasive exclusion and disablement. A focus on enrolment of children who experience disability in school serves to gloss over the exclusion children face within the classroom, where educators feel ill-equipped to support children’s communication needs effectively. Support needs recorded at school-level appear to not transfer to central registration systems, and therefore needs remain unknown to service planners.

As such, the very STPs that are in place to offer protection to refugees with specific needs, themselves contribute to the disablement of refugees with CIs. The ubiquitous, multi-faceted nature of exclusion and discrimination may be, for the most part, passive and unintended, but is no less systemic, affecting every aspect of service access and participation and negatively impacting upon families and communities. Moreover, the disabling exclusion from involvement in community consultations means the opinions and experiences of this group are seldom heard and so their needs remain unknown (findings reflected in Jagoe, McDonald, Rivas et al, 2021).

Furthermore, a misunderstanding that all refugees with CIs are hearing impaired or D/deaf, or should be treated as such, has resulted in the belief that sign language instruction and interpretation is a ‘quick fix’ to address the exclusion of people who experience CD. Indeed, as hearing impairment and D/deafness are the most understood and recognised (and therefore identified and registered) communication-related difficulties, services have been designed in response to the communication needs of this group of refugees, to the exclusion of others. As such, there is a perception that services *are* provided to meet the needs of refugees who experience CD, in the absence of understanding that only a subgroup is being served. The provision of sign language services, although useful for some, potentially masks the need for other communication access strategies to meet the needs of all refugees with a wide range of CIs and associated support needs, including those for whom sign language may be useful but who may find themselves communicating with a non-signing partner, or who may experience stigma when using sign language. This may further contribute to the disablement of those for whom sign language is not appropriate, and for those who find it unusable in certain situations. Furthermore, the situation increases exposure to risk for those who cannot access the support they need. This not only affects the identification and registration process but may go on to negatively impact upon everyday experiences across services, as well as opportunities for autonomous participation in community life. It also appears to result in frustration on the part of service providers who feel powerless to help and unable to access the support they need to do so.

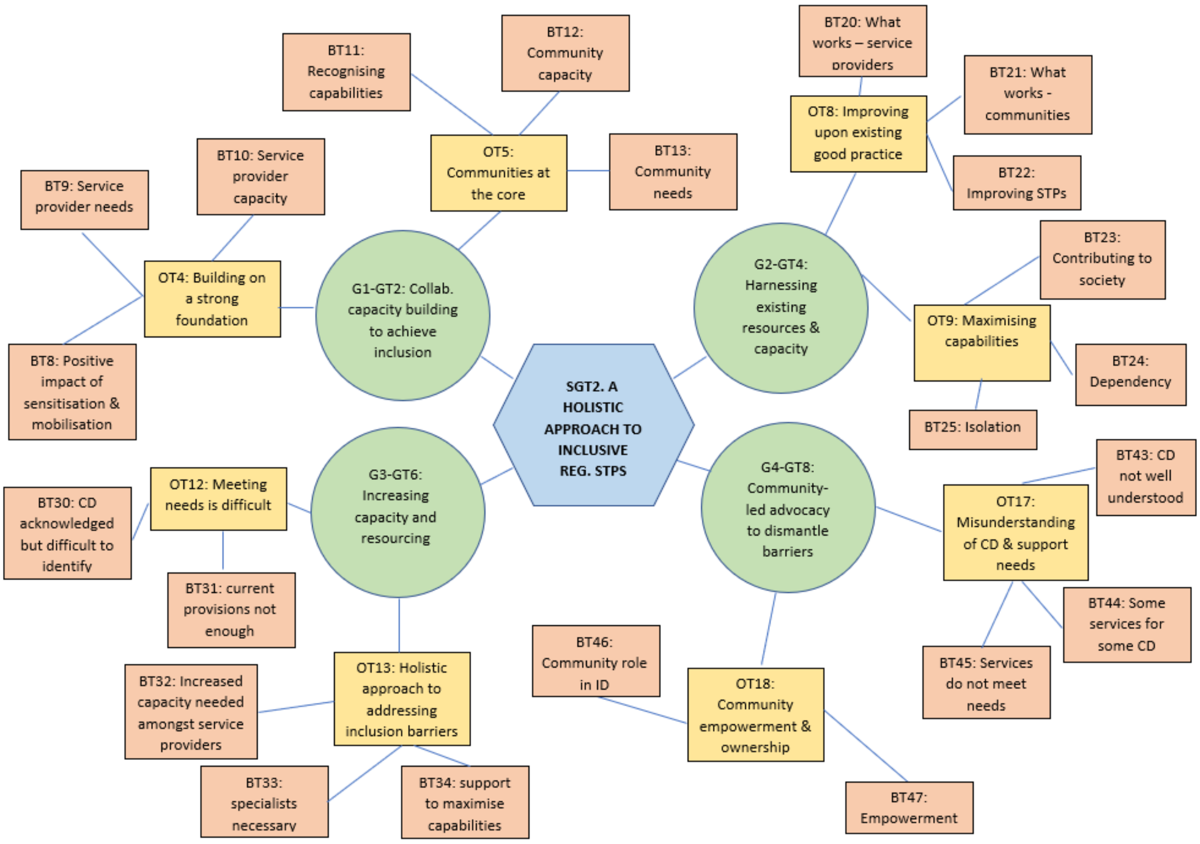
Supra-global theme 2 (SGT2): A holistic approach to achieving inclusive registration STPs.

Incorporating:

- *G1-GT2: Collaborative capacity building to achieve inclusion.*

- *G2-GT4: Harnessing existing resources and capacity of partners and communities.*
- *G3-GT6: Increasing stakeholder capacity and resourcing to address barriers to inclusion.*
- *G4-GT8: Community-led advocacy to dismantle structural and human barriers to inclusion.*

Figure 20: Thematic Network, supra global theme 2 (SGT2): All stakeholder group



Key:

Blue: Supra-global theme
Green: Global theme
Yellow: Organising theme
Orange: Basic theme

This supra-global theme represents the potential for improvement of the identification and registration, and the subsequent inclusion, protection, and rights realisation of, refugees who experience CD.

There is the potential to harness existing capacity, particularly in terms of human resources, to build upon the wider disability inclusion work that has already been carried out in the camps. Whilst recognising that not all refugees who experience disability (with particular reference to CD) have been targeted for rehabilitation and support or have had their needs addressed through sensitisation and mobilisation, there is an acknowledgement that the work to reduce stigma and discrimination against refugees who experience disability more broadly, has had a positive effect on community attitudes and behaviours. These strategies have the potential to be modified to focus attentions on communication. This, in collaboration with a focus on increasing knowledge, understanding and skills amongst service providers, and continuing to review and improve registration STPs, could result in ongoing improvements in the service access and community participation experiences of refugees who experience CD.

5.17 Implications of the findings from the FGDs

Analysis and interpretation of data across the four stakeholder groups from three camps, tells the story of the disabling experiences of refugees with CIs which are constructed through a combination of personal, environmental, structural, and organisational factors. These are exacerbated by the intersection of disability with the status of being a refugee and circumstances associated with forced migration, such as dependence upon aid for survival, disrupted social networks, and heightened protection risk.

The combination of personal communication limitations with insufficient refugee registration STPs, means that refugees with CI risk being excluded from services from the outset. In addition, a lack of knowledge, skills, understanding and capacity of communities and service providers (including implementing partners, community volunteers, educators, and refugee committees), along with negative attitudes and behaviours, increase the likelihood of non- or mis-registration. This toxic combination of exclusionary factors means that the very STPs put in place to ensure refugee protections, contribute to the systemic disablement of refugees with CIs. This results in: service coordinators (Government and UNHCR) remaining unaware of the true prevalence of CI, and associated CD; services (including registration) remaining inaccessible to refugees with CI; and the cycle of exclusion and discrimination continuing, with serious consequences for individuals and families and implications for human, disability, and refugee, rights.

A basic understanding of the intersectional nature of the biopsychosocial model of disability (WHO, 2001) amongst participants leads to a recognition that a multifaceted approach to inclusion is required for refugees who experience CD, to tackle exclusion at policy, operational, behavioural, and attitudinal levels. To address these systemic issues of exclusion, discrimination and rights infringements, service providers (including those in formal and ‘formalised’ voluntary services) believe that there is a firm foundation on which to build improved identification and registration of refugees who experience disability, including CD. Whilst recognising and celebrating the improvements in specialist service provision for some groups of people with visible or more understood impairments (such as physical impairment, hearing impairment) since 2015, stakeholders also acknowledge that these services do not meet the needs of all refugees, particularly for those with wide-ranging communication support needs. Indeed, the provision of some services for some refugees masks the exclusion of others and there is much more to be done to ensure equity and access. The dominant preference is for an increase in provision of sign language training for individuals and service providers, in the relative absence of understanding that this method of communication is not suitable for all refugees who experience CD and requires a huge investment in ongoing, long-term, human resources.

PART D

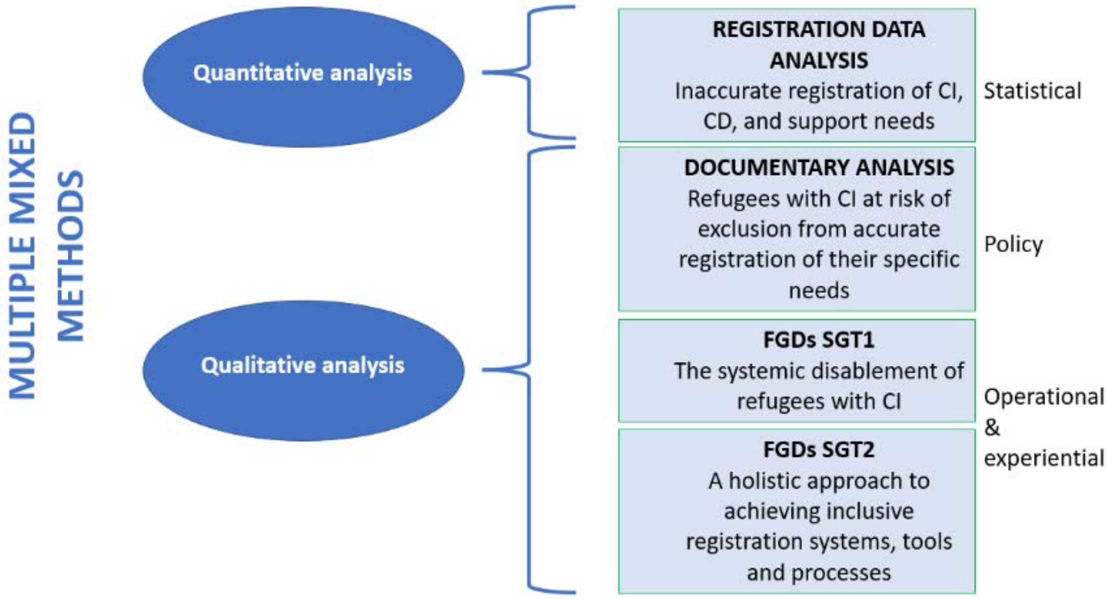
PHASE 1 DATA INTEGRATION AND DISCUSSION

5.18 Introduction

The aim of phase one of the research was to *'describe and critically interrogate the current systems, tools, and processes used to identify and register refugees with communication impairments, who experience disability, in Rwanda'.*

Conducting multiple and mixed method, research (data sets 1, 2, and 3) facilitated the construction of data from statistical, policy, operational, and experiential perspectives (see figure 21). This provided a holistic view of the issues affecting identification and registration of refugees with CIs, who experience CD, in pursuit of understanding if, and why, they were excluded from registration services, as suspected (Lange, 2015; UNHCR, 2015a).

Figure 21: Phase 1 results overview from data sets 1, 2 and 3.



5.19 Key findings, implications, and possible actions

The following points respond to the phase 1 research objectives (see chapter 1). To do this, I integrated data from across the three data sets in this phase of the research by doing a broad thematic analysis and by using a weaving approach. As described by Fetters et al (2013: 2142), *"the weaving approach involves writing both qualitative and quantitative findings together on a theme-by-theme or concept-by-concept basis."* Integration was carried out using manual (paper based) analysis, using the principles of thematic analysis (see chapter 5 section 5.15).

1. **Refugees with CI, who experience CD, are under-registered (Objectives 1a; 1b).**

   Document analysis (data set 2) highlighted that humanitarian organisations and their guiding bodies strongly advocate for more effective disability data collection, disaggregation, monitoring, and evaluation, to identify needs, meet those needs through service provision, and ensure rights realisation. However, despite a firm, documented, commitment to a 'leave no one behind' agenda, the humanitarian sector is aware that refugees who experience disability continue to be some of the most marginalised people in existence, which threatens their human, child, refugee, and disability rights, and contributes to increased protection risk – the very antithesis of their mandate. The fact that, in data set 1, regional disability-related refugee registration data were unavailable upon request, highlights this point. Although strategies to enhance inclusion in identification and registration services are recommended in guidance documents, there is also an acknowledgement that poor implementation of these guidelines, along with other social and environmental factors such as stigma, contribute to inaccurate registration of impairment and disability.

   In relation to CD, these findings are corroborated by FGD participants (data set 3), who discussed their first-hand experiences of the challenges they face as service providers, and those faced by refugees with communication support needs, in accurately identifying and registering refugees with CI, who experience

CD. Not only do their stories tell of registration STPs that actively contribute to the disablement of refugees with CI, but also the interplay of individual limitations, social and environmental factors (such as negative attitudes and behaviours), as well as wider institutional and organisational factors, that impact upon accurate identification and registration of CI and CD, and therefore the known prevalence rates.

The results of the analysis of registration data in data set 1 suggest that, as corroborated by data from data sets 2 and 3, refugees who experience disability are indeed highly likely to be under-identified and under-registered in Rwanda, in comparison to global and regional prevalence data (e.g., WHO and WBG, 2011). Existing research reports this on a global scale for every age group of refugees who experience disability (e.g., Tanabe et al, 2015; Smith Khan et al 2014) and this research reflects lower rates of disability registration than those previously reported, even following a specific, targeted, disability identification and registration exercise (data set 1, data sub-set 4).

Registration of CD under the existing ProGres (DS-SD) code is startlingly low against expected figures, particularly for children, and analysis of disability codes which could involve some form of CI (named communication-related impairment/disability – or CRID – codes – see this chapter, part A) illustrates that many refugees who may have communication support needs have these documented under primary, or more 'visible' disability codes, affecting recorded CI/CD data, and therefore perceptions of prevalence and subsequent support needs.

The three data sets together demonstrate that, in contrast to the favourable policy environment which commits to disability inclusion in humanitarian action, and the belief that disability disaggregated data are vital, an inextricable web of personal, social, environmental, and institutional, factors impact upon accurate CI/CD data collection. Since data are vital to service planning, this translates into inadequate service design and provision for refugees who experience CD in Rwanda.

2. Misuse of disability terminology confuses issues of identification and registration of CI and CD (Objectives 1b; 1c)

Data across the three data sets have demonstrated misuse and inconsistency of disability terminology. The interchangeable use of the terms ‘impairment’ and ‘disability’ spans data collection tools (data set 1), operational and procedural guidelines, policy (data set 2), and parlance amongst service providers and refugee communities (data set 3), causing confusion in terms of identification of impairment, and documentation of disability experiences and support needs. The use of phrases such as ‘*speech impairment/disability’* (UNHCR, 2006a) and ‘*speech and hearing impairment’* (used by FGD participants), further perpetuates misunderstandings, such as that CD is synonymous with hearing impairment. This serves to mask the existence and needs of people with other types of CIs and support needs (Barrett et al, 2019), resulting in only one form of service provision (sign language) that meets the needs of only a small group of refugees with CIs, to the exclusion of others. This illustrates the pervasive misunderstanding of CI and CD, even amongst the specialist service providers responsible for the wellbeing of all refugees who experience disability, as well as a possible lack of exposure to other alternative, augmentative and/or acceessible forms of communication.

Furthermore, the reported registration of only one type of impairment per person by some implementing partners demonstrates potential for under-documentation of impairment prevalence, associated disability, and support needs. Indeed, analysis of CRID codes (data set 1) resulted in estimates that approximately 34% of refugees registered under disability SNCs could *potentially* have CI – a startling difference to the 0.1% registered under DS-SD code alone.

3. There is a rights-realisation gap for refugees who experience CD (Objectives 1b; 1c)

Although the refugee right to accurate registration of specific needs is well documented (data set 2) and understood amongst professional and volunteer service providers (data set 3), all three data sets highlight that, despite humanitarian commitments to a ‘no one left behind’ agenda, and suggestions of how to ensure registration service equity, this appears to have not been effectively operationalised. Interconnecting factors, including human and physical resource capacity; knowledge, understanding and skills of staff; suitability of STPs; and negative attitudes and behaviours, impact upon how effective implementation of inclusive policy can be in a humanitarian context (even protracted situations) – factors also identified in the literature in data set 2 and reflected in evidence from FGDs (data set 3). This is particularly relevant for those with ‘invisible’ impairments, such as CI, who are more likely to be overlooked.

The rights-realisation gap identified in the Document Analysis (data set 2) is supported by evidence from analysis of the Rwandan refugee registration data (data set 1) and is further emphasized by service providers during FGDs (data set 3). Integrated evidence from the three data sets suggests that, not only are refugees with CIs at risk of disabling exclusion from critical registration services, which are the gateway to receiving life protecting and life promoting assistance, but that the very STPs that are put in place to protect refugees contribute to the systemic disablement of those with CI who are unable to access them effectively. This not only contributes to inequity, but infringes upon their rights, as well as having substantial impacts upon their own, and their families’ lives and futures.

STPs and guiding documents ostensibly align with the human rights approach to disability inclusion, as do the guiding principles of implementing organisations. A major stumbling block appears to be that the issue of communication is neglected in documentation at the highest level, including in the definition of disability in the CRPD itself. As such, documents that centre their guidance on the CRPD lack focus on communication and, consequently, service providers and communities may neglect to identify issues of communication support - they are largely unaware of what CIs are, what CD is, and who may benefit from communication accessibility strategies. This is articulated by a FGD participant who states that *“the eye can only see what it knows” (B1G1)* and is reflected in low rates of DS-SD registration (data set 1). The neglect spans services across the board, from refugee registration (which subsequently affects eligibility to support services, evidenced in data set 3), right through to health, education, legal, social, food, shelter, and protection services, affecting every aspect of a refugee’s life.

4. Humanitarian innovation could contribute to meaningful change, through ‘systems thinking’ (Objectives 1b; 1c)

Interpretation of FGD participant stories in data set 3, revealed the importance of addressing issues of exclusion at organisational, service, community, and individual levels. Document analysis in data set 2 highlighted the need for explicit reference to communication in definitions of disability, and in the key guiding documents for the humanitarian sector. These observations together fit within a humanitarian innovation model of ‘systems thinking’ (Campbell 2021a; 2021b; Elrha, 2018; Meadows, 2008) - a 360^{o} approach to addressing an identified problem through considering the interconnectedness of all elements of a system (World Economic Forum, 2021) – in this case the humanitarian system and/or education system - including policy, legal, organisational, social, environmental, and personal factors influencing an issue. This enables exploration and development of effective action in complex situations (Government Office for Science, 2012), facilitating systems change (York, Lavi, Dori et al, 2019; School of System Change, undated). Although the term ‘systems thinking’ is also used outside of the humanitarian sector (e.g., in engineering, policymaking and health care), its concept and application does not differ significantly. In all cases it focuses on interconnectedness and wholeness of elements of systems, as well as leverage points where small changes can have larger multiplier effects within a system (Meadows, 2008). The constantly dynamic landscape of humanitarian contexts, however, means that systems thinking is a particularly helpful way of conceptualising the interconnections between decision-making, planning, implementation, and outcomes - as well as the impact that gaps in these may have. Elrha, in their 2018 Humanitarian innovation Guide (HIG), states that:

> *“The humanitarian environment isn’t static: it’s constantly changing, and changes to one part of the system affect other parts of the system; good innovators and innovation teams need to think about systems. Systems thinking means identifying different component parts of a system and seeking to understand their relationship with each other” (Elrha, 2018: online).*

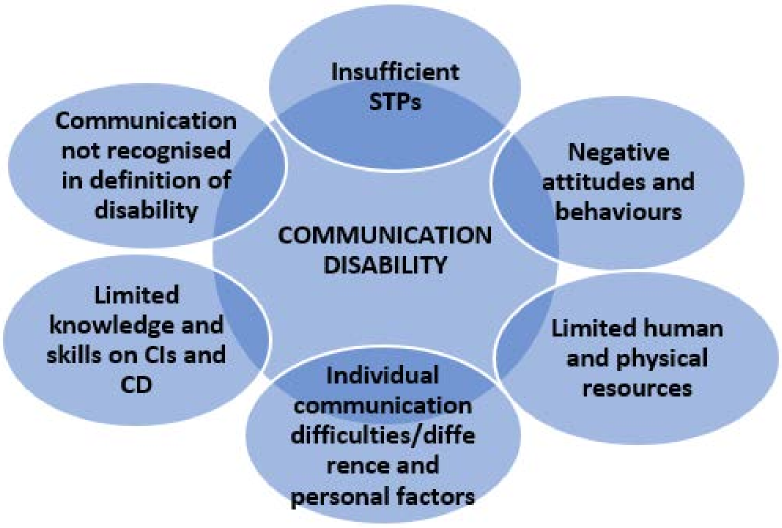
The evidence generated from the three data sets has contributed to a ‘root cause analysis’ (Elrha, 2018) of the issues influencing the exclusion of refugees with CIs, who experience CD, from registration and other humanitarian services. Service providers in data set 3 demonstrate an understanding of the concept of disability through a biopsychosocial lens - as an interaction between person and environment. As such, they see a way forward through empowerment of individuals who experience CD, along with strengthening existing strategies to improve inclusive service provision through further capacity-building of individuals, families, and service providers (including implementing organisations, community volunteers, educators, and disability committees) through training. Improved knowledge, understanding, and skills, can then be cascaded to communities through expansion of existing sensitisation and mobilisation activities, to ensure rights enshrined in the CRPD (UNGA, 2006) are realised.

Service providers also suggest review and revision of registration STPs, which they recognise as insufficient for refugees with CIs, and which potentially under-document CI and CD prevalence (data set 1) These strategies, in combination with the need to make explicit the need for communication access in policies and guidelines (data set 2), tackle the issue of exclusion and heightened protection risk from numerous perspectives, ensuring a holistic approach to inclusion and fulfilment of rights. The evidence therefore suggests that a ‘systems thinking’ approach may be useful in addressing the issue of exclusion of refugees who experience CD from accurate registration of their specific needs.

5.20 Phase 1 conclusion

In conclusion, evidence from the three data sets suggests that refugees with CIs in Rwanda experience disabling, systemic, exclusion from registration services (see figure 22), placing them at risk of rights infringements – the very antithesis of the mandate of refugee protection services. Multiple factors implicitly and explicitly influence this exclusion, from lack of recognition of communication in the CRPD human rights definition of disability (UN General Assembly, 2006) (which perpetuates the invisibility of CD in wider policies and guidelines), to deep-rooted misunderstandings of the causes, nature, and impacts of CIs, that fosters stigma, discrimination, exclusion, and alterity.[56]

Figure 22: Factors contributing to communication disability amongst refugees, as identified in data sets 1, 2 and 3.



To ensure refugees with CIs fulfil their right to accurate registration of their specific needs, all root causes of exclusion must be addressed in a holistic manner, considering the perspectives of all stakeholders, from policy makers to service users. A 'systems thinking' approach to problem identification and resolution offers potential for change at policy, legal, organisational, social, environmental, and personal levels to achieve meaningful change and rights fulfilment (see figure 23).

Guiding principles on the identification of CI, and inclusion of refugees who experience CD, must be enshrined in policy, and enacted at every level of refugee

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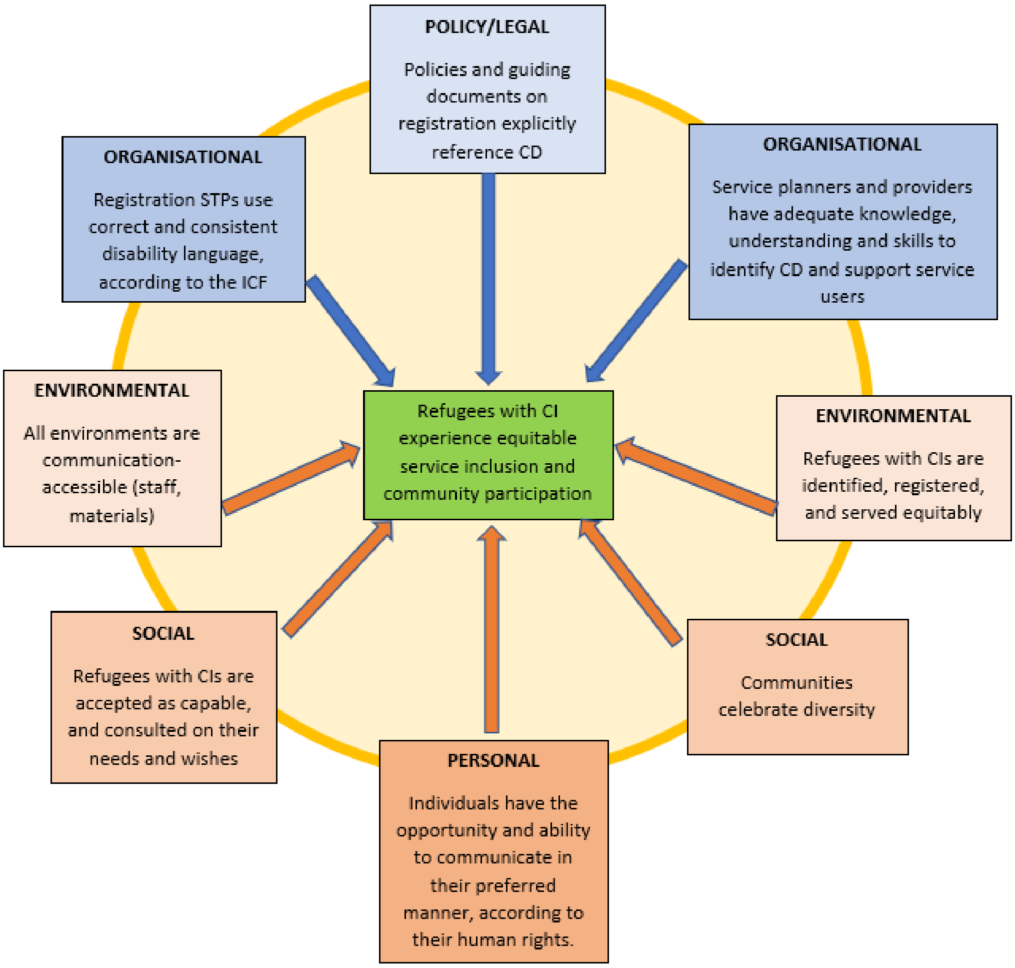
[56] Alterity is an anthropological term with a cultural orientation to describing 'otherness' (Merriam Webster, 2023)

engagement, whilst registration STPs require careful revision. Meanwhile, increasing knowledge, skills and understanding of CD amongst service providers, and improving community acceptance of people who experience CD, will enhance participation and service access for refugees who experience CD and their families. Enacting this systems thinking approach could reduce the disablement of refugees with CI, ensuring rights are realised and protection risks minimised.

Figure 23: The future of inclusive refugee identification and registration services – using systems thinking to achieve change.



Chapter 6: Phase 2

6.1 Overview

As described in chapter 1, The UNHCR Rwanda country office expressed concerns that children with communication impairments (CIs) may be disproportionately excluded from educational opportunities in Rwanda's refugee communities. Following analysis of data pertaining to the opportunities and barriers facing refugee children during identification and registration processes, it was also important to understand the opportunities and barriers to accessing appropriate early childhood development (ECD) and education services, to address the research question, aims and objectives (see table 25). Phase two of the research therefore focuses on the issues of education rights, eligibility, and access for refugee children who experience CD, in Rwanda.

In this chapter I report on three data sets, drawn from three data construction methods, that were carried out independently and then the results integrated, in response to the phase 2 aim and objectives. The same multiple qualitative methods were used to construct and analyse data in this phase of the research as in phase 1 of the project, and which are described in detail in chapter 5 (see figure 24).

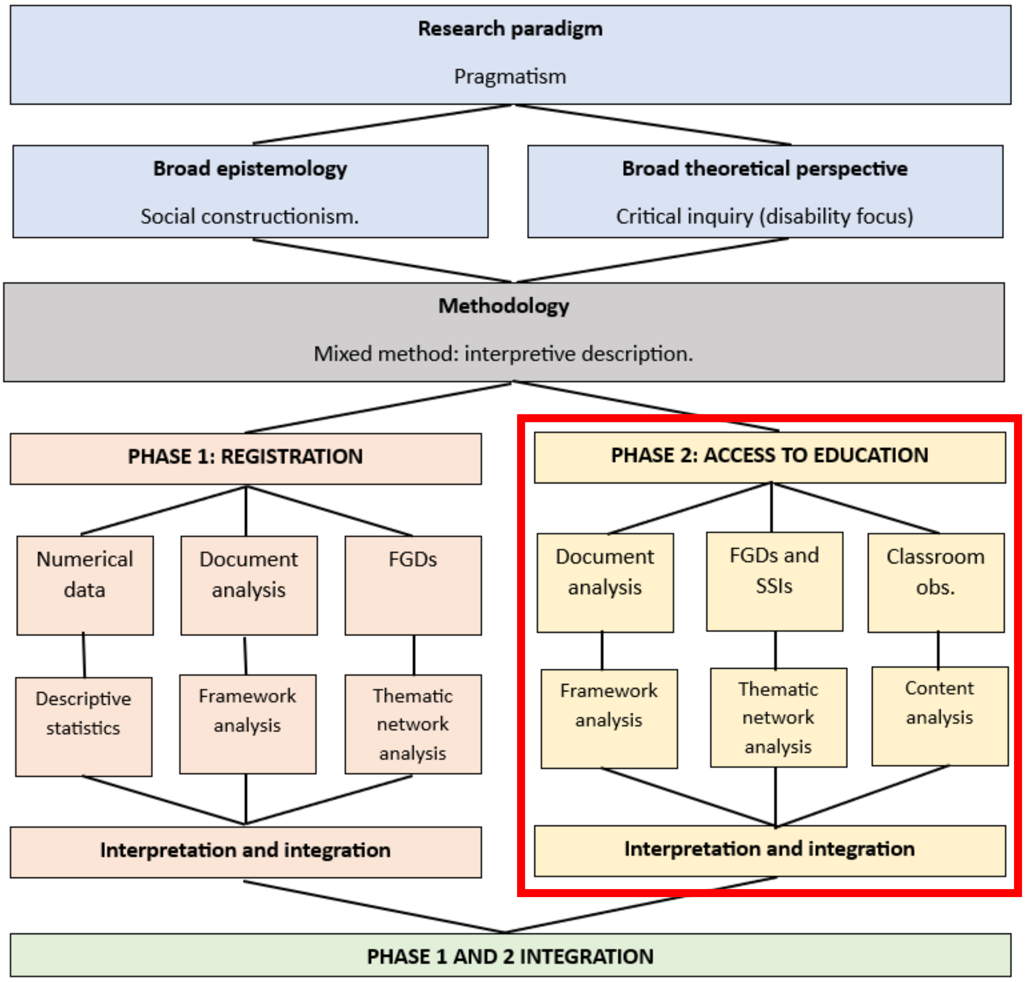
- **Data set 1:** Document analysis (DA) of guiding documents, relevant to refugee eligibility for education, and provision of inclusive ECD and education services, analysed using the Framework method.

- **Data set 2:** Focus Group Discussions (FGDs) and interviews with service providers (implementing organisation (IOs) and educators), community volunteers, and carers of refugee children who experience CD, analysed using Thematic Network Analysis (TNA).

- **Data set 3:** Classroom observations, analysed using conventional content analysis.

I present the data construction methods and process, data analysis methods, and results for each data set. At the end of the chapter, I bring the results of all three data set analyses together in integration and discuss overall findings and implications, with reference to existing literature (see chapter 3).

Figure 24: Phase 2 structure



6.2 Phase 2 aims and objectives.

The aim of phase two of the research was:

> *A2: To map the opportunities and barriers to accessing appropriate inclusive ECD and education services, for refugee-children with communication impairments, who experience communication disability, in Rwanda.*

I set out to achieve this through three research objectives that, together, address different but complementary aspects of the research aim, as follows (table 25).

Table 25 Phase 2 aims and objectives

	Objective	**Data construction method**	**Data analysis method**
O2a	To document the inclusive early childhood development and education services that are provided to refugee-children in Rwanda and the opportunities for, and barriers to, the educational inclusion of refugee-children with communication impairment, who experience communication disability.	• Document analysis • FGDs / Interviews • Classroom observations	• Framework analysis • Thematic Network Analysis • Content analysis
O2b	To document early childhood development and education service-providers' views of opportunities and barriers to including refugee-children who experience communication disability in Early Childhood Development /education services.	• FGDs / Interviews	• Thematic Network Analysis
O2c	To document the views of parents/carers of children who experience communication disability regarding opportunities and barriers to including their children in early childhood development/ education services.	• Interviews	• Thematic Network Analysis

PART A

PHASE 2, DATA SET 1

DOCUMENT ANALYSIS

6.3 Introduction

This section reports on the document analysis (DA) of inclusive ECD and education guidance for refugee children, sourced through direct requests and online searching, to achieve objective O2a. Here I report on data construction, data analysis, results, and end with a discussion of the findings and implications.

6.4 Data construction, sources, and procedures

I chose DA as a method to facilitate understanding of the policy and operational context of the topic of inclusive ECD and education provision for refugee children in Rwanda – particularly for those who experience CD. I used it to facilitate deeper understanding of the educational entitlements and provisions for refugee children who experience CD, and to elucidate opportunities and potential challenges for equitable service provision at global and country levels. Themes constructed during this analysis were further explored through FGDs and semi-structured interviews with service providers and (potential) service users (see data set 2, section B). Documents providing top-down (e.g., global UNHCR and humanitarian directives) and bottom-up (from refugees in Rwanda e.g., consultation reports) information were sought to identify similarities and disparities between expected and experienced contexts.

In response to objective O2a, documents describing the educational entitlements of refugees globally, and in Rwanda, the educational services available, as well as the processes and procedures for inclusion of children who experience disability, were identified for consideration in the analysis, through several channels (see appendix 17 for search strategy). Searches were conducted at the beginning of the search window (January 2016) and repeated monthly throughout the search window time frame (January 2016-June 2018) to identify any missed, new, or updated documents. Academic databases were not used in this document search as I was primarily seeking to analyse guidelines and policy directly applicable to humanitarian action, rather than theory or research. Search terms for open web searching are listed in table 26 below.

Table 26: Phase 2 document analysis search terms

Refugee terms	ECD and education terms	Disability terms	Inclusion terms
Refugee*	Early childhood service*	Disab*	Inclu*
Forced migra*	Early childhood educat* (ECE)	Impair*	Exclu*
	Early childhood development (ECD)	Handicap*	Integrat*
	Early childhood care and development (ECCD)	Specific needs	Participat*
	Day care	Special needs	
	Creche	Special educational needs (SEN)	
	Baby group	Special needs education (SNE)	
	Educat*	Special school	
	Special educat*	Special cent*	

The search terms did not include terms related to communication disability and/or impairment specifically, as a preliminary search of the literature indicated that few results were likely to be found on this very specific issue. Instead, documents referring to disability inclusion more broadly were sought, and any specific information on communication disability and/or impairment extracted and coded. Documents included in the analysis included refugee-related terms, ECD/education terms, and one or both of disability and/or inclusion terms in their full text, as not all had abstracts or executive summaries to review as a first filtering step.

Basic information (authors, title, source, year, search term success) about each document was extracted and entered onto an Excel spreadsheet according to the categories detailed in chapter 5 section 5.9.1 (see appendix 8 for image). Each document was read in full and inclusion/exclusion criteria applied as per appendix 17.

6.5 Data analysis: methods and process

Data were analysed using the Framework method, as described in detail in chapter 5, section 5.9.1.1.

6.6 Results

Forty-eight documents were identified for potential inclusion in the analysis, based on their titles and any introductory text (e.g., abstract, or executive summary). After application of the inclusion criteria to the full document (appendix 17), thirty-three documents were analysed in full. Each document was given an identification code from S2.01 through S2.48 (see appendix 18).

Twelve documents had been produced as reports and advocacy documents and ten as guidance, to support humanitarian actors to implement effective inclusive ECD/education activities. Those published between 2015-2017 often made explicit reference to Agenda 2030 and to SDG4 (including the Incheon Declaration and its framework for action - UNESCO, 2015). Reports mostly documented the situation faced by children who experience disability, including refugee children, going on to offer suggestions to make education services more inclusive. Advocacy documents included published evidence and a call to action for governments to address the specific issue of disability and educational inclusion in humanitarian contexts. These documents were primarily produced by UN agencies and/or International NGOs with specific rights agendas, including UNICEF and Save the Children. The documents were mainly produced for global use. Five documents had been specifically written for

Rwanda based on their titles but, on reading the full documents, four did not meet inclusion criteria (appendix 17) and were removed from the final analysis.

In summary, the documents analysed were, by and large, produced by and for multilateral agencies, Government agencies, and humanitarian actors. They represent a relatively unified perspective, guided by global initiatives such as the Millennium Development Goals (2000-2015) (United Nations, n.d.) and the Sustainable Development Goals (2015-2030) (UNDP, 2015).

Following application of the Framework method of analysis to the final selection of documents, twenty-eight codes were identified (appendix 19) that were subsequently grouped into four sub-themes and two themes, that summarised the essence of the documents' content and meaning (table 27). As described by Braun and Clarke (2019a) 'codebook' approaches to thematic analysis, such as the Framework method, conceptualise themes as summaries of data on a particular topic, rather than the 'stories' that they tell (such as in reflexive TA), which is more applicable to FGD and interview data.

Table 27: Phase 2 DA sub-themes and themes

Sub-theme	Theme
1 Disability leads to exposure to heightened risk in forced migration contexts	1 EDUCATIONAL EXCLUSION EXACERBATES CURRENT AND FUTURE RISKS, FOR REFUGEE CHILDREN WHO EXPERIENCE DISABILITY AND THEIR COMMUNITIES
2 Exclusion is multidimensional and pervasive	
3 Inclusive education contributes to inclusive futures	2 INCLUSIVE EDUCATION UNDERPINS THE CREATION OF EQUITABLE, PEACFUL AND JUST SOCIETIES
4 Systemic change to achieve education for all	

6.6.1 Theme 1: Educational exclusion exacerbates current and future risks for refugee children who experience disability and their communities.

Incorporating sub-themes 1 and 2 (see table 27 and appendix 20).

This theme summarises information on the heightened exposure to current and future risks for refugee children who experience disability, derived from the documents included in the DA. At the intersection of their disability and refugee statuses lies pervasive discrimination, exclusion, and human rights violations, including a lack of access to appropriate education, that can have significant impacts across the lifespan. Systemic barriers to inclusion across communities, organisations, services, and legal entities combine to render refugee children who experience disability some of the most at-risk children on earth (S2.11: UNICEF, 2017).

> *"Exclusion from education, then, is not a single 'one-off' event in the lives of the children affected. Having no access to school, or access only to those that are ineffectual and harmful, needs to be understood as part of a pattern of systemic exclusion, one linked to other social, economic and political conditions which can, in effect, serve as proxy. The child who consistently does not go to school is also the child who consistently suffers from poor nutrition and health care, from inadequate water, sanitation, and shelter; who lives in a family with an unstable income and limited opportunities to participate; whose community is in conflict." (S2.33: UNESCO, 2000: 2)*

Ironically, documents suggest that out-of-school children (including those who experience disability) fail to access the protective benefits of an inclusive, community-based education. This includes: a physically and psychologically safe and protective environment; a supportive network of friends and advocates; access to information on personal safety and protection; lifelong learning and independence skills; as well as active participation in community life, and the peaceful restructuring of their community post-emergency. They fail to have their voices heard and their capabilities valued. Moreover, their classmates miss the opportunity to experience and appreciate diversity – a lesson with transformative potential.

6.6.2 Theme 2: Inclusive education underpins the creation of equitable, peaceful, and just societies.

Incorporating sub-themes 3 and 4 (see table 27 and appendix 20)

This theme describes the transformative potential of inclusive ECD and education on society, from the immediate effects on the individual and their family, to the future economic and social impacts on nations.

The documents included in this theme make the case for investment in inclusive education in humanitarian contexts as an investment in the future of children, families, and society. They advocate that the benefits of inclusive education cannot be overstated, particularly in humanitarian contexts, and specifically those involving forced migration. In these situations, children who experience disability are known to be overlooked and often fail to realise their rights on a multitude of levels (see sub-theme 2, appendix 20). Education is documented to foster dignity and participation and to provide opportunities for visibility and attitudinal and behavioural change amongst peers and community members. It also facilitates the realisation of other human rights, paving the way for a dignified and independent future. Critically, education for all (EFA) is purported to provide the opportunity for every child to play a role in the creation of equitable, peaceful, and just societies – the goal of Sustainable Development Goal (SDG) 16.

> *"Inclusive schools are able to change attitudes toward diversity by educating all children together and form the basis for a just and non-discriminatory society" (S2.31: UNESCO, 2016: 9).*

6.7 Implications of the findings from the document analysis

DA of thirty-three documents produced two themes and four sub-themes related to inclusive ECD and education and its application to the situation of refugee children with impairments, who experience disability. Notably, there was limited consideration of communication impairment and disability across the documents included in the analysis, as well as markedly more documented about inclusive primary education, than ECD.

Results indicate that an appropriate education for every child is a right enshrined in global policy. This right constitutes the core of modern humanitarian education response for children in crisis, including situations of displacement and forced migration, yet is widely acknowledged to be largely unrealised by children with impairments, who continue to experience well-documented disabling exclusion and rights infringements, in humanitarian contexts. This group of children experience heightened risk of discrimination, marginalisation, and protection violations in comparison to other children, which may be further exacerbated by intersections with risk factors associated with age, gender, ethnicity, language, and/or religious affiliation. Stigma, misunderstanding, and misconceptions related to impairment and disability within communities and amongst policy makers and service providers means that families may not wish to send their child to school, and teachers may not welcome them into their classrooms. The children become 'invisible' and, paradoxically, fail to access the physical and psychological protection that education affords children and families (safe spaces, education on sexual and reproductive health, hygiene, and environmental threats, for example), further exacerbating their disablement and exposure to protection risk.

It is widely accepted that humanitarian education provisions are failing refugee children – especially those who experience disability, and that the current situation is contributing to the failure to achieve Agenda 2030, through SDG 4 (quality education for all). Humanitarian organisations are therefore committed to improving the identification, needs assessment, and inclusive education service provision, for refugee children who experience disability. To gain traction with policy makers, service providers, and communities, they reiterate the rights-based agenda for EFA and make the case that inclusive education is an investment in the future stability and prosperity of host and home nations.

Unlike the situation with exclusion from identification and registration services described in chapter 5, which suffers from a lack of clarity on *how* to improve systems, tools and processes, there is abundant advice on how to instigate change to achieve inclusive education at community, organisational, and political levels. This not only involves the systemic changes described, but also a fundamental paradigm shift in pedagogy within education systems and within the classroom. Unfortunately, little has changed since the Incheon Declaration (UNESCO 2015) came into existence in 2015 (S2.37: Save the Children, 2017), with little explanation provided for the inertia.

Key findings from this document analysis include:

1. **Refugee children, who experience disability, are subject to rights violations that have significant impacts on their future.**
   This includes subjection to pervasive discrimination, exclusion from essential services (health, education, and protection), and social participation restrictions that render them invisible, unheard, unprotected, and underserved.

2. **Reference to communication impairment and/or disability is notably limited in humanitarian sector professional guidance.**
   Where communication is mentioned, there is little guidance on the 'how' of inclusion in ECD and education for children with communication support needs.

3. **Inclusive education holds transformative potential.**
   EFA is central to the development of a society that values diversity, treats all people with dignity, and is free from inequality and injustice. It is also a critical component in the realisation of other human rights and the development of human capital.

4. **The humanitarian sector needs to close the gap between policy and practice, to put an end to child rights infringements.**

   Acknowledgement of the problem of educational exclusion for refugee children who experience disability, and advice on how to solve the issues identified, has yet to be translated into effective practice. The international community acknowledges this gap but is struggling to operationalise meaningful change towards inclusive practice.

PART B

PHASE 2, DATA SET 2

FGDs AND INTERVIEWS

6.8 Introduction

This section reports on data construction, data analysis, and results, and ends with a discussion of key findings from FGD and interview data gathered from service providers and refugee carers. This includes coordinating and implementing organisations (GoR, UNHCR, (I)NGOs), community volunteers, educators, and refugee committee members, as well as carers of children who experience CD, to achieve objectives O2a, O2b, and O2c.

6.9 Data construction procedure

6.9.1 Participant identification and recruitment

Service providers were identified and recruited as described in chapter 5, section 5.13 (see table 28 for inclusion criteria). Refugee carers of children who experience CD, and children who experience CD themselves, were identified by the RA through several channels:

a) Registration under code DS-SD (speech impairment/disability) in the UNHCR ProGres database.
b) Already known to the RA.
c) RA consultation with community mobilisers working for the disability implementing organisation, Humanity and Inclusion.

Carers and children meeting inclusion criteria (tables 28 and 29) were approached directly by the RA with basic information about the research. This was presented verbally and through a PIS available in three languages and three levels of accessibility format (see appendix 12). They were then given two weeks to decide if they would like to participate, ask questions, and give written consent. Consent was explained to be ongoing, and that they could withdraw at any time, without reason or consequence. The RA returned after two weeks to obtain consent or declination to participate.

As in phase 1, data set 3, a target of eight participants per FGD was set (see table 31). A target of four carers and four children per camp was set due to the additional time it would take to conduct separate individual interviews. Carers and children were asked if they would prefer to participate in an individual or small group interview (figure 25).

Table 28: Inclusion criteria for phase 2, data set 2: Service providers

Inclusion criteria
Over 18 years of age at time of recruitment
Fluent in at least one of: Spoken or signed Kinyarwanda, French, or English language
Involved in a formal capacity in the identification and/or registration of refugees with impairments and disabilities
Has capacity to give full, voluntary, informed consent as per the PIS and consent procedure
Able to attend *either* a FGD *or* individual interview at a time when the researcher would visit the camp for data collection

Table 29: Inclusion criteria for phase 2 data set 2: Carers

Inclusion criteria
Over 18 years of age at time of recruitment
Is a registered refugee
Resides in one the three research location camps
Fluent in at least one of: Spoken or signed Kinyarwanda, French, or English language
Assumes a primary caregiver role for a child who experiences CD
Has capacity to give full, voluntary, informed consent as per the PIS and consent procedure
Able to attend individual or group interview at a time when the researcher would visit the camp for data collection

Table 30: Inclusion criteria for phase 2, data set 2: Children

Inclusion criteria
Between 8;0 and 12;11 years old at time of recruitment[57]
Is a registered refugee
Resides in one the three research location camps
Can understand spoken or signed Kinyarwanda, French, and/or English language, at a basic conversational level
Carer has given consent to participate
Has capacity to assent to participation, as per the PIS and consent procedure
Able to attend individual or group interview at a time when the researcher would visit the camp for data collection

Table 31: Target number of participants for FGDs and interviews: Phase 2, study 2

Study population	Target number per camp	Total number (3 camps)
Implementing organisations (Government, UNHCR, and NGO partners)	8	24
Educators (ECD caregivers and teachers)	8	24
Refugee disability committee	8	24
TOTALS	**32**	**80**
Carers of refugee children who experience CD	4	12
Children who experience CD	4	12
TOTALS	**8**	**24**
GRAND TOTAL	**40**	**104**

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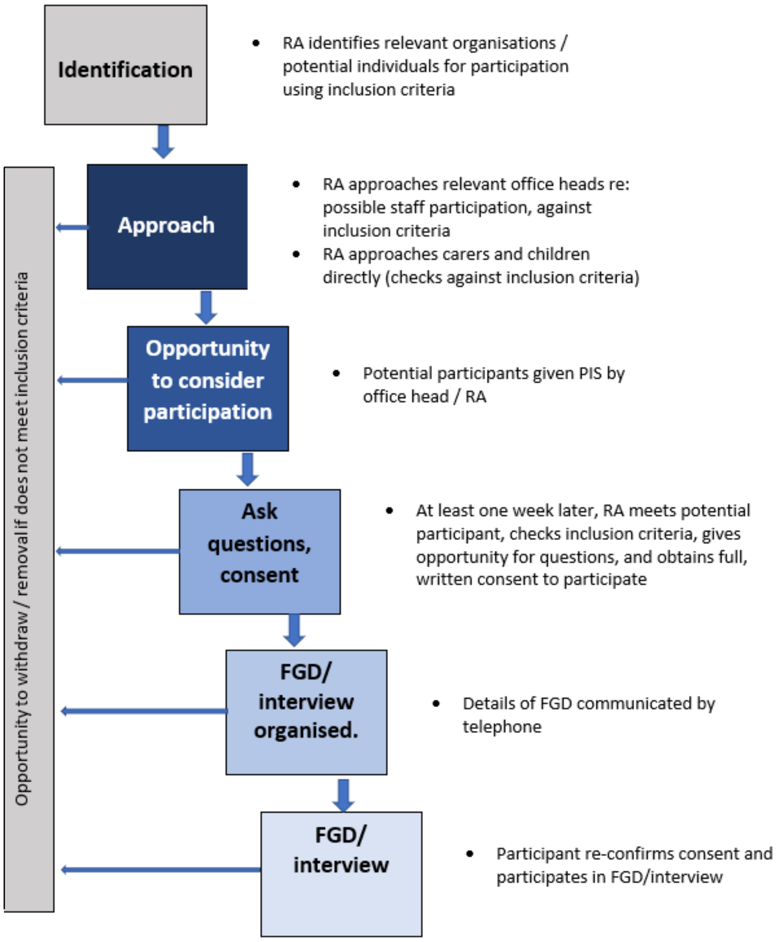
[57] The age group covered across the research project is 0-12;11 (up to the end of compulsory primary education in Rwanda). However, I chose the upper age limits only to participate in interviews, based on ability to participate and respond to verbal/signed prompts during interviews. In addition, older children are more likely able to be able to offer clearer assent/dissent to the process.

Figure 25: Participant recruitment process for stage 2, study 2: FGDs and interviews



6.9.1.1 Participants

The FGDs and interviews involved thirty-five participants (appendix 21). Demographic information on gender identity and age, along with years of professional experience for service providers, is provided. The final selection was necessarily influenced by the identification and recruitment process, as well as factors outside of my control such as research advisor time and the window of availability in which I was permitted to access the camps to conduct FGDs and interviews.

Only one child was identified for participation in the study, in one camp. It is unclear why this was the case but, upon discussing with the RAs, it seemed the children were not easily identifiable through the sourcing mechanisms included in the recruitment process (see above and chapter 7, section 7.4.2). However, upon attendance at the interview with his aunt, it became clear that the child that had been identified did not meet the communication inclusion criteria detailed in table 29 and was therefore excluded from the study. Their demographic details are therefore not represented in appendix 21.

Arrangements were made for the FGDs and interviews in each location, according to the clearance granted by the Government for me to enter the camps at specific times. The primary qualitative data were constructed in the same sequence in each of the three assigned camps (A, B, C) between April-May 2018.

6.9.2 Data construction and analysis processes

As no children who were initially identified for potential participation fully met the inclusion criteria, no children's interviews could be carried out. Participants meeting inclusion criteria were asked to attend the relevant FGD/interview according to their stakeholder group (1: educators; 2: implementing organisations; 3: carers, 4: Refugee Disability Committee) to ensure the conversation was relevant to their experiences and that they would feel comfortable talking either individually or with each other. The FGDs and interviews were held in locations chosen to be familiar, neutral, and to offer as much privacy as possible. This was usually the UNHCR camp-based office buildings or the community centre. All discussions took place on normal working days.

Procedures for conducting the FGDs and interviews, data storage and management, and procedures for data analysis, are described in chapter 5, part C.

6.10 Results

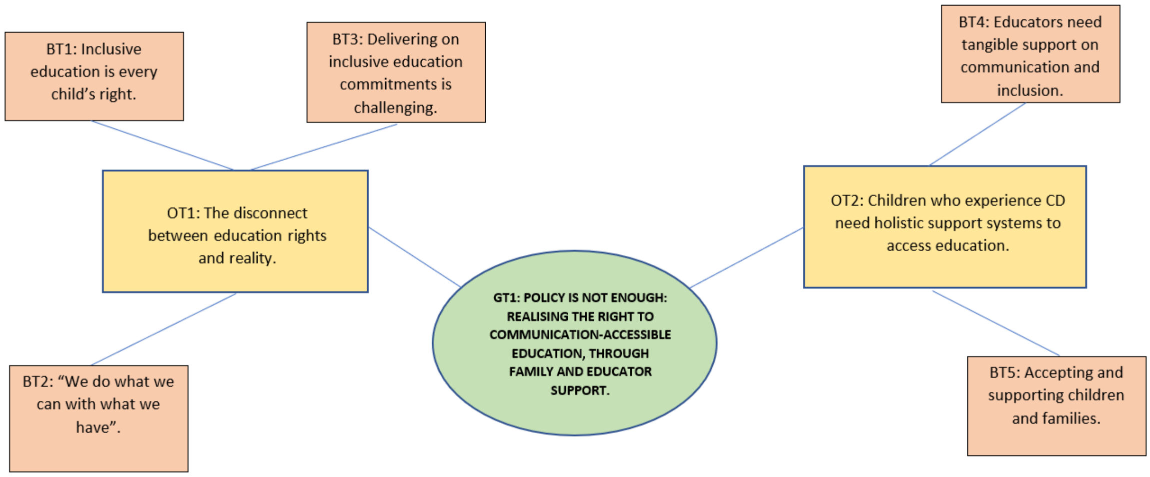
Following analysis of the FGD and interview data by stakeholder group, a series of codes and basic, organising, and global themes were generated. These are illustrated in figures 26-29 throughout, and listed in appendix 22, by stakeholder.

6.10.1 Stakeholder group 1: Educators

Data from each camp (A, B, C) were coded, transcript by transcript (the same process was employed for all groups), resulting in forty-five codes being constructed from the data sub-set.

As the analysis progressed, these codes facilitated the construction of five basic themes, two organising themes, and one global theme. The themes are represented as a visual thematic network (figure 26) to aid further analysis. A full table of codes and themes can be found in appendix 22.

Figure 26: Thematic network – group 1 (educators)



Group 1, global theme 1 (G1-GT1): Policy is not enough: realising the right to communication-accessible education, through family and educator support.

This theme represents the stories of educators as related to their experiences and understandings of the realities of implementing inclusive education policy in the context of extremely limited resources, lack of knowledge and skills, and prevailing negative attitudes and behaviours towards children with impairments. Their belief in the transformative power of education for all children is dampened by the lack of support that they, families, and children, receive to enable effective implementation of policy to fulfil a basic human right to education, upon which the realisation of other human rights depend. Indeed, educators believe that, with the right knowledge, skills, and resources, they could be instigators of societal change – creating shifts in attitudes and behaviours, supporting social cohesion, and ensuring every child has the chance to achieve their potential.

Group 1, organising theme 1 (G1-OT1): The disconnect between education rights and reality.

Incorporating basic themes:

- *BT1: Inclusive education is every child's right.*
- *BT2: "We do what we can with what we have".*
- *BT3: Delivering on inclusive education commitments, for children who experience CD, is challenging.*

Participants believe that children, undoubtedly, have the right to an education. A huge focus on enrolment of refugee children in school, including children who experience disability, has resulted in most children in the camps attending school at some point. Educators in the camps believe in the transformative power of education for all children and are ready and willing to accept children with different learning support needs in their classrooms:

> *A2JI1: "Children need to come in the school to have a basic knowledge about numeracy, about literacy, about lifelong… their*

> *life. And they need to have some discipline that help them to be integrated into society. They need to have some knowledge about health care in order to include their mind on their rights. They cannot know the rights of humans, the basic human rights, when they cannot come in the class. That is the reason why we have to help that children to come in the class in order to be integrated in the life of their country."*

They see Rwanda's inclusive education policy as an opportunity for children to maximise their potential and to become agents of change, breaking down societal barriers to inclusion.

> *A2JI1: "Another there is to give a part to those children in society. It's greater because then everyone is open minded on those questions of children who have disability".*

Despite the enthusiasm and support for inclusive education amongst educators, however, their stories also tell of the disconnect between the policy on inclusive education, and the realities of implementation. They, and children who experience CD, face daily obstacles to making the right to education a reality.

Educators are resourceful, and do everything they can with what they have, but feel inadequate in their job because they feel that they lack the knowledge, understanding, skills, teaching support, and material resources, to provide a truly accessible education for all children. They acknowledge that the teaching environment is less than ideal for many, but that the consequences affect some children disproportionately – most notably those who experience increased levels of disability due to the restrictive circumstances. Despite the national education policy on inclusive education, they have received minimal, or no, training or support to enable them to do their job effectively.

> *A2JI1: "When they come though, you have a problem, because you don't feel like you have the skills or resources to meet their*

> *needs. So, as a teacher, what do you feel as a teacher? You need to be able to support those children better".*

Educators describe how children with CI may be able to physically access school, but can experience disabling exclusion from the curriculum, which relies heavily on the ability to use and understand spoken and written language. Training provided thus far is described as focusing on basic sign language instruction for a small number of educators and translates into the desire for more sign language instruction for more staff, in the belief this will help include all children who experience CD. Educators describe how individual communication limitations and lack of educator knowledge and skills on inclusive and accessible communication methods means these children may not progress through the education system – school becomes nothing more than day-care in the absence of the knowledge, understanding and resources to provide a suitable, accessible education.

> *B2I1: "the major problem for us as [ECD] caregivers, when the child [experiencing CD] is looking at you, when you are before other children, they do not know what you are doing"*

This raises questions as to the dignity afforded to older children and young people, who find themselves trapped within, and failed by, the education system.

> *B2I1: "She has seventeen, - she's more than being in P3. We just keep her but she's not learning at all. We just keep her in school just to keep her to going somewhere, to help her to be cleaned." (NB: Children in P3 are generally eight/nine years old).*

Children with intellectual impairments, or multiple impairments, are reported to face numerous barriers to education. Although Rwandan education policy is 'inclusive' for 'all children', this appears to only extend so far: educators tell of children who are considered too difficult/ineducable by their families and/or service providers and are excluded and remain at home.

> *B2I1: "In inclusive education there are some cases which are not studying in the school for example, a child with impairment, mental disability, intellectual impairment, those children are not here. They are still being there in the camp."*

<u>Group 1, organising theme 2 (G1-OT2): Children who experience CD need holistic support systems to access education.</u>

Incorporating basic themes:

- *G1-BT4: Educators need tangible support on communication and inclusion.*
- *G1-BT5: Accepting and supporting children and families.*

Support for inclusive policy is strong amongst educators, but their stories tell of more holistic support needs for children who experience CD and their families, if inclusive policy is to be effective. They are acutely aware of their own professional support needs in relation to communication, to ensure they can provide an accessible curriculum. They also advocate for training to begin with ECD caregivers, to ensure early intervention and mitigation of future disabling sequelae of inaction.

> *C2I1: "It would be better if all teachers can benefit from training on communication – especially ECD teachers as it's the entry point for the child when the child is changing a lot. It's when they are starting to establish friendships and new social events".*

In addition, policy cannot be enacted in the absence of physical and human resources to support implementation. Class sizes are large, materials are limited, and access to specialist support, including assistive devices and training on their use, inadequate.

Educators also understand that education is not purely about academic achievement, and that social interaction is crucial to child development. Despite this, they see fear, shame, and isolation amongst children who experience CD in class, and feel ill-equipped to deal with these emotions and experiences through communication barriers.

> *A2JI1: "They have many fear to communicate with others. As a teacher it is very, very difficult. They have many fear."*
>
> *A2JI1: "Loneliness is many challenges we observe on those children because when it means the person needs to communicate it become they are going to be alone."*

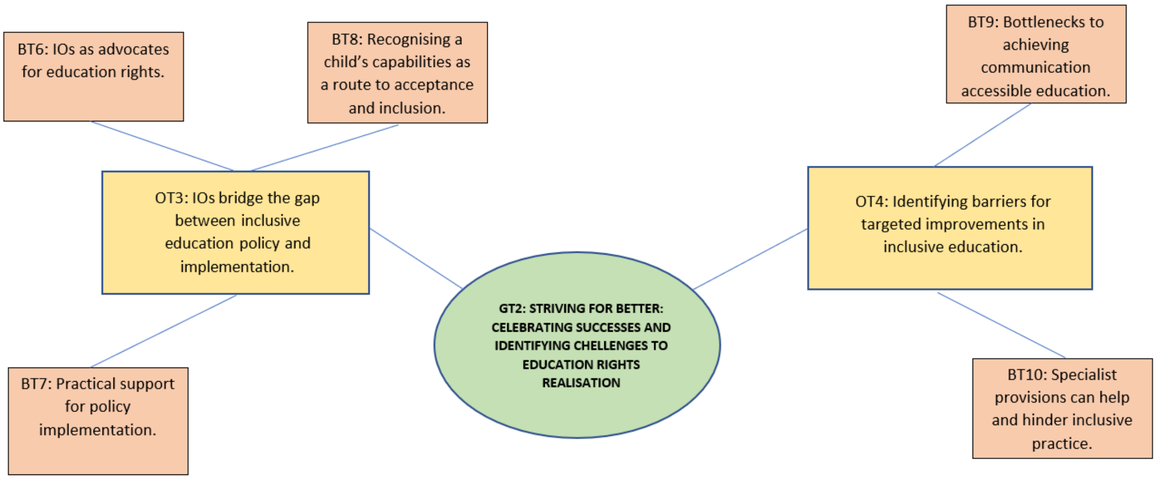
Educators feel they play a role in bridging the gap between home and school, encouraging attendance, and motivating and supporting families. Sensitisation is considered important for families and fellow students, to ensure each child feels accepted and can thrive within their environment. Presence and acceptance from other children are thought to be excellent starting points for inclusion to begin to take place in the classroom.

> *C2I1: "At first sight the children were so surprised to see a child in that condition but I explained to them that's its normal and after some days they started to include the child in school."*

6.10.2 Stakeholder group 2: Implementing organisations

Twenty-six codes were constructed from this data sub-set. As the analysis progressed, these codes facilitated the generation of five basic themes, two organising themes, and one global theme. The themes are represented as a visual thematic network (figure 27). Full codes and themes are detailed in appendix 22.

Figure 27: Thematic network - group 2 (implementing organisations)



Group 2, global theme 2 (G2-GT2): Striving for better: celebrating successes and identifying challenges to education rights realisation.

This theme represents implementing organisation (IO) staff members' experiences and understandings of progression towards achieving inclusive ECD and education in Rwanda's refugee camps. IO staff see their role as offering practical support to bridge the gap between policy and practice and as advocates for child rights, focusing on children's strengths and capabilities. Whilst acknowledging that there is some way to go to achieve effective inclusive education for all children, IO staff celebrate what has been achieved in recent years, since Rwanda introduced their inclusive education policy and applied it to refugee children. They identify the ongoing challenges that need to be addressed to achieve EFA and, with acknowledgement of resource constraints in context, envisage doing so by building upon their achievements so far, for example, in offering sign language instruction.

In contrast to their mandate to provide inclusive community-based education, IOs also appear to take pride in a programme of sponsorship for segregated special education provision in boarding centres and schools, albeit with a vision of future reintegration into community education settings.

Group 2, Organising theme 3 (G2-OT3): IOs bridge the gap between inclusive education policy and implementation.

Incorporating basic themes:

- *G2-BT6: IOs as advocates for education rights.*
- *G2-BT7: Practical support for policy implementation.*
- *G2-BT8: Recognising a child's capabilities as a route to acceptance and inclusion.*

Implementing organisation staff see their role as delivering on rights-based inclusive education policy, as is the law in Rwanda. They are well-versed in inclusive education policy and feel they are the ones to ensure it is enacted within the refugee camps.

> *A2I2: "So here [organisation name] is so much concerned with it, inclusive education, where all the children are given their rights to education, especially those children with disabilities who had been left out previously. Why is it inclusive? Because they have to include those children with disabilities which is the whole system in Rwanda education".*

Implementing organisation staff report feeling responsible for supporting children to enrol in school, and to access education effectively, with appropriate support for their individual learning needs. For children who experience CD, sign language instructors have been hired to support educators and children in the ECD centres and schools. Educators have also been provided with basic sign language instruction through IO programmes. However, there is little awareness that sign language is one approach amongst many and that it may not be a panacea for all children who experience CD, in some cases, potentially perpetuating their exclusion.

> *A2I2: "That's why it has taken a step to get a [sign language] facilitator, especially for children with communication challenges, who is permanently in the school - the primary. Even he helps the teachers of ECD, visit them and arranges sometimes training for them in sign language."*

Much of the support offered to families and educators is reported to focus on sensitisation to overcome disability-related stigma and allow the children to be accepted by others. There is a focus on getting the children into school, wanting to be there, and for other children to accept them.

> *A2I2: "I have told teachers to look at their abilities, forget about the academic thinking that they excel like others. So, I have told the teachers don't worry about the academic side but look at their social ability and then sensitise other children to understand them, work with them and then let them, you teachers observe the ability of those children and just strengthen their ability."*

Social acceptance and enrolment in school are seen as critical precursors for inclusive education to be effective. Related to the idea of 'not focusing on academics', however, is an undercurrent of disbelief that inclusive education can really be of benefit to children who experience CD, and that segregated provisions may be a preferable route for them to achieve academically (see OT-4 below). In fact, there appears to be an understanding that some children who experience CD in mainstream classrooms, may benefit from an alternative pathway through the education system. It is not clear if this is because they are thought to not be capable of achieving in mainstream school because of their own communication limitations, or that mainstream schools are unable to provide accessible education for them to benefit from.

> *A2I2: "These children with communication barriers, you find that some may not go far, even those with physical may not go far, but most of those with communication barriers, so they need vocational skills, life skills."*

IOs therefore claim to support implementation of IE policy through offering practical support to students and educators, whilst potentially being influenced by their own (mis)understandings of (communication) disability, capability, and models of integration, vis-à-vis inclusion.

Group 2, organising theme 4 (G2-OT4): Identifying barriers for targeted improvement in inclusive education.

Incorporating:

- *G2-BT9: Bottlenecks to achieving communication accessible education.*
- *G2-BT10: Specialist provisions can help and hinder inclusive practice.*

Implementing organisation staff are keen to discuss the successes of their programmes to implement inclusive education in the camps, but they are also aware of ongoing barriers to fully achieving their inclusive goals. Identifying these is thought to be crucial if inclusive education access and service provision is to improve in the camps, leaving no child behind. Some of the biggest identifiable barriers centre around a) capacity: knowledge, understanding and skills of educators to implement inclusion in the classroom and b) funds to ensure there are enough educators, that educators are well remunerated and motivated as well as to provide teaching materials and improve ECD centre and school facilities.

> *A2I2: "Some of them they have never known how to work with children with disabilities. They have had some training though not enough follow up."*

In agreement with educators themselves (see group 1 results above) IO staff acknowledge that negative attitudes and behaviours around disability continue to hamper full inclusion but consider that they are already being addressed through ongoing community engagement. IO staff believe that educators, however, continue to struggle to teach children with communication support needs, despite their changing attitudes and the practical support they are being given, as it is insufficient for them to build the skills and confidence to deliver a communication-accessible curriculum effectively.

> *A2I2: "They find that these children in their classrooms are not easy. It is a challenge for them."*

In accordance with national policy (MINEDUC, 2018a), a 'twin track' approach to disability inclusion is reportedly taken in education services in the camps, whereby specialist services, such as provision of assistive devices and (re)habilitation, are provided to support children to access community-based mainstream services. In contradiction, IE service providers also appear to support segregation of some children with certain impairments, such as hearing or intellectual impairment, and seek to find additional funding to support this programme for more children. Far from supporting *all* children to access an appropriate education in their local community, however, and against global guidance and the national vision for IE (MINEDUC, 2018a), segregation for *some* children appears to be considered acceptable, if not preferable.[58] It is unclear whether these children attend (and possibly fail in) mainstream school in the camps before sponsorship can be secured, or not.

> *A2I2: "Right now we are trying to see for a school which can accommodate those children who have difficulty in communication so that they can have those vocational skills and academic, at least they try, but we are still working on that."*

Whilst these practices continue, the goal of rights-based, fully inclusive, community-based education for all children, as per the Incheon Declaration (UNESCO, 2015), and Rwandan Special Needs and Inclusive Education Policy (MINEDUC, 2018a), is far from being achieved. In fact, segregation appears to be celebrated and sought after, and social stigma and discrimination potentially reinforced, by the very organisations charged with challenging their existence.

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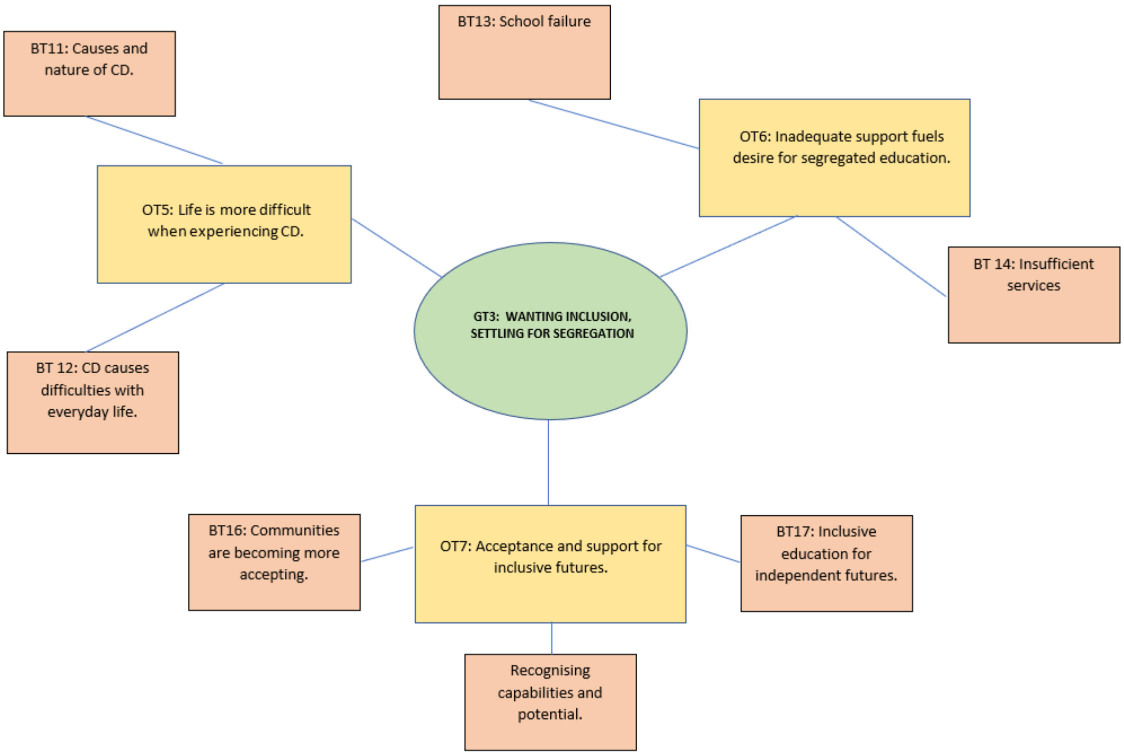
[58] This is not unique to the Rwandan context - segregated education continues to exist across the globe.

6.10.3 Stakeholder group 3: Carers

Data from each camp (A, B, C) were coded, transcript by transcript, resulting in twenty-four codes being constructed from the data sub-set. As the analysis progressed, these codes facilitated the construction of eight basic themes, three organising themes, and one global theme. The themes are represented as visual thematic networks (figure 28) to aid further analysis. A full table of codes and themes can be found in appendix 22.

Figure 28: Thematic network – group 3 (carers)



Group 3, global theme 3 (G3-GT3): Wanting inclusion, settling for segregation.

This theme tells the story of carers' experiences, needs, and wishes for their children's education and futures. Life is reported to be hard for refugee families. Their children with CI experience further disabling stigma, abuse, and rejection despite the small steps being made through community sensitisation to reduce the negative attitudes and behaviours towards people with impairments, contributing to their experience of disability. Implementation of inclusive education policy has meant that most children with CI now attend school in the camps, which carers appreciate. They also, however, feel that physical presence in the classroom is not enough for their children's development and that their children are being failed by an education system that continues to cater for the majority and provides little for those with specific communication access needs.

Carers worry that the inaccessibility of education provided to their children in the camp mainstream classrooms means that their children are not preparing for independent and productive futures within their own communities. Although most participants want their children to be educated with their peers and believe in the short and long-term societal benefits of their children being part of their local community, they feel the current lack of support in local mainstream education means that their child may receive better, more fulfilling, educational experiences in segregated educational settings, often at specialist centres located outside of the camps.

Group 3, organising theme 5 (GT-OT5): Life is more difficult when experiencing CD.

Incorporating basic themes:

- *Causes and nature of CD.*
- *CD causes difficulties in everyday life.*

Carers of children who experience CD told their story of how life is hard for their family and their child. Their experiences frequently begin with not knowing why their child does not communicate clearly – often knowing that their child was sick or had difficulties early on, but without medical diagnosis or support. They are left feeling lost, without knowing where to turn for support.

> *C2JI3: "I was told by the elders that there was something under the tongue and that if she has that thing she can't talk. I took her to the health centre to check but there was nothing and they told me there was no need to seek further assistance – there was nothing more to do."*

Often, their child is misunderstood, resulting in them being treated differently or in ways not appropriate to their abilities and needs.

> *B2I3-2: "People think he's deaf even though he can hear…. Some people do not insist, they just say this one is deaf, let him go. Even though he can hear they don't communicate with him".*

Families and children face challenges across daily life, from engaging in community activities, to accessing services.

> *B2I3-1: "There [are] difficulties, especially when she is sick because she cannot know what she's suffering from and when they reach to the doctor, when the doctor asks her how she is she cannot explain because they cannot communicate but she can cry."*

This can cause frustration on the part of the child and their communication partners, including adults and peers, which may serve to further alienate them from the community.

> *B2I3-2: "He feels frustrated, he gets angry, he wants to beat the person that doesn't understand."*

Despite these challenges, families do their best to communicate with their child using any method available to them. Children are also considered to be resourceful and resilient, persevering to participate and make themselves understood to the best of their abilities, given the resources they have.

> *B2I3-2: "I can say that he uses all. You saw that when he was interacting how he was shaking his head. So sometimes he uses signs* and other times he uses words, but I can say that he tries to use all kinds of communication ways."*
> **The use of the word 'sign' here refers to natural gesture, rather than formal sign language.*

Group 3, organising theme 6 (G3-OT6): Inadequate support fuels desire for segregated education.

Incorporating basic themes:

- *School failure.*
- *Insufficient services.*
- *Negative community experiences.*

Carers describe how they are thankful for their children being able to go to school – that this is an improvement on the previous situation where not all children were able to access a community-based education – but that physically being in the classroom is not enough to help them get on in life and become self-sufficient. Ongoing stigmatisation, targeted abuse, and peer rejection, remain barriers to children wanting to go to school.

> *B2I3-2: "They are laughing at him, they are stigmatising him, that he cannot talk."*

A difference of opinion on the appropriateness and availability of support in schools was evident across the three locations, with carers of children with hearing impairment in camp A more pleased with the basic level of sign-language support available for their children than those in camps B and C, or for those with children for whom sign language is not appropriate. The carers with children for whom sign language is not appropriate bemoan the lack of knowledge, skills, and resources to support their children's communication in other ways. The reported lack of support available to children in the classroom in some locations means that families experience different levels of service provision and access within the refugee population and some schools offer little more than what is described as childcare for some who experience CD.

> *C2JI3: "The teacher says he can't follow the class because he can't talk, he can't hear. They don't have the appropriate*

> *materials to facilitate him. The only thing is for him to remain with students as an occupation, but he can't progress."*

Despite families wanting their children to be included in their local community schools, and to be educated to their full potential, the current lack of capacity to support them appropriately in some locations leaves carers feeling that segregated education may be a better option for their child.

> *B2I3-1: "I think it is difficult for her to get enough education from that school because only one teacher is trained, and that teacher is the one who is also looking after other children. I think he cannot have time for only her so that's why I wish she can be in a school where other children with same problems are."*

Even the specialist disability service providers in the camp seem unaware of how to support children with various communication support needs, beyond offering sign-language training or interpretation services. This leaves families feeling dejected and hopeless.

> *C2JI3: "When you go to Humanity and Inclusion, they are more focusing on other disabilities. There is nowhere else to go."*

Group 3, organising theme 7 (G3-OT7): Acceptance and support for inclusive futures.

Incorporating basic themes:

- *BT-16 Communities are becoming more accepting.*
- *BT-17 Inclusive education for independent futures.*
- *BT-18 Recognising capabilities and potential.*

Carers discussed how they recognise and appreciate the effects of disability-related sensitisation in their community, and that there have been noticeable improvements in attitudes and behaviours amongst some community members. This is not to say that they and their children no longer experience negative reactions (see BT-15), but they recognise that communities are slowly becoming more accepting of people who experience disability and offer more support than in the past.

> *A2G3: "For me with neighbours, because the child is not moving around, when if I left her at home, neighbours are caring for her very well indeed… If the child got any other need they assist because they have accepted our condition and they sympathise."*

Despite this progress, they continue to worry about their child's future when they are no longer around to support them. Carers wish that their child could be effectively included in their local community schools, so that they become equal members of their community with opportunities to reach their potential, become independent, and live a dignified life where they are appreciated for their capabilities and supported by their peers. In this sense, carers' wishes reflect the wider, longer-term, benefits of inclusive education illustrated in data sub-set 1 above.

> *A2G3: "What we wish is that our children learn and get knowledge and skills and be able to compete with others at the market of job where they can be leaders of any agency or other services that be providing service, not asking services."*
>
> *A2G3: "What I need is that my child learns and gets skills in order that they succeed in life because I will not remain with the child forever. When I will be not with her, she will be strong enough to compete in the life for herself."*

Critically, carers recognise that this cannot be achieved by supporting segregated education for groups of children with different learning support needs. Removing children from their peer group early in life means both they and their peers fail to learn to live together, valuing each other's capabilities. This is recognised amongst carers to potentially lead to unequal, unjust future societies, fostering negative attitudes and behaviours such as perceptions of alterity, and perpetuating exclusion.

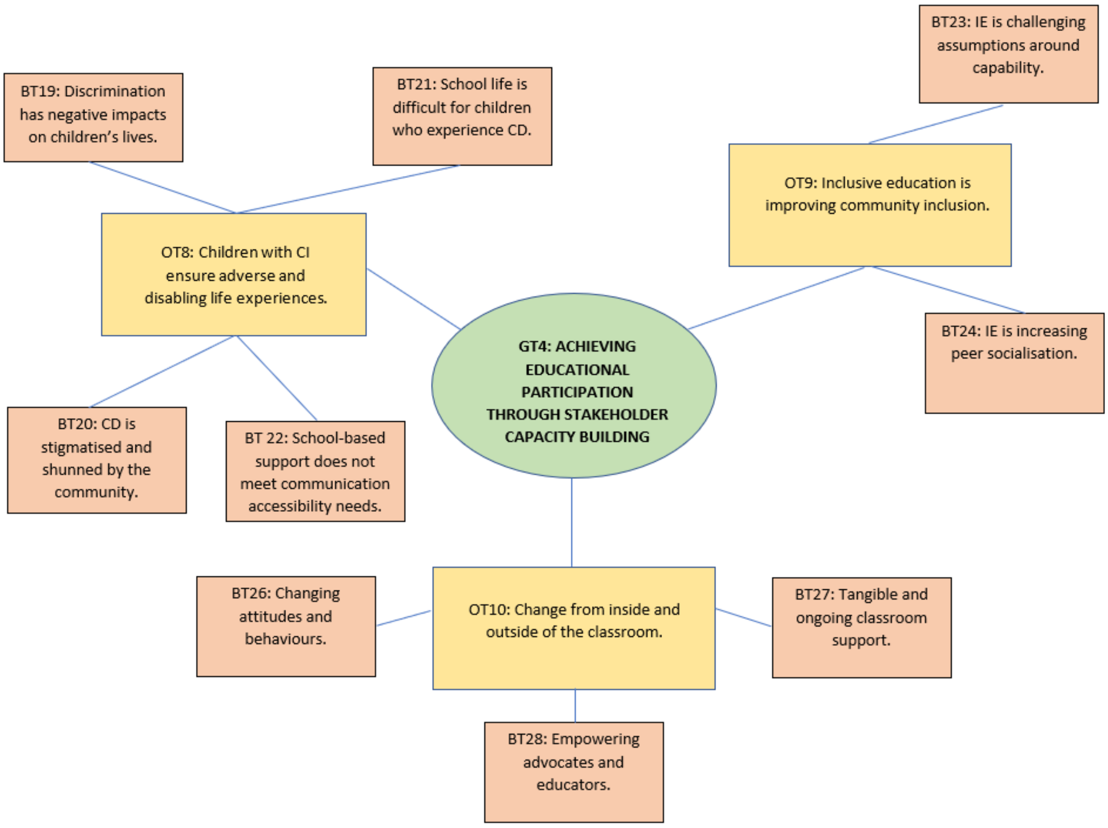
> *A2G3: "Support is needed when they are in the same community because if you take them to a specialised centre it means they would lose the part of living with other community and the community will lose how to live with this community then when they come close then it will not be easy for them to work and cooperate and socialise."*

Despite these insights, the limited capacity of the current refugee education system to deliver on inclusion means carers are forced to consider segregated education as the better of two poor options.

6.10.4 Stakeholder group 4: Refugee Disability Committee (RDC)

Data from each camp (A, B, C – total 17 participants) were coded, transcript by transcript, resulting in twenty-five codes being constructed from the data set. This facilitated the construction of nine basic themes, three organising themes, and one global theme. The themes are represented as a visual thematic network (figure 29). A full table of codes and themes can be found in appendix 22.

Figure 29: Thematic network – group 4 (refugee disability committee)



Group 4, global theme 4 (G4-GT4): Achieving educational participation through stakeholder capacity building.

This theme tells the story of the positive spiral of benefits created by community-based inclusive education for refugee children who experience CD. The RDC members identify that improving community attitudes and behaviours towards children who experience CD (through community-focused sensitisation and mobilisation campaigns on disability and inclusion more broadly) has allowed children to enrol in and attend mainstream schools with their peers. This has led to further positive impacts upon the attitudes and behaviours of peers, educators, family members and the community towards children who, because of being included in mainstream school, are newly perceived as capable and sociable. Peer fear is reduced and the children with CI gain dignity, reducing their disabling experiences. This contrasts with previous perceptions of children with CI being 'useless' before attending school.

Although negative attitudes and behaviours persist, they are understood to be changing slowly. This is balanced against the acknowledgement that, once in the classroom, children with CI experience disabling exclusion from teaching and learning as they struggle to access the curriculum effectively. Educators are severely resource-constrained and lack adequate knowledge and skills to include children successfully. This can lead to reduced participation, academic stagnation (lack of progress through grades), and lack of motivation to attend (both the child's motivation to attend and family's motivation to send the child to school). The physical presence of the children in schools, however, contributes to service providers raising these issues with service planners and increasing demands for better training and resource allocation.

Improving attitudes and behaviours towards children with CI, who experience CD, therefore, is considered necessary but not sufficient to reduce disabling experiences and for successful inclusion for rights realisation, full societal participation, and the development of future inclusive societies. Capacity building in terms of knowledge, understanding, skills, and improved resource allocation, are all necessary to effect change towards true educational participation and realisation of children's rights.

Group 4, organising theme 8 (G4-OT8): Children with communication impairment endure adverse and disabling life experiences.

Incorporating basic themes:

- *BT-19 Discrimination has negative impacts on children's lives.*
- *BT-20 CD is stigmatised and shunned by the community.*
- *BT-21 School life is difficult for children who experience CD.*

The RDC discussed how refugee children with CIs in Rwanda face individual, social, and environmental, barriers to inclusion and participation, that contribute to them experiencing disability. This often begins within the home since family members belong to a culture where impairment and disability are highly stigmatised. The household members can also be stigmatised because of a family members impairment(s), causing an experience of household-wide ‘disability by proxy’.

> *A2G4: “Some communities view the family as a family who maybe before went for witchcrafts…. They hide them because they feel they are unfortunate to have those children.”*

Cultural understandings of disability means that some families believe their child is ‘useless’. Furthermore, a long history of discrimination and exclusion impacts upon the children’s desire and ability to benefit from the educational opportunities made available to them by the current inclusive education policy.

> *A2G4: “Because in [our country] they were not facilitated to go to school because of the culture stigma so they come when they're old and they start at the low level and also they study with people with the different ages with them and it is a challenge also.”*

The children’s lives as refugees are made harder still by intersecting factors, such as their disability status, that increase their exposure to both passive and active mistreatment and discrimination.

> *A2G4: “In [our] community children also isolate or abuse a child who doesn't ... who has difficulties in communication. Like that one doesn't hear and speak.”*

The negative treatment they receive from the community because of their differences is considered to negatively impact them both inside and outside of the school environment, since peers and teachers are from the same community. School dropout is reported to be common for children who experience CD.

> *A2G4: "The environment at school is not welcome for them because those children are coming from the community, which is from their culture, it's not welcoming to people with communication disability…. They start fearing other children and sometimes drop out from school because they find it is not a social life."*

The lack of capacity (in terms of knowledge, skills, physical, and human resources) available in schools further hinders access to the curriculum.

> *A4G4: "Due to sensitisation initiative from education department and Handicap [International] and the community leaders many children are now going to school, but the challenge is still there because there is no facilitation for them to communicate with others."*

These negative attitudes and behaviours inside and outside the classroom, coupled with lack of capacity to facilitate communication accessible education, create avoidable communication-related disability that is experienced across the child's home, social and educational life.

<u>Group 4, organising theme 9 (G4-OT9): Inclusive education is contributing to attitudinal and behavioural change.</u>

Incorporating basic themes:

- *BT-23 IE is challenging assumptions around capability.*
- *BT-24 IE is increasing peer socialisation.*

The RDC reported that families, communities, and educators are starting to notice changes in people's attitudes and behaviours towards children with CI when they attend mainstream school in their own community, gradually reducing some aspects of CD. Not only are they thought to see improvements in the child's knowledge and skills, but the RDC members attribute a change in attitude towards children's 'social value' to a newly formed perception of their capabilities because they are in school. Being included in school brings with it a community understanding that the child has potential and can *"be more" (A2G4)*, in contrast to the belief that, before attending school, they were 'useless' and unworthy of educational investment (see quote below). The social benefits of being included in friendships and peer groups is also appreciated, and considered to contribute to new, more positive, family and community attitudes and behaviours.

> *A2G4: "So there is a difference between before going and now. There is a positive. Even the parents become happy and they start value the kid because there is improvement."*
>
> *A2G4: "Before in [our country], before he have a kid who doesn't, who is useless who can't do anything, but when he came here and the kid went to school he's now finding that he is now doing the activity others do yet he doesn't know how to speak, but he can play with the other children."*

Group 4, organising theme 10 (GT-OT10): Change from inside and outside of the classroom.

Incorporating basic themes:

- *BT-26 Changing attitudes and behaviours.*
- *BT-27 Tangible and ongoing classroom support.*
- *BT-28 Empowering advocates and educators.*

The RDC members discussed their belief that the existence of inclusive education policy alone is not enough to ensure all children access an appropriate education. They recognise that the social environment inside and outside of school affects how successful the implementation of inclusive education can be, as much as the physical and human resources available. As key members of their community, with the responsibility for advocating for people who experience disability and their families, they understand that communities consist of families, peers, educators, and other service providers - both advocates and discriminators - who all need to understand CD better to facilitate attitudinal and behavioural change towards acceptance, participation, and rights realisation.

> *A2G4: "They need to be taught that those children it's normal and any person can have it because people, refugees here, come from different part of [country], even the cultural values or perceptions are different, so they need to be sensitised enough so that they can understand that the person with a communication disability is a child, like others."*

> *A2G4: "They need skills, teachers need skills. Sometimes they train people with disability but also other children and the community which associate with them need to have that skill so that they can communicate - families, children."*

In tandem, it is important that educators are supported to facilitate communication accessible education, through training and provision of tangible resources such as classroom support. RDC members consider provision of learning support assistants (LSAs) an important and feasible strategy to ensure children who need additional support in class are afforded the time and attention they require to succeed, instead of being left behind and experiencing the exclusion and failure that leads to demotivation and school dropout.

> *A2G4: "I support the idea of a support teacher or if the school can have teaching aids which can be helpful for people with communication disability. There is an alternative way where the teacher can be one, and then he [the other] can teach alternatively … If the teacher is empowered, they can know how they can."*

6.10.5 Supra-global themes

As described in chapter 5, section 5.16.5, I combined data from each camp by stakeholder group, resulting in four sets of data for analysis (G1-G4).

Following analysis of each of the four data sub-sets (i.e., by stakeholder group), I then combined the global themes and further analysed the results together. From this analysis I constructed one supra-global theme (SGT1) that portrays the stories of all stakeholders (educators, implementing organisations, carers, RDC) across the three research locations (camps A, B, C) (table 32).

Table 32: Phase 2, study 2: FGD and interview supra-global themes.

Global themes	Supra-global theme
GT-1 Policy is not enough: realising the right to communication-accessible education, through family and educator support	SGT-1 THE CHILD AT THE CENTRE: INCREASING SOCIAL AND ENVIRONMENTAL SUPPORT TO ENSURE INCLUSIVE EDUCATION RIGHTS REALISATION
GT-2 Striving for better: celebrating successes and identifying challenges to education rights realisation	
GT-3 Wanting inclusion, settling for segregation	
GT-4 Achieving educational participation through stakeholder capacity building	

Supra-global theme 1 (SGT-1): The child at the centre: increasing social and environmental support to ensure inclusive education rights realisation.

This supra-global theme represents an interpretation of the stories told by stakeholders involved in educational decision-making affecting refugee children who experience CD. Stakeholders, including carers, identify an implementation gap between inclusive education policy and the disablement that refugee children with CI continue to experience within refugee education services. Although stakeholders recognise and appreciate the great strides that have been made in enrolling children who experience CD in mainstream schools in the camps, as well as the slow but meaningful progress being made in attitudinal and behavioural change more broadly, they also feel that IE policy has been implemented in the absence of a supportive social environment within schools. Furthermore, they feel that the capacity and resources required to deliver accessible and appropriate education are sorely lacking. This has resulted in tokenistic provision of ‘day care’ services in many instances, with carers continuing to worry about their children’s life chances and futures. IE rhetoric has led carers and educators to consider segregated special education as a preferable option – an idea supported by the implementing organisations tasked with providing the support required to make inclusive, community-based, inclusion a success.

Disheartening though it may be, identifying the challenges to operationalising inclusive education policy is a vital stage in progression towards inclusive participation for children who experience CD - a step that should facilitate a move towards more inclusive future societies in which those children can thrive. This requires placing the child at the centre of all considerations and ensuring that the people and places that surround them offer safe and accessible support. The most influential factors affecting participation in education for children who experience CD are considered to centre around a) community understanding of, and attitudes and behaviours towards, refugee children who experience CD and b) school-based capacity and resources. Having identified the key barriers and bottlenecks[59] to inclusion, it remains for service providers to address them systematically by involving service users (including families) and educators in the planning and delivery of solutions.

Although tackling pervasive negative attitudes and behaviours appears to be of primary importance to stakeholders, they do recognise that tackling this challenge in isolation would potentially exacerbate the problem of increased enrolment rates in the absence of educator skills and resources to facilitate access to learning, perpetuating issues of educational stagnation and lack of progression through the education system. It is therefore critical to identify and plan to address all identified challenges to ensure successful implementation of inclusive education policy and educational rights realisation for all children.

6.11 Implications of the findings from the FGDs and interviews

Analysis and interpretation of data from across the four stakeholder groups from three camps, tells the story of an ambitious, rights based, inclusive education policy that is struggling to be actualised for refugee children with CI in Rwanda, thereby contributing to children's disablement. Opinions and understanding of the situation vary across stakeholders, but with an overall perception that there is slow, but steady, progress towards educational inclusion, with some barriers that prevent progress, and bottlenecks that slow progress, towards inclusion.

A bottleneck to progress occurs around the cultural understandings, attitudes, and behaviours, of communities (including service planners, implementing organisation staff, educators, families, and peers) towards people with impairments, who experience disability, which, although are slowly changing, are deeply rooted in fear and misunderstanding. An identified barrier to inclusion is a lack of educator capacity, including knowledge and skills as well physical and human resources allocated to schools to deliver on IE, which contributes to a perceived lack of educational 'achievement' and exacerbates the belief that children with CI cannot achieve and progress within in a mainstream school. Stakeholders approach this from two angles: a) schools cannot offer adequate support to the child; and b) children cannot cope in a mainstream environment. One places the child 'at fault' and demonstrates a medical understanding of disability - the child must change to fit the system. The other demonstrates a more progressive, social, and rights-based understanding of disability – the system must change to accommodate the child. Both, however, contribute to the perception amongst some stakeholders that children with CI are better served in segregated educational settings, often delivered at a distance from the camps. This is supported by the very organisations tasked with implementing inclusive education policy, legitimising family, and community perceptions that segregation may be better for the child.

Not all stakeholders believe this and hold a more progressive understanding of the transformative power of education. Some carers envisage a future where their child can live a fulfilled and independent life, valued for their capabilities, and some believe that inclusive education in their own community is the only way to deliver on this vision. Carers and the RDC see a way forward through the provision of LSAs in class to give children with communication needs the additional support they require to access the curriculum effectively.

PART C

PHASE 2, DATA SET 3

CLASSROOM OBSERVATIONS

6.12 Introduction

This section reports on the content analysis of classroom observation data gathered from three research locations, to contribute to the achievement of objective O2a.

I report on data generation, data analysis, and results, and end with a discussion of findings.

6.13 Data construction procedure

One classroom in each study location was identified and targeted for direct observation by the RAs according to the teaching timetable during the research window in each camp and the availability of educators. The RA in each location sought consent from the education implementing organisation, headteachers, and the educators, for me to attend a class in session and to observe the environment as well as the teaching and learning happening. Each educator involved in the observations had already been approached to be a participant in an interview or FGD, and had consented to do so, so was familiar with the purpose of the study, had given consent to participate, and understood about ongoing consent and withdrawal.

Ensuring assent from children within the classroom was discussed with the head teacher prior to visiting the classrooms and an agreement made that if any child made it known that they did not want to continue with the observation, that it would be closed. The visit was monitored by the RA and children were introduced to us upon our arrival and given an age-appropriate explanation of why we were there by the teacher. The RA observed whether any child appeared uncomfortable with our presence or looked like they wanted to withdraw. Quite the opposite occurred, with children appearing excited to have us visit their class. This was demonstrated by the children's enthusiasm during our welcome.

Observations took place during the phase 2 visit to each study location when the educator FGDs/interviews were held. Each educator knew when the observation would take place, so there was therefore potential for them to 'prepare' for the visit (e.g., gathering resources, planning a special lesson, ensuring focus on children with CI etc.) Being familiar with classrooms in Rwanda generally, and in the refugee camps through my wider work, I was relatively confident that I would be able to detect this, should it occur. If educators did prepare for the visit, it would only demonstrate inclusive ECD/education in practice at its best in context, which would also be of value to the research.

All the targeted implementing organisations and their educators met inclusion criteria (table 33) and gave consent to participate in classroom observations.

Table 33: Inclusion criteria for phase 2, data set 3: Classroom observations.

Inclusion criteria
ECD centre/school delivers ECD/education services to refugee children from study location A, B or C
Consent to observe is granted by the education implementing organisation and educator
Classes are in session during the data collection window in each location
Child(ren) with communication impairment is/are in attendance during the observation

Observations in each camp location were conducted by me, sitting at the back or side of each classroom, with the RA and education IO representative in attendance. Observations lasted 30-45 minutes. Educators introduced us to the class, then started or continued with their usual teaching. The RA or IO representative informed me of which children had a CI. Anonymised notes were made throughout the observation, against broad guiding headings designed to capture information about the learning environment, teaching and learning resources and materials, teaching methods, and inclusion strategies (table 34). However, any information that did not fit within these headings but was considered of relevance was also documented under ‘other’. These notes were typed into digital documents upon completion of the observations. No pictures or audio-visual recordings were taken during the observations.

Table 34: Phase 2, data set 3: observation guide headings.

Observation guide headings
School/ECD centre setup
Children and educators
Classroom setup
Environment
Resources
Educator interactions and style
Child interaction and engagement
Inclusion/exclusion
Other

6.14 Data analysis: methods and process

Data from classroom observations were analysed using conventional content analysis - a technique not unlike other forms of thematic analysis, but often used to *“describe a phenomenon”* (Hsieh and Shannon, 2005: 1279) rather than aiming to be interpretive. This was more suitable for analysis of written observation notes describing environments and activities than, for example, reflexive TA which is more useful for interpreting patterns and developing theory (see chapter 5, section 5.15). Electronic copies of observation notes from each session were uploaded into computer assisted data analysis software (CAQDAS) NVivo12 to facilitate the analysis. Observation guidance headings were not used to direct the analysis, to avoid assumptions being made in advance of the analysis and to allow categories to *“flow from the data”* (Hsieh and Shannon, 2005: 1279) inductively, although it was anticipated that the resulting codes would, in part, reflect the guiding headings under which data were constructed, but with additional details potentially being identified. As the data were not constructed from participants directly, the analysis aimed to be mainly descriptive, but with the potential to be used in wider integration of data during the integration stage of phase 2.

6.15 Results

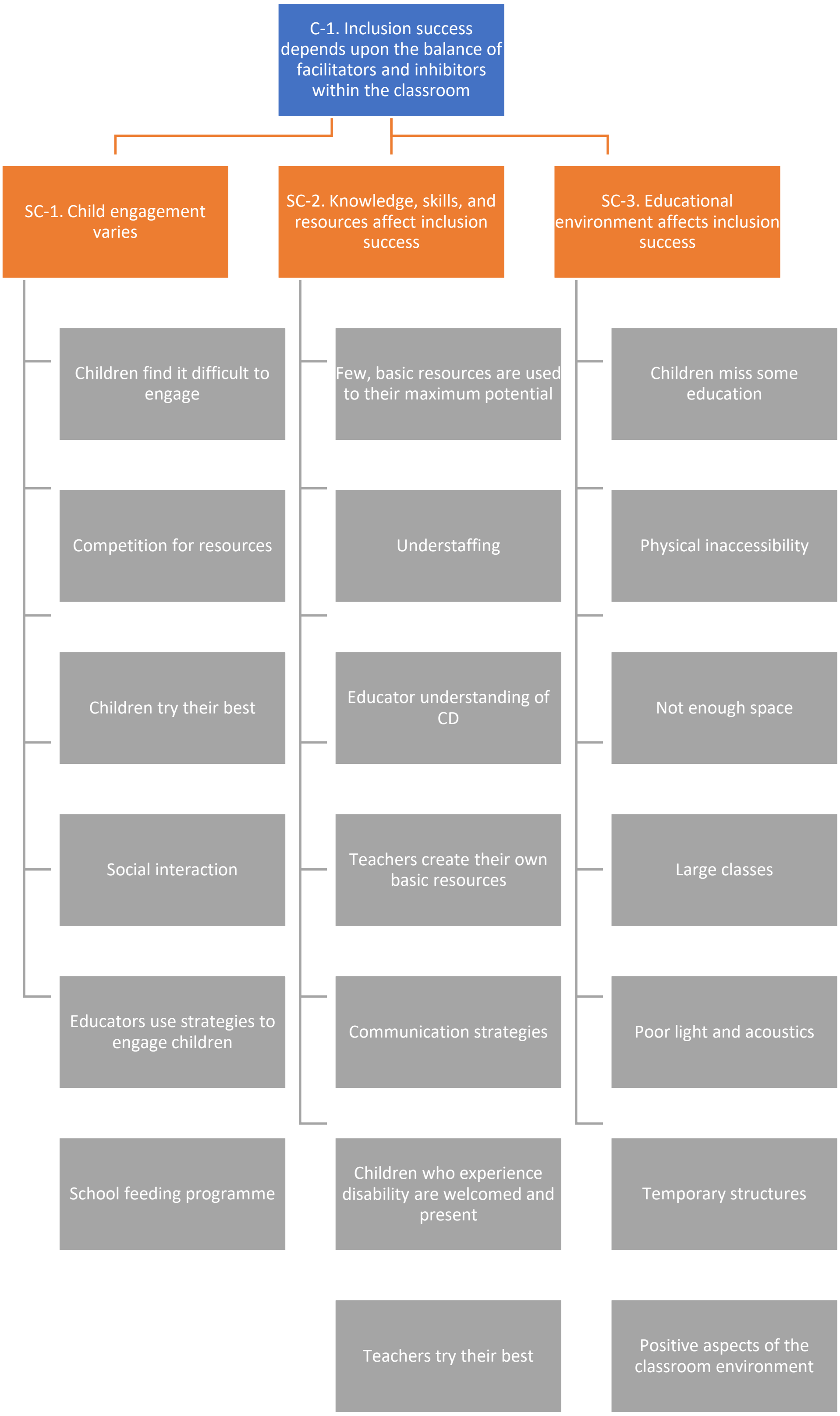
Each class observed was attended by between forty to sixty-nine children, aged between five and nine years old (see table 35). The gender balance was almost equal in all cases.

Table 35: Classroom information by research location

Class information	Camp A	Camp B	Camp C
Age of children in class	5-6 years old	5-6 years old	8-9 years old
Education stage	ECD	ECD	Primary
Number of children in class	69	40	~40
Number of teachers/ assistants	2	1	1
Camp-based/ host community integrated	Camp-based	Camp-based	Host community

Following analysis of the observation data by research location, a series of twenty codes, three sub-categories and one category were constructed. The results are displayed in a category hierarchy (Hsieh and Shannon, 2005) in figure 30 below, as well as a table in appendix 23.

Figure 30: Phase 2, study 3: Classroom observation content analysis results



Category 1 (C-1): Inclusion success depends upon the balance of facilitators and inhibitors within the classroom.

This category summarises information, gathered from classroom observations, on the reality of inclusive practice on the ground in the three study locations. The three classrooms observed highlighted both the facilitatory and inhibitory potential of the physical environment, educator knowledge and skill, and resource availability (including human resources), on inclusion of children with CI. The classrooms featuring smaller class sizes, better lighting, and acoustics, and engaging, resourceful educators, appeared to be more conducive to successful inclusion, thereby minimising disablement. In contrast, the noisier, overcrowded, and understaffed, classes struggled to demonstrate effective inclusion during the sessions observed, thereby potentially contributing to exclusion, and disablement of the children with CI. Observed facilitators to inclusion illustrated how simple improvements can contribute significantly to reducing disability and driving progress towards successful inclusive education and rights realisation. It is noted, however, that the observations were only made in one classroom per research location, that they were short, one-off events giving only a snapshot of life in the classroom, and that only one of the classrooms was in a host-community school. Findings should be considered with these limitations in mind.

Sub-category 1 (SC-1): Child engagement varies.

The three classrooms observed were very different: one was an emergency, temporary, tented structure, one an older permanent structure in poor condition, and the other a newer permanent structure in relatively good condition, but with the class observed taught outside due to the limited space to accommodate all students indoors. Each had unique physical attributes, resources, and educator capacity, and there was a noticeable difference in the levels of child engagement between the three.

In all classrooms, the children with CI appeared welcome. In some locations the educators were engaging and involved all children in the learning activities as best they could, using the limited resources available to their maximum potential.

> *B2EO: 'Although limited in teaching resources, he used the children themselves in the teaching process and managed to engage all of the children.'*

> *C2EO: 'The teacher used everything at her disposal to engage the children - an established routine that the children were familiar with, songs, clapping, individual chalk boards, and the chalk board at the front of the class.'*

Despite children with CI being present in each class, the capacity to engage and include those children also varied, and appeared to be influenced by the environment, educator skill, and resource (material and human) availability.

> *A2EO: 'She [child with CI] eventually walked out of the classroom, but no-one was available to follow her and bring her back. She returned when it was time for porridge when she knew the routine to stand in line.'*

Sub-category 2 (SC-2): Knowledge, skills, and resources affect inclusion success.

Educational resource availability in all locations was limited, and educational materials were often in poor condition, sometimes hand-made by teachers and/or shared between multiple classes. Children were eager to use the resources, which caused some disruption when only a few could do so at any one time.

> *A2EO: 'Whenever the teacher gave resources to the group, there was a scramble for each child to get hold of one so that, rather than doing the counting activity together, they fought over who got a brick.'*

One educator used a multitude of augmentative and accessible communication strategies within his lesson, directed at all children and not just the child with CI in his class, although he paid additional attention to her to ensure she was following the lesson.

> *B2EO: 'He used engaging voice, movement, facial expression, and signs, plus repetition, to engage the children. He pointed to the picture, said the word, wrote it on the blackboard, and signed.'*
>
> *B2EO: 'He engaged her individually, repeating the vocabulary with signs in her eye-line.'*

These low-resource strategies to ensure all children were engaged and learning, in a way that was accessible to each of them, demonstrated not only the willingness to welcome children with communication support needs into class but also to include them as much as possible despite limited resources and training (verified during educator interviews in phase 2, data set 2 – see this chapter, part B).

Sub-category 3 (SC-3): Educational environment affects inclusion success.

Classrooms in temporary or poor condition suffered from poor lighting, poor acoustics, overcrowding, and dusty environments.

> *A2EO: 'The classrooms are next to each other, separated by a plastic sheet wall.'*
>
> *C2EO: 'The small windows were open but the light coming through so dim that it was difficult to see the small chalk board in each child's hand, as well as the one at the front of the class.'*

The outdoor classroom in camp B, although a more pleasant environment overall, also suffered noise pollution and poor acoustics, along with weather-related restrictions on usage.

> *B2EO: ‘There are classrooms, but not enough for all the children so some learn outside. This is a problem in the rainy season when the classes sometimes have to share the rooms and are overcrowded.’*

The environment in all three of the classrooms appeared to have negative impacts upon child engagement and learning, to varying degrees. Less successful inclusion appeared possible in the emergency context with temporary structures, overcrowding, and understaffing, although the educators tried their best no less than those teaching in more conducive environments. This impacted all children but appeared to have a disproportionate effect upon the children with CI who, for example in camp A, struggled to engage at all despite teacher efforts to encourage the child to join in activities with other children.

6.16 Data set 3 limitations.

Limitations related to this data set are discussed in chapter 7, section 7.4.2.

6.17 Implications of the findings from the classroom observations

Classroom observations enabled me to experience some of the stakeholder perspectives discussed in FGDs and interviews (data set 2, this chapter, part B), first hand. It gave me a deeper understanding of some of the successes and challenges educators experience in delivering inclusive ECD/education, and those that the children with CIs face as consumers of community based inclusive education.

Changes to national education policy in favour of inclusive practice appear to have resulted in the successful identification and enrolment of some children with CI (although it is not clear how many still do not attend school, or how many children attended before inclusive education policy became applicable to refuge children in Rwanda) and other impairments. These children are now encouraged to attend school, which is potentially contributing positively to peer education on impairment and disability, understanding, and experiences of the value of diversity. Barriers to successful inclusion in the classroom appear to occur around classroom environment, educator knowledge and skill on inclusive practice, as well as resources (both material and human), to facilitate inclusion. This means inclusive education provision for refugee children has reached an impasse where children are in the system but have little opportunity for progression.

Counterbalancing these barriers are glimmers of hope: In the classrooms observed there is some evidence of better classroom environments being created as camps move from emergency response to post-emergency (e.g., camp A) and protracted contexts with a greater focus on longer term 'development' agendas; teachers receiving some basic support on inclusive practice (as reported in data set 2 above); and children accepting their peers with CI into their classrooms and friendship groups. Overall success of current inclusion efforts, therefore, appears to depend upon the balance of facilitators and inhibitors present in each classroom. Some are making strides towards children realising their right to a community-based inclusive education, whilst others are practising integration, with some way to go before inclusion and participation can take effect.

PART D

PHASE 2

DATA INTEGRATION, DISCUSSION AND CONCLUSION

6.18 Phase 2 data integration and discussion

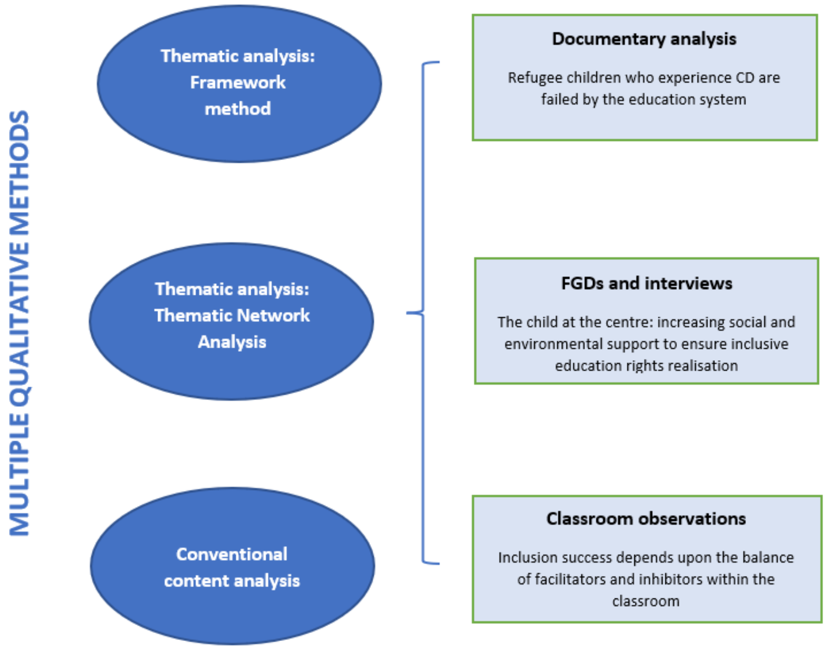
The aim of phase two of the research (A2) was *‘to map the opportunities and barriers to accessing appropriate inclusive ECD and education services, for refugee children with communication impairments, who experience communication disability, in Rwanda.*

Conducting multiple method, qualitative, research across three data sets facilitated the construction and analysis of data from policy, operational, and experiential perspectives (figure 31). This provided a holistic view of the issues affecting education provision, and experiences of educational services, from the perspectives of a wide range of stakeholders involved in the care, protection, and promotion of refugee children with CIs, who experience CD.

These data construction activities were conducted in pursuit of understanding if, and why, refugee children with CI may be excluded from ECD and education services, as suspected by UNHCR (Lange, 2015; UNHCR 2015a), as well as understanding the potential for addressing any challenges to inclusion that exist. The three data sets reported address objectives O2a, 02b and O2c.

The following points respond to these objectives by integrating the data from across the three data sets in this phase of the research using a thematic approach (see chapter 5, section 5.15), interpreting them, and relating them to existing peer-reviewed literature (see chapter 3). I also consider implications and the potential for action.

Figure 31: Phase 2 results overview from data sets 1, 2 and 3



1. **Inclusive education policy is necessary, but not sufficient, to ensure educational rights realisation for refugee children with CI, who experience CD (objectives O2a; O2b; O2c)**

   The document analysis (data set 1) illustrates that the publication of the Incheon Declaration, and its framework for action (UNESCO, 2015), represents a landmark global commitment to inclusive EFA in pursuit of achieving Agenda 2030 (UNGA, 2015a). The declaration sets out a comprehensive set of actions for national governments to implement to achieve educational equity for all, including refugee children, with measurable targets. This was the catalyst for national governments across the globe to review their education policies to make them inclusive of children who, historically, have been marginalised and excluded from the education system due to factors such as gender inequality, (dis)ability, socioeconomic status, forced migration, or any combination of factors – an observation supported by the peer reviewed literature (chapter 3): Karangwa et al, 2010; Njelesani et al, 2018; Sagahutu et al, 2013; Talley and Brintnell, 2015).

In response to Rwanda's commitments to Agenda 2030 and SDG4 (see chapter 2), the country's inclusive education policy was reviewed to ensure it was inclusive of children who experience disability, as well as other marginalised and/or excluded groups (MINEDUC, 2018b). Rwanda's steps towards nationalising global conventions for human rights is well documented in the peer reviewed literature (chapter 3: Karangwa (2014), Karangwa et al (2010), Njelesani et al (2018), and Sagahutu et al (2013)). The response to Agenda 2030 within the humanitarian sector was for the UNHCR in Rwanda to recruit a disability-focused implementing organisation, as well as to ensure the education implementing organisations would be responsible for enacting IE policy (data set 2). Evidence from data sets 2 and 3 illustrates how a huge effort to sensitise communities on disability and stigma reduction, as well mobilisation campaigns for families to send their children to school, has resulted in children who experience disability, including CD, being enrolled in mainstream camp and host-community ECD centres and schools. Authors of the peer reviewed literature (chapter 3), however, caution against this in a context where there is little robust evidence of what works for inclusive education in crisis settings (Miles, 2013).

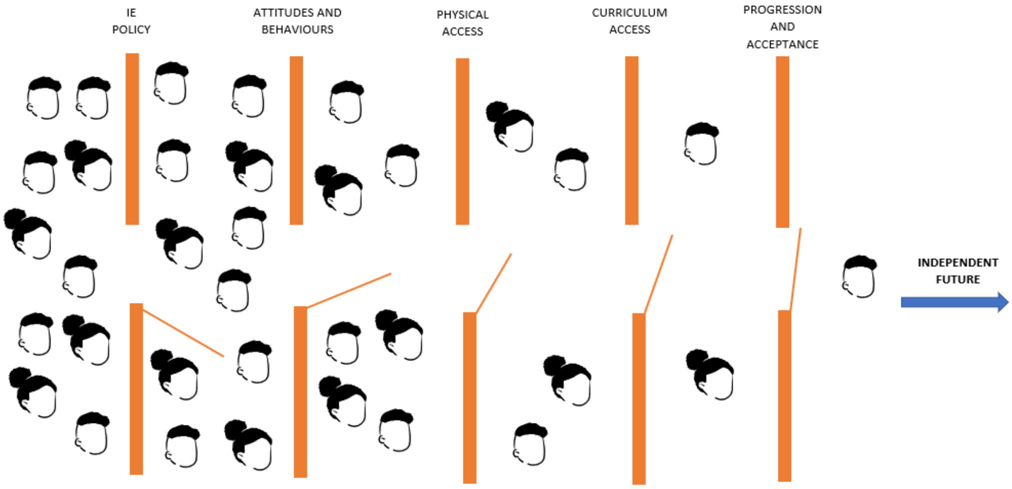
Abundant guidelines and toolkits have been created globally, including in Rwanda (e.g., REB, 2016), to help teachers to operationalise inclusive education in their classrooms. These efforts, however, have not yet produced the envisaged outcomes - children with CI are known to continue to experience disabling exclusion from appropriate, community-based, inclusive, education that enables them to fulfil their potential and take their place in an equal, fair, and just society – a concept supported by Sagahutu et al's (2013) primary research in Rwanda (chapter 3). Quite the opposite has occurred for some children, who are known to experience more stigma and discrimination in school than before they attended and suffer educational alienation and stagnation within a system that struggles to provide the support and flexibility required for them to succeed (data sets 2 and 3).

Data set 2 evidences the increasingly positive attitudes and behaviours of educators towards EFA, although this is contradicted somewhat by the findings of Karangwa (2006) in the literature review (chapter 3), who reports entrenched negative attitudes and behaviours among educators. Despite some positive changes, constraints within the national- and humanitarian-provided ECD and education systems mean that progress towards full inclusion is often severely limited. This was further evidenced during classroom observations (data set 3), where non-conducive learning environments, limited human and material resources, and lack of teacher knowledge and skill, appeared to inhibit inclusion success to varying degrees. Commitment to, and proper resourcing of, inclusive education for refugee children is known to be a critical factor in inclusion success, as evidenced by Alborz et al (2013), Karangwa (2014), Talley and Brintnell (2015) and Krupar (2016) (chapter 3).

The set of circumstances described demonstrates how linear thinking on education reform has resulted in singular change - altering one part of the education system (in this case, education policy), in the absence of adequate planning and resource allocation for successful implementation, has resulted in the physical presence of children with CI in class, but who continue to experience disabling exclusion ‘from within’ (findings supported by Kearney, 2011 and evidenced in data sets 1, 2 and 3). A change in policy, whilst raising awareness of the right to inclusive education for all, has arguably masked educational exclusion in mainstream facilities, through relatively successful enrolment and integration (Karangwa, 2014). Children must then, however, navigate through a series of filters that become progressively more difficult to pass through. It appears that one wide open door (IE policy) leads to a series of increasingly narrow ones (attitudes and behaviours, physical access, curriculum access, progression, and acceptance), through which fewer and fewer students can pass without adequate systemic adjustment (see figure 32). In a context where global inclusive guidance has influenced national policy development, implementing organisations, educators, and families are aware of the lack of capacity to deliver on national promises and have therefore been forced to reconsider their options: is segregated education better than inclusive education in a context where IE simply cannot be operationalised under current constraints (evidenced in data set 2)? The familiar rhetoric of providing inclusive education ‘with caveats’ therefore continues to play out as reality for refugee children, perpetuated and supported by the organisations tasked with its eradication in fulfilment of the CRPD (UNGA, 2006) and Incheon Declaration (United Nations, 2015).

The above discussion provides a clear example of a rapid national response to the imperative to comply with international agendas (in this case the CRPD and Agenda 2030), whilst being unable to operationalise them effectively – a policy-implementation gap identified in existing literature (chapter 3 - Battle, 2015; Karangwa, 2014, Miles, 2013; Trani et al, 2011) and supported and expanded upon by this research. Doubts are therefore cast on the relative value of a ‘one size fits all’ approach to the global imposition of education, and other internationally led, policies in severely resource-limited and crisis-responsive contexts. It is not to say that global inclusive education policy lacks value to broadly guide change, or should not be adopted locally, but that it should be done so considering the nuances of different situations and with the expertise of local actors (a concept supported by evidence in chapter 3, by Alborz et al, 2013; Njelesani et al, 2018; Karangwa, 2014; Krupar, 2016, and Pinnock and Hodgkin, 2010). As Chataika, McKenzie, Swart et al (2012) state, stakeholders can lead the way towards, and take ownership of, responsive and contextualised solutions to locally identified problems.

Figure 32: Disablement through educational 'filtering' for children with communication impairment.



2. **Educational segregation and/or exclusion pose threats to rights realisation, social cohesion, and human capital formation (Objectives O2a; O2c)**

   The literature review presented in chapter 3 evidences the devastating impacts of exclusion from education beyond academic achievement (see section 3.5.2 – LRC2), including those on child protection and the future of societies and nations. Data sets 1 and 2 in this research phase provide updated and new evidence on how disenfranchisement from the education system is understood not only to negatively impact a child's development, but also to result in longer-term heightened protection risk, rights infringements, and threats to future social cohesion and human capital development. Education is core to the achievement of many of the SDG goals and indicators, with relevance to SDG1 (no poverty); SDG2 (zero hunger); SDG4 (quality education); SDG5 (gender equality); SDG10 (reduced inequalities); SDG16 (peace and justice, strong institutions), and therefore to the achievement of Agenda 2030. Without education, children can become disempowered, alienated, and vulnerable.

> *"In our world, knowledge is power, and education empowers. It is an indispensable part of the development*

> *equation. It has intrinsic value – extending far beyond the economic – to empower people to determine their own destiny. That is why the opportunity to be educated is central to advancing human development".*
> *Helen Clark, UNDP Administrator (UNESCO, 2015: 13)*

Carers of children who experience CD (data set 2) also recognise that, although the prospect of special, segregated, education for their child seems compelling in a context where mainstream providers struggle to deliver a communication-accessible curriculum, segregating their children from their peers in their community risks more entrenched ostracisation upon their return and takes them further away from the vision of inclusive futures in which their children are accepted, valued, and can participate as equal citizens – a perspective supported by the human rights agenda expounded in the CRPD. Although carers value appropriate education that enables their children to progress academically, they also value their child's place as a member of their community and want others to do so too.

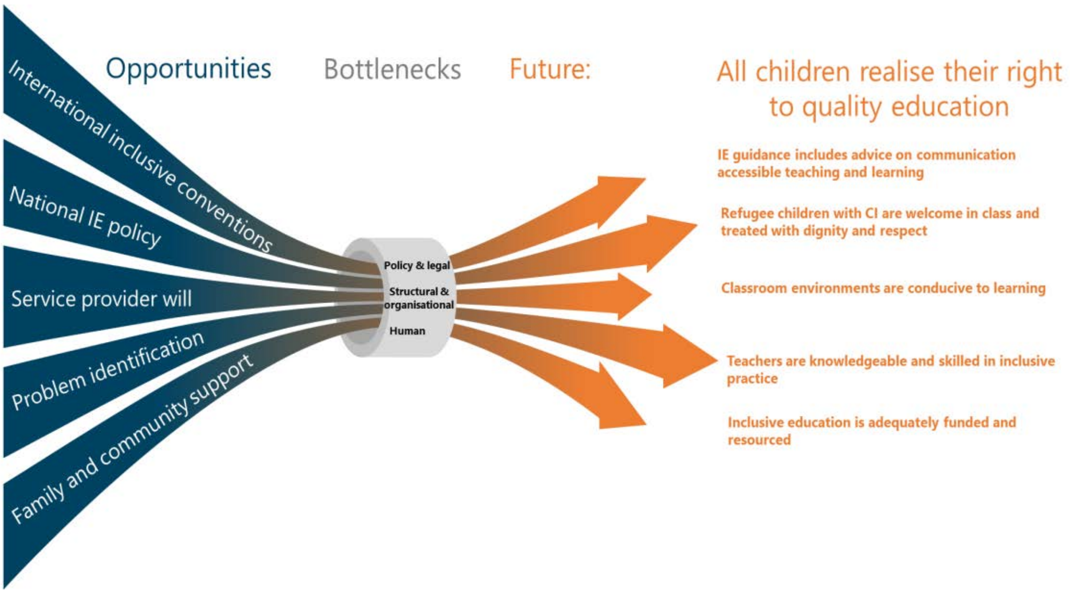
The Incheon Declaration, and the subsequent enactment of country-level inclusive education policy, has raised the bar for inclusive education provision across the globe (literature review, chapter 3; data set 1). It has also raised hopes for more equitable societies and inclusive futures amongst service providers and service users (data set 2). It has been the catalyst for huge efforts to address disability-related stigma and discrimination (literature review, chapter 3; data set 2), as well as to increase disability identification and school enrolment (data sets 2, 3). But realising the right to inclusive education and all that it entails for each individual child, as well as wider society, is complex. Efforts thus far has been successful for children with some forms of impairment (e.g., physical), more than others (e.g., communication) (literature review, chapter 3; data sets 1 and 2). Changing one part of the system has ramifications for how other parts function and can have unintended, unidentified, ripple effects into the future (data set 1). As identified in the literature review (chapter 3) in the work of Ayazi et al (2015), Krupar (2016), Miles, (2013), Pinnock and Hodgkin (2010) and Talley and Brintnell (2015), it is therefore critical for service planners to work with service providers and service users, to understand the consequences of decision-making on different stakeholders, and how decision-making affects people's lives – from individual to societal impacts, from the present day to the future. Karangwa et al (2010) call for more participatory action research as a method to ensure the agency, autonomy, and dignity of persons of concern and ensure their contributions to the decisions that affect them are respected – a foundational concept in critical disability and critical refugee theory, as well as in the human-rights based approach to 'nothing about us without us', as led by the global disability movement.

3. Opportunities for, and barriers to, inclusive ECD and education, for refugee children who experience CD, require systemic analysis and action (objectives O2a; O2b; O2c)

All three data sets in this phase of the project, as well as the literature review reported in chapter 3, have played an important role in developing a deeper understanding the opportunities and barriers to inclusive ECD and education, facing refugee children who experience CD in Rwanda. The literature review (chapter 3), as well as data sets 1 and 2, indicate that the right to community-based inclusive education, enshrined in global and national policy, presents a clear opportunity for all children to access the services to which they are entitled, and which contributes to the realisation of numerous human, child, refugee, and disability rights. Data set 2 indicates that this opportunity has been bolstered by a slow but steady change in community attitudes and behaviours towards people with CI, reducing socially disabling experiences for some (data set 2). Ongoing limitations to progress persist, however, caused by ongoing deep-rooted negative attitudes and behaviours within communities, and amongst service providers (data set 1; literature review: Karangwa, 2006) and is reflected in some carer experiences in data set 2. There is some evidence that some groups of children who experience disability are marginalised more than others – such as those with intellectual, communication and/or psychosocial impairments (literature review, ch3; data sets 1, 2, 3). Attendance at school itself has been acknowledged and evidenced to be a tool for changing attitudes and behaviours – for reducing stigma and encouraging acceptance (data set 1) - and has been facilitated by IE policy. The social benefits of this cannot be overstated and hold potential to contribute to the achievement of independent, participatory, and dignified, lives for refugee children with CI (see literature review, chapter 3, SC7 and SC8, in which the impacts of exclusion on individuals and societies are evidenced). This is, however, only one part of the inclusion story.

Despite the opportunities presented by policy changes and social advancements, further barriers and bottlenecks to full inclusion have been evidenced to exist at policy/legal, structural/institutional, and human levels, preventing or slowing progress and stifling opportunities (data sets 1, 2, 3; literature review, chapter 3; figure 33). Dismantling identified systemic barriers and bottlenecks is likely to result progressive realisation of educational rights for all children, facilitating the realisation of other rights such as safety and security and the right to be heard (Grover, 2007). It is clear, therefore, that considering the perspectives and needs of a wide range of stakeholders, including service planners, providers, and users, is critical to the development of inclusive education systems and services that work in different contexts (Miles, 2013; Talley and Brintnell, 2015; Trani et al, 2011). Analysis of what contributes to the disablement of children with CI within the education system, is key to this process – the child's wellbeing always being core to all considerations – and demands a systemic approach to thinking and action (supported by literature review conclusion, chapter 3, section 3.6). Ultimately, the creation of inclusive societies can be achieved through systemic changes, incorporating attitudes, behaviours, tools, processes, practices, pedagogy, and policy.

Figure 33: Opportunities, bottlenecks to progress, and the potential future of inclusive ECD and education, for refugee children who experience CD.

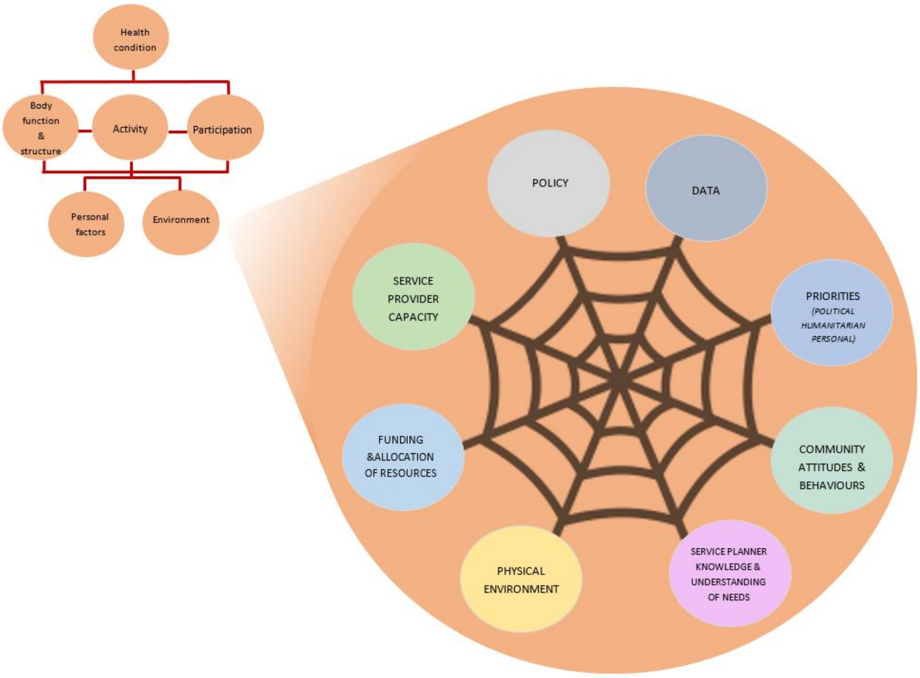


There is little doubt, therefore, that the situation is complex and influenced by numerous factors in law and policy, society, the environment, organisational management, and the individual. All three data sets highlight different and overlapping opportunities and barriers facing policy developers, service planners, service providers, and service users (children and families). All are deeply connected – interwoven in rights, politics, economics, culture, and day-to-day survival in extreme circumstances. Each factor has the potential to be an opportunity or a barrier to education access, and, in turn, to influence other factors.

Understanding the education system, and its impact on refugee children with CI, in this systemic way reflects the importance of considering the interconnections of education systems with a biopsychosocial understanding of the experience of disability, as expounded in the International Classification of Functioning, Disability and Health (ICF: WHO, 2001). This considers that the experience of disability arises from the interactions between the individual's health condition and/or impairment, their social environment, their physical environment, and their personal context (see chapter 2). Mapping how the inclusive education system impacts upon how disability is experienced by refugee children with CI, places the child at the centre of analysis, facilitates identification of barriers to progress and opportunities for change, and enables child-focused reconceptualization of the education system to make it work for those who continue to be excluded (figure 36).

To effect true systemic change for successful inclusion, taking a child-centred approach to systems analysis necessarily also involves analysing linkages with other aspects of their life that contribute to disability (e.g., health condition/impairment) and related services, including health, (re)habilitation, and child protection services, therefore evaluating change from a humanitarian systems perspective, rather than from a singular education viewpoint.

Figure 34: Interconnections between a child's experience of disability using the ICF model, and the education system.



Data sets 1 and 2, as well the literature review (chapter 3) demonstrate that changing inclusive education policy alone is not enough to ensure educational rights realisation for children who experience CD (see discussion point 1 above): that threats to progress need to be identified in all parts of the system (including policy, people, and programmes), and addressed in such a way as to make all parts of the system work together more effectively – pulling on all strings of the ‘web’ together, rather than pulling on one thread at a time, using a ‘systems thinking’ approach.

4. **Realising education for all requires a sustained, holistic approach to education systems development (objectives O2a; O2b; O2c)**

   Evidence on the interconnected opportunities and barriers to inclusive education and educational rights realisation, for refugee children who experience CD (points 2 and 3 above; literature review, chapter 3), demonstrates how humanitarian and host community responses need to evolve to meet the complex and changing needs of refugee populations – particularly those in long-term displacement due to protracted crises.

   Traditional, single-mandate, humanitarian response is reactive, short-term, lifesaving, and often isolated from interactions with policy and governance (see chapter 2). The risk of failing to think systemically in humanitarian settings, then, is that traditional emergency ways of working transfer into more protracted responses that require more nuanced and responsive approaches to planning based on a wide range of perspectives and needs (Campbell, 2021). Interventions to promote human rights in protracted crises demand that humanitarian organisations occupy a new space at the humanitarian-development-peace nexus (HDPN – see chapter 2, section 2.2.5) between classical/traditional humanitarianism and development agendas- differing approaches with traditionally very different mandates. Now focusing on ensuring the realisation of human rights beyond basic survival, humanitarian organisations must move away from historically reductionist and linear approaches to problem-solving and towards rights-based interventions that involve more systemic, long-term, and sustainable, approaches to problem solving for people in situations of forced migration (Campbell, 2021).

The three data sets in this phase of the research together present evidence that stakeholders involved in service planning, provision, and use, have different experiences of, and perspectives on, the barriers and opportunities to inclusive education for refugee children who experience CD. Together, however, their views represent an understanding of the nuanced and holistic response required for successful inclusive education for all.

To address barriers to inclusion, humanitarian organisations call for increased capacity (in terms of human resources, teaching and learning materials, increased knowledge, and skills) to deliver inclusive education for all children (data set 1). This is reflected in stakeholders' calls for social support to promote inclusion, family and educator skills building on communication accessibility, and investment in mainstream school environments and resources, to avoid the need to be segregate children into specialist education environments (data set 2). In classrooms where children feel welcome, engaged, and their families see progress (both social and academic), the children are more likely to continue to attend in the longer term, reinforcing the social and protective benefits of education (e.g., reduced stigma, peer acceptance, value, participation, and safe spaces) and potentially contributing to more inclusive societies outside of the classroom (data set 2, data set 3). Small, but significant, changes to the education environment, and investment in resources and educators, could contribute to closing the gap that currently exists between rights-based inclusive education policy (currently operationalised with a focus on enrolment – data set 2), and a failure to include children with CI effectively in the classroom (data set 2). Indeed, although funding is recognised to be one constraint to achieving inclusion in camp and local community ECD centres and schools, there is potential for the funding currently allocated for segregated educational opportunities that serves only a few children (data set 2), to instead be invested in the provision of LSA support and educator training to support more (if not all) refugee children with communication support needs within their local ECD centres and schools – an approach supported by families of refugee children who experience barriers to inclusion. Not only would this provide greater support for more children locally but would also reduce family separation and support wider community inclusion and acceptance – contributing to the achievement of SDG4 and Agenda 2030.

When the data from guiding documents (data set 1), stakeholder consultations (data set 2), and classroom observations (data set 3) are considered together with data from the literature review (chapter 3), the message is clear: for children to benefit from the opportunities that inclusive education policy presents, a fundamental paradigm shift is required within the education sector from believing the child must fit the system, to the system needing to fit each child. This will ensure that no child is excluded from receiving and appropriate and accessible education, stagnates within the system, or is segregated from their community because the system cannot meet their needs. This paradigm shift must incorporate service planners, providers, and users, as well as involve the community, to ensure it occurs in a strategic, sustained, and well-resourced manner. Critically, it must occur within a broader systemic evolution of the education and humanitarian response systems.

6.19 Conclusion

In conclusion, results from all three data sets and the literature review (chapter 3) suggest that the opportunities that global inclusive education policy presents are counterbalanced by barriers and bottlenecks that prevent or slow progress to achieving inclusive education for many children in forced migration contexts, including those who experience CD. These barriers and bottlenecks within the education system appear to contribute directly to the ongoing disablement of refugee children with CI, who continue to experience disabling stigma, alterity, exclusion from the curriculum, and (in some cases) segregation, which itself reinforces negative attitudes and behaviours within communities. The very system charged with educational rights realisation is, itself, arguably contributing to disablement through: poor conceptualisation of the issues facing children who experience disability (in this case, CD); poor planning; chronic under-resourcing; endemic views of the benefits of segregation; and linear, reductionist approaches to problem solving, whereby changes are made to one part of a complex system, with little awareness of the impacts (or otherwise) on other parts. Until Governments, humanitarian agencies, and local service providers, fully understand and respond to the root causes and disabling impacts of exclusion, as well as the significance of intersectionality of risk factors, education rights violations in forced migration contexts will remain pervasive for children with impairments – especially those from under-represented groups (such as those with cognitive impairment or communication impairment).

Opportunities exist for the creation of inclusive communities through the transformative power of education. If SDG4 (quality education for all) is to be achieved by 2030, and refugee children who experience CD are to realise their rights under the CRPD (UNGA, 2006), the disabling impacts of the current education and humanitarian systems must be evaluated carefully within their social context, and each discriminatory, exclusionary, practice eliminated. To do so effectively, it is critical that the experiences of children and families are known and understood, that their needs and wishes are considered and valued, and that policy makers and service planners are encouraged to listen to the perspectives of all stakeholders – a critical component of systems thinking to achieve change (Campbell, 2021). To neglect these responsibilities is to adopt a top-down, ill-informed, single-focused, imposition of change in a situation that requires consultative, collaborative, and innovative reimagination of education and humanitarian systems within a human rights framework, for transformation to occur. Collaboration, innovation, dedication, and commitment to resourcing are required to fulfil EFA goals in the long term, and to secure productive, participatory, and dignified, futures for all children.

Chapter 7: Data integration, discussion, and conclusion

7.1 Introduction

This final chapter presents an integration and discussion of the findings from phases one and two of the research in relation to the existing literature and overall research question: *‘to what extent do refugee children with communication impairment, who experience communication disability, realise their right to inclusive education in Rwanda?’*

Section 7.2 presents an integration of data from phases one and two of the study, relates it to the available literature, and considers the findings against critical disability, critical refugee, and human rights frameworks. The implications of findings, as well as possible future research directions, are considered. Section 7.3 presents a reflexive account of the research project and section 7.4 presents research challenges and limitations. Section 7.5 presents implications of the research, including those for future practice and research directions, and section 7.6 concludes the thesis.

7.2 Data integration: findings and implications

To conclude this thesis, it is prudent to revisit the research question and aims and objectives corresponding to each phase of the project, to determine if they have been addressed. The research question was a product of a conversation with UNHCR Rwanda who, in 2015, were concerned that refugee children with communication impairments may not be accessing educational opportunities on an equal basis with their peers and were being left behind. Considering renewed global efforts to ensure the right to education is enjoyed by all children, without exception, UNHCR and I asked the question:

> *'To what extent do refugee children with communication impairment, who experience communication disability, realise their right to inclusive education in Rwanda?*

Phase one of the project aimed to describe and critically interrogate the current systems, tools and processes used to identify and register refugees with communication impairments, who experience communication disability, in Rwanda. I set out to achieve this aim through three research objectives, as detailed in chapter 1.

The aim of phase two was to map the opportunities and barriers to accessing appropriate inclusive early childhood development and education services, for refugee children with communication impairments, who experience communication disability, in Rwanda. I set out to achieve this aim through three research objectives, as detailed in chapter 1.

This research was conducted as an Interpretive Description (Thorne 2016): a research methodology designed to address real-world research questions in a realistic, practical, and useable way (see chapter 4, section 4.5.2.1). – research that is often "complex and messy" (Thorne 2016: 11). Research into 'diffuse topics' (Alborz and McNally, 2004), such as 'access', is also often difficult to define and study. When conducted with historically marginalised and oppressed groups, such as persons who experience disability, in unstable and fragile contexts such as humanitarian crises, 'messy' is an accurate way to describe the data construction and analysis processes. This study employed multiple research methods and approaches with a critical lens, conducted with numerous stakeholders, in three different locations, to address a complex and real-world research problem, identified by key stakeholders.

7.2.1 Summary of findings

The ten key findings from data sets 1-3 in phase one, and eight key findings from data sets 1-3 in phase two, are presented in table 36 below. These are related, as far as possible, to each objective although there is some overlap between, for example, stakeholder and service user experiences and viewpoints. These overlaps are discussed further in the discussion below.

Table 36: Key findings from phases 1 and 2

Phase	Aim	Objective	Data sets	Findings
One	**A1:** To describe and critically interrogate the current systems, tools and processes used to identify and register refugees with communication impairments, who experience disability, in Rwanda.	**O1a:** to determine the proportion of refugees, including children, registered with communication impairments and/or disability in Rwanda, using current tools and processes.	**Phase 1, data set 1** Analysis of secondary refugee registration data	1. Refugees with CIs, who experience CD, are likely to be under-identified and under-registered in the refugee database in Rwanda 2. Disability registration codes are insufficiently sensitive 3. Recording of multiple impairments and disability experiences is not catered for
		O1b: to describe and critique the current tools and processes used to identify and register refugees with communication impairments and/or disability in Rwanda.	**Phase 1, data set 2** Document analysis **Phase 1, data set 3** Focus group discussions	4. Use of disability language is inconsistent across guiding humanitarian registration documents 5. Refugees with CI are at risk of exclusion from registration of specific needs 6. Refugees with CI experience heightened protection risk 7. There is a disconnect between commitment and experience
		O1c: to document the self-reported understanding,	**Phase 1, data set 3** Focus group discussions	8. Refugees with CI experience disabling

		behaviours, and experience of staff responsible for determining if refugees have a communication impairment and/or experience communication disability.		exclusion from humanitarian services 9. Humanitarian systems, tools, and processes contribute to the disablement of refugees with CI 10. A multifaceted approach to inclusion is required to ensure service equity for refugees with CI, who experience CD
Two	**A2:** To map the opportunities and barriers to accessing appropriate inclusive early childhood development and education services, for refugee children with communication impairments, who experience communication disability, in Rwanda.	**O2a:** to document the early childhood development and education services that are provided to refugee-children in Rwanda and the opportunities for, and barriers to, the educational inclusion of refugee-children who experience communication disability	**Phase 2, data set 1** Document analysis **Phase 2, data set 2** Focus group discussions and interviews	11. Refugee children, who experience disability, are subject to rights violations that have significant impacts on their future 12. Reference to communication impairment and/or disability is notably limited in humanitarian sector professional guidance 13. Inclusive education holds transformative potential

			Phase 2, data set 3 Classroom observations	14. The humanitarian sector needs to close the gap between policy and practice, to put an end to child rights infringements
		O2b: to document early childhood development and education service-providers' views of opportunities and barriers to including refugee-children who experience communication disability in Early Childhood Development /education services.	**Phase 2, data set 2** Focus group discussions and interviews	15. An ambitious, rights-based, inclusive education policy is stifled by barriers to implementation 16. Policy, structural/institutional, and human barriers to progress exist. 17. Existing segregated education opportunities threaten the advancement of inclusive practice 18. Families want what is best for their child
		O2c: to document the views of parents/carers of children who experience communication disability regarding opportunities and barriers to including their children, in early childhood development/ education services.	**Phase 2, data set 2** Focus group discussions and interviews	

7.2.2 Data integration and discussion

Interpretive Description necessitates a study of different perspectives and integration of data to tackle applied research problems. The process of data integration pulls together and analyses data from several sources, to gain a better understanding of the evidence on a given topic from a holistic perspective (Fetters, Curry, and Creswell, 2013). That said, there is little guidance available on *how* to conduct a data integration within one research project with a mixed-methods design. Integration strategies for qualitative data can be classed as either descriptive, using narrative and tabulation, or interpretive, utilising strategies such as finding patterns and common themes between data sets (Evans, 2002). As this study is an Interpretive Description, I have taken an interpretive approach to data integration, as far as possible, in the discussion below. Findings from the quantitative study (phase 1, data set 1) are interwoven with qualitative findings as appropriate, using a method of data weaving (see also chapter 5, section 5.19). Integration was carried out using manual (paper based) analysis, using the principles of thematic analysis (see chapter 5, section 5.15).

Integration of the findings from phases one and two resulted in three thematic areas for discussion:

a) **power** (seven findings)
b) **priorities** (seven findings) and
c) **potential** (four findings).

As is to be expected when integrating data from different sources on the same topic, overlaps and intersections exist, for example, some findings from the document analyses reflect the experiences and needs of participants discussed in FGDs. Overlaps between topics themselves also exist, for example findings related to power may also be related to priorities, and some priorities may be inextricably linked to potential.

7.2.2.1 Power

The following findings from phases one and two relate to the topic of power, including induced dependency and experienced oppression. They are interwoven with findings from the literature (literature review, chapter 3; document analyses, chapters 5 and 6) throughout the discussion.

1. Refugees with CIs, who experience CD, are likely to be under-identified and under-registered in the refugee database in Rwanda.
4. Use of disability terminology is inconsistent across guiding humanitarian registration documents.
5. Refugees with CI are at risk of exclusion from registration of specific needs.
6. Refugees with CI experience heightened protection risk.
8. Refugees with CI experience disabling exclusion from humanitarian services.
9. Humanitarian systems, tools, and processes contribute to the disablement of refugees with CI.
15. Refugee children, who experience disability, are subject to rights violations that have significant impacts on their future.

**NB: Numbers correspond to findings in table 36.*

The findings related to power were evident in data across phases one and two. Power differentials were found to exist between refugees and humanitarian service providers (UN agencies and IOs), with refugees rendered dependent upon humanitarian service providers for their very survival - a phenomenon similarly evidenced Krupar's (2016) work in Sudan. With the power to decide who is registered and with what information, including that related to impairment and/or (dis)ability, humanitarian agencies are considered the gatekeepers of refugee assistance (phase 1, data set 3). The humanitarian agency staff acknowledge this themselves, as well as the responsibility that this position of power holds.

Humanitarian agencies operate within a protection mandate (see chapter 2, section 2.3) – one that is defined by humanitarian agencies (rather than refugees themselves) and endeavours to ensure basic needs are met and protection risk is reduced, particularly for those considered to be most at risk due to multiple and intersecting 'vulnerability' factors (see chapter 1, section 1.5.3.1). This protection mandate, and its associated power, places humanitarian staff in a paternalistic position as protectors, givers, and decision-makers – primarily driven by externally imposed donor agendas (Karangwa et al, 2010; Krupar, 2016). The phrases 'humanitarian assistance' and 'granting assistance' used in humanitarian documentation and by participants – of which the service providers are gatekeepers - exemplifies this perception of benevolence. The most senior staff tend to be 'outsiders', adding another dimension to power imbalances, both perceived and experienced, and with possible post/neo-colonial connotations (see chapter 2, section 2.3.3). This is very much reflected in the literature on the historical evolution of humanitarianism and its classical principles, grounded in the moral imperative to assist those in need (see chapter 2, section 2.2.5).

The very nature of camp-based refugeehood in Rwanda entails dependency upon humanitarian agencies – a phenomenon recognised by Krupar (2016), who also describes the dependency refugees have on a *"system in flux"* (Krupar, 2016: 115) – itself answerable to powerful donors (including politically motivated governments) who decide where the money goes, for what purpose, and for how long. Refugee risk increases with factors associated with 'vulnerability' (chapter 1, section 1.5.3.1), including impairment and/or disability, which can intersect with age, sex, gender, culture, ethnicity, religion, sexuality, and a multitude of other factors to increase the risk of dependency, exclusion, marginalisation and/or oppression (Battle, 2015; Krupar, 2016; Rose and Shevlin, 2004; Trani et al, 2011). As identified by the service provider participants in phase one of this research, the responsibility for identifying risk factors, and those exposed to them in forced migration contexts, lies with the humanitarian agencies. Since assistance is granted based upon the risk assessment conducted by humanitarian agency staff, the systems, tools, and processes they use to identify those who need additional support, as well as the attitudes, beliefs, knowledge, understanding, skills, and practices of service providers, were found to play a substantial role in determining who is identified as needing support, and what support they need or are granted access to, in this research. Power lies within the humanitarian *system* but is executed by individuals who form an integral part of that system.

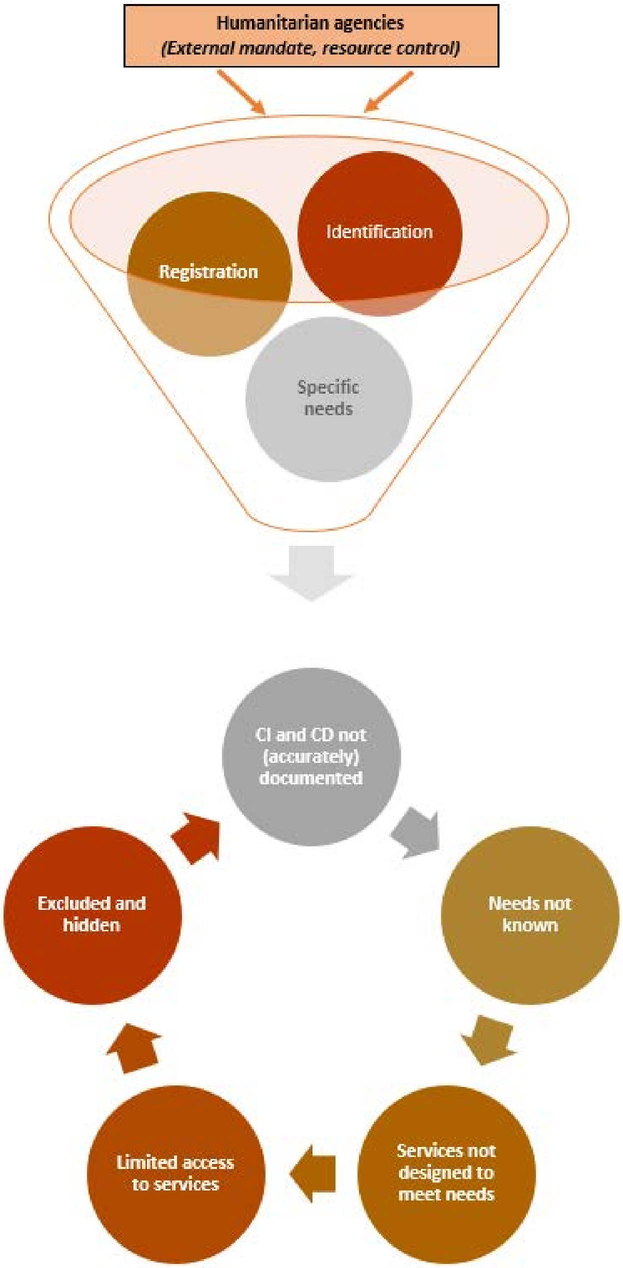
In a context where impairment and disability (particularly CI and CD) are poorly understood by communities and service providers (evidenced across both phases), and humanitarian systems, tools, and processes insufficient for accurate identification of those who require communication support (phase 1, data sets 1 and 3), refugees with communication impairments are at increased risk of disabling marginalisation and exclusion. The experiences of both service users and service providers documented in phases one and two, as well as the literature in the document analyses (phase 1, data set 2; phase 2, data set 1) and literature review (chapter 3), reflect not only that this is the lived experience of refugees with CI, who experience CD in Rwanda, but that relatively little is being done to improve the situation. The data in this research support the literature, which reports inertia amongst humanitarian agencies to act upon the problems of service inequity that they see and experience, despite advancements in global, national, and sector-specific guidance (chapter 3). Power imbalances between the individual humanitarian agency staff and their organisation (policies, mandate, capacity) also exist, so that the staff feel 'their hands are tied' and there is little they can do to address the inequalities and inequities that some groups of refugees, such as those with CI, experience (phase 1, data set 3; phase 2, data set 2). Exclusion from participation and service access therefore becomes tolerated, if not accepted (albeit uncomfortably) by the service providers (phase 1, data set 3).

The power that humanitarian agencies hold, combined with the dependency of refugees who experience CD upon their services (Krupar, 2016), means that the most at risk of exclusion may be the least protected from it, in situations of low capacity (including knowledge, skills, material and human resources, time). Indeed, for refugees with CI in Rwanda, the insufficient humanitarian systems, tools, and processes for identification of CI have been identified to potentially *contribute* to their disablement (phase 1, data set 1), exemplifying perpetuation of the historically imposed marginalisation and oppression of under-represented groups in already marginalised refugee communities.

Power imbalances between refugees who experience disability, and those in the refugee community who do not (including those in positions of power within that community, such as educators), were also evident in the primary data (particularly phase 1, data set 3 and phase 2, data set 2) and literature (document analyses and literature review). Stigmatisation, marginalisation, and other exclusionary attitudes and behaviours were some of the most identifiable barriers to inclusive education for refugee children with CI, contributing to the experience of CD (literature review; phase 1, data sets 2 and 3; phase 2, data sets 1 and 2). Refugee children with CI therefore experience multiple power differentials – between themselves and their elders, their communities, and the humanitarian agencies charged with their protection – that contribute to their experiences of continued oppression and disablement, despite an enabling refugee, humanitarian, and educational policy context.

Oppression, marginalisation, and exclusion can result in rights violations. In a world where human rights are ostensibly applicable to all, differentiation based on (dis)ability should not exist. Power, however, influences who is able to realise those rights, and who is not. In the case of education for refugee children with CI in Rwanda, under-identification, and inaccurate registration in the refugee assistance system, implemented by those with power, results in their support needs being under-reported and services not meeting needs (phase 1, data sets 2 and 3; phase 2 data set 2). Even if children are enrolled in ECD centres or schools, educators feel poorly prepared to meet their learning support needs (phase 2, data set 2) – they may learn little, fail to progress, or drop out, therefore failing to realise their right to education (literature review, chapter 3) – yet those in positions of power (host governments, humanitarian agencies, donors) appear to do little to address these issues. A cycle of exclusion ensues, whereby 'invisible' children do not access the services they need, which reinforces their invisibility and exclusion (see figure 34).

Figure 34: The influence of power on the cycle of invisibility and exclusion experienced by refugee children with CI in Rwanda



This perspective is reflected in the literature (phase 1 data set 2; phase two data set 1; literature review) and in the accounts relayed by participants in this research (phase 1 data set 3, phase 2 data set 2). Findings align with the critical nature of the inquiry, as discussed in chapter 4, section 4.5.1, since the aims of critical inquiry are to understand why power inequities exist and to link them to meaningful emancipatory action (Robson, 2002). From a critical disability theory perspective, those with less power remain unseen (phase 1, data set 1) and unheard and their participation remains limited – their oppression perpetuated, if not reinforced (evidence across all data sets). From a critical refugee studies perspective, similar oppressive practices further limit the autonomy and self-determination of refugees who experience marginalisation and exclusion at the intersection of CI and refugeehood. From a human rights perspective, refugee children with CI in Rwanda not only experience disabling exclusion from education but are consequently subjected to rights infringements that affect their current and future wellbeing and capacity for independence, societal contribution, and nation-building (phase 1, data sets 2, 3; phase 2, data sets 1, 2; literature review).

A key outcome of this data integration is the understanding that:

Refugee children with CI in Rwanda experience oppression and rights violations in the forms of invisibility, stigmatisation, and marginalisation that contribute to their disablement. These experiences occur, in part, due to those in positions of power failing to ensure refugee children with CI realise their human rights on an equal basis with others.

7.2.2.2 Priorities

The following findings from phases one and two relate to the theme of priorities, including those that facilitate and inhibit inclusive education practices for refugee children in Rwanda.

2. Disability registration codes are insufficiently sensitive.

3. Recording of multiple impairments and disability experiences is not catered for.

7. There is a disconnect between commitment and reality.

12. Reference to communication impairment and/or disability is notably limited in humanitarian sector professional guidance.

15. An ambitious, rights-based, inclusive education policy is stifled by barriers to implementation.

16. Policy, structural/institutional, and human barriers to progress exist.

17. Existing segregated education opportunities threaten the advancement of inclusive practice.

**NB: Numbers correspond to findings in table 36*

Provision of education services in emergency contexts was identified in the literature review (chapter 3) as being a relatively new endeavour for humanitarian organisations (Trani et al, 2011), born of the ever-growing need for long-term humanitarian service provision in protracted crises and resulting in humanitarian agencies operating at the Humanitarian Development Peace Nexus (HDPN – see chapter 2, section 2.3.3). In this context, humanitarian agencies now straddle the gap between providing traditional humanitarian, life protecting, assistance and longer-term, more development-focused agendas, focusing on life promoting and peacebuilding interventions. Within this, refugees who experience disability have been historically viewed as simply one of many groups of refugees who are 'vulnerable' (see chapter 1, section 1.5.3.1) (Trani et al, 2011). In comparison to other (sometimes larger and more visible) 'vulnerable' groups such as unaccompanied children, women and girls, older persons, and those with conflict-related injuries, persons experiencing disability (especially those pre-existing an emergency) have been placed low down on the priority list for humanitarian response (Alborz et al, 2013).

Findings from phase one of this research support Alborz et al (2013), suggesting that little priority has historically been given to humanitarian systems for the identification of, and assistance to, refugees who experience disability. This may be exacerbated in the case of CI: an example of an impairment that is less visible to the onlooker (in this case, the person providing registration and/or education services) and known to be poorly understood (literature review, phase 1 data set 3). Despite the publication of the International Classification of Functioning, Disability, and Health (ICF: WHO, 2001) and the CRPD (UNGA, 2006), little advancement in knowledge and understanding of the classification, causes, nature, and impacts, of some impairments and related disability, appears to have been made within humanitarian agencies providing registration and education services in Rwanda and across the globe (literature review, phase 1 data sets 2 and 3, phase 2 data sets 1 and 2). This is evident in the UNHCR registration data tools which, at the time of data construction (2017/18), employed confusing and interchangeable impairment and disability terminology[60] (Phase 1, data sets 1, 2). Humanitarian staff using these tools identified that both the tools and the processes employed during registration were insufficient to elicit information from registrants about their specific challenges and support requirements (phase 1, data set 3). A major impediment to accurate registration of disability was found to be that a registrant would only be referred for a specific needs assessment if/when the first registrar refers them, but there is/was an absence of guidance for that registrar to identify specific needs to make the referral (phase 1, data set 3). Guidance for verification clerks to better identify CD and make more accurate referrals to the community service desk was piloted in phase 1 (see data set 1), with some indicative positive outcomes (chapter 5, section 5.5), but requires further testing and evaluation.

The document analysis in phase one, data set 2, illustrates the major headway that has been made since the turn of the millennium, in disability policy and guidance within the

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[60] During the writing of this thesis, UNHCR implemented the ProGres 4 – an updated database used in many UNHCR country offices. This now includes the use of Washington Group Questions to identify refugees who experience disability more accurately, based on functional limitation (but still in the absence of identification of barriers to participation more broadly).

humanitarian sector. It also, however, tells of the enormous policy-implementation gap, describing the barriers to implementation of disability-inclusion registration practice, reflecting findings in the peer reviewed literature (chapter 3). Despite this knowledge, participants in the FGDs (phase 1, data set 4; phase 2, data set 2) reiterated these challenges within their own experiences in Rwanda's refugee camps. Actual commitment to disability inclusive registration services at country-level appeared to be minimal at the time of data construction.

Despite some efforts to address disability issues amongst refugees, such as the appointment of a disability implementing organisation (IO) in 2015, experiences of service users and service providers in this research confirm that communication impairment and disability remain misunderstood, under identified, and the refugees with CI under-served and excluded (phase 1, data set 3; phase 2, data set 2). Amongst refugees with impairments, participants in FGDs felt that priority was given to those with physical and, in some cases, sensory impairments - a phenomenon evidenced in the literature (Alborz et al, 2013). Those with psychosocial, cognitive/intellectual, or communication impairments were acknowledged to be further excluded from rehabilitation services, and from support to access mainstream services, by the disability IO (phase 1, data set 3; phase 2, data set 2). When this was pointed out to UNHCR in a debrief, staff were shocked to hear that some groups of refugees continued to be excluded from services, despite the disability-specialist IO being in place, suggesting that accountability mechanisms also did not recognise communication support (beyond sign-language provision) as an area requiring inclusive programming attention. This is not surprising, given that the global guiding document on disability rights and inclusion – the CRPD (UNGA, 2006) – upon which much humanitarian inclusion guidance is based, fails to identify communication impairment as a possible contributor to disability (see chapter 2, section 2.2.6). Communication impairment and disability are therefore arguably overlooked for action by humanitarian agencies, as they are invisible 'on paper'.

This potentially translates into real-life invisibility for those with CI, leading to potential exclusion and subsequent disablement (phase 2, data set 3; phase 2, data set 2).

In relation to inclusive education, a lack of accurate identification and registration of CI, CD, and related support needs was found to feed into access to inclusive education services (phase 2, data set 2) – only ten children in the whole of Rwanda's refugee population were officially registered as having 'special educational needs' at the time of data construction (phase 1, data set 1), despite IO reports indicating far more children in the education system requiring curriculum access support (phase 1, data set 3; phase2 data set 2). Although ostensibly offering inclusive education for all children in the camps, ECD and education services were designed to cater to the majority and insufficient inputs (such as one week of sign language training) were given to educators to enable them to provide accessible learning opportunities for children with specific learning access requirements, such as communication support (phase 1, data set 1; phase 2, data set 2). Despite accessibility guidance for schools and evidence on the financial benefits of universal design being available (Alborz et al, 2013; Sagahutu et al, 2013; phase 2, data set 1), most education facilities were reported and observed to be physically, sensorily, and communicatively inaccessible to some children (phase 2, data set 2) – an indication of their de-prioritisation in comparison to the normative population.

A focus on 'quick wins', such as community-based identification of out-of-school children, has resulted in some children with impairments attending school, but experiencing disabling exclusion from learning opportunities within the classroom (Trani et al, 2011; phase 2, data sets 1, 2 and 3). Prioritisation of enrolment in the absence of strategy and resourcing for inclusion has led inclusive education to be devalued in the eyes of some families – simply viewed as day-care rather than their child's future being viewed with the same value as their non-disabled peers (phase 2, data set 2). A grey area of responsibility between the disability IO and the education IO existed at the time of data construction, with neither apparently taking full responsibility for inclusive education strategy, practice, or accountability mechanisms, yet both claiming to provide disability sensitive services and support to other IOs (phase 2, data set 2). Further threats to advancement of inclusive practice exist in the form of established segregated education opportunities in Rwanda (phase 2, data set 2). Their existence arguably contributes to the de-prioritisation of inclusive education in the camps – the simple solution being to send a small number of children away to receive specialist services, rather than providing rights-responsive community-based inclusive services that would not only benefit more children with access needs but would benefit entire communities in the longer term (phase 2, data set 2).

A strong connection between findings related to priority, and those related to power, is evident. The policy, structural, institutional, and human barriers to implementation of communication-accessible education in refugee camps in Rwanda, identified in this research, reflect those identified in the limited literature on the topic (reported in chapter 3, section 3.5.1). Participants in this research described, through their own experiences and perceptions, how the power to change the status quo lies primarily with the humanitarian organisations working in close collaboration with the local community (phase 1, data set 3; phase 2, data set 2). This is not an entirely new endeavour – humanitarian organisations do *consult* with local communities on their needs and their views on how best to implement services, but rarely is this a true collaboration, involving power sharing or shift. Moreover, findings illustrated that refugees with communication impairments are regularly excluded from those consultations (phase 1, data set 3; phase 2 data set 2, and reflected in Jagoe et al, 2021). First, they and their families are frequently unknown to service providers seeking community inputs, and second, service providers are unsure how to interact with a person who does not communicate easily using spoken language (phase 1, data set 3; phase 2, data set 2). Service providers describe the time pressures they face, meaning those who require more time to participate are side-lined (phase 1, data set 3; phase 2, data set 2) – the verbally communicative population given priority to contribute to power-rebalancing consultations (phase 1, data set 3). Service providers know this is happening but feel unable to do anything to address the situation due to organisational expectations for what constitutes ‘good outcomes’ (see discussion in section 7.4.5 below, on humanitarian-academic collaboration) – often based on the number of people served and the time taken to complete a task, rather than concerns related to equality and equity (literature review; phase 1, data set 3). This also accounts for why a focus on enrolment of children who experience disability in education services (quick and easy to measure) takes precedence over ensuring their inclusion once in the classroom (more resource-intensive, time consuming, and difficult to measure).

In relation to human rights frameworks, the efforts made by humanitarian services providers to deliver specialist (often exclusively rehabilitation) services to support the population of refugees who experience disability (a pre-requisite for broader inclusion) arguably mask the exclusion that the same population faces from participation in everyday community life and equitable service access. Agencies consider themselves to be ‘providing services’ whilst unwittingly contributing to participation restrictions and human rights infringements that go unrecognised, since sub-sections of the population of refugees who experience disability are also routinely excluded from community consultations – the primary mechanism utilised by humanitarian agencies to give voice and agency to the refugee community. Considered from critical perspectives at the intersection of disability and refugee identities, the provision of specialist services in the absence of inclusive mainstreaming practices (i.e., only one element of the ‘twin track’ approach to inclusion- see chapter 5, section 5.10.4) constitutes a perpetuation of segregation rooted in a medical understanding of disability (see chapter 2, section 2.5). This promotes the understanding that disability can be and should be ‘fixed’, rather than existing as part of the diverse human condition. As such, social injustice inevitably plays out in the form of cyclical invisibility through humanitarian de-prioritisation (see diagram 34), resulting in continued oppression of those with non-normative bodies and minds (Garland Thompson, 1996).

A key outcome of data integration within this theme is the understanding that:

Refugee children with CI in Rwanda are caught in a cycle of humanitarian de-prioritisation, rooted in power differentials, and externally imposed normative attitudes, behaviours, and practices, that results in perpetuated exclusion, disablement, and human rights infringements.

7.2.2.3 Potential

The following findings from phases one (chapter 5) and two (chapter 6), as well as the literature review (chapter 3) relate to the topic of potential, including possible approaches to inclusive education policy, practice, and rights realisation.

10. A multifaceted approach to inclusion is required to ensure service equity for refugees with CI, who experience CD.
13. Inclusive education holds transformative potential.
14. The humanitarian sector needs to close the gap between policy and practice, to put an end to child rights infringements.
18. Families want what is best for their child.

    **NB: Numbers relate to those in table 36.*

The peer reviewed literature in chapter 3 and the document analyses in chapters 5 and 6 all illustrate the global shift towards rights-based inclusive education policy that has occurred over the last two decades -the most significant and possibly influential changes being the publication of the CRPD in 2006 (UNGA, 2006) and the Incheon Declaration and Framework for Action in 2015 (UNESCO, 2015). In the humanitarian sphere, the INEE inclusive education guidelines (20010a) and ADCAP standards (Age and Disability Consortium, 2018), linking directly to the Sphere standards for humanitarian action (Sphere, 2018), further demonstrate a global human rights-based vision for education for all (EFA), that includes displaced (including refugee) children. The literature reports on the transformative potential of inclusive education for individuals and societies, particularly for children in adverse contexts such as forced migration and for those who have been historically marginalised, including children who experience disability (Karangwa, 2014; Krupar, 2016; Sagahutu et al, 2013; Trani et al, 2011). Moreover, education for all children is reported to be the vehicle through which several rights are realised, including access to protection, healthcare, nutrition, and voice and agency (phase 2, data set 1).

The potential that education holds for transforming the life of each individual child, as well as for families, communities, and nations, is recognised to be of almost incalculable value (Karangwa, 2014) It is also well documented across the literature that this potential is, as yet, largely untapped for some groups as children, such as refugee children with impairments and/or learning support needs, who experience disabling exclusion from these transformative opportunities (phase 2, data set 1) – an observation supported by findings from participant data in this research (phase 1, data set 3; phase 2 data set 2).

Service providers in phases one and two of this research were able to draw upon their experiences of implementing Rwanda's inclusive education policy for refugee children and offer insights into the barriers, opportunities, and potential for change towards full inclusive practice and rights fulfilment, for those who have been historically marginalised and excluded (phase 2, data set 2). The perception that improved inclusive policy (both global and national) has catalysed enrolment of more children with impairments in ECD centres and schools in Rwanda's camps demonstrates some commitment towards inclusion by humanitarian organisations, who can be seen to be making initial steps towards trying to implement inclusive policy (phase 2, data set 2). The funding of a disability-focused IO in Rwanda also demonstrates a level of commitment to disability inclusion across sectors, as does an inclusive education specialist being funded within one of the education-IOs responsible for services in the largest camp included in this project.

The findings in the peer reviewed literature (chapter 3) document analyses (phase 1, data set 2; phase 2, data set 1), as well as from interviews and FGDs across both phases (phase 1, data set 3; phase 2, data set 2), suggest that service planners, providers, and users, as well as the refugee community, all recognise that barriers to inclusion are present across the board, within policy, humanitarian programming, and within people (individuals and communities). They collectively recognise that insufficiently sensitive policy, systems, tools, and processes combine with negative attitudes, behaviours, and practices to deprioritise refugees with impairments, particularly those less visible and understood (such as CI). This affects their ability to access services and support equitably, and impacts upon their participation, perceived value to the community, as well as reinforcing marginalisation and exclusion. They did, however, also recognise the potential to harness the power of inclusive policy to strive for better inclusive behaviours and practices (phase 1, data set 3; phase 2, data set 2).

Some participants in this research recognise elements of existing good practice that could be built upon in the future, to specifically address the ongoing exclusion of refugee children with CI from educational opportunities in Rwanda's camps. This research was welcomed by the refugee disability committee and community mobilisers for raising awareness of this excluded group of children amongst stakeholders, and for giving families the chance to voice their experiences, needs, and wishes, to influence needs-led change (transcripts for phase 1, data set 3; phase 2 data set 2). Families fear for their children's future (a fear supported by evidence in the literature that a lack of access to education contributes to a lifetime of exclusion, limited livelihoods opportunities, poor health outcomes, and cyclical poverty – Krupar, 2016; Pinnock and Hodgkin, 2010; Trani et al, 2011) and want what will give them the best opportunities to be included, valued and to be as independent as possible in life (phase 2; data set 2). They therefore desire opportunities for their children to realise their right to an inclusive education in their local community, supported by those with the power to make those opportunities a reality (phase 2, data set 2). Communities identify collaboration between service providers and the community as key to improving education enrolment, retention, and progression, for children who experience disability (phase 2, data set 2), reflecting findings in the research literature (Alborz et al, 2013; Karangwa, 2014; Karangwa et al, 2010; Miles, 2013).

As identified across this research, the current policy-implementation gap on disability inclusion in humanitarian contexts can only be closed when inclusion is prioritised and resourced effectively – a finding supported by the work of Alborz et al (2013); Battle (2015); Miles (2013); Sagahutu et al (2013); and Trani et al (2011). In phase two, findings indicate that tackling only one barrier to inclusion at a time, is thought to be ineffective (phase 2, data set 1, and phase 2, data set 2). An example has been a focus on enrolment of children with impairments into education in Rwanda's refugee camps, spurred on by new national inclusion policy, whilst the capacity to provide an accessible and inclusive learning environment has been under-resourced, resulting in children being excluded within the education system (phase 2, data sets 2 and 3).

While access to education is a privilege extended to some, rather than a right realised by all children, the potential for the creation of inclusive, fair, peaceful, and just societies, as envisioned in the SDGs, remains nothing more than a pipe dream. Whilst children who experience any form of disability are excluded from education and considered 'different' and 'incapable', the system that should support them fails to be acknowledged as discriminatory and oppressive. From a critical theory perspective, the potential for change towards emancipation and rights realisation has been identified in this research as lying within meaningful collaboration and authentic partnership between those who experience exclusion and those charged with ensuring their inclusion. Only then can the right to education for all be realised.

A key outcome of data integration resulting in this theme is the understanding that:

The potential for refugee children with CI in Rwanda to realise their right to education, and subsequent dignified futures, depends upon a collaborative approach to humanitarian systems strengthening – one which seeks to actively value and respond to the lived experiences and support needs of historically excluded children and families in its reconceptualisation.

7.2.3 Research rigour

In chapter 4, section 4.6.2, I presented a range of considerations to ensure research rigour in Interpretive Description research. Below, I summarise the actions taken to ensure as much research rigour as possible during this project, guided by Thorne's (2016) nine quality evaluation criteria (see section 4.6.2).

1. Epistemological integrity

   I endeavoured to demonstrate clear reasoning for decision-making throughout the research, beginning with explaining and proving a rationale for the philosophical underpinnings of the project, leading to the methodological choices to best answer the research question (chapter 4). According to Thorne (2016), findings are therefore likely to be considered credible.

2. Representative credibility

   Although this project did not utilise prolonged engagement with the participants, it did involve a prolonged, eight-year engagement with the organisation with, and for whom, the research was conducted (UNHCR Rwanda). Integration[61] of the analyses of six data sets (three in phase one, three in phase two), as well as with data from a comprehensive semi-systematic literature review (chapter 3)

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[61] Thorne (2016) refers to this as 'triangulation', which is contested by Clarke (2022) on epistemological grounds.

enhanced rigour. Thorne (2016) also advocates for the consideration of different perspectives within research. This was achieved by involving a range of participant groups, from service providers to refugee representatives, across phases one and two, framed by the global perspectives ascertained from the literature review (chapter 3).

3. Analytic logic

   I endeavoured to make decision-making explicit throughout the project and anticipate that the research would be replicable by another researcher, based on the information detailed in this thesis. Interpretations of data were grounded in verbatim data examples, which were given in chapters 5 and 6, to illustrate context.

4. Interpretive authority

   I ensured explicit reflexivity about my involvement, influence, and position in the research in section 7.3 below, to ensure this was acknowledged in the way I interpreted data and presented findings.

5. Moral defensibility

   I ensured the need for, and potential benefits of, the research were made explicit to the participants by employing a two-stage recruitment process, provision of participant information sheets in three languages and three levels of accessibility, as well as giving a verbal explanation before FGDs and interviews commenced.

6. Disciplinary relevance

   This research was designed with UNHCR Rwanda to fill a knowledge and understanding gap that affected their inclusive practice. It was therefore designed to be relevant to UNHCR and their practice from the outset. The disciplinary relevance of this research to host governments, humanitarians, educators, and speech and language therapists, is outlined in section 7.5 below, along with recommendations for future practice and research.

7. Pragmatic obligation

   Thorne (2016) describes how this relates to a pragmatic research paradigm in which research in applied fields at the same time appreciates the individuality of participants, whilst aiming to be practically relevant to a wider audience. This research project was designed and carried out on the understanding that the results would be of practical benefit to UNHCR Rwanda and their implementing organisations, as well as to the population of refugee children who experience CD, and their families. Individual contributions are valued, as well as acknowledged to feed into the wider data analysis (chapters 5 and 6).

8. Contextual awareness

   Thorne (2016) advocates for research findings to be presented as contextual, recognising that *"the issues being researched are not unique to one context, but [the researcher] recognises the context in which the research occurs" (Brewer et al, 2014: 1294).* A reflexive research process is consequently critical to this quality measurement. As such, I present a critically reflexive account of my position within the research in section 7.3 below.

9. Probable truth

   Thorne (2016) describes how ID researchers must understand truth to be fallible, which may alter perceptions and understandings of a phenomenon for a time but be altered by new evidence further down the line. The rationale for this project being philosophically grounded in a pragmatic research paradigm (chapter 4), with a broadly constructionist epistemology, provides an explanation of how I understand Deweyen inquiry and fallibility (section 4.2.3.1). I applied this to the results of my research by acknowledging its contextual nature and the need for more extensive research to deepen understanding of wider individual and collective experiences (see sections 7.4 and 7.5).

7.2.4 Discussion summary

In summary, the rigorously generated, analysed, and interpreted, data from this research, in combination with the existing literature, suggest that the extent to which children who experience CD realise their right to inclusive ECD and education in Rwanda is affected by the way in which humanitarian agencies, with the power to ensure rights realisation, choose to prioritise their interventions and resources. For refugees who experience CD to be heard, valued, and to realise their rights, humanitarian agencies that purport to implement rights-based interventions must be held to account through their own accountability mechanisms, and by the refugee community. This requires a cross-sectoral analysis of the humanitarian system, including education, and a conscious effort to engage, and value the contributions of, the historically marginalised and oppressed towards a transformative, inclusive, humanitarian agenda.

7.3 Reflexivity

Reflexivity is a process undertaken by researchers as part of an ethical, quality approach to research. It can be considered an act of self-reflection by the researcher during the research process (Lincoln and Guba (1985). Reflection and reflexivity are interrelated, yet also distinct (Pässilä, Oikarinen and Harmaakorp, 2015). As described by Cunliffe and Jun (2005), reflection is based on the idea that there is a reality from which the researcher can be separated, and therefore originates from a realist philosophical stance (see chapter 4, section 4.3.2.3 for a discussion on ‘bracketing’). In contrast, reflexivity is considered an action founded upon the notion that we continually construct the meaning of our world and is therefore grounded in (de)constructionist philosophy (Cunliffe and Jun, 2005). According to Cunliffe and Jun (2005), they therefore result in different social practices within research. Reflexivity requires deconstruction of a researcher's assumptions in a way that reflection does not (Cunliffe, 2009; Cunliffe and Easterby-Smith, 2004). Despite their differences, Pässilä et al (2015) acknowledge the potential for both reflection and reflexivity to contribute to critical thinking.

As this research is an Interpretive Description, carried out within a pragmatist paradigm, and with a broadly constructionist epistemology (see figure 1, chapter 1), reflexivity is the most appropriate form of providing a critical deconstruction of my positionality, power, perceptions, ingrained prejudices, and biases, as experienced through my experiential and cultural lenses. To aid this process, I kept a reflexive research journal throughout the research process, as suggested by Wall, Glenn, Mitchinson, et al (2004), with particular focus on the data construction period. In addition, I undertook reflexive debriefing activities with the RAs throughout the research process to help iteratively adjust interactions with participants.

7.3.1 Positionality and power

When conducting qualitative research as an 'outsider' (Liamputtong, 2010) from the research participant group(s), across differences such as culture, language, gender, age, and experience, perceptions of power and positionality affect how researchers and participants interact in different situations. Power dynamics can be fluid, changing throughout the research process (Ozano and Khatri, 2018). This, along with researcher skill, ultimately affects data richness and quality and therefore research outcomes. Transparency, therefore, is of the utmost importance.

Positionality incorporates the context of a person – their historical, cultural, religious, economic, educational, and social experiences and attributes – and what they bring to a research context. The positionality of a person is not only reliant upon what they see themselves bringing to the research, but also what those with whom interact during the research process perceive them to bring. As such, each research context is constructed through the perceptions of, and by, everyone involved. It is for this reason that reflexivity, and transparency of reflexive thought, is so critical to understanding the influences on, and outcomes of, research in different contexts. It is also partly why generalisability, as a measurement of research rigour, is almost impossible to achieve (and of little significance) in qualitative research design (see chapter 4, section 4.6).

Reflexive awareness and deconstruction of my positionality in this research played a significant role in the way I designed and implemented the project from the outset (see chapter 4, section 4.6). Initially, I considered my awareness and understanding of my history, power (and power shifts), experiences, preconceptions, and implicit biases. My history as national of a previously colonial power that had a significant impact upon the GLR, could not be ignored and had the potential to impact the research in different ways. I considered my positionality associated with factors as an 'outsider' to participant groups that could impact upon interaction with participants, including the following:

1. I am a mid-career, white, educated, European conducting research in refugee camps in the GLR, where resources and opportunities are severely limited. Origin, education level, and financial resources bring with them possible perceptions of status (and therefore power) in a hierarchical society and in a community that relies upon humanitarian aid for survival.
2. I have never lived through direct conflict, and never been forced to flee. I can therefore not currently understand the experiences of refugee participants through anything other than my own cultural and experiential lenses.
3. I am a woman, conducting research with men and women[62], older and younger than me. Gender, sex, and power dynamics may affect interactions, including the expectation for deference to elders, men, and/or those in positions of power, as determined by their community status or job role.

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[62] In this research, no participants identified as non-binary or any other gender.

4. I am associated with Universities and UNHCR – likely to be considered prestigious and powerful organisations. This may affect people's participation (consent to participant and contributions), both in positive and negative ways.

7.3.2 Cultural humility

Reflexive consideration of these aspects of my position placed me far away from the lived experiences of many of the participants. It was therefore critical that I considered my position and options to minimise impacts of my 'outsider' status, where possible. I did this through endeavouring to develop (and continuing to develop) cultural competence and humility during the research process. As I described in a paper I wrote on ethical SLT practice in east Africa (Barrett, 2016: 139):

> *"For speech-language pathologists to become sufficiently competent to practise internationally, it is essential to reflect upon motivations, skills and learning needs … and upon what cultural competence means in relation to their home, and overseas, practice. In addition, it is critical to consider the concept of cultural humility in relation to cultural competence; cultural humility being the acceptance that it is not possible to be fully knowledgeable about a culture other than that which one is born into... Practitioners must therefore understand that cultural competence and cultural humility are critical prerequisites to the delivery of appropriate, relevant and effective services and apply both concepts to their practice."*

Cultural humility underpins an iterative process of developing awareness, knowledge, and sensitivity of one's own and other cultures, whilst developing relevant, appropriate, and effective attitudes, behaviours, and practices to facilitate working across cultural and linguistic variation (Greene-Moton and Minkler, 2020). My previous experiences working in the GLR contributed to my development, as did the new understanding and experiences developed during the research process.

7.3.3 Utilising research assistants (RAs)

In this research, UNHCR staff were seconded as RAs to facilitate the research process with service provider and refugee participants (see chapter 5, section 5.13.1). Staff were Rwandan nationals who spoke English, Kinyarwanda[63] and French, so were able to interact with Burundian and Congolese refugees in their preferred language. Rwandan culture is also similar to Burundian and the eastern Congolese cultures, as the border areas share ethnic groups, traditions, behaviours, and practices. Despite these similarities and 'insider' attributes with the refugee community, RAs were set apart by their role as employees of UNHCR, which brought with it status and inherent power.

In addition to their mixed insider and outsider attributes (Liamputtong, 2010) positionality of the RAs is also a consideration in qualitative research as another person, with their own attributes, attitudes and beliefs, and perceived position and power, is involved in interactions with participants. The intersection of the positionality of the researcher, the RA, and the participants can lead to 'triple subjectivity' (subjectivity arising from three sources), affecting group power dynamics and interactions (Temple and Edwards, 2002). This can be fluid, depending upon contexts and participants.

It was therefore critical to engage in reflexive practice with the RAs during data construction planning, as well as during debriefing following FGDs and interviews. During these sessions, the RAs and I discussed aspects of power, positionality, envisaged and experienced impacts, and ways to mitigate any negative effects on the research as we progressed.

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[63] Kinyarwanda is linguistically similar to Kirundi (considered dialects of the same language) – the language spoken in Burundi, and is commonly spoken in Kivu state in DRC, from which refugees in Rwanda originate.

7.4 Ethical, methodological, and practical challenges and limitations

Several limitations associated with this research are related to research design, methodology, and scope. The complexity of the study, employing two research phases, and multiple data generation and analysis methods, across three locations and with multiple stakeholders, meant that practical limitations were also experienced. Some challenges were 'relational', or responses to unexpected dilemmas arising from spontaneous interactions (Aellah et al, 2016). In these cases, rapid decisions needed to be made with the best judgement possible in the circumstances. Any time this occurred, the experience was reflected upon in debriefs with RAs and notes made for transparency and iterative research adaptation.

7.4.1 Identification of research need

For this research to truly be transformative, as its sequential transformative research design suggests, the need for the research would ideally have been identified by the community to which it applies – in this case refugee children (or the families of) who experience CD in Rwanda – and led by the refugee community itself, for example using a Participatory Action Research approach (Gillis and Jackson, 2002). Although this was not the case, the need for the research was identified by a service provider, grounded in evidence generated from community consultations. As such, the research question can still be considered to have been generated by partial 'insiders'. Service providers (including UNHCR) were participants in the study themselves, and were co-creators of the research aims, objectives, and design. The fundamental role that UNHCR Rwanda staff played in the co-creation of the research project also means the research is co-owned and the findings of value to the organisation, increasing the likelihood of findings being given serious consideration and potentially contributing to transformation.

7.4.2 Research design and methodology

A discussion of benefits and limitations related to research methodology and each research method is provided in chapters 4, 5 and 6. Here I describe some actions, risks, and limitations, identified during the research process, as well as how these risks were mitigated.

1. Interpretive description

   Conducting the kind of flexible, applied, research that responds to real-world problems is not without risk. Such flexible designs can be subject to criticism and/or considered of less value than purist designs associated with clear ontological and epistemological schools of thought (e.g., Morse, 1989). This risk was mitigated somewhat by providing a clear description and rationale for the theoretical grounding of the project (chapter 4) and ensuring that the results and interpretations were clearly linked to the research question (chapters 5 and 6).

2. Practical limitations

   This study, although comprehensive, was conducted in only three out of seven refugee camp locations in Rwanda and was limited by practical factors such as camp access (granted by the Government of Rwanda in short bursts), time, and human resources. Ideally, the research would be carried out in all refugee communities in Rwanda, to ensure a more comprehensive representation of the population in different contexts (e.g., country of origin and crisis response stage). This would, however, realistically require a team of researchers.

3. Identification and recruitment of refugee children who experience CD.

   The original research design incorporated the identification and participation of refugee children who experience CD, to ensure the voices of those to whom the research intends to support, were elevated. It was, however, not possible to interview any children as a) only one was recruited according to inclusion criteria and b) it became apparent that the child who was recruited did not meet inclusion criteria during the interview. This may have been due to several factors inherent in the identification and recruitment process, including inaccurate registration of children who experience CD in the ProGres system (as identified in chapter 5, data set 1), lack of capacity of the RAs involved in identification and recruitment (including knowledge, skill, time), and lack of availability of potential participants during the research window. A review and redesign of participant recruitment processes is therefore required for any future research initiatives involving children who experience CD.

4. Consent

   Issues relating to consent in cross cultural research, and my experiences in this project, are described in chapter 5, section 5.14.1.

5. Data recording

   Data recording using written/typed notes during interviews and/or FGDs carries risks – data may be missed, misheard, or overtalked, especially in group conversation. Risks increase when there is live translation, where data fidelity is already compromised through a third-party. To increase data accuracy for analysis, audio recordings of FGDs and interviews were made so that transcription could be carried out as accurately as possible.

   In addition to being wary of 'heavy handed' and unfamiliar consent processes, some participants were also initially reluctant to have their voices audio recorded during FGDs and interviews. I was careful to explain the ethical checks and measures in place from MMU, University of Rwanda, MINEDUC, MIDIMAR, and UNHCR, to ensure that I would treat the data confidentially and according to the methods set out in the PIS. I explained that, if any participant felt that I violated any of these regulations at any point, I could be reported to any, or all, of the regulatory/monitoring bodies. This satisfied most participants.

6. Data availability

   The secondary data used in the statistical analysis of phase 1, data set 1 were limited by the data made available by UNHCR Headquarters and Rwanda Country Office. Certain data were not available, and some data were not shared by disability code (e.g., regional data), limiting the scope for full analysis. Furthermore, global data on CD are notoriously limited (see chapter 1 and chapter 5, part A) and therefore analysis of refugee data against global data, also severely limited in scope.

7. FGDs and interviews: socially desirable responses

   Limitations associated with conducting FGDs and interviews include the risk of participants giving socially desirable responses – *"the tendency to present oneself and one's social context in a way that is perceived to be socially acceptable, but not wholly reflective of one's reality" (Bergen and Labonté, 2019: 783).* There is minimal literature on these issues, particularly in cross-cultural research. Bergen and Labonté (2019), however, identify that socially desirable responses are more common in research on sensitive issues, in societies where certain behaviours and norms are strictly adhered to, and can be dependent upon the affluence of the country or location in which research is conducted. Although the risk is minimised in individual interviews, where peer-pressure to respond in culturally acceptable ways is reduced, participant responses may be impacted by researcher and RA positionality, as well as the perceived purpose of the research (King, Jackson, Dietsch et al, 2016; Jackson, Tesfay, Gebrehiwot et al, 2017).

   Socially desirable responses impact upon data, and therefore research outcomes. Although difficult to mitigate, regular planning meetings and debriefs with the

RAs allowed for discussion of these issues in a reflexive manner, and identification of some instances of perceived socially desirable responses. One example was from an implementing organisation member of staff responsible for providing inclusive services, who insisted that all refugee services were communication-accessible, no child was left behind, and that their organisation had the knowledge and skills to cater for refugee children who experience CD, whilst other staff members of the same organisation identified gaps and challenges. This was understood to be related to a perceived reputational risk by the individual who responded in a way also identified by Bergen and Labontés research – that *"everything is perfect and we have no problems"* (Bergen and Labonté, 2019: 783).

8. Classroom observations

   Data constructed in phase 2, data set 3, were limited by the small number and short nature of classroom observations able to be conducted during the research window. Data from the observations were integrated (Fetters et al, 2013) with data from data sets 1 and 2, to corroborate and/or identify differences between findings. The results, however, would benefit from data construction from a larger number of education locations (ECD and primary classrooms across research locations), with longer observations, multiple, possibly spontaneous, visits and, possibly, without the RA or education IO representative present to reduce the risk of preparation or performance.

9. Participant attendance

   It was common for either more than the maximum number of participants to attend the FGD, or for only a small number of people to be able to attend on the designated day and time. To mitigate non-attendance risk, more than eight participants per group were recruited to each session, on the assumption that a small number of people may not be able to attend. On occasion, all recruited participants did attend. In such cases, if all attendees had given prior written informed consent, I allowed the FGD to continue with more participants out of respect for the time people had dedicated to attend and as I judged that the number of participants remained reasonable, and that the data would remain relevant and manageable.

10. <u>Environment</u>

    Interviews generally took place in UNHCR camp offices or camp community buildings which were areas of high activity. Despite using a high-quality digital audio recording device, the poor acoustics of the interview venues affected the RA's ability to hear all the information accurately, and negatively affected the quality of the audio recordings. These factors will have ultimately affected the accuracy and quality of the data.

7.4.3 Translation and cultural brokering

As discussed in section 7.3 above, my position as an 'outsider' (Liamputtong, 2010) to the research participants was unequivocal. One method employed to mitigate this was the training and utilisation of bi-cultural RAs. As described in section 7.3.3 above, RAs were culturally members of, or closer to, the participant groups than I and were able to understand and iteratively adjust behaviours to meet their expectations. This cultural brokering came with implications for positionality and power dynamics within the FGDs and interviews but were reflected upon and taken into consideration during data interpretation and integration, as recommended by Hennick (2007).

I do not speak fluent Kinyarwanda or French, as the participants did, and was therefore faced with several options for constructing data, and choices regarding the role I played in data construction. Training RAs to conduct the interviews by themselves could have brought several benefits to the discussions beyond the practical, including mitigating the potential effects of my position as an ‘outsider’, with possible connotations of influence and/or power (see section 7.3.1). I discussed this with the RAs during training and they assured me that, in the context of working with UNHCR and their partner organisations, I would be viewed as ‘staff’ and that refugees in the camps are used to interacting with ‘outsiders’ from UNHCR and implementing organisations on a regular basis.

Considering this, and as time was very limited for RA training (one day) due to UNHCR staff commitments, I felt that it was unrealistic to train the RAs to conduct the FGDs and interviews in their entirety to be translated from audio-recordings later. I felt that doing so could compromise the quality of the data. I also did not have the resources to translate such a lot of data from audio-recordings later. Moreover, previous experience of third-party transcription of multi-lingual group audio-recordings also taught me of the challenges associated with accurate transcription due to accent, code switching, and use of technical terminology across languages. As such, I felt that my experience living and working in Rwanda, and subsequent grasp of accents, phraseology, and technical terminology, was valuable to the transcription process.

Despite the possible negative effects of my being present in the FGDs and interviews, I also felt that being present would allow me not only to pursue interesting avenues of discussion, but also to get a sense of people’s engagement with the topics being discussed, gauging people’s level of interest/motivation, and taking note of their body language, facial expression, animation and the mood of the room, to enable me to adjust my responses accordingly. Considering these issues, I decided to use real-time live translation during FGDs and interviews, with the RAs acting not only as translators, but co-facilitating the discussions as peer interviewers, As described by Elliott, Watson, and Harries (2002), peer interviewers can act as a bridge between an ‘outsider’ researcher and group participants, not only vouching for the researcher but also bringing their trusted relationship with participants to the research. This is particularly the case for ‘hard to reach’ groups who are often excluded from research activities, such as people who experience CD (Jagoe et al, 2021).

Each RA received training in qualitative research methods, including conducting FGDs and interviews, and the importance of accurate translation for data fidelity. This included discussion about the need for word-for-word translation where possible and pausing to translate small chunks of data.

Upon conducting live-translated, peer interviewer, discussions I encountered several challenges. These included:

1. **The Kinyarwanda language does not always have an accurate translation for some English terms**, and vice versa. Thorne (2016: 139) cautions that *“what we can verbalise begins to shape what we are able to think about.”* It is therefore important to consider that translation of new ideas and concepts related to CD into Kinyarwanda may have affected how people were able to think about and articulate their thoughts and experiences. Similarly, it may have affected the translated English version of whatever the participants were trying to convey in Kinyarwanda, such as the concept of ‘ubuntu’ (see G1, GT2 in chapter 6). It may have also influenced who was recruited to the study based on RAs’ understanding of CD.

2. **The need for accurate translation was possibly not understood clearly and/or the RAs were not sufficiently practised in translation for research purposes.** For example, I noticed (with my rudimentary understanding of Kinyarwanda) that once when I said ‘disability’, the resulting translation included ‘communication disability’, when I was referring to disability more broadly at that point in the discussion.

3. **Participants sometimes elaborated on their contributions** so that it was difficult for the RA to keep up or to interrupt to translate smaller chunks. Sometimes larger chunks of information were condensed into a ‘summary’ by the RA, thus potentially affecting the richness and accuracy of the data.

These challenges were discussed with the RAs after each discussion when time allowed, or at the end of each day. However, the challenges remained throughout both stages of the data collection. More extensive training for RAs would be desirable for any future research, alongside better resourcing for post-FGD/interview translation, so as not to interrupt participant discussions.

7.4.4 ‘Spot checking’

A further ethical quandary occurred when a senior government official joined a FGD with the camp disability committee without prior discussion. This posed a threat to the confidentiality of the discussion for the participants (which had been stipulated as part of the consent process) and may have affected their level of participation and/or the content of the discussion. Under the circumstances I did not feel able to question their presence due to their position and the cultural implications associated with hierarchy and positions of power and responsibility in Rwanda, which are highly respected and conformed to. As Government representative, it was their responsibility to ensure that they were well informed about things happening in the camp. The RA did not question their presence and appeared comfortable with them being there during the FGD, as did the participants who, as a camp committee, were used to working closely with management. Their presence, however, may have influenced what participants were willing to discuss during the session.

7.4.5 Humanitarian-academic partnership

Humanitarian-academic partnerships are a relatively new development, despite the need for humanitarian best practice to be evidence-based. The very nature of humanitarian emergencies means that there is often little bandwidth for humanitarian agencies to accommodate research within a crisis response, without compromising their limited resources. As more and more protracted crises occur, there is increasing opportunity for research partnerships to be established. Humanitarian and academic organisations, however, operate very differently – with different mandates, priorities, and measures of success – and don't always understand each other's organisational culture in their collaborations. As described by Levine (2016: 2), *"Much of the disconnect between academic institutions and humanitarian organisations comes down to basic cultural differences between the two communities."*

Despite the organisational cultural differences, the need for this research was identified by UNHCR Rwanda, who supported the logistics and human resource allocation for carrying out the study – a very positive indication of the increasing value of, and support for, generation of high-quality evidence in humanitarian contexts. The partnership meant that some of the difficulties identified by Levine (2016) were mitigated from the start. Supporting the partnership, required rapport-building, clear communication, honesty, and flexibility throughout, on both parts - a finding supported by other humanitarian-academic partnerships with UNHCR Rwanda (Marshall et al, 2016).

7.4.6 Research with refugees hosted in low resource communities

There is little question that refugee communities – particularly those hosted in refugee camps – are resource-poor and sometimes have limited access to host community resources and services. In cases where refugees are hosted by resource-limited local communities,[64] however, the resources and services provided to refugees by

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[64] up to 71% of refugees globally (Ahmed, 2023).

humanitarian agencies can far supersede those available in the host communities. Access to communication-accessible services, for example, could be considered an example of striving for better service provision for refugees than those their host communities have access to. It is important, therefore, to be cognizant of the opportunities for host communities to also benefit from research outcomes and their impacts upon service delivery. This not only assists a larger group to access services more effectively but may also promote refugee integration and social cohesion (Winkler, Sacks and Wong, 2022).

7.5 Practice and research implications

Discussion of integrated findings, as well as recognition of the limitations of this research project, leads to considering future directions for both practice and research. In this section, I present implications for practice relevant to humanitarian and development actors (including host governments), speech and language therapists practising in humanitarian (and similar resource constrained) contexts, and disability and social inclusion practitioners, as well as considerations of future research directions that could enhance understanding of how to ensure educational rights realisation for refugee children who experience CD in Rwanda and beyond.

7.5.1 Future practice

For refugee children with CI, who are dependent upon humanitarian services, the power to change the status quo and ensure rights realisation lies primarily with humanitarian organisations. The potential to shift power from humanitarian organisations and towards those who have been marginalised requires a fundamental paradigm shift in how humanitarians conceptualise their involvement in crises and value the contributions of populations of concern. Reflecting critical theory perspectives, this is most important for those who have been historically excluded within the humanitarian system (in this case refugees who experience CD), moving them towards inclusion, participation, and emancipation. This involves knowing who they are, opening a seat at the table, then listening, valuing, and being responsive to, their experiences, needs, and wishes.

The current practice of consulting with communities, during which humanitarian organisations continue to hold power, has the potential to be reimagined as a collaborative relationship, where power is rebalanced between service users and providers. Historically, refugees who experience CD have been excluded from consultations that other refugees in their community typically have access to (reflected in Jagoe et al, 2021). Collaboration and authentic partnership, however, hold the potential for a refugee-led agenda, with increased participation and value of the capabilities of those who experience intersecting identities of refugeehood and CI, increased dignity, and respect for their lived experiences of exclusion, and the creation of responsive, communication-inclusive, communities and services.

Considering the perspectives, experiences, and needs of a wide range of stakeholders, including service planners, providers, and users, is critical to the development of inclusive education systems and services that work in different contexts. Analysis of what contributes to disablement for children with CI within the humanitarian education system is key to the process of inclusive service design and demands a systemic approach to thinking and action. Indeed, if those in positions of power fail to use that power to ensure equity of access in their services for those with communication impairments, they will, by default, *contribute* to inequity and communication-related disablement. To be aware of barriers to participation and service access for this group, and to fail to address those barriers, constitutes discriminatory behaviour. No amount of policy will bring about change without commitment and action and pulling on only one string of the system (e.g., policy), will not necessarily instigate change if the other contributors to the system remain unchanged (see figure 34). A systemic overhaul of humanitarian assistance, framed around human rights, is therefore required. This must, however, be done with sensitivity to local contexts – a 'one size fits all' approach is unlikely to be sufficient for successful inclusion for children with different impairment types and lived experiences in different humanitarian situations.

Capitalising upon global inclusion agendas was identified in this research as holding the potential to address the identified barriers to communication inclusion in Rwanda. Although humanitarian systems suffer from under-resourcing across the board (phase 1, data set 2; phase 2, data set 1), inclusive practice (including in the education in emergencies system) is evidenced to be more resource efficient than segregation and/or specialist service provision and the costs of exclusion (both to individuals and societies) are reported to be incalculable (Karangwa, 2014). The potential for refugee children who experience CD to realise their right to education lies within a fundamental reconceptualisation of humanitarian, and within that refugee education, systems, in line with the 'no-one left behind' (Agenda 2030, UNDESA, 2015a) philosophy, that would benefit all children.

Humanitarian systems review, and strengthening, to achieve full inclusion, participation, and rights realisation for refugees who experience CD, may, at first glance, seem like an insurmountable task. Stakeholders in this research, however, were able to identify entry points for immediate attention that may serve as a realistic and motivational starting point for increasing understanding, acceptance and inclusion of refugee children who experience CD in Rwanda. These suggestions span improvements to the areas of policy, institutions/organisations, and people and include:

1. **Local policy and implementation plan review** to ensure clear inclusive practice, monitoring and evaluation, and accountability mechanisms are in place to ensure inclusion of the most marginalised, including refugee children who experience CD.

2. **Data collection tool review and redesign** to ensure information on communication abilities challenges, accessibility requirements, and barriers to participation, is collected accurately.
3. **Inclusive budgeting,** to redistribute funding from provision of segregated education for a small number of children, towards funding inclusive practice in local education services, for all children, including those with communication impairments.
4. **Community and service provider sensitisation** and training to increase understanding of the causes, nature and impacts of communication impairment and disability.
5. **Service provider (including educator) capacity building and ongoing support** to provide adapted and communication accessible ECD and education services.
6. **Inclusive monitoring, evaluation and learning systems,** including those related to inclusive policy**,** holding actors to account for the services they provide and ensuring no group of children is left behind.

Identifying immediately implementable and achievable goals may go some way to mitigating implementer overwhelm and progress stagnation on inclusion that is well documented in the literature (literature review; phase 1, data set 2; phase 2 data set 1). Participants in this research also identified the importance, and motivational power, of appreciating what has been achieved so far, building upon successes, and celebrating the small wins that can add up to more significant changes in the longer term. It is also critical for this learning to be documented throughout the change process and for it to inform the iterative development of humanitarian systems, tools, and process for inclusive practice. Using a systems thinking approach (Campbell, 2021a; 2021b - see chapter 5, section 5.19) to identify opportunities for practical steps towards communication-accessible inclusive education practice, could motivate those in positions of power to implement immediately actionable changes, whilst planning for longer-term, more sustainable development opportunities.

This study was carried out in Rwanda, and therefore contributes new knowledge and understanding specific to the Rwandan context. It does, however, also shed light on the role global policy and humanitarian systems play in educational access for refugee children who experience CD – a group that appears to experience neglect from humanitarian service inclusion worldwide. Findings may, therefore, be applicable to refugee children who experience CD in similar contexts in the GLR and across the world. Indeed, there is potential for Rwanda to lead the way on research, practice-based learning, and impact evaluation of improvements to humanitarian education systems, tools, and processes that could be used as a starting point for the development of other communication-accessible humanitarian services and sectors, and to other humanitarian contexts across the globe. UNHCR headquarters has shown a keen interest in the research from its inception and has commented on the potential for the findings to applied regionally and globally in similar humanitarian contexts. The results of this research, therefore, have the potential to influence thinking and decision making on inclusive education that may benefit refugee children who experience CD beyond Rwanda.

7.5.2 Future research

The literature review in chapter three illustrates the paucity of evidence on CD within refugee populations, and more so when considering the intersection of CD, refugeehood, and educational rights realisation. Although this research has addressed a research gap on the extent to which refugee children who experience CD realise their right to education in Rwanda, further research is now required to bolster the evidence base on opportunities and barriers to communication accessible education in Rwanda, as well as other forced migration contexts. This evidence could assist in making the case for investment of humanitarian resources in communication accessible ECD and education services for refugee children in Rwanda and beyond.

To ensure that future practice in inclusive education is communication inclusive and improves participation and rights realisation for refugee children who experience CD, a participatory research agenda on these issues should, ideally, be identified and led by the refugee community, supported by humanitarian and research institutions who can facilitate implementation. This presents a challenge as CD is yet to be an area flagged by refugees as a priority for research, possibly because the issue is only now being raised by researchers in CD who are beginning to engage in humanitarian contexts. At this point in time, therefore, the agenda may have to be more expert (and therefore primarily 'outsider') led.

From an outsider's perspective, and based on the outcomes of this research, further evidence to make the case for investment in communication accessible education for refugee children is required on several issues, including (but not limited to):

1. Identification and registration of CI and CD within refugee communities regionally/globally, including piloting and evaluating the effectiveness of various methods to improve identification and registration systems, tools, and processes.
2. Drivers of negative attitudes, behaviours, and practices related to CI and CD in varied humanitarian contexts.
3. The impacts and outcomes of communication (in)accessible environments and societies on refugee children and their families, beyond (but with impacts on) the education sector, from a systems thinking perspective.
4. The impacts and outcomes of segregated education practices on refugee children who experience CD and their families.
5. Outcomes of investment in communication inclusive ECD services, on refugee children's later access to primary school.
6. What works most effectively (and what does not work) to improve knowledge, understanding, and skills on CI and CD among humanitarian service providers?

7. Pain points/barriers to implementing inclusive policy effectively in humanitarian settings, with regards to CD.
8. Existing communication-inclusive education practices in different forced migration contexts – successes and challenges (and reasons why).
9. Cost-benefit analysis of communication-inclusive education services for refugee children who experience CD in Rwanda, the GLR, and globally.

Evidence of 'what works' (and what does not) in humanitarian contexts is lacking across the board, often driven by ongoing crisis response and a lack of time or capacity to engage in meaningful and robust research with refugee communities (Levine, 2016). This creates situations where non-evidence- based interventions are implemented, repeated, and seldom evaluated for impact, thus contributing to cavalier resource use in already resource-limited settings. The recognition of some organisations (such as Elrha) that research in humanitarian contexts (especially research driven by the refugee community itself) is essential to the design and provision of quality services for displaced populations, demonstrates a step in the right direction towards responsive, appropriate, and effective service provision.

7.6 Thesis conclusion

This study has contributed to addressing a significant research gap, as identified by key humanitarian stakeholders and supported by the limited evidence base. It answered the research question *'to what extent do refugee children, who experience communication disability, realise their right to inclusive ECD and education in Rwanda?*

Conducting an Interpretive Description (ID: Thorne, 2016) enabled me to locate the research within existing theory and knowledge (chapter 3), to appreciate new, emerging knowledge and understanding (chapters 5 and 6), and to relate its practical applications to the field context (this chapter). As described in chapter 4, section 4.5.2.2, the ID methodology supports the generation of both service-relevant (in this case registration, ECD and education services for refugees) and socially relevant findings, with the voices of persons of concern at the core. In analysing the data and presenting findings to UNHCR and their partners, the opinions of the excluded and their service providers can be brought to the fore, fulfilling an advocacy function culminating in a call for social action.

This comprehensive analysis of refugee policy and guidance on inclusive registration and education systems, in combination with service providers and service user experiences and perceptions, offers a new, 360^{o}, understanding of the opportunities and barriers to inclusive humanitarian practice in Rwanda, for refugee children who experience CD, and their facilitatory or inhibitory impacts upon rights realisation. Moving beyond a deeper understanding of the underlying and interlinking causes of the problem of educational exclusion, the research also offers insights into the opportunities that exist to improve educational access in Rwanda and offers suggestions for embarking upon a systems-thinking approach to holistic education and humanitarian systems review and reconceptualisation, with rights realisation for refugee children who experience CD as a guiding principle. The findings from this research will be of value to humanitarian policymakers, donors, service planners and service providers in Rwanda, and may be applicable in similar humanitarian contexts across the world, with local contextualisation.

Change and impact take time and often more resources and funding, but stakeholders in Rwanda have identified several opportunities for immediate improvement in access to current inclusive education services for refugee children who experience CD (such as sensitisation, increased collaboration with communities, teacher training), whilst commitment and funding are secured for longer-term change. The generation of new evidence on the barriers and opportunities for educational rights realisation from a systems perspective, elevating the voices of refugee families living with the impacts of

CD within their households, is a sound starting point for generating renewed interest in, and longer-term commitment to, inclusive education opportunities for all children.

Approaching change from a 360^0 perspective, as occurs when using a systems-thinking approach, can ensure communication-accessible education becomes a reality for refugee children in Rwanda. Education for *all* children must be framed by human rights so that no child is left behind. The long-term individual, national, and global benefits of inclusive education for refugee children who experience communication disability across the world today, cannot be underestimated.

Bibliography

¡Ntgrty. (2016). *Research Paradigms: Postmodernism.* [Online]. [Accessed 13th February 20202]. http://www.intgrty.co.za/2016/09/20/research-paradigms-postmodernism/

Abdullahi, S.A., and Farouk, M.K. (2014). 'Mixed methods research in global education: Towards a new paradigm for global citizenship education'. *International Journal of Secondary Education*, 2(3) pp. 52-60

Adelaine, A. (2015). *Participatory Inquiry in Practice [PIP] NGO Accountability, Action Research and Urban Youth in Kampala*. Ph.D. De Montford University. [Online]. [Accessed on 7th July 2023] https://www.researchgate.net/publication/316228435_PARTICIPATORY_INQUIRY_IN_PRACTICE_PIP_NGO_ACCOUNTABILITY_ACTION_RESEARCH_AND_URBAN_YOUTH_IN_KAMPALA

Aellah, G., Chantler, T., & Geissler, P.W. (2016). *Global Health Research in an Unequal World: Ethics Case Studies from Africa.* Croydon, UK: CABI.

African Union. (1969). *OAU Convention Governing the Specific Aspects of Refugee Problems in Africa*. [Online]. [Accessed on 14th November 2023]. https://au.int/en/treaties/oau-convention-governing-specific-aspects-refugee-problems-africa.

African Union. (2018). *Protocol to the African Charter on Human and Peoples' Rights on the Rights of Persons with Disabilities in Africa.* [Online]. [Accessed on 24th November 2023]. https://au.int/en/treaties/protocol-african-charter-human-and-peoples-rights-rights-persons-disabilities-africa.

African Union. (2019). *List of Countries which have Signed, Ratified/Acceded to the OAU Convention Governing the Specific Aspects of Refugee Problems in Africa.* [Online]. [Accessed on 24th November 2023]. https://au.int/sites/default/files/treaties/36400-sl-

OAU%20Convention%20Governing%20the%20Specific%20Aspects%20of%20Refugee%20Problems%20in%20Africa.pdf

Age and Disability Consortium. (2018). *Minimum Standards for Age and Disability Inclusion in Humanitarian Action.* London: ADCAP. [Online]. [Accessed on 12th February 2022]. <https://reliefweb.int/sites/reliefweb.int/files/resources/Minimum_Standards_for_Age_and_Disability_Inclusion_in_Humanitarian_Action_0.pdf>

Ahmed, S. (2023). *A Perfect Storm of Crises: Why Refugee-Hosting Countries Need More Support.* International Centre for Migration Policy Development. [Online]. [Accessed on 2nd July 2023]. https://www.icmpd.org/blog/2023/a-perfect-storm-of-crises-why-refugee-hosting-countries-need-more-support

Alborz, A., and McNally, R. (2004). 'Developing methods for systematic reviewing in health services delivery and organization: an example from a review of access to health care for people with learning disabilities. Part 1. Identifying the literature'. *Health Information and Libraries Journal,* 21. Pp. 182-192.

Alborz, A., Slee, R., and Miles, S. (2013). 'Establishing the foundations for an inclusive education system in Iraq: reflection on findings from a nationwide survey'. *International Journal of Inclusive Education,* 17(9) pp. 965-987.

Alam, S. (2019). 'Majority World: Challenging the West's Rhetoric of Democracy'. *Amerasia Journal,* 34(1) pp. 88-98.

Alkire, S., and Foster, J. (2011). 'Counting and multidimensional poverty measurement'. *Journal of Public Economics*, 97(7-8) pp. 476-487.

Anderson, K., and Saeed, S. (2022). *Research in Young Children in Emergencies: Current Evidence and New Directions*. Moving Minds Alliance. [Online]. [Accessed on 14th May 2023]. https://movingmindsalliance.org/wp-content/uploads/2022/12/MMA_ResearchForum_Research-on-Young-Children-in-Emergenices_Dec2022.pdf

Andoh-Arthur, J. (2019). 'Gatekeepers in Qualitative Research'. *In* Atkinson, P., Delamont, S. Cernat, A., Sakshaug, J.W., & Williams, R.A. (Eds.) *SAGE Research Methods Foundations*. London: SAGE.

Andrews, E.E., Powell, R.M., and Ayres, K. (2022). 'The evolution of disability language: Choosing terms to describe disability'. *Disability and Health Journal,* 15 pp. 1-5.

Angrosino, M.V. and Meys de Perez, K.A. (2000). 'Rethinking observation: From method to context'. *In* Denzin, N.K., and Lincoln, Y.S. (eds). *Handbook of Qualitative Research*. Second Edition. Thousand Oaks, CS: Sage.

Atkinson, P.A., and Coffrey, A. (1997). 'Analysing documentary realities.' *In* Silverman. D. (ed.) *Qualitative Research: Theory, Method and Practice.* London: Sage.

Attride-Stirling, J. (2001). 'Thematic networks: an analytic tool for qualitative research.' *Qualitative Research,* 1(3) pp. 385-405.

Ayazi, T., Swartz, L., Eide, A.H., Lien, L., and Hauff, E. (2015). 'Perceived current needs, psychological distress and functional impairment in a war-affected setting: a cross-sectional study in South Sudan.' *BMJ Open*, 5:e007534. [Online]. [Accessed 7th July 2023]. https://pubmed.ncbi.nlm.nih.gov/26289449/

Ballard, J., Wieling, E., Solheim, C., and Dwanyen, L. (eds). (2016). *Immigrant and Refugee Families, 2nd edn.* M Libraries Publishing. [Online]. [Accessed on 14th May 2023]. https://open.lib.umn.edu/immigrantfamilies/

Barnett, M., and Weiss, T.G. (2008). 'Humanitarianism: A brief history of the present.' *In* Barnett, M., and Weiss, T.G. (eds.). *Humanitarianism In Question: Politics of Military and Humanitarian Interventions.* New York: Zone Books.

Barnett, M., and Weiss, T.G. (2011). *Humanitarianism Contested: Where Angels Fear to Tread.* Manchester: Routledge Global Institutions Series.

Barrett, H. (2016). 'Applying theories of cultural competence to speech-language pathology practice in East Africa.' *Journal of Clinical Practice in Speech-Language Pathology,* 18(3) pp. 139-144.

Barrett, H. (2021). *Language Matters: Why We Need to Rethink Disability Language.* Helen Barrett Inclusion Consultancy: Blog (21st October). [Online]. [Accessed on 13th May 2023] https://www.helenbarrettinclusion.com/post/language-matters-why-we-need-to-reimagine-disability-terminology

Barrett. H., and Marshall, J. (2013). 'Implementation of the World Report on Disability: developing human resource capacity to meet the needs of people with communication disability in Uganda'. *International Journal of Speech-Language Pathology,* 15(1) pp. 48-52.

Barrett, H., and Marshall, J. (2017). *Sexual and Gender-Based Violence against Refugees with a Communication Disability and Challenges to Accessing Appropriate Support: A literature review.* Humanitarian Innovation Fund. [Online]. [Accessed on 26th February 2020]. https://www.elrha.org/wp-content/uploads/2017/03/sgbv-literature-review-2.pdf

Barrett, H., Marshall, J., and Goldbart, G. (2019). 'Refugee children with communication disability in Rwanda: providing the educational services they need'. *Forced Migration Review* (March), Pp. 36-38. [Online]. [Accessed 7th July 2023]. https://www.fmreview.org/sites/fmr/files/FMRdownloads/en/education-displacement/FMR60_Education_2019.pdf

Barrett, H., Turatsinze, F., and Marshall, J. (2016). 'Strategic Thinking Achieves Change'. *RCSLT Bulletin*, July edition pp. 18-19.

Battle, D. (2015). ‘Persons with communication disability in natural disasters, war and/or conflict’. *Communication Disorders Quarterly*, 36(4) pp. 231-240.

Baumeister, R.F., and Leary, M. (1997). ‘Writing narrative literature reviews’. *Review of General Psychology,* 1(3) pp. 311-320.

Bentley, A. F., and Dewey, J. (1949). *Knowing and the Known.* Boston: Beacon Press.

Bergen, N., and Labonte, R. (2019). ‘“Everything is perfect and we have no problems”: Detecting and Limiting Social Desirability Bias in Qualitative Research.’ *Qualitative Health Research,* 30(5), pp. 783-792.

Berger, M.T. (2004). ‘After the Third World? History, destiny and the fate of Third Worldism’. *Third World Quarterly.* [Online]. ‘First online’. [Accessed on 7th July 2023]. https://www.tandfonline.com/doi/abs/10.1080/0143659042000185318?journalCode=ctwq20

Berkowitz, S. (1997). Analyzing qualitative data. *In* Frechtling, J., and Sharp, L. (Eds.), *User-friendly Handbook for Mixed Method Evaluations.* Arlington, VA: Division of Research, Evaluation and Communication, National Science Foundation. [Online]. [Accessed on 8th November 2019]. http://www.nsf.gov/pubs/1997/nsf97153/start.htm

Betts, A., & Collier, P. (2017). *Refuge. Transforming a Broken Refugee System.* Milton Keynes: Penguin Random House.

Betts, A., Loescher, G., & Milner, J. (2012). *UNHCR: The Politics and Practice of Refugee Protection.* Manchester: Routledge Global Institutions Series.

Bickenbach, J. (2011). The World Report on Disability. *Disability & Society* 26(5), pp. 655-658.

Bickenbach, J.E., Chatterji, S., Badley, E.M., & Ustün, T.B. (1999). Models of disablement, universalism and the international classification of impairments, disabilities and handicaps. *Social Science and Med*. 48(9), pp. 1173-87.

Biritwum, R.B., Devres, J.P., Ofosu-Amaah, S., Marfo, C., and Essah, E.R. (2001). ‘Prevalence of children with disabilities in central region, Ghana.’ *West African Journal of Medicine,* 20(3): 249-255.

Boesten, K. (2018). *The Bantu Expansion.* Oxford Research Encyclopaedias: African History. [Online]. [Accessed 7th July 2023]. https://oxfordre.com/africanhistory/display/10.1093/acrefore/9780190277734.001.0001/acrefore-9780190277734-e-191;jsessionid=ADA9DE3E09FE47493B561B5AFCB5488F

Booth, A., Sutton, A., Clowes, M., and Martyn-St James, M. (2021*). Systematic Approaches to a Successful Literature Review*. London: SAGE publications.

Bouchane, K., Yoshikawa, H., Murphy, K.M., and Lombardi, J. (2018). *Early Childhood Programs for Refugees*. Paris: UNESCO.

Bowen, G.A. (2009). ‘Document analysis as a qualitative research method’. *Qualitative Research Journal*, 9(2) pp.27-40.

Boyatzis, R. E. (1998). *Transforming Qualitative Information: Thematic Analysis and Code Development.* Ca: Sage Publications, Inc.

Bradbury-Jones, C., Breckenridge, J., Clark, M.T., Herber, O.R., Wagstaff, C., and Taylor, J. (2017). ‘The state of qualitative research in health and social science literature: A focused mapping review and synthesis.’ *International Journal of Social Research Methodology,* 20(6) pp. 627-645.

Braun, V. and Clarke, V. (2006). ‘Using thematic analysis in psychology.’ *Qualitative Research in Psychology,* 3(2) pp.77-101.

Braun, V., and Clarke, V. (2013). *Successful Qualitative Research: A Practical Guide for Beginners*. London: Sage.

Braun, V., and Clarke, V. (2019a). ‘Reflecting on reflexive thematic analysis.’ *Qualitative Research in Sport, Exercise and Health*, 11(4): 589-597.

Braun, V., and Clarke, V. (2019b). *Answers to Frequently Asked Questions about Thematic Analysis.* [Online]. [Accessed on 13th July 2022]. https://cdn.auckland.ac.nz/assets/psych/about/our-research/documents/Answers%20to%20frequently%20asked%20questions%20about%20thematic%20analysis%20April%202019.pdf

Braun, V., and Clarke, V. (2021a). ‘Can I use TA? Should I use TA? Should I not use TA? Comparing reflexive thematic analysis and other pattern-based qualitative analytic approaches.’ *Counselling and Psychotherapy Research,* 21 pp. 37-47.

Braun, V., and Clarke, V. (2021b). ‘One size fits all? What counts as quality practice in (reflexive) thematic analysis?’. *Qualitative Research in Psychology,* 18(3) pp. 328-352.

Brewer, K.M., Harwood, M.L.N., McCann, C.M., Crengle, S.M., and Worrall, L.E. (2014). ‘The use of interpretive description within Kuapapa Māori Research.’ *Qualitative Health Research,* 24(9) pp. 1287-1297.

Bryman, A. (2006). ‘Integrating quantitative and qualitative research: How is it done?’. *Qualitative Research*, 6: 97–113.
Burch, R. (1989). ‘On phenomenology and its practice.’ *Phenomenology and Pedagogy*. 7 pp. 187-217. [Online]. [Accessed on 31st August 2020]. https://journals.library.ualberta.ca/pandp/index.php/pandp/issue/view/1059

Burns, N. (1989). ‘Standards for qualitative research.’ *Nursing Science Quarterly,* 21(1) pp. 44-52.

Byatnal, A. (2021, August 24th). *Deep dive: Decolonizing Aid – from Rhetoric to Action.* Devex Newswire. [Online] [Accessed on 6th May 2023]. https://www.devex.com/news/deep-dive-decolonizing-aid-from-rhetoric-to-action-100646

Byrne, M. (2001). 'The concept of informed consent in qualitative research'. *AORN Journal,* 74(3) pp. 401-403.

Calhoun, C. (2010). 'The idea of emergency: humanitarian action and global (dis)order'. *In* Fassin, D., and Pandolfi, M. (eds). *Contemporary States of Emergency: The Politics of Military of Humanitarian Interventions.* New York: Zone Books.

Campbell, L. (2021a). *Systems Thinking Handbook for Humanitarians.* ALNAP Paper. London: ODI/ALNAP. [Online]. [Accessed on 7th July 2023] https://www.urban-response.org/system/files/content/resource/files/main/ALNAP%20Systems%20thinking%20handbook.pdf

Campbell, L. (2021b). *Systems Thinking for Humanitarians: An Introduction for the Complete Beginner.* ALNAP Paper. London: ODI/ALNAP. [Online]. [Accessed on 7th July 2023]. file:///C:/Users/HelenBarrett/Downloads/Systems%20thinking%20for%20complete%20beginner%20ALNAP%20(1).pdf.

Carcary, M. (2009). 'The research audit trail: Enhancing trustworthiness in qualitative inquiry.' *The Electronic Journal of Business Research Methods,* 7(1) pp. 11-24.

Casha, S. (2016). *Speaking of Angels: Intellectual Disability, Identity and Further Education in Malta.* Ph.D. University of Birmingham. [Online]. [Accessed 15th May 2021]. https://etheses.bham.ac.uk/id/eprint/66010/

Cambridge Dictionary. (2022). *The International Community.* [Online]. [Accessed on 6th May 2023]. https://dictionary.cambridge.org/dictionary/english/international-community.

Chance for Childhood. (2022). *'"They Take Pictures of Our Pain": Grace's Story'.* Latest News (13th September). [Online]. [Accessed 13th May 2023]. https://chanceforchildhood.org/latest-news/they-take-pictures-of-our-pain-graces-story/

Charmaz, K. (1994). ‘Grounded theory: Objectivist and contructivist methods.’ *In* Denzin, N.K., and Lincoln, Y.S. (Eds). *Handbook of Qualitative Research (2nd ed.)* Thousand Oaks, CA: Sage.

Chataika, T., McKenzie, J.A., Swart, E., and Lyner-Cleophas, M. (2012). ‘Access to education in Africa: responding to the United Nations Convention on the Rights of Persons with Disabilities.’ *Disability and Society,* 27(3) pp. 385-398.

Clarke, V. (2022). ‘A thread of musings starting with generalisability - a term often associated solely with quant’. *Twitter.* September 17th, 2022. [Online]. [Accessed on 10th June 2023]. https://twitter.com/drvicclarke/status/1571181338308345856

Claydon, L.S. (2015). ‘Rigour in quantitative research.’ *Nursing Standard,* 29(47) pp. 43-48.

Collins, P.H. (2017). ‘Social inequality, power and politics: Intersectionality in dialogue with American Pragmatism.’ *In* Dieleman, S., Rondel, D., and Voparil, C. (Eds). *Pragmatism and Justice.* New York: Oxford University Press.

Costello, C., and Briddick, C. (2022). *The Legal Approach*. University of Oxford Refugee Studies Centre: Oxford.

Creeley, E.A. (2011). *An Ethno-Phenomenological Study of Actors’ Experiences of Performing in Theatre.* Ph.D. Monash University. [Online]. [Accessed on 27th August 2020]. https://bridges.monash.edu/articles/An_ethno-phenomenological_study_of_actors_experiences_of_performing_in_theatre/4597681

Creswell, J. (2007). *Qualitative Enquiry and Research Design – Choosing Among Five Approaches.* (2nd ed.). London: Sage.

Creswell, J. (2009). *Research Design: Qualitative, Quantitative and Mixed Method Approaches* (3rd ed.). California: SAGE.

Creswell, J. (2013). *Developing Mixed Methods Research*. Sage Research Methods. [Online Video]. [Accessed on 7th July 2023]. https://dx-doi-org.mmu.idm.oclc.org/10.4135/9781506358383

Creswell, J., and Plano Clark, V. (2007). *Designing and Conducting Mixed Methods Research.* Thousand Oaks, CA: SAGE.

Creswell, J.W., and Plano Clark, V.L. (2011) *Designing and Conducting Mixed Methods Research. 2nd* Edition. Thousand Oaks, CA: SAGE.

Crotty, M. (1998) *The Foundations of Social Research: Meaning and Perspective in the Research Process.* Saint Louis: SAGE.

Cruz-Cardenas, J. (2018). '*Re: Can I apply multiple codes that may reflect different themes to a quote when doing qualitative analysis?'* ResearchGate Online discussion forum. [Online]. [Accessed on 6th February 2021]. https://www.researchgate.net/post/Can_I_apply_multiple_codes--that_may_reflect_different_themes--to_a_quote_when_doing_qualitative_analysis/5a5f3b2296b7e4864b7bf6ce/citation/download

Cuniffe Gilson, E. (2016). 'Vulnerability and victimization: Rethinking key concepts in feminist discourses on sexual violence.' *Signs: Journal of Women in Culture and Society,* 14(1) pp. 71-98.

Cunliffe, A.L. (2009). 'The philosopher leader: On relationalism, ethics and reflexivity – A critical perspective on teaching leadership.' *Management Learning,* 40(1) pp. 87–101.

Cunliffe, A.L., and Easterby-Smith, M. (2004). 'From reflection to practical reflexivity: Experiential learning as lived experience.' *In*: Reynolds, M., and Vince, R. (eds) *Organizing Reflection*. Aldershot: Ashgate.

Cunliffe, A.L., and Jun, J.S. (2005). 'The need for reflexivity in public administration.' *Administration & Society,* 37(2) pp. 225–242.

Dados, N., and Connell, R. (2012). The Global South. *Contexts.* 11(1), 12-13. [Online]. [Accessed on 18th November 2023]. https://doi.org/10.1177/1536504212436479

Degener, T. (2016a). 'Disability in a human rights context.' *Laws.* 5(35) pp. 2-25.

Degener, T. (2016b). 'A human rights model of disability.' *In* Blanck, P., and Flynn, E. (Eds.). *Routledge Handbook of Disability Law and Human Rights (1st ed.)*. Routledge.

DeJonckheere, M., and Vaughn, L.M. (2019). 'Semistructured interviewing in primary care research: a balance of relationship and rigour.' *Family Medicine and Community Health.* 7(2): e000057. [Online]. [Accessed on 7th July 2023]. https://pubmed.ncbi.nlm.nih.gov/32148704/

Denzin, N.K. (1978). 'Triangulation: A Case for Methodological Evaluation and Combination.' *Sociological Methods*, 339-357.

Denzin, N.K. (2012). 'Triangulation 2.0.' *Journal of Mixed Methods Research*. 6(2) pp. 80-88.

Department for International Development (DFID). (2000). *Disability, Poverty, and Development.* DFID: London. [Online]. [Accessed on 12th February 2022]. https://hpod.law.harvard.edu/pdf/Disability-poverty-and-development.pdf

Dewey, J. (1954). *The Public and its Problems*. Chicago: Swallow Press.

Disabled World. (2021). *Definitions of Disability*. [Online]. [Accessed on 16th September 2022]. https://www.disabled-world.com/definitions/disability-definitions.php#:~:text=Disabilities%20is%20an%20umbrella%20term%2C%20covering%20impairments%2C%20activity,each%20person%20but%20there%20are%20common%20impacting%20factors .

Dunn, D.S. and Andrews, E.E. (2015). ‘Person-first and identity-first language: developing psychologists’ cultural competence using disability language.’ *American Psychologist,* 70(3) pp.255–264.

Elliott E., Watson A. J., and Harries U. (2002). ‘Harnessing expertise: Involving peer interviewers in qualitative research with hard-to-reach populations.’ *Health Expectations.* 5 pp. 172–178

Elrha. (2018). *Humanitarian Innovation Guide.* [Online]. [Accessed on 12th February 202]. The Humanitarian Innovation Guide is a growing online resource to help individuals and organisations define humanitarian problems and successfully develop innovative solutions. | Humanitarian Innovation Guide (elrha.org)

Erfanian, A. F., Latifnejad Roudsari, R., Heydari, A., and Noghani Dokht, B.M. (2019). ‘Men's confrontation with pregnancy from women's point of view: an ethno phenomenological approach.’ *Journal of Caring Sciences*, 8(4) pp. 231-9.

Evans, D. (2002). ‘Systematic reviews of interpretive research: interpretive data synthesis of processed data.’ *The Australian Journal of Advanced Nursing,* 20(2) pp. 22–6.

Fehrenbach, H. and Rodongo, D. (2016). ‘“A horrific photo of a drowned Syrian child”: Humanitarian photography and MGO media strategies in historical perspective.’ *International Review of the Red Cross*. [Online]. [Accessed on 7th July 2023]. https://www.cambridge.org/core/journals/international-review-of-the-red-cross/article/horrific-photo-of-a-drowned-syrian-child-humanitarian-photography-and-ngo-media-strategies-in-historical-perspective/D637C9EE64B2682EB5850F6F26C1357E

Fetters, M.D., Curry, L.A., and Creswell, J.W. (2013). ‘Achieving integration in mixed methods designs-principles and practices.’ *Health Services Research,* 48(6, Pt2) pp. 2134-56.

Fetters, M.D., and Molina-Azorin, J.F. (2017). ‘The Journal of Mixed Methods Research Starts a New Decade: Principles for Bringing in the New and Divesting of the Old Language of the Field.’ *Journal of Mixed Methods Research*, 11(1) pp. 3-10.

Finlay, L. (2011). *Phenomenology for Therapists: Researching the Lived World.* Chichester: Wiley-Blackwell.

Fontana, A., & Frey, J.H. (2000). 'The interview: From structured questions to negotiated text.' *In* Denzin, N.K., and Lincoln, Y. S. (Eds.). *The Sage Handbook of Qualitative Research*. London: SAGE.

Fontana, A., & Frey, J. H. (2008). 'The interview: From neutral stance to political involvement.' *In* Alasuutari, P., Bickman, L., and Brannen, J. (Eds.) *The SAGE Handbook of Social Research Methods* Los Angeles: SAGE.

Forber-Pratt, A.J., Mueller, C.O., and Andrews, E.E. (2019). 'Disability identity and allyship in rehabilitation psychology: Sit, stand, sign, and show up.' *Rehabilitation Psychology.* 64(2) pp.119-129.

Freedman, J. (2019). 'The uses and abuses of "vulnerability" in EU asylum and refugee protection: Protecting women or reducing autonomy?'. *International Journal on Collective Identity Research.* [Online]. [Accessed 15th March 2021]. https://ojs.ehu.eus/index.php/papelesCEIC/article/view/19525

Freire, P. (1970). *Pedagogy of the Oppressed.* New York: Seabury Press

Gadamer, H.G. (2013). *Truth and Method*. London: Bloomsbury Press

Gale, N.K., Heath, G., Cameron, E., Rashid, S., and Redwood, S. (2013). 'Using the framework method for the analysis of qualitative data in multi-disciplinary health research.' *Medical Research Methodology,* 13 pp. 117

Garland-Thomson, R. (1996). *Extraordinary Bodies: Figuring Disability in American Culture and Literature.* New York: Columbia University Press

Geertz, C. (1973). 'The Interpretation of Cultures.' Cited in: P. Crotty (1998). *The Foundations of Social Research: Meaning and Perspective in the Research Process*. SL: Sage.

Gentles, S.J., and Vilches, S.L. (2017). 'Calling for a shared understanding of sampling terminology in qualitative research: Proposed clarifications derived from critical analysis of a methods overview by McCrae and Purssell.' *International Journal of Qualitative Methods,* 16 pp. 1-7.

Gentles, S. J., Charles, C., Ploeg, J., & McKibbon, K. (2015). 'Sampling in Qualitative Research: Insights from an Overview of the Methods Literature'. *The Qualitative Report*, 20(11) pp. 1772-1789.

Gernsbacher, M.A. (2017). 'Editorial perspective: The use of person-first language in scholarly writing may accentuate stigma.' *Journal of Child Psychology and Psychiatry*, 58(7) pp. 859-861.
Gibney, M. (2022). *Introduction to Politics.* University of Oxford Refugee Studies Centre: Oxford.

Gillis, A., & Jackson, W. (2002). *Research Methods for Nurses: Methods and Interpretation*. Philadelphia: F.A. Davis Company.

Glaser, B.G., and Strauss, A.L. (1967). *The Discovery of Grounded Theory: Strategies for Qualitative Research*. Chicago: Aldline.

Global Partnership on Education. (2016). *Children With Disabilities Face the Longest Road to Education.* [Online]. [Accessed 13th October 2022]. https://www.globalpartnership.org/blog/children-disabilities-face-longest-road-education#:~:text=UNICEF%20estimates%20that%2090%25%20of%20children%20with%20disabilities,the%20world%2C%20out%20of%20which%2010%25%20are%20children.

Glogowska, M. (2011). 'Paradigms, pragmatism and possibilities: mixed methods research in speech and language therapy.' *International Journal of Language & Communication Disorders,* 46(3) pp. 251-260.

Goodley, D. (2017). *Disability Studies: An Interdisciplinary Introduction.* London. Sage Publications.

Goodley, D., Liddiard, K., and Runswick-Cole, K. (2018). 'Feeling disability: Theories of affect and critical disability studies,' *Disability and Society*, 33(2) pp. 197-217.

Gordon-Gibson, A. (2016). 'Goma 1994: Notes from the Field.' *Genocide Studies International*. 10(2) pp. 254-267.

Gourevitch, P. (1999). *We Wish to Inform You that Tomorrow We Will be Killed With Our Families: Stories from Rwanda.* London: Picador/Pan Macmillan.

Government Office for Science. (2012). *Introduction to Systems Thinking.* [Online]. [Accessed on 24th November 2023]. https://assets.publishing.service.gov.uk/government/uploads/system/uploads/attachment_data/file/285442/12-1043-introduction-to-systems-thinking-gse-seminar.pdf

Government of Rwanda. (2003). *The Constitution of the Republic of Rwanda.* Kigali: Government of Rwanda. [Online]. [Accessed 13th October 2022]. https://www.ilo.org/dyn/natlex/docs/ELECTRONIC/64236/90478/F238686952/RWA64236.pdf

Graneheim, U.H. & Lundman, B. (2004). 'Qualitative content analysis in nursing research: concepts, procedures and measures to achieve trustworthiness.' *Nursing Education Today*, 24 pp. 105–112.

Grant, M. J., and Booth, A. (2009). 'A typology of reviews: An analysis of 14 review types and associated methodologies.' *Health Information & Libraries Journal,* 26 pp. 91–108.

Graue, M.E., and Walsh, D. (1998). *Studying Children in Context: Theories, Methods and Ethics.* London: SAGE.

Green, B.N., Johnson, C.D., and Adams, A. (2006). ‘Writing narrative literature reviews for peer reviewed journals: secrets of the trade.’ *Journal of Chiropractic Medicine,* 5(3) pp. 101-117.

Green, J., &; Thorogood, N. (2018). *Qualitative Methods for Health Research (4th ed).* London: SAGE.

Greene-Moton, E., and Minkler, M. (2020). ‘Cultural Competence or Cultural Humility? Moving Beyond the Debate.’ *Health Promotion Practice,* 21(1) pp. 142-145.

Grover, S. (2007). ‘Children's right to be educated for tolerance: minority rights and inclusion.’ *Education and the Law,* 19(1) pp. 59-70.

Guba, E.G. (1990). *The Paradigm Dialog.* Newbury Park, Ca: SAGE

Guba, E.G., and Lincoln, Y.S. (1994). ‘Competing paradigms in qualitative research.’ *In* Denzin, N.K., and Lincoln, Y.S. (Eds). *Handbook of Qualitative Research.* Thousand Oaks, Ca: SAGE

Guba, E. G., and Lincoln, Y. S. (2005). ‘Paradigmatic Controversies, Contradictions, and Emerging Confluences.’ *In* Denzin, N. K., and Lincoln, Y. S. (Eds.) *The Sage handbook of qualitative research*. Ca: SAGE

Guendouzi, J.A., and Müller, N. (2006). ‘Orthographic transcription in multi-layered transcription.’ *In* Muller, N. (ed.) *Multilayered Transcription.* Plural Publishing. [Online] [Accessed on 12th February 2022]. https://books.google.com.my/books?hl=en&lr=&id=JNWFCwAAQBAJ&oi=fnd&pg=PA19&dq=orthographic+transcription&ots=0W75eRBVx&sig=Pky2V6s_UCzX98KoZ3W04IJx4dc&redir_esc=y#v=onepage&q=orthographic%20transcription&f=false

Gupta, A., and Ferguson, J. (1996). ‘Culture, power and place: Ethnography at the end of an era.’ *In* Gupta, A., and Ferguson. J. (Eds). *Culture, Power, Place: Explorations in Critical Anthropology.* Durham: Duke University Press.

Haider, H. (2014). *Conflict: Topic Guide. Revised Edition with B. Rohwerder*. Birmingham: GSDRC.

Hall, J., (2013). 'Pragmatism, evidence and mixed method evaluation.' *New Directions for Evaluation,* 138 pp. 15-26.

Hall, M. (2019).' Critical Disability Theory.' In: Zalta, E.N., Nodelman, U., Allen, C., and Anderson, R.L. (eds). *The Stanford Encyclopedia of Philosophy*. [Online]. [Accessed 11th March 2020]. https://plato.stanford.edu/entries/disability-critical/

Handicap International. (2015). *Disability in Humanitarian Context: Views from Affected People and Field Organisations.* World Humanitarian Summit.

Harley, B., and Cornelissen, J. (2022). 'Rigor with or without templates? The pursuit of methodological rigor in qualitative research.' *Organizational Research Methods,* 25(2) pp. 239-261.

Hartley, S.D., and Wirz, S.L. (2002). 'Development of a 'communication disability model' and its implication on service delivery in low-income countries.' *Social Science and Medicine,* 54 pp. 1543-1557.

Harvard Center on the Developing Child. (2022). *Brain Architecture.* [Online]. [Accessed on 14th May 2023]. https://developingchild.harvard.edu/science/key-concepts/brain-architecture/

Hays, D.G., and Singh, A.A. (2012). *Qualitative Inquiry in Clinical and Educational Settings.* New York: Guilford Press.

Heckman, J. (2011). 'The Economics of Inequality: The Value of Early Childhood Education.' *American Educator,* 35(1) pp. 31-35.

Heffernan, C. (n.d.) *Document Analysis.* Ask Dr. Cath. [Online]. [Accessed 12th March 2020]. http://www.drcath.net/toolkit/document-analysis

Hennick, M. M. (2007). *International Focus Group Research.* Cambridge, Cambridge University Press.

Henrich, J., Heine, S.J., & Norenzayan, A. (2010). 'Most people are not WEIRD.' *Nature* 466 p. 29

Hesse-Bieber, S. (2012). 'Feminist approaches to triangulation: Uncovering subjugated knowledge and fostering social change in mixed-method research.' *Journal of Mixed Methods Research*, 6 pp. 137-146

Hindle, S. (2004). 'Civility, honesty and the identification of the deserving poor in seventeenth-century England.' *In* French, H., Barry, J. (eds). *Identity and Agency in England, 1500–1800.* Palgrave Macmillan, London

Hinds, R. (2015). *Relationship between Humanitarian and Development Aid*. University of Birmingham, Governance, Social Development Hum, Conflict (GSDRC) Helpdesk Report. [Online]. [Accessed on 13th May 2023]. https://assets.publishing.service.gov.uk/media/57a08969ed915d3cfd00022a/hdq1185.pdf

Hoey, B.A. (n.d.). *Research Project Summaries: What is Ethnography?* [Online]. [Accessed on 24th August 2020]. https://brianhoey.com/research/ethnography/

Hseih, S.F., and Shannon, S.E. (2002). 'Three approaches to qualitative content analysis.' *Qualitative Health Research,* 15(9) pp. 1277-1288.

Hunt, M. R. (2010). 'Moral experience of Canadian healthcare professionals in humanitarian work.' *Prehospital and Disaster Medicine,* 24(6) pp. 518-524.

Hussain, N., Jagoe, C., Mullen, R., O'Shea, A., Sutherland, D., Williams, C., & Wright, M. (2018). *The Importance of Speech, Language and Communication to the United Nations Sustainable*

Development Goals: A Summary of Evidence. Melbourne, Vic: International Communication Project.

ICF Education. (2022). *What is ICF?* [Online]. [Accessed on 1st September 2022]. http://icfeducation.org/what-is-icf

International Association of Professionals in Humanitarian Assistance and Protection (PHAP). (2021). *Humanitarianism.* [Online]. [Accessed on 13th May 2023]. https://phap.org/PHAP/PHAP/Themes/Humanitarianism.aspx

International Association for the Study of Forced Migration. (2016). *Home Page.* [Online]. [Accessed on 5th July 2022]. http://iasfm.org/

International Disability and Development Consortium. (IDDC). (2008). *Discussion paper on Access to Quality Educational Activities for Children with Disabilities in Conflict and Emergency Situations.* Brussels: IDDC.

International Network on Education in Emergencies (INEE). (2010a). *Minimum Standards for Education: Preparedness, Response, Recovery.* Geneva: INEE.

International Network on Education in Emergencies (INEE). (2010b). *INEE Thematic Issue Brief: Inclusive Education.* Geneva: INEE.

International Network on Education in Emergencies (INEE). (2010c). *INEE Pocket Guide to Supporting Learners with Disabilities*. Geneva: INEE.

International Network on Education in Emergencies (INEE). (2016). *Education in Emergencies: Including Everyone INEE pocket guide to inclusive education Inter-Agency Network for Education in Emergencies Task Team on Inclusive Education and Disability*. Geneva: INEE.

International Network on Education in Emergencies (INEE)., and Global Education Cluster. *Module 15: Inclusive education in emergencies.* Geneva: INEE & GEC.

Jackson, R., Tesfay, F. H., Gebrehiwot, T. G., and Godefay, H. (2017). ‘Factors that hinder or enable maternal health strategies to reduce delays in rural and pastoralist areas in Ethiopia.’ *Tropical Medicine & International Health*, 22(2) pp. 148–160

Jagoe, C., McDonald, C., Rivas, M., and Groce, N. (2021). ‘Direct participation of people with communication disabilities in research on poverty and disabilities in low and middle income countries: A critical review.’ *PLoS ONE.* 16(10) e0258575. [Online]. [Accessed 7th July 2023]. https://doi.org/10.1371/journal.pone.0258575

Jakobsen, H. (2012). ‘Focus groups and methodological rigour outside the minority world: making the method work to its strengths in Tanzania.’ *Qualitative Research*, 12(2) pp. 111–130

Janz, M.R., Soi, N., and Russell, R. (2009). *Collaboration and Partnership in Humanitarian Action.* Humanitarian Practice Network. [Online]. [Accessed on 12th July 2022]. https://odihpn.org/publication/collaboration-and-partnership-in-humanitarian-action/

Jeong, J., Bliznashka, L., Sullivan, E., Hentschel, E., Jeon, Y., Strong, K.L., and Daelmans, B. (2022). ‘Measurement tools and indicators for assessing nurturing care for early childhood development: A scoping review.’ *PLOS Global Public Health.* 2(4) e000373. [Online]. [Accessed on 7th July 2023]. Doi: 10.1371/journal.pgph.0000373

Karangwa, E. (2006). *Grassroots Community-Based Inclusive Education. Exploring Educational Prospects for Young People with Disabilities in the Post-Conflict Rwandan Communities*. Ph.D. Centre for Disability, Special Needs Education and Child Care, Leuven, Belgium. [Online]. [Accessed on 17th September 2018]. https://repository.libis.kuleuven.be/dspace/handle/1979/424

Karangwa, E. (2014). ‘Towards Inclusive Education in Rwanda: An assessment of the socio-political contributors to inclusive education developments.’ *Rwandan Journal of Education*, 2(1) pp. 46-60.

Karangwa, E., P. Ghesquire, & P. Devlieger. (2007). ‘The grassroots community in the vanguard of inclusion: The post-genocide Rwandan prospects.’ *International Journal of Inclusive Education,* 11 pp. 607– 626.

Karangwa, E., Miles, S., and Lewis, I. (2010). ‘Community-level responses to disability and education in Rwanda.’ *International Journal of Disability, Development and Education,* 57(3) pp. 267-278

Kaushik V., and Walsh, C.A. (2019). ‘Pragmatism as a research paradigm and its implications for social work research.’ *Social Sciences*, 8 pp. 1-17

Kayesa, N.K., & Shung-King, M. (2021). ‘The role of document analysis in health policy analysis studies in low and middle-income countries: Lessons for HPA researchers from a qualitative systematic review.’ *Health Policy OPEN 2,* 100024 pp. 1-13. [Online]. [Accessed on 7th July 2023]. https://doi.org/10.1016/j.hpopen.2020.100024

Kayess, R., and French, P. (2008). ‘Out of the darkness into light? Introducing the Convention on the Rights of Persons with Disabilities.’ *Human Rights Law Review,* 8(1) pp. 1-34.
Kearney, A. (2011). *Exclusion from and within: Issues and solutions.* New York: Springer Science and Business Media.

Killam, L. (2013). *Research Terminology Simplified: Paradigms, Axiology, Ontology, Epistemology and Methodology.* Sudbury, ON: Author.

Kincheloe, J. L., McLaren, P., and Steinberg, S. (2011). ‘Critical pedagogy and qualitative research: Moving to the bricolage.’ *In* Denzin, N.K., and Lincoln, Y. S. (Eds.), *The SAGE Handbook of Qualitative Research (4th ed.*) Thousand Oaks, Ca: Sage Publications.

King, R., Jackson, R., Dietsch, E., and Hailemariam, A. (2016). ‘Utilisation of maternal health services in Ethiopia: A key informant research project.’ *Development in Practice*, 26(2) pp. 158–169.

Kitzinger, J. (1995). ‘Introducing focus groups.’ *British Medical Journal,* 311 pp. 299-302.

Knoema. (2017). *Burundi – Poverty >> Population in Multidimensional Poverty, Headcount (%).* [Online]. [Accessed on 6th May 2023]. https://knoema.com/HDREPT2020/human-development-report-2021-22-statistical-update?tsId=1232180

Krauss de Camargo, O. (2022). *Personal Communication.* (Video conference call on disability language, 16th February 2022).

Krippendorff, K. (2004). *Content Analysis: An Introduction to its Methodology.* Thousand Oaks, Ca: SAGE publications.

Krupar, A. (2016). ‘Being untaught: How NGO field workers empower parents of children with disabilities in Dadaab.’ *Global Education Review*, 3(3) pp.105-121

Kuhn, T. (1996). ‘The structure of scientific revolutions’ (3rd ed.) Cited in Morgan, D.L. (2014). Pragmatism as a paradigm for social research. *Qualitative Inquiry* [Online], ‘First online’. [Accessed on 7th July 2023]. https://doi.org/10.1177/1077800413513733

Lange, K. (2015). *Strengthening Protection of Persons with Disabilities in Forced Displacement: Rwanda Mission Report.* Geneva: UNHCR.

Lange, M., Mahoney, J. and Vom Hau, M. (2006). ‘Colonialism and development: a comparative analysis of Spanish and British colonies.’ *American Journal of Sociology,* 111(5) pp. 1412-1462.

Lau, J., Ioannidis, J.P.A., and Schmid, C.H. (1998). ‘Summing up evidence: one answer is not always enough.’ *Lancet.* 351 pp.123–7.

Lawson, A., and Beckett, A. (2021). ‘The social and human rights models of disability: towards a complementarity thesis.’ *The International Journal of Human Rights,* 25(2) pp. 348-379.

Levine, A.C. (2016). ‘Academics are from Mars, humanitarians are from Venus: Finding common ground to improve research during humanitarian emergencies.’ *Clinical Trials,* 13(1) pp. 19-82.

Levy Firestone Muse. (2021). *A Foreseeable Genocide: The Role of the French Government in Connection with the Genocide Against the Tutsi in Rwanda*. Government of Rwanda. [Online]. [Accessed on 6th May 2023]. https://www.gov.rw/fileadmin/user_upload/gov_user_upload/2021.04.19_MUSE_REPORT.pdf

Liamputtong, P. (2010). *Performing Qualitative Cross Cultural Research.* Cambridge: Cambridge University Press

Lincoln, Y. (2010). ‘“What a long, strange trip it’s been…”: Twenty-five years of qualitative and new paradigm research.’ *Qualitative Inquiry,* 16 pp. 3-9.

Lincoln, Y.S., and Guba, E.G. (1985). *Naturalistic Inquiry.* Newbury Park, Ca: SAGE.

Lincoln, Y.S., and Guba, E.G. (2000). ‘Paradigmatic controversies, contradictions, and emerging confluences.’ *In*. Denzin, N.K., and Lincoln. Y.S. (eds). *Handbook of Qualitative Research.* Thousand Oaks, Ca: SAGE.

Lu, C., Black, M.M., and Richter, L.M. (2016). ‘Risk of poor development in young children in low-income and middle income countries: an estimation and analysis at the global, regional, and country level.’ *Lancet Glob Health,* 4(12) e916–e22. [Online]. [Accessed on 7th July 2023.] Doi: 10.1016/S2214-109X(16)30266-2

MacInnes, J. (2020). ‘Secondary analysis of quantitative data.’ *In* Atkinson, P., Delamont, S., Cernat, A., Sakshaug, J.W., and Williams, R.A. (Eds.), *SAGE Research Methods Foundations.* [Online]. [Accessed on 7th July 2023]. https://methods.sagepub.com/foundations/foundations

MacKenzie, S., McAllister, L., Hudson, K., Worrall, L., Davidson, B., and Howe, T. (2019). ‘Phenomenology and its uses in communication disorders research.’ *In* Lyons, R., and

McAllister, L. (eds). *Qualitative Research in Communication Disorders: An Introduction for Students and Clinicians.* Croydon: J&R Press.

Madriz, E. (2000). 'Focus groups in feminist research.' *In* Denzin, N. K., and Lincoln, Y.S. (eds.) *The Sage Handbook of Qualitative Research*. Ca: Sage Publications Ltd.

Male, C., and Wodon, Q. (2017). *Disability Gaps in Educational Attainment and Literacy, The Price of Exclusion: Disability and Education Notes Series*. Washington, DC: The World Bank.

Mano, A.P. (2017). 'An innovative approach to sex trafficking research: The methodological advancement of Attride-Stirling's Thematic Network Analysis.' *International Annals of Criminology,* 55:40-59.

Marshall, J., Barrett., H., and Ebengo, A. (2017). 'Vulnerability of refugees with communication disabilities to SGBV: evidence from Rwanda.' *Forced Migration Review*. 55 (June) pp. 74-76. [Online]. [Accessed on 28th May 2023]. https://www.fmreview.org/sites/fmr/files/FMRdownloads/en/shelter.pdf

McAllister, L., and Lyons, R. (2019). 'Introduction and overview of qualitative research.' *In*: Lyons, R., and McAllister, L. (eds). *Qualitative Research in Communication Disorders: An Introduction for Students and Clinicians.* Croydon: J&R Press

McAllister, L., Wylie, K., Davidson, B., and Marshall, J. (2013). 'The World Report on Disability: an impetus to reconceptualize services for people with communication disability.' *International Journal of Speech Language Pathology,* 15(1) pp. 118-26.

McFadden, P., Taylor, B., Campbell, A., and McQuilkin, J. (2012). 'Systematically identifying relevant research: Case study on child protection social workers' resilience.' *Research on Social Work Practice*, 22(6) pp. 626-636.

McIntosh, M.J., and Morse, J.M. (2015). 'Situating and constructing diversity in semi-structured interviews.' *Global Qualitative Nursing Research.* [Online]. [Accessed on 7th July 2023]. https://doi.org/10.1177%2F2333393615597674

McRuer, R. (2006). 'Crip theory: Cultural signs of queerness and disability.' Cited in: Weiss, G. (2015). 'The normal, the natural, and the normative: A Merleau-Pontian legacy to feminist theory, critical race theory, and disability studies.' *Continental Philosophy Review,* 48 pp.77–93.

McRuer, R., (2018). *Crip Times: Disability, Globalization, and Resistance.* New Yor: Ne York University Press.

Meadows, D.H. (2008). *Thinking in Systems: A Primer.* London: Chelsea Green Publishing.

Mednick, S. (2022). *People with Disabilities Left Behind During the War in Ukraine*. [Online]. [Accessed 10th July 2022]. https://www.devex.com/news/people-with-disabilities-left-behind-during-the-war-in-ukraine-103530

Meekosha, H., and Shuttlewoth, R. (2009). 'What's so 'critical' about critical disability studies?' *Australian Journal of Human Rights,* 15(1) pp. 47-75.

Merleau-Ponty, M. (2002). *Phenomenology of Perception.* Abingdon: Routledge.

Merriam Webster. (2023). *Alterity.* [Online]. [Accessed 15th June 2023]. https://www.merriam-webster.com/dictionary/alterity Accessed 15.6.2023

Mertens, D.M. (1998). 'Research Methods in education and Psychology. Integrating Diversity with Quantitative and Qualitative Approaches.' Cited in: Creswell, J. (2009). *Research Design: Qualitative, Quantitative and Mixed Method Approaches* (3rd ed.). Ca: Sage

Mertens, D. (2010). 'Transformative mixed methods research.' *Qualitative Inquiry,* 16(6). {Online]. {Accessed on 8th July 2023]. https://doi.org/10.1177/1077800410364612

Merton, R.K., Fiske, M., and Kendall, P.L. (1956). 'The focused interview.' Cited in Fontana, A. and Frey, J.H. (2000). 'The interview: From structured questions to negotiated text'. *In* Denzin, N.K. and Lincoln, Y.S. (eds.) *The Sage Handbook of Qualitative Research*. Sage Publications Ltd.

Miles, S. (2013) 'Education in times of conflict and the invisibility of disability: A focus on Iraq?' *Disability & Society,* 28(6) PP. 798-811.

Miles, M.B., and Huberman, A.M. (1994). *Qualitative Data Analysis (2nd ed).* Thousand Oaks, Ca: Sage.

Miles, M.B., Huberman, A.M., and Saldaña, J. (2020). *Qualitative Data Analysis: A Methods Sourcebook. 4th ed. (International Student Edition).* Ca: SAGE.

Mill, J.E., and Ogilvie, L.D. (2003). 'Establishing methodological rigour in international qualitative nursing research: a case study from Ghana.' *Methodological Issues in Nursing Research,* 41(1) pp. 80-87.

Mills, A.J., Durepos, G., and Wiebe, E. (2010). *Encyclopedia of Case Study Research*. CA: Sage.

Minich, J.A. (2016). 'Enabling whom: Critical disability studies now'. *Lateral. Journal of the Cultural Studies Association*, Issue 5.1 (Spring 2016). [Online]. [Accessed on 7th July 2023]. https://doi.org/10.25158/L5.1.9 Accessed 11.03.2020.

Ministry of Education. (MINEDUC). (2018a). *Revised Special Needs and Inclusive Education Policy.* Kigali, Government of Rwanda Ministry of Education. [Online]. [Accessed on 24th June 2023].
https://planipolis.iiep.unesco.org/sites/default/files/ressources/rwanda_sne_policy_2018.pdf

Ministry of Education (MINEDUC). (2018b). *Education Sector Strategic Plan 2018/19-2023/24.* Kigali, Government of Rwanda. [Online]. [Accessed on 14th May 2023].
https://www.mineduc.gov.rw/index.php?eID=dumpFile&t=f&f=57563&token=6b306c5412dc6e99d82c4bf288ffccc68a4880b8

Mirza, M. (2011). ‘Unmet needs and diminished opportunities: disability, displacement and humanitarian healthcare.’ *New Issues in Refugee Research.* Research paper 212. Geneva, UNHCR. [Online]. [Accessed on 10th July 2022]. https://www.unhcr.org/4e0dbdb29.html

Mladenov, T. (2016). *Critical Theory and Disability: A Phenomenological Approach.* London: Bloomsbury.

Mont, D. (2007) *Measuring Disability Prevalence. Social Protection Discussion Paper 0706.* Washington DC, World Bank. [Online]. [Accessed on 12th February 2022]. https://www.researchgate.net/publication/257262995_Measuring_Disability_Prevalence_Social_Protection_Discussion_Paper_No_0706_World_Bank_2007

Moran, D. (2000). *Introduction to Phenomenology.* London: Routledge.

Morgan, D.L. (2014). ‘Pragmatism as a paradigm for social research.’ *Qualitative Inquiry.* [Online]. ‘First online’. [Accessed on 7th July 2023]. https://doi.org/10.1177/1077800413513733

Morris, J. (1991). *Pride against Prejudice: Transforming Attitudes to Disability.* Philadelphia: New Society.

Morse, J.M. (1989). ‘Qualitative nursing research: A free-for-all?’ *In* Morse, J.M. (ed.) *Qualitative Nursing Research: A Contemporary Dialogue.* Rockville: Aspen.

Morse, J.A. (1994). ‘”Emerging from the data”: The cognitive process of analysis in qualitative inquiry.’ *In* Morse, J.M. (ed.) *Critical Issues in Qualitative Research Methods*. Thousand Oaks, Ca: Sage.

Morse, J. M. (2003). ‘Principles of mixed methods and multi-method research design.’ *In* Teddlie, C., and Tashakkori, A. (eds.). *Handbook of Mixed Methods in Social and Behavioral Research*. Thousand Oaks, CA: Sage.

Morse, J.M. (2015). ‘Critical analysis of strategies for determining rigor in qualitative enquiry.’ *Qualitative Health Research*, 25(9) pp. 1212-1222.

Moving Minds Alliance. (2018). *ECD and Early Learning for Children in Crisis and Conflict.* [Online]. [Accessed on 14th May 2023]. https://movingmindsalliance.org/wp-content/uploads/2019/03/ecd-and-early-learning-for-children-in-crisis-and-conflict.pdf

Mpangala, G.P. (2004). *The origins of Political Conflicts and Peace Building in the Great Lakes Region.* Ramifications of Instability in the Great Lakes Zones Symposium, Command and Staff College, Arusha, Tanzania: 23rd February 2004. [Online]. [Accessed on 6th May 2023]. Available online at https://repositories.lib.utexas.edu/bitstream/handle/2152/5727/3000.pdf

National Institute of Statistics Rwanda (NISR). (2017). *Statistical Yearbook 2017.* Kigali: Government of Rwanda. [Online]. [Accessed on 14th May 2023]. https://www.statistics.gov.rw/publication/statistical-yearbook-2017

National Institute of Statistics Rwanda. (NISR). (2021). *Statistical Yearbook 2021*. Kigali, Government of Rwanda. [Online]. [Accessed on 14th May 2023]. https://statistics.gov.rw/publication/1767

Njelesani, J., Siegel, J., & Ullrich, E. (2018). ‘Realization of the rights of persons with disabilities in Rwanda.’ *PLoS ONE,* 13(5) e0196347. [Online]. [Accessed on 7th July 2023]. https://doi.org/10.1371/journal.pone.0196347

Noble, H., and Heale, R. (2019). ‘Triangulation in research, with examples.’ *Evidence Based Nursing,* 22(3) pp. 67-68.

Noble, H., and Mitchell, G. (2016). ‘What is grounded theory?’ *Evidence Based Nursing,* 19(2) pp. 34-35.

Noel, L. (2016). 'Promoting an emancipatory research paradigm in design education and practice.' *Design Research Society*. [Online]. [Accessed on 7th July 2023]. https://doi.org/10.21606/drs.2016.355

Ntanyoma, D. (2022). 'Transformative Methodologies: How emancipatory research can help prevent the misrepresentation of marginalised groups in conflict-prone settings.' *Bliss.* [Online]. [Accessed on 29th May 2023]. https://issblog.nl/2022/01/26/transformative-methodologies-how-emancipatory-research-can-help-prevent-the-misrepresentation-of-marginalised-groups-in-conflict-prone-settings-2/

O'Donnell, R. (2021). *Re: What is the difference between framework analysis and thematic analysis.* ResearchGate discussion. [Online]. [Accessed on 7th July 2023]. https://www.researchgate.net/post/what_is_the_different_between_framework_analysis_and_thematic_analysis/602a4159d00c70214b7126f8/citation/download.

Office of the High Commissioner for Human Rights. (OHCHR). (2023). *About Internally Displaced Persons.* [Online]. [Accessed on 29th April 2023]. https://www.ohchr.org/en/special-procedures/sr-internally-displaced-persons/about internally-displaced-persons

Oliver, M. (1986). 'Social Policy and Disability: Some Theoretical Issues.' *Disability, Handicap & Society,* 1(1) pp. 5-17.

Olopade, D. (2014). *The End of the Developing World.* Op-ed. New York Times. February 28th edition. [Online]. [Accessed on 22nd September 2022]. https://www.nytimes.com/2014/03/01/opinion/sunday/forget-developing-fat-nations-must-go-lean.html

Olusanya, B.O., Kancherla, V., Shaheen, A., Ogbo, F.A., and Davis, A.C. (2022). 'Global and regional prevalence of disabilities among children and adolescents: Analysis of findings from global health databases.' *Front. Public Health* 10: 977453. [Online]. [Accessed on 7th July 2023]. https://doi.org/10.3389/fpubh.2022.977453

Olusanya, B.O., Wright, S.M., Nair, M.K.C., et al. (2020). 'Global Burden of Childhood Epilepsy, Intellectual Disability, and Sensory Impairments.' *Pediatrics,* 146(1): e20192623. [Online]. [Accessed on 7th July 2023]. https://doi.org/10.1542/peds.2019-2623

Oh, S.A., and van der Stouwe, M. (2008). 'Education and Inclusion in Refugee Camps in Thailand.' *Comparative Education Review,* 52(4): pp. 589–617.

Onwuegbuzie, A.J., Dickinson, W.B., Leech, N.L., and Zoran, A.G. (2009). 'Toward more rigor in focus group research: A new framework for collecting and analyzing data.' *International Journal of Qualitative Methods,* 8(3). [Online]. [Accessed on 28th August 2020]. https://ejournals.library.ualberta.ca/index.php/IJQM/article/view/4554

One World Nations Online. (2016). *The Human Development Index 2016*. [Online]. [Accessed on 6th May 2023]. https://www.nationsonline.org/oneworld/human_development.htm

O'Reilly, C.F., Jagoe, C., Brahmbhatt, K., and Lidlow, O. (2022). *Should you Use the WG questions in your Humanitarian Programming? A tool to help you decide*. Washington Group Blog, 16th June 2022. [Online]. [Accessed on 10th July 2022]. https://www.washingtongroup-disability.com/wg-blog/should-you-use-the-wg-questions-in-your-humanitarian-programming-a-tool-to-help-you-decide-579/

Organization for Economic Cooperation and Development. (2023). *About.* [Online]. [Accessed on 18th November 2023]. https://www.oecd.org/about/

Otto, R. and Weingärtner, L. (2013). *Linking Relief and Development: More than Old Solutions for Old Problems?* IOB Study, Netherlands, Ministry of Foreign Affairs. [Online]. [Accessed on 15th February 2022]. http://www.government.nl/documents-and-publications/reports/2013/05/01/iob-study-linkingrelief-and-development-more-than-old-solutions-for-old-problems.html

Overseas Development Institute (ODI). (2009). *Research Tools: Focus Group Discussions.* [Online]. [Accessed on 31st January 2021].https://www.odi.org/publications/5695-research-tools-focus-group-discussion#:~:text=FGD%20sessions%20need%20to%20be,is%20between%20six%20and%20eight

Ozano, K., and Khatri, K. (2018). ‘Reflexivity, positionality and power in cross-cultural participatory action research with research assistants in rural Cambodia.’ *Educational Action Research,* 26(2) pp. 190-204.

Ozawa, S., and Pongpirul, K. (2014). ‘10 best resources on … mixed methods research in health systems.’ *Health Policy and Planning*, 29(3) pp. 323–327.

Page, M.J., McKenzie, J.E., Bossuyt, P.M., Boutron, I., Hoffmann, T.C., Mulrow, C.D., et al. (2021). ‘The PRISMA 2020 statement: an updated guideline for reporting systematic reviews.’ *British Medical Journal,* 372(71) 372:n71. [Online]. [Accessed on 7th July 2023]. https://doi.org/10.1136/bmj.n71

Park, Y.S., Konge, L.M.D., and Artino, A.R. (2020).’ The Positivism Paradigm of Research.’ *Academic Medicine*, 95(5) pp. 690-694.

Parthasarathy, B. (2008). ‘The ethnographic case study approach.’ *The Global Impact Study.* [Online]. [Accessed on 8th July 2016].http://www.globalimpactstudy.org/2008/07/the-ethnographic-case-study-approach/

Pässilä, A.H., Oikarinen, T., and Harmaakorp, V. (2015). ‘Collective voicing as a reflexive practice.’ *Management Learning,* 46(1) pp. 67-86.

Paterson, K. (2012). ‘It’s about time! Understanding the experience of speech impairment.’ *In*: Watson, N., Roulstone. A., and Thomas, C. (eds). *Routledge Handbook of Disability Studies.* New York: Routledge

Patton, M.Q. (1990). *Qualitative Evaluation and Research Methods. 3rd ed.* London: Sage.

Pictet, J. (1966). ‘The principles of international humanitarian law.’ *International Review of the Red Cross,* 6(66) p. 455

Pinnock, H., and Hodgkin, M. (2010). ‘Education access for all.’ *Forced Migration Review,* 35, pp. 34-35

Plan International. (2013). *Outside the circle: A Research Initiative by Plan International into the Rights of Children with Disabilities to Education and Protection in West Africa*. [Online]. [Accessed 9th July 2016]. https://planinternational.org/outside-circle

Plan International. (2017). *Planning for Inclusion: How Education Budgets and Plans Target the Most Marginalized. Summary Version.* London: Plan International.
Plattner, D. (1996). *ICRC Neutrality and Neutrality in Humanitarian Assistance*. International Committee of the Red Cross, Article 311. [Online]. [Accessed on 13th May 2023]. https://www.icrc.org/en/doc/resources/documents/article/other/57jn2z.htm

Polynational War Memorial. (2018). *Rwandan Social Revolution.* [Online]. [Accessed 7th July 2023]. http://www.war-memorial.net/Rwandan-Social-Revolution-3.334

Ponterotto, J.G. (2006). ‘Brief notes on the origins, evolution, and meaning of the qualitative research concept “thick description”.’ *The Qualitative Report,* 11(3), pp. 358-459.

Popenoe, R., Langius-Eklöf, A., Stenwall, E., & Jervaeus, A. (2021). ‘A practical guide to data analysis in general literature reviews.’ *Nordic Journal of Nursing Research,* 41(4) pp. 175-186

Population Pyramid. (2016a). *Population of Rwanda, 2016*. [Online]. [Accessed on 6th May 2023]. https://www.populationpyramid.net/rwanda/2016/

Population Pyramid. (2016b). *Population of Burundi, 2016.* [Online]. [Accessed on 6th May 2023]. https://www.populationpyramid.net/burundi/2016/

Population Pyramid. (2016c). *Population of Democratic Republic of the Congo 2016.* [On;ine]. [Accessed on 6th May 2023]. https://www.populationpyramid.net/democratic-republic-of-the-congo/2016/

Reinhardt, A., Kreiner, G., Gioia, D., and Corley, K. (2018). 'Conducting and publishing rigorous qualitative research.' *In* Cassell, C., Cunlife, A., and Grandy, G. (eds.). *The SAGE Handbook of Qualitative Business and Management Research Methods (Vol. 1).* Thousand Oaks, Ca: SAGE

Richardson, L. (2000). 'Writing: A method of inquiry.' *In* Denzin, N.K., and Lincoln, Y.S. (eds.) *Handbook of Qualitative Research (2nd ed*.) Thousand Oaks, Ca: SAGE

Ritchie, J., Lewis, J., McNaughton Nicolls, C., and Ormston, R. (2014). *Qualitative Research Practice: A Guide for Social Science Students and Researchers.* London: Sage

Ritchie, J. and Spencer, L. (1994). 'Qualitative Data Analysis for Applied Policy Research.' *In* Bryman, A. and Burgess, B., (eds.) *Analyzing Qualitative Data*. London: Routledge

Republic of Rwanda. (2015). *Vision 2050.* [Online]. [Accessed on 6th May 2023]. https://plasticsdb.surrey.ac.uk/documents/Rwanda/Republic%20of%20Rwanda%20%282015%29%20Rwanda%20Vision%202050.pdf

Rieff, D. (2002). *A Bed for the Night: Humanitarianism in Crisis.* London: Vintage.

Rioux, M., Basser, L.S., and Jones, M. (eds). (2011). *Critical Perspectives on Human Rights and Disability Law.* Martinus Neuhoff Publishers.

Robson, C. (2002). *Real World Research*. 2nd ed. Blackwell, Oxford.

Rogers, C.R. (1951). 'Client-Centred Therapy.' Cited in: MacKenzie, S., McAllister, L., Hudson, K., Worrall, L., Davidson, B., and Howe, T. (2019). 'Phenomenology and its uses in communication disorders research'. *In* Lyons, R., and McAllister, L. (eds). *Qualitative Research in Communication Disorders: An Introduction for Students and Clinicians.* Croydon: J&R Press.

Rose, R., and Shevlin, M. (2004). ‘Encouraging voices: listening to young people who have been marginalised.’ *Support for Learning,* 19(4) pp. 155-161.

Rosling, H. (2015). *Beyond Open Data: A New Challenge from Hans Rosling.* World Bank Live. [Online]. [Accessed on 18th November 2023]. https://live.worldbank.org/en/event/2015/hans-rosling-beyond-open-data

Roulstone, A., Thomas, C., and Watson, N. (2012). ‘The changing terrain of disability studies.’ *In* (eds). Watson, N., Roulstone, A. and Thomas, C. (eds). *Routledge Handbook of Disability Studies.* New York: Routledge

Rwanda Education Board (REB). (2016). *Guide to Inclusive Education in Pre-Primary, Primary, and Secondary Education in Rwanda.* Kigali: Government of Rwanda.

Ryan, G.W., and Bernard, H.R. (2000). ‘Data management and analysis method.’ *In* Denzin, N., and Lincoln, Y. (eds). *Handbook of Qualitative Research, 2nd Edition.* Thousand Oaks, CA: Sage.

Sagahutu, J.B., Tuyizere, M., and Struthers, P. (2013). ‘Physical environmental barriers to school attendance among children with disabilities in two community based rehabilitation centres in Rwanda.’ *Rwanda Journal of Health Sciences,* 2(1) pp. 10-15.

Sandelowski M. (1986). ‘The problem of rigour in qualitative research.’ *Advances in Nursing Research,* 8 pp. 27–37.

Sandelowski, M. (2016). ‘Forward to the first edition.’ *In* Thorne, S. *Interpretive Description: Qualitative Research for Applied Practice.* New York: Routledge.

Save the Children. (2002). *Schools for All: Including disabled children in Education.* London: Save the Children.

Save the Children. (2003). *Education in Emergencies A Tool Kit for Starting and Managing Education in Emergencies.* London: Save the Children.

Save the Children. (2008a). *Making Schools Inclusive. How Change can Happen - Save the Children's Experience.* London: Save the Children.

Save the Children. (2008b). *Non-discrimination in Emergencies Training Manual and Toolkit*. London: Save the Children.

Save the Children. (2016a). *Half of All Refugee Children are Out of School Leaving them Exposed to Exploitation and Abuse*. [Online]. [Accessed on 13th October 2022]. https://www.savethechildren.net/news/half-all-refugee-children-are-out-school-leaving-them-exposed-exploitation-and-abuse

Save the Children. (2016b). *Inclusive Education: What, Why, and Wow - A Handbook for Program Implementers.* London: Save the Children.

Save the Children. (2017). *Losing Out on Learning. Providing refugee children the education they were promised.* London: Save the Children.

Schwab, M.M. (2021). *How the Term "Third World" Perpetuates Poverty.* [Online]. [Accessed 18th November 2023]. https://borgenproject.org/term-third-world/

Scior, K. (2011). 'Public awareness, attitudes and beliefs regarding intellectual disability: A systematic review.' *Research in Developmental Disabilities,* 32 pp. 2164-2182

School of System Change. (undated). *Why do We Need Systems Change?* [Online]. [Accessed 13th November 2023]. https://schoolofsystemchange.org/systems-change/why-systems-change

Scott-Smith, T. (2016). 'Humanitarian Dilemmas in a Mobile World.' *Refugee Survey Quarterly,* 35(2) pp. 1-21

Scott-Smith, T. (2021). *Briefing Note on Definition Debates in Humanitarian Action.*: Oxford, University of Oxford Refugee Studies Centre

Scott-Smith, T. (2022a). *Anthropological Approach.* Oxford, University of Oxford Refugee Studies Centre

Scott-Smith, T. (2022b). *The Politics of Humanitarianism.* Oxford, University of Oxford Refugee Studies Centre

Serrano-Fuentes, N. (2021). *Re: What is the difference between framework analysis and thematic analysis*. [Online]. [Accessed on 7th July 2022]. https://www.researchgate.net/post/what_is_the_different_between_framework_analysis_and_thematic_analysis/60fd566e0de161186a3ee5cc/citation/download

Shacknove, A. E. (1985). 'Who Is a Refugee?' *Ethics*, 95(2) pp. 274–284.

Shakespeare, T. (2018). *Disability: The Basics.* London: Routledge.

Shakespeare, T. (2006). *Disability Rights and Wrongs.* London: Routledge.

Shakespeare, T., and Erikson, M. (2000). 'Different strokes: Beyond biological determinism and social constructionism.' *In* Rose, H., and Rose, S. (ed.) *Alas, Poor Darwin: Arguments Against Evolutionary Psychology.* London: Crown.

Shakespeare, T., and Watson, N. (2001). 'The social model of disability: An outdated ideology?' *Research in Social Science and Disability*, 2 pp. 9-28.

Shonkoff, J.P., and Garner, A.S. (2012). 'The lifelong effects of early childhood adversity and toxic stress.' *Pediatrics*, 129(1): e232-46. [Online]. [Accessed on 7th July 2023]. https://doi.org/10.1542/peds.2011-2663

Siddique, A.K. (1994). 'Cholera epidemic among Rwandan refugees: Experience of ICDDR in Goma, Zaire.' *Glimpse,* 16(5) pp. 3-4.

Silverman, D. (2013). *Doing Qualitative Research*. *4th ed*. London: Sage.
Simmons, S. (1995). 'From paradigm to method in interpretive action research.' *Journal of Advanced Nursing,* 21 pp. 837-844.

Sixsmith, J., Boneham, M., and Goldring, J.E. (2003). 'Accessing the community: gaining insider perspectives from the outside.' *Qualitative Health Research,* 13(4) pp. 578-89.

Slim, H. (1997). 'Relief Agencies and Moral Standing in War: Principles of humanity, Neutrality, Impartiality and Solidarity.' *Development in Practice,* 7(4) pp. 342-352.

Smillie. I., and Minear, L. (2004). *The Charity of Nations: Humanitarian Action in a Calculating World.* Connecticut, Kumarian Press.

Smith Khan, L., Crock, M., Saul, B., and McCallum, R. (2014). 'To 'Promote, Protect and Ensure': Overcoming Obstacles to Identifying Disability in Forced Migration.' *Journal of Refugee Studies,* 28(1) pp. 38-68.

Smith, J., and Firth, J. (2011). 'Qualitative data analysis: The framework approach.' *Nurse Researcher*, 18(2) pp. 52-62.

Spencer, L., Ritchie, J., O'Connor, W., Morrell, G., and Ormston, R. (2014). 'Analysis in practice.' *In* Ritchie, J., Lewis, J., McNaughton Nicholls. C., and Ormston, R (eds). *Qualitative Research Practice: A Guide for Social Science Students and Researchers.* London, SAGE.

Spencer, L., Ritchie, J., Ormston, R., O'Connor, W., and Barnard, M. (2014). 'Analysis: Principles and Processes.' *In* Ritchie, J., Lewis., J., McNaughton Nicholls, C., and Ormston, R. *Qualitative Research Practice: A Guide for Social Science Students and Researchers.* London, SAGE.

Sphere. (2018). *The Sphere Handbook: Humanitarian Charter and Minimum Standards in Humanitarian Response.* 4th edn. Geneva, Switzerland: Sphere. [Online]. [Accessed on 14th February 2022]. https://spherestandards.org/handbook-2018/

Snyder, H. (2019). 'Literature review as a research methodology: An overview and guidelines.' *Journal of Business Research,* 104 pp. 333-339.

Srivastava, P., and Hopwood, N. (2009). 'A practical iterative framework for qualitative data analysis.' *International Journal of Qualitative Methods,* 8(1) pp. 76-84.

Stanovich, S., Ecke, J., and Wirtz, E. (2021). 'Forced Migration.' *Anthropology.* [Online]. 'First online'. [Accessed on 7th July 2023]. https://doi.org/10.1093/acrefore/9780190854584.013.468

Stern, P. (1994). 'Eroding grounded theory.' *In* Morse J. (ed.) *Critical Issues in Qualitative Research Methods.* Thousand Oaks, Ca: Sage.

Stevano, S., and Deane, K. (2019) 'The Role of Research Assistants in Qualitative and Cross-Cultural Social Sciences Research.' *In* Liamputtong, P, (ed.) *Handbook of Research Methods in Health Social Sciences.* Singapore: Springer.

Stillman, W. (2006). *Autism and the God Connection. Redefining the Autistic Experience Through Extraordinary Accounts of Spiritual Giftedness*. Naperville, Illinois: Sourcebooks.

Stubbs, S. (2002). *Inclusive education: Where there are Few Resources*. London: Atlas Alliance. [Online]. [Accessed on 28th May 2023]. https://www.inclusive-education-in-action.org/resources/inclusive-education-where-there-are-few-resources

Sue, D. W. and Sue, D. (2015). *Counseling the Culturally Diverse: Theory and Practice*. *7th edn.* London: Wiley

Sutherland, A. (1981). 'Disabled we stand.' Cited in: Shakespeare, T. and Watson, N. (2001). 'The social model of disability: An outdated ideology?' *Research in Social Science and Disability,* 2 pp. 9-28

Talley, L., and Brintnell, E.S. (2016). 'Scoping the barriers to implementing policies for inclusive education in Rwanda: an occupational therapy opportunity.' *International Journal of Inclusive Education*, 20(4) pp. 364-382

Tanabe, M., Nagujjah, Y., Rimal, N., Bukania, F., and Krause, S. (2015). 'Intersecting sexual and reproductive health and disability in humanitarian settings: Risks, needs and capacities of refugees with disabilities in Kenya, Nepal and Uganda.' *Sexuality and Disability,* 33(4) pp. 411–427.

Tariq, S., and Woodman, J. (2013). 'Using mixed methods in health research.' *Journal of the Royal Society of Medicine (short reports),* 4(6).

Teddlie, C., and Tashakkori, A. (2010). 'Overview of Contemporary Issues in Mixed Methods Research.*' In* Tashakkori, A., and Teddlie, C. *SAGE Handbook of Mixed Methods in Social & Behavioral Research. (2nd ed.)* SL: Sage.

Tedlock, B. (2000). 'Ethnography and Ethnographic Representation.*' In* Denzin, N. and Lincoln, Y. (eds.) *The Handbook of Qualitative Research*. Thousand Oaks: Sage

Temple, B., and R. Edwards. (2002). 'Interpreters/Translators and Cross-language Research: Reflexivity and Border Crossings.' *International Journal of Qualitative Methods,* 1(2) pp. 58–67

Terry, F. (1998). 'The Paradoxes of Humanitarian Aid.' *Agenda: A Journal of Policy Analysis and Reform*, 5(2) pp.135–146

Terry, F. (2000). *The Principle of Neutrality: Is it Relevant to MSF?* [Online]. [Accessed on 21st September 2022]. https://www.msf.fr/sites/default/files/2000-12-01-Terry.pdf

Terry, F. (2002). *Condemned to Repeat?: The Paradox of Humanitarian Action*. New York: Cornell University Press.

The Black Agenda Report. (2022, July). *Excerpt: On the Pan American Congress, José Martí, 1989.* [Online]. [Accessed on 8th July 2023]. https://www.blackagendareport.com/excerpt-pan-american-congress-jose-marti-1889

The Universal Design Project. (2023). *What is Universal Design?* [Online]. [Accessed on 28th May 2023]. https://universaldesign.org/definition

Thomas, C. (2004). 'How is disability understood? An examination of sociological approaches.' *Disability & Society,* 19(6) pp. 569-583.

Thomas, P. (2005). *Mainstreaming Disability in Development: Country-Level Research.* London: Disability Knowledge and Research.

Thompson, B.P. (1997). 'H.L Wesseling. Divide and Rule: The Partition of Africa, 1880–1914. Arnold J. Pomerans, trans.' *Ufahamu: A Journal of African Studies,* 25(1) pp. 162-163.

Thorne, S.E. (2001). 'The implications of disciplinary agenda on quality criteria for qualitative research. *In* Morse, J.M., Swanson, J.A., and Kuzel A. (EDS.) *The Nature of Qualitative Evidence.* Thousand Oaks, Ca: Sage.

Thorne, S. (2016). *Interpretive Description: Qualitative Research for Applied Practice (2nd ed).* New York: Routledge

Thorne, S., Reimer Kirkham, S.R., and MacDonald-Emes, J. (1997). 'Focus on qualitative methods. Interpretive Description: A noncategorical qualitative alternative for developing nursing knowledge.' *Research in Nursing and Health*, 20 pp. 169–177

Thorne, S., Reimer Kirkham, S., and O'Flynn-Magee, K. (2004). 'The analytic challenge in interpretive description.' *International Journal of Qualitative Methods,* 3(2) pp. 1-11.

Tobler, C. (2008). *Limits and Potential of the Concept of Indirect Discrimination*. Luxembourg: Office for the official publications of the European Commission. [Online]. [Accessed on 14th February 2022]. https://www.bing.com/search?q=Tobler%2C+C.+%282008%29.+Limits+and+Potential+of+the+Concept+of+Indirect+Discrimination.+Luxembourg%3A+Office+for+the+official+publications+of+the+European+Commission&form=ANNH01&refig=aa4aacb9b70047a4a75848cd847a4db0

Tranfield, D., Denyer, D., and Smart, P. (2003). 'Towards a methodology for developing evidence-informed management knowledge by means of systematic review.' *British Journal of Management,* 14(3) pp. 207–222.

Trani, J.F., Kett, M., Bakhshi, P., and Bailey, N. (2011). 'Disability, vulnerability and citizenship: to what extent is education a protective mechanism for children with disabilities in countries affected by conflict?' *International Journal of Inclusive Education*, 15(10) pp. 1187-1203.

Tregaskis, C. (2002). 'Social Model Theory: The story so far.' *Disability & Society,* 17(4) pp. 457-470.

Trade Union Advisory Committee to the OECD (TUAC). (2018). *OECD Membership and the Values of the Organisation*. [Online]. [Accessed on 13th November 2023]. https://tuac.org/wp-content/uploads/2018/06/140PS_E_8-membership.pdf

Union of the Physically Impaired Against Segregation (UPIAS). (1976). *Union of the Physically Impaired Against Segregation: Policy Statement.* UPIAS. [Online]. [Accessed on 13th May 2023]. https://disability-studies.leeds.ac.uk/wp-content/uploads/sites/40/library/UPIAS-UPIAS.pdf

United Nations. (n.d). *Millennium Development Goals and Beyond 2015.* [Online]. [Accessed on 29th April 2023]. https://www.un.org/millenniumgoals/

United Nations. (2004). *International Norms and Standards Related to Disability.* [Online]. [Accessed on 28th May 2023]. http://www.un.org/esa/socdev/enable/comp501.htm

United Nations. (2007). *Convention on the Rights of Persons with Disabilities*. 24 January 2007, A/RES/61/106. [Online]. [Accessed on 5th May 2022]. https://www.refworld.org/docid/45f973632.html

United Nations. (2015). *Education 2030: Towards Inclusive and Equitable Quality Education and Lifelong Learning for All.* Incheon, South Korea: United Nations.

United Nations. (2016). *New York Declaration for Refugees and Migrants.* New York: United Nations. [Online]. [Accessed on 14th October 2022]. https://refugeesmigrants.un.org/declaration

United Nations. (2018). *Global Compact on Refugees*. New York, United Nations. [Online]. [Accessed on 13th May 2023]. https://www.unhcr.org/media/37797

United Nations (2019). *More than Half of World's Refugee Children 'Do Not Get an Education', Warns UNHCR.* UN News: Global Perspective Human Stories. [Online]. [Accessed on 13th October 2022]. https://news.un.org/en/story/2019/08/1045281

United Nations Children's Fund (UNICEF). (n.d.) *Inclusive Education*. [Online]. [Accessed on 7th July 2023]. https://www.unicef.org/education/inclusive-education

United Nations Children's Fund (UNICEF). (2007). *The Participation of Children and Young People in Emergencies: A Guide for Relief Agencies, Based Largely on Experiences in the Asian Tsunami Response*. Bangkok: UNICEF

United Nations Children's Fund (United Nations Children's Fund (UNICEF). (2010). *Core Commitments for Children in Humanitarian Action.* New York: UNIUCEF.

United Nations Children's Fund (United Nations Children's Fund (UNICEF). (2013). *The State of the World's Children 2013: Executive Summary – Children with Disabilities.* New York: UNICEF.

[Online]. [Accessed on 13th October 2022].https://www.unicef.org.uk/wp-content/uploads/2013/05/sowc-2013-children-with-disabilities-exce-summary.pdf

United Nations Children's Fund (UNICEF). (2014). *Early Childhood Development in Emergencies Integrated Programme Guide.* New York: UNICEF.

United Nations Children's Fund (UNICEF). (2017). *Including Children with Disabilities in Humanitarian Action. General Guidance.* New York: UNICEF.

United Nations Children's Fund (UNICEF). (2021). *Seen, Counted, Included: Using Data to Shed Light on the Well-Being of Children with Disabilities.* New York: United Nations Children's Fund. [Online]. [Accessed on 22nd August 2022]. https://data.unicef.org/resources/children-with-disabilitiesreport-2021/

United Nations Children's Fund (UNICEF). (2022). *The Humanitarian-Development Nexus*. [Online]. [Accessed on 13th May 2023]. https://www.unicef.org/eu/humanitarian-development-nexus

United Nations Children's Fund (UNICEF)., and Education Development Trust (EDT). (2016). *A Study on Children with Disabilities and their Right to Education: Republic of Rwanda*. [Online]. [Accessed on 1st May 2022]. https://www.unicef.org/esaro/Rwanda-children-with-disabilities-UNICEF-EDT-2016.pdf

United Nations Children's Fund (UNICEF)., and UNESCO. (2007). *A Human Rights-Based Approach to Education for All.* New York: UNICEF & UNESCO.

United Nations Conference on Trade and Development. (2023). *UN List of Least Developed Countries.* [Online]. [Accessed on 18th November 2023]. https://unctad.org/topic/least-developed-countries/list

United Nations Department for Economic and Social Affairs (UNDESA). (2015a). *Transforming Our World: The 2030 Agenda for Sustainable Development*. [Online]. [Accessed on 13th October 2022]. https://sdgs.un.org/2030agenda

United Nations Department for Economic and Social Affairs (UNDESA). (2015b). *Goal 4: Ensure Inclusive and Equitable Quality Education and Promote Lifelong Learning Opportunities for All.* [Online]. [Accessed on 13th October 2022]. https://sdgs.un.org/goals/goal4

United Nations Department of Economic and Social Affairs. (UNDESA). (2022). *Convention on the Rights of Persons with Disabilities (CRPD).* Geneva: UNDESA. [Online]. [Accessed on 14th May 2023]. https://social.desa.un.org/issues/disability/crpd/convention-on-the-rights-of-persons-with-disabilities-crpd

United Nations Development Programme (UNDP). (2022). *Human Development Index.* [Online]. [Accessed on 22nd September 2022]. https://hdr.undp.org/data-center/human-development-index#/indicies/HDI

United Nations Development Programme (UNDP). (2020). *The 2020 Global Multidimensional Poverty Index (MPI).* UNDP Human Development Reports. [Online]. [Accessed on 7th July 2023]. http://hdr.undp.org/en/2020-MPI

United Nations Educational, Scientific and Cultural Organization (UNESCO). (1994). *The Salamanca Statement and Framework for Action on Special Needs Education*. Salamanca: UNESCO. [Online]. [Accessed on 28th May 2023]. https://unesdoc.unesco.org/ark:/48223/pf0000098427

United Nations Educational, Scientific and Cultural Organization (UNESCO). (2000). *Education for All and Children who Are Excluded: Thematic Studies.* Education for All 2000 Assessment. Dakar: World Education Forum.

United Nations Educational, Scientific and Cultural Organization (UNESCO). (2001). *Understanding and Responding to Children's Needs in Inclusive Classrooms: A Guide for Teachers.* Paris: UNESCO.

United Nations Educational, Scientific and Cultural Organization (UNESCO). (2009). *Policy Guidelines of Inclusion in Education.* Paris: UNESCO.

United Nations Educational, Scientific and Cultural Organization (UNESCO). (2015). *Incheon Declaration– Education 2030: Towards Inclusive and Equitable Quality Education and Lifelong Learning for All.* [Online]. [Accessed on 7th July 2022]. https://iite.unesco.org/publications/incheon-declaration-education-2030-towards-inclusive-and-equitable-quality-education-and-lifelong-learning-for-all/

United Nations Economic, Social and Cultural Organisation. (UNESCO). (2022a). *Transforming Education Together for Just and Sustainable Futures.* Statement from the International Commission on the Futures of Education. [Online]. [Accessed on 13th October 2022]. https://unesdoc.unesco.org/ark:/48223/pf0000381984

United Nations General Assembly (UNGA). (1948). *Universal Declaration of Human Rights, 10 December, 217 A (III).* [Online]. [Accessed on 14th May 2023]. https://www.refworld.org/docid/3ae6b3712c.html

United Nations General Assembly (UNGA). (1951). *Convention Relating to the Status of Refugees, 28 July 1951.* United Nations, Treaty Series, vol. 189, p. 137. [Online]. [Accessed on 13th October 2022]. https://www.refworld.org/docid/3be01b964.html

United Nations General Assembly. (UNGA). (1967). *Protocol Relating to the Status of Refugees. Resolution 2198 (XXI)*. [Online]. [Accessed on 6th May 2023]. https://www.ohchr.org/en/instruments-mechanisms/instruments/protocol-relating-status-refugees

United Nations General Assembly (UNGA). (1989). *Convention on the Rights of the Child.* 20 November 1989. United Nations Treaty Series, vol. 1577, p. 3. [Online]. [Accessed on 13th October 2022]. https://www.refworld.org/docid/3ae6b38f0.html

United Nations General Assembly (UNGA). (2000). *United Nations Millennium Declaration. New* York: UNGA. [Online]. [Accessed on 12th March 2017]. https://www.un.org/millennium/declaration/ares552e.pdf

United Nations General Assembly (UNGA). (2006). *Convention on the Rights of Persons with Disabilities.* 24 January 2007. Resolution A/RES/61/106. [Online]. [Accessed on 12th October 2022]. https://www.refworld.org/docid/45f973632.html

United Nations General Assembly (UNGA). (2015a). *Transforming our World: The 2030 Agenda for Sustainable Development.* 21 October 2015. A/RES/70/1. [Online]. [Accessed on 14th May 2023]. https://www.refworld.org/docid/57b6e3e44.html

United Nations General Assembly (UNGA). (2015b). *Thematic Study on the Rights of Persons with Disabilities under Article 11 of the Convention on the Rights of Persons with Disabilities, on Situations of Risk and Humanitarian Emergencies.* New York: UNGA.

United Nations General Assembly (UNGA). (2016). *Convention on the Rights of Persons with Disabilities General Comment No 4. Article 24: Right to Inclusive Education.* New York: UNGA.

United Nations High Commissioner for Refugees (UNHCR). (2003). *Handbook for Registration (provisional release).* Geneva: UNHCR.

United Nations High Commissioner for Refugees (UNHCR). (2005). *Procedural Standards for RSD under UNHCR's Mandate: Unit 3 -Reception and Registration in RSD Operations*. Geneva: UNHCR.

United Nations High Commissioner for Refugees (UNHCR). (2006a). *Guidance on the use of Specific Needs Codes.* Geneva, UNHCR. [Online]. [Accessed on 14th February 2023]. https://www.bing.com/newtabredir?url=aHR0cHM6Ly9jbXMuZW1lcmdlbmN5LnVuaGNyLm9yZy9kb2N1bWVudHMvMTE5ODIvNDMyNDgvR3VpZGFuY2Urb24rdGhlK1VzZStvZitTdGFuZGFyZG l6ZWQrU3BlY2lmaWMrTmVlZHMrQ29kZXMrJTI4RW5nbGlzaCUyOS84N2IxZmViYi02MzMxLTQ3MjctYjE5Ni1kNjJkNTZhMDJhZGI%3D&be=1

United Nations High Commissioner for Refugees (UNHCR). (2006b). *UNHCR & International Protection Chapter 4: Access to Asylum, Registration and Quality Protection*. Geneva, UNHCR.

United Nations High Commissioner for Refugees (UNHCR). (2007). *UNHCR Global Appeal 2007 – Mission Statement.* [Online]. [Accessed on 10th June 2023]. https://www.unhcr.org/media/unhcr-global-appeal-2007-mission-statement

United Nations High Commissioner for Refugees (UNHCR). (2008). *The Heightened Risk Identification Tool User Guide*. Geneva, UNHCR.

United Nations High Commissioner for Refugees (UNCHR). (2009). *Guidance on the Use of Specific Needs Codes – Internal Memorandum 030/2009*. Geneva, Switzerland: UNHCR.

United Nations High Commissioner for Refugees (UNHCR). (2010a). *Conclusion on Refugees with Disabilities and Other Persons with Disabilities Protected and Assisted by UNHCR (No. 100 LXI).* [Online]. [Accessed on 9th May 2016]. http://www.unhcr.org/4cbeb1a99.html

UNHCR (2010b). *Heightened Risk Identification Tool. 2nd edn*. Geneva: UNHCR
United Nations High Commissioner for Refugees. (UNHCR). (2011). *Action Against Sexual and Gender-Based Violence. An updated strategy*. Geneva: UNHCR.

United Nations High Commissioner for Refugees. (UNHCR). (2013). *Protection in Emergencies Toolbox: Protection Checklists.* Geneva: UNHCR Division of International Protection; Division of Emergency Security and Supply.

United Nations High Commissioner for Refugees (UNHCR). (2015a). *Personal Communication with UNHCR Rwanda Community-Based Protection Officer*. June 2015. Kigali, Rwanda.

United Nations High Commissioner for Refugees. (UNHCR). (2015b). *Standard Operating Procedure: Urban Refugees' Access to Education.* Kigali: UNHCR Rwanda.

United Nations High Commissioner for Refugees UNHCR. (2017a). *UNHCR Rwanda: Monthly Population Statistics (as of 31 May 2017).* [Online]. [Accessed on 17th September 2018]. file:///C:/Users/HelenBarrett/Downloads/Population%20Statistics%20-%20UNHCR%20Rwanda%20May%202017.pdf

United Nations High Commissioner for Refugees (UNHCR). (2017b). *Contribution to the Fifteenth Coordination Meeting on International Migration.* United Nations Department of Economic and Social Affairs, 16-17 February 2017. [Online]. [Accessed on 15th April 2018]. https://www.un.org/en/development/desa/population/migration/events/%20coordination/15/documents/papers/14_UNHCR_nd.pdf

United Nations High Commissioner for Refugees (UNHCR). (2017b). *UNHCR Emergency Handbook: Persons with Disabilities*. Geneva: UNHCR.

United Nations High Commissioner for Refugees (UNHCR). (2017c). *Left Behind. Refugee Education in Crisis.* Geneva, UNHCR.

United Nations High Commissioner for Refugees (UNHCR). (2018). *UNHCR Global Trends. Forced Displacement in 2017.* [Online]. [Accessed on 6th May 2023]. https://www.unhcr.org/statistics/unhcrstats/5b27be547/unhcr-global-trends-2017.html?query=how%20many%20people%20displaced%20in%202017

United Nations High Commissioner for Refugees (UNHCR). (2019). *Stepping Up: Refugee Education in Crisis*. [Online]. [Accessed on 13th October 2022]. https://www.unhcr.org/steppingup/wp-content/uploads/sites/76/2019/09/Education-Report-2019-Final-web-9.pdf

United Nations High Commissioner for Refugees (UNHCR). (2020). *The Sustainable Development Goals and the Global Compact on Refugees.* [Online]. [Accessed on 19th May

2021]. https://globalcompactrefugees.org/sites/default/files/2020-08/How%20the%20SDGs%20and%20the%20GCR%20are%20aligned.%20UNHCR..pdf

United Nations High Commissioner for Refugees (UNHCR) (2021) *UNHCR Rwanda Operation Data Map - December 2020*. [Online]. [Accessed on 10th July 2022]. https://data.unhcr.org/en/documents/details/90365

United Nations High Commissioner for Refugees (UNHCR). (2022a). *Operational Data Portal: Rwanda.* [Online]. [Accessed on 3rd July 2022]. https://data.unhcr.org/en/country/rwa#_ga=2.267155918.1112037930.1667107072-1495037636.1656510660

United Nations High Commissioner for Refugees (UNHCR). (2022b). *Refugee Data Finder*. [Online]. [Accessed on 6th May 2022]. https://www.unhcr.org/refugee-statistics/

United Nations High Commissioner for Refugees (UNHCR). (2022c). *Operationalizing the Humanitarian, Development and Peace Nexus. UNHCR Global Compact on Refugees.* Geneva, UNHCR. [Online]. [Accessed on 13th May 2023]. https://globalcompactrefugees.org/good-practices/operationalizing-humanitarian-development-and-peace-nexus

United Nations High Commissioner for Refugees (UNHCR). (2023). *Asylum Seekers.* [Online]. [Accessed on 7th July 2023]. https://www.unhcr.org/asylum-seekers
United Nations High Commissioner for Refugees (UNHCR) and Handicap International. (2011). *Working with Persons with Disabilities in Forced Displacement*. *Need to Know Guidance 1.* Geneva: UNHCR.

United Nations Human Rights Council (UNHRC). (2021). *Universal Periodic Review – Rwanda.* [Online]. [Accessed on 1st May 2021]. https://www.ohchr.org/EN/HRBodies/UPR/Pages/RWindex.aspx

United Nations Rwanda Country Office. (2017). *United Nations Development Assistance Plan (UNDAP) July 2018 to June 2023 for Rwanda*. Kigali: United Nations. [Online]. [Accessed on 14th

May 2023]. https://rwanda.un.org/sites/default/files/2019-04/United%20Nations%20in%20Rwanda%20Development%20Assistance%20Plan%202018-2023%20%28UNDAP%20II%29_0_0.pdf

Vaismoradi, M., Turunen, H. and Bondas, T. (2013) 'Content analysis and thematic analysis: Implications for conducting a qualitative descriptive study.' *Nursing & Health Sciences*, *15*(3), pp.398-405.

Van Manen, M. (1990). *Researching Lived Experience: Human Science for an Action Sensitive Pedagogy.* Ontario: The University of Western Ontario.

Wafula, F.N., and Goodman, C.A., (2010). 'Are interventions for improving the quality of services provided by specialized drug shops effective in sub-Saharan Africa? A systematic review of the literature.' *International Journal for Quality in health Care*, 22(4) pp. 316-323.

Walker, S.P., Wachs, T.D., Gardner, J.M., Lozoff, B., Wasserman, G.A., Pollitt, E., and Carter, J.A. (2007). 'Child development: risk factors for adverse outcomes in developing countries.' *Lancet*, 369(9556) pp. 145–57

Walker, S.P., Wachs, T.D., Grantham-McGregor, S., Black, M.M., Nelson, C.A., Huffman, S.L., Baker-Henningham, H., Chang, S.M., Hamadani, J.D., Lozoff, B., Gardner, J.M., Powell, C.A., Rahman, A., and Richter, L. (2011). 'Inequality in early childhood: risk and protective factors for early child development.' *Lancet,* 8;378(9799) pp. 1325-38

Wall, C., Glenn, S., Mitchinson, S. and Poole, H. (2004) 'Using a reflective diary to develop bracketing skills during a phenomenological investigation.' *Nurse Researcher*, 11(4), pp. 20-29

Washington Group on Disability Statistics. (2020). *The Washington Group Short Set on Functioning.* [Online]. [Accessed on 10th July 2022]. https://www.washingtongroup-disability.com/fileadmin/uploads/wg/Documents/Questions/Washington_Group_Questionnaire__1_-_WG_Short_Set_on_Functioning.pdf

Webster, J., & Watson, R. T. (2002). ‘Analyzing the past to prepare for the future: Writing a literature review.’ *MIS Quarterly*, 26(2) pp. xiii–xxiii.

Weiss, G. (2015).’ The normal, the natural, and the normative: A Merleau-Pontian legacy to feminist theory, critical race theory, and disability studies.’ *Continental Philosophy Review,* 48 pp. 77–93.

Werner, O., and Shoepfle, G.M. (1987). *Systematic Fieldwork Vol 1: Foundations of Ethnography and Interviewing.* Newbury Park, Ca: Sage.

Wheelan, C. (2014). *Naked Statistics: Stripping the Dread from the Data.* New York: W.W. Norton & Co.

Wheeler, N. (2000). *Saving Strangers: Humanitarian Intervention in International Society*. Oxford: Oxford University Press.

Willis, J.W., and Jost, M. (2007). *Foundations of Qualitative Research: Interpretive and Critical Approaches.* Thousand Oaks, Ca: Sage.

Wilson, L., and Martin, N. (2018). ‘Models of disability affect language: Implications for Disability, Equality and inclusivity practice.’ *The Journal of Inclusive Practice in Further and Higher Education,* 10(1) pp. 4-19

Wimpenny, P., and Gass, J. (2000). ‘Interviewing in phenomenology and grounded theory: is there a differene?’ *Journal of Advanced Nursing,* 31(6) pp. 1485-1492.

Winkler, S., Sacks, A., and Wong, S. (2022). *Inclusive Policies are Needed to Help Refugees and Host Communities Flourish.* World Bank Blogs. [Online]. [Accessed on 2nd July 2023]. https://blogs.worldbank.org/dev4peace/inclusive-policies-are-needed-help-refugees-and-host-communities-flourish

Wong, G., Greenhalgh, T., Westhorp, G., Buckingham, J., and Pawson, R. (2013). 'RAMESES publication standards: Meta-narrative reviews.' *BMC Medicine*, 11(20). [Online]. [Accessed on 7th July 2023]. https://bmcmedicine.biomedcentral.com/articles/10.1186/1741-7015-11-20

World Bank. (2017). *GDP per Capita PPP. Congo Dem. Rep, Rwanda, Burundi*. [Online]. [Accessed 6th May 2023]. https://data.worldbank.org/indicator/NY.GDP.PCAP.PP.CD?locations=CD-RW-BI

World Bank. (2022). *The World Bank in DRC*. [Online]. [Accessed on 6th May 2023]. https://www.worldbank.org/en/country/drc/overview

World Economic Forum. (2016). *Why is the World Bank Getting Rid of the Term 'Developing Country'?* [Online]. [Accessed on 18th November 2023]. https://www.weforum.org/agenda/2016/05/why-is-the-world-bank-getting-rid-of-the-term-developing-country/

World Health Organisation. (WHO). (1980). *International Classification of Impairments, Disabilities, and Handicaps: A manual of classification relating to the consequences of disease published in accordance with resolution WHA29.35 of the Twenty-ninth World Health Assembly.* May 1976. [Online]. [Accessed 13th May 2023]. https://apps.who.int/iris/handle/10665/41003

World Health Organisation (WHO). (2001). *International Classification of Disability, Functioning, and Health* (ICF). [Online]. [Accessed 29th April 2023]. https://www.who.int/standards/classifications/international-classification-of-functioning-disability-and-health

World Health Organisation (WHO). (2023). *Disability.* [Online]. [Accessed 7th July 2023]. https://www.who.int/health-topics/disability#tab=tab_1

World Health Organisation (WHO) and World Bank Group (WBG). (2011). *World Report on Disability.* [Online]. [Accessed on 7th July 2023].

https://www.who.int/teams/noncommunicable-diseases/sensory-functions-disability-and-rehabilitation/world-report-on-disability

World Health Organisation (WHO) & UNICEF. (2012). *Early Childhood Development and Disability: A Discussion Paper.* [Online]. https://apps.who.int/iris/bitstream/handle/10665/75355/?sequence=1

Women's Refugee Commission (WRC). (2014). *Disability Inclusion: Translating Policy into Practice in Humanitarian Action.* [Online]. [Accessed on 15th May 2016]. https://www.womensrefugeecommission.org/disabilities/disability-inclusion

Women's Refugee Commission (WRC). (2015). *"I see that it is possible": Building Capacity for Disability Inclusion in Gender-Based Violence Programming*. [Online]. [Accessed on 15th May 2016]. https://www.womensrefugeecommission.org/disabilities/resources/document/945-buildingcapacity-for-disabilityinclusion-in-gender-based-violence-gbv-programming-in-humanitarian-settings-overview?catid=232

World Economic Forum. (2021). *What 'Systems Thinking' Actually Means – and Why it Matters for Innovation Today*. [Online]. [Accessed on 24th November 2023].

World Health Organization (WHO), UNICEF, & World Bank Group (WBG). (2018). *Nurturing Care for Early Childhood Development: A Framework for Helping Children Survive and Thrive to Transform Health and Human Potential*. New York, WHO, UNICEF, & WBG. [Online]. [Accessed on 14th May 2023]. https://nurturing-care.org/

Writepass. (2017). *How to Write a Methodology: Dissertation Help.* [Online]. [Accessed on 12th March 2020]. https://writepass.com/journal/2017/08/write-methodology-dissertation-help.

Wrong, M. (2000). *In the Footsteps of Mr. Kurtz: Living on the Brink of Disaster in the Congo.* Michigan: Fourth Estate.

Wylie, K., McAllister, L., Davidson, B., and Marshall, J. (2013). ‘Changing practice: implications of the World Report on Disability for responding to communication disability in under-served populations.’ *International Journal of Speech-Language Pathology,* 15(1) pp.1-13.

Yin, R.K. (1994). *Case Study Research: Design and Methods (2nd ed.).* Thousand Oaks, CA: Sage.
Yonge, O., and Stewin, L. (1988). ‘Reliability and validity: misnomers for qualitative research.’ *Canadian Journal of Nursing Research,* 20 pp. 61–67

York, S., Lavi, R., Dori, Y.D., and Orgill, M. (2019). Applications of Systems Thinking in STEM. *Education Journal of Chem. Educ.* 96(12) pp. 2742–2751.

Zola, I.K. (1989). ‘Towards the necessary universalizing of a disability policy.’ *The Millbank Quarterly,* 83(4), pp. 1-27.

Appendices

Appendix 1: Ethical approvals and clearances

1.1 Ethical approval – Manchester Metropolitan University

Manchester Metropolitan
University

M E M O R A N D U M

FACULTY ACADEMIC ETHICS COMMITTEE

**Faculty of Health,
Psychology & Social Care**

Brooks Building
Birley Fields Campus
53 Bonsall Street
Manchester
M15 6GX

+44 (0)161 247 2569

HPSCresearchdegrees@mmu.ac.uk

To: Helen Barrett

From: Prof Carol Haigh

Date: 15/11/2016

Subject: Ethics Application 1388

Title: Access to early childhood development and inclusive education services for refugee children with communication disability in Rwanda.

Thank you for your application for ethical approval.

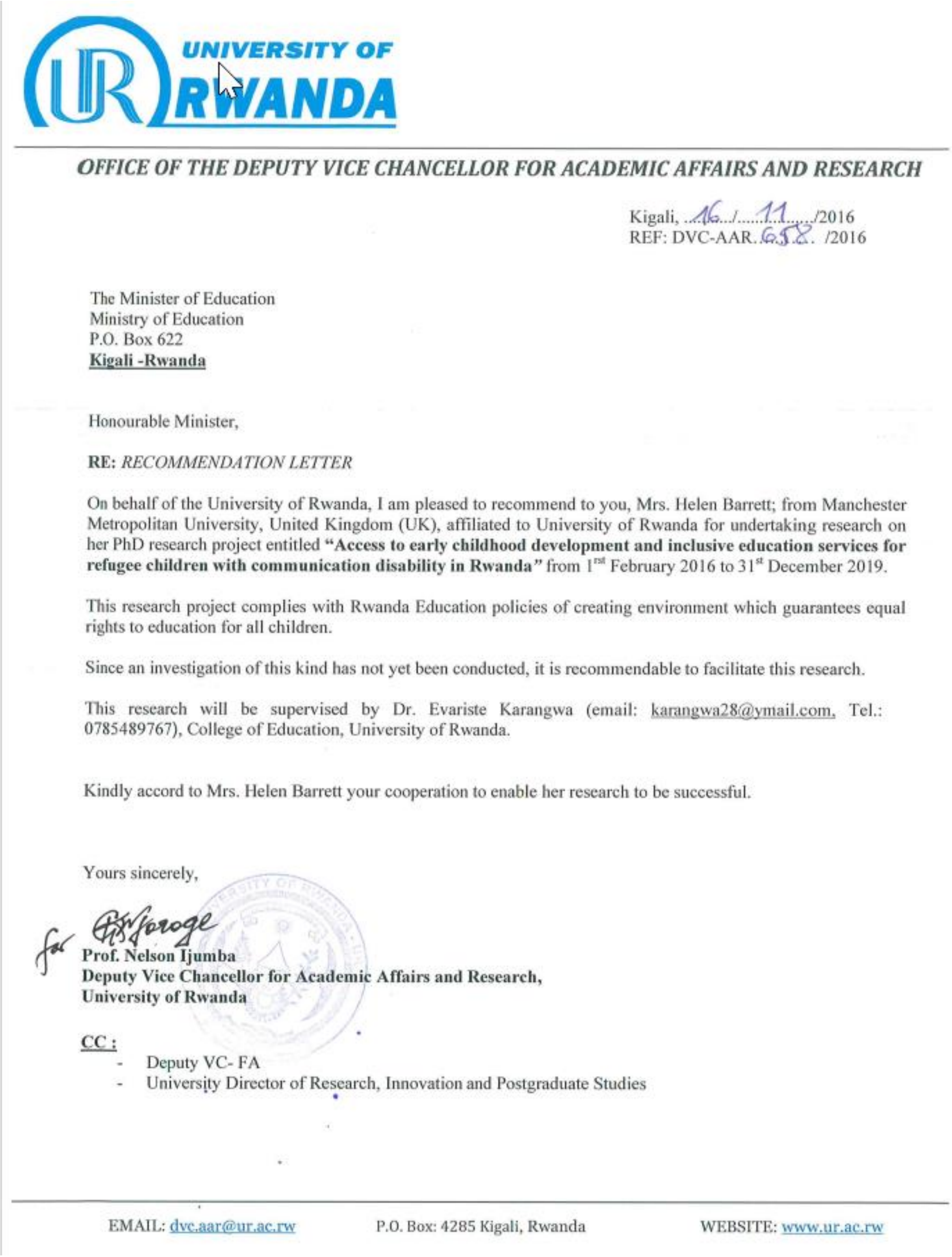
The Faculty Academic Ethics Committee review process has recommended approval of your ethics application. This approval is granted for 42 months for full-time students or staff and 60 months for part-time students. Extensions to the approval period can be requested.

If your research changes you might need to seek ethical approval for the amendments. Please request an amendment form.

We wish you every success with your project.

Prof Carol Haigh and Prof Jois Stansfield
Chair and Deputy Chair
Faculty Academic Ethics Committee

1.2 University of Rwanda recommendation to Ministry of Education



UNIVERSITY OF RWANDA

OFFICE OF THE DEPUTY VICE CHANCELLOR FOR ACADEMIC AFFAIRS AND RESEARCH

Kigali, 16/11/2016
REF: DVC-AAR.658. /2016

The Minister of Education
Ministry of Education
P.O. Box 622
Kigali -Rwanda

Honourable Minister,

RE: *RECOMMENDATION LETTER*

On behalf of the University of Rwanda, I am pleased to recommend to you, Mrs. Helen Barrett; from Manchester Metropolitan University, United Kingdom (UK), affiliated to University of Rwanda for undertaking research on her PhD research project entitled **"Access to early childhood development and inclusive education services for refugee children with communication disability in Rwanda"** from 1st February 2016 to 31st December 2019.

This research project complies with Rwanda Education policies of creating environment which guarantees equal rights to education for all children.

Since an investigation of this kind has not yet been conducted, it is recommendable to facilitate this research.

This research will be supervised by Dr. Evariste Karangwa (email: karangwa28@ymail.com, Tel.: 0785489767), College of Education, University of Rwanda.

Kindly accord to Mrs. Helen Barrett your cooperation to enable her research to be successful.

Yours sincerely,

for

Prof. Nelson Ijumba
Deputy Vice Chancellor for Academic Affairs and Research,
University of Rwanda

CC :
- Deputy VC- FA
- University Director of Research, Innovation and Postgraduate Studies

EMAIL: dvc.aar@ur.ac.rw P.O. Box: 4285 Kigali, Rwanda WEBSITE: www.ur.ac.rw

1.3 Rwanda Ministry of Education ethical approval (1 & 2)

REPUBLIC OF RWANDA

MINISTRY OF EDUCATION
P.O.BOX 622 KIGALI

Kigali, 09/12/2016
N°2413/12.00/2016

Ms. Helen Louise Barrett
Ph.D. student
Manchester Metropolitan University
Email: Helen.l.barrett@stu.mmu.ac.uk
United Kingdom

Dear Ms. Helen,

RE: Approval to Conduct Research in Rwanda under the Project Title: "Access to Early Childhood Development and Inclusive Education Services for Refugee Children with Communication Disability in Rwanda"

I am pleased to attach a copy of research clearance, which has been granted to you to conduct research on the above title.

I wish to remind you that the research clearance number should be cited in your final research report. The research will be carried out under affiliation of the University of Rwanda, under supervision of **Dr. Evariste Karangwa**, College of Education, University of Rwanda.

You are requested to submit the progress report after six months and the final report after completion of your research activities to the Ministry of Education of Rwanda.

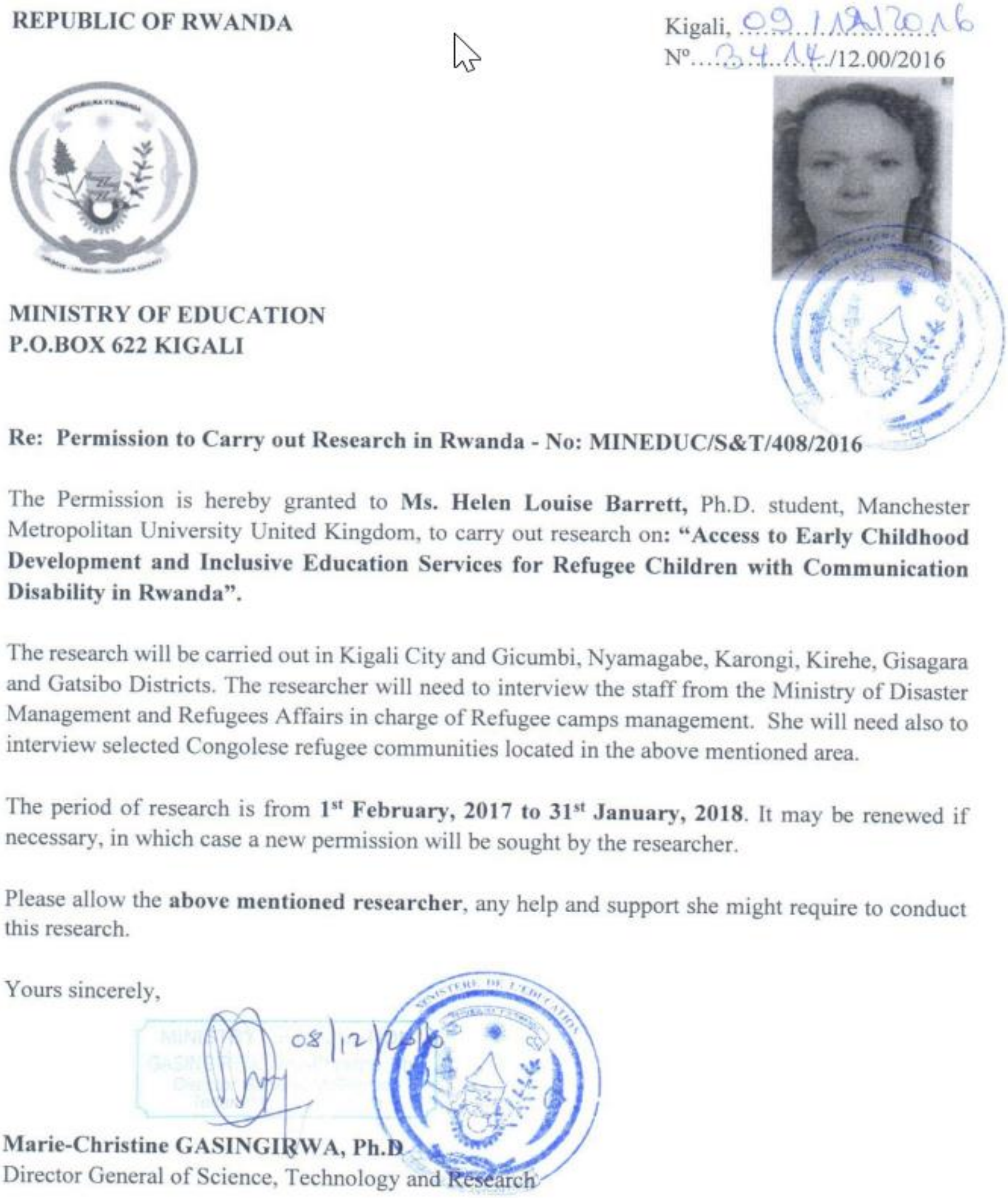
I wish you success in your research.

Yours sincerely,

08/12/2016

Marie-Christine GASINGIRWA, Ph.D
Director General of Science, Technology and Research

Cc.
- Hon. Minister of Education
- Hon. Minister of State in Charge of TVET
- Hon. Minister of State in Charge of Primary and Secondary Education
- Permanent Secretary, Ministry of Education
- Dr. Evariste Karangwa, College of Education, University of Rwanda.



REPUBLIC OF RWANDA

Kigali, 09/12/2016
Nº…3414/12.00/2016

MINISTRY OF EDUCATION
P.O.BOX 622 KIGALI

Re: Permission to Carry out Research in Rwanda - No: MINEDUC/S&T/408/2016

The Permission is hereby granted to **Ms. Helen Louise Barrett,** Ph.D. student, Manchester Metropolitan University United Kingdom, to carry out research on: **"Access to Early Childhood Development and Inclusive Education Services for Refugee Children with Communication Disability in Rwanda".**

The research will be carried out in Kigali City and Gicumbi, Nyamagabe, Karongi, Kirehe, Gisagara and Gatsibo Districts. The researcher will need to interview the staff from the Ministry of Disaster Management and Refugees Affairs in charge of Refugee camps management. She will need also to interview selected Congolese refugee communities located in the above mentioned area.

The period of research is from **1st February, 2017 to 31st January, 2018**. It may be renewed if necessary, in which case a new permission will be sought by the researcher.

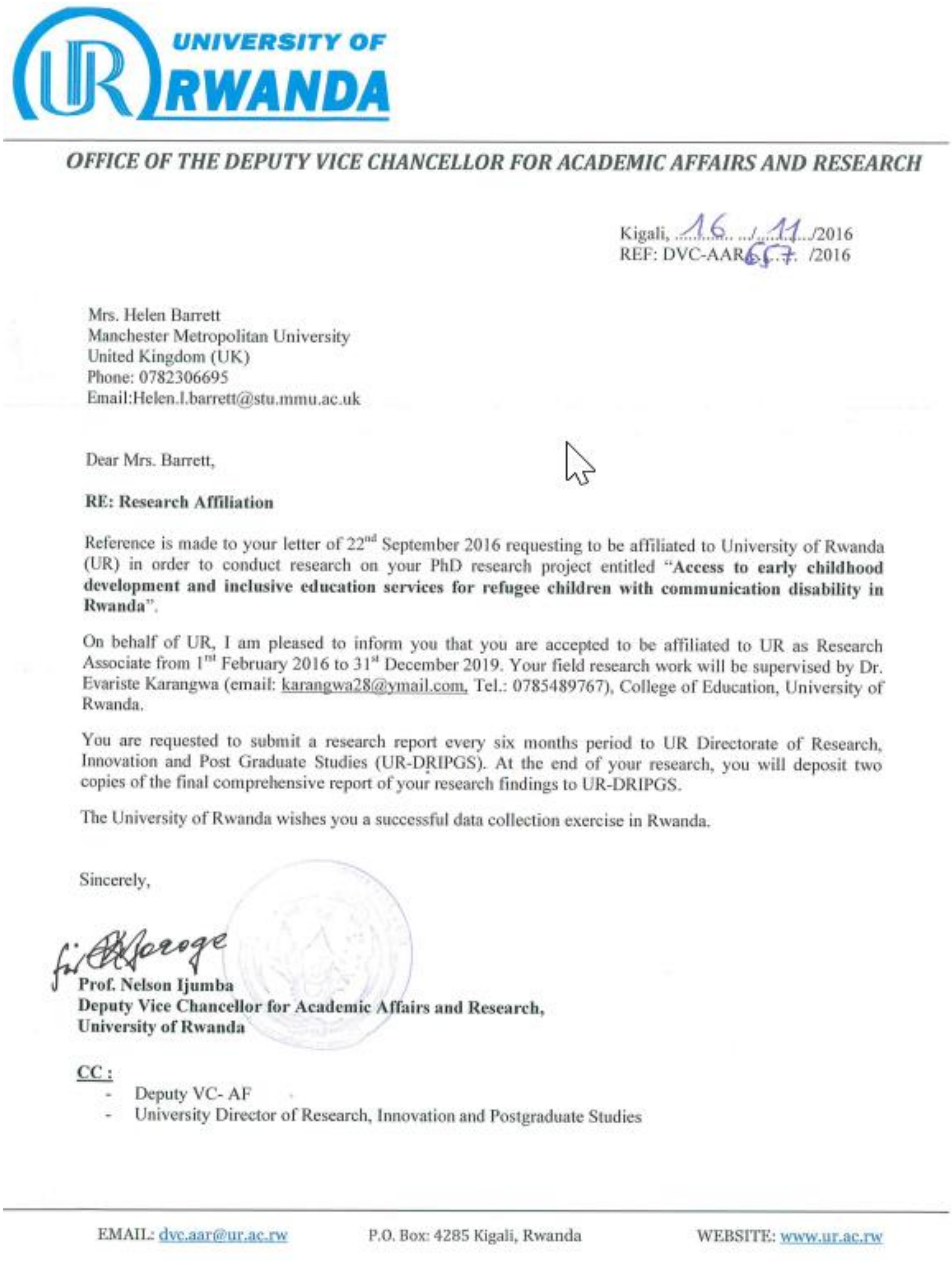
Please allow the **above mentioned researcher**, any help and support she might require to conduct this research.

Yours sincerely,

08/12/2016

Marie-Christine GASINGIRWA, Ph.D
Director General of Science, Technology and Research

1.4 University of Rwanda affiliation confirmation



UNIVERSITY OF RWANDA

OFFICE OF THE DEPUTY VICE CHANCELLOR FOR ACADEMIC AFFAIRS AND RESEARCH

Kigali, 16/11/2016
REF: DVC-AAR657 /2016

Mrs. Helen Barrett
Manchester Metropolitan University
United Kingdom (UK)
Phone: 0782306695
Email:Helen.l.barrett@stu.mmu.ac.uk

Dear Mrs. Barrett,

RE: Research Affiliation

Reference is made to your letter of 22nd September 2016 requesting to be affiliated to University of Rwanda (UR) in order to conduct research on your PhD research project entitled "**Access to early childhood development and inclusive education services for refugee children with communication disability in Rwanda**".

On behalf of UR, I am pleased to inform you that you are accepted to be affiliated to UR as Research Associate from 1st February 2016 to 31st December 2019. Your field research work will be supervised by Dr. Evariste Karangwa (email: karangwa28@ymail.com, Tel.: 0785489767), College of Education, University of Rwanda.

You are requested to submit a research report every six months period to UR Directorate of Research, Innovation and Post Graduate Studies (UR-DRIPGS). At the end of your research, you will deposit two copies of the final comprehensive report of your research findings to UR-DRIPGS.

The University of Rwanda wishes you a successful data collection exercise in Rwanda.

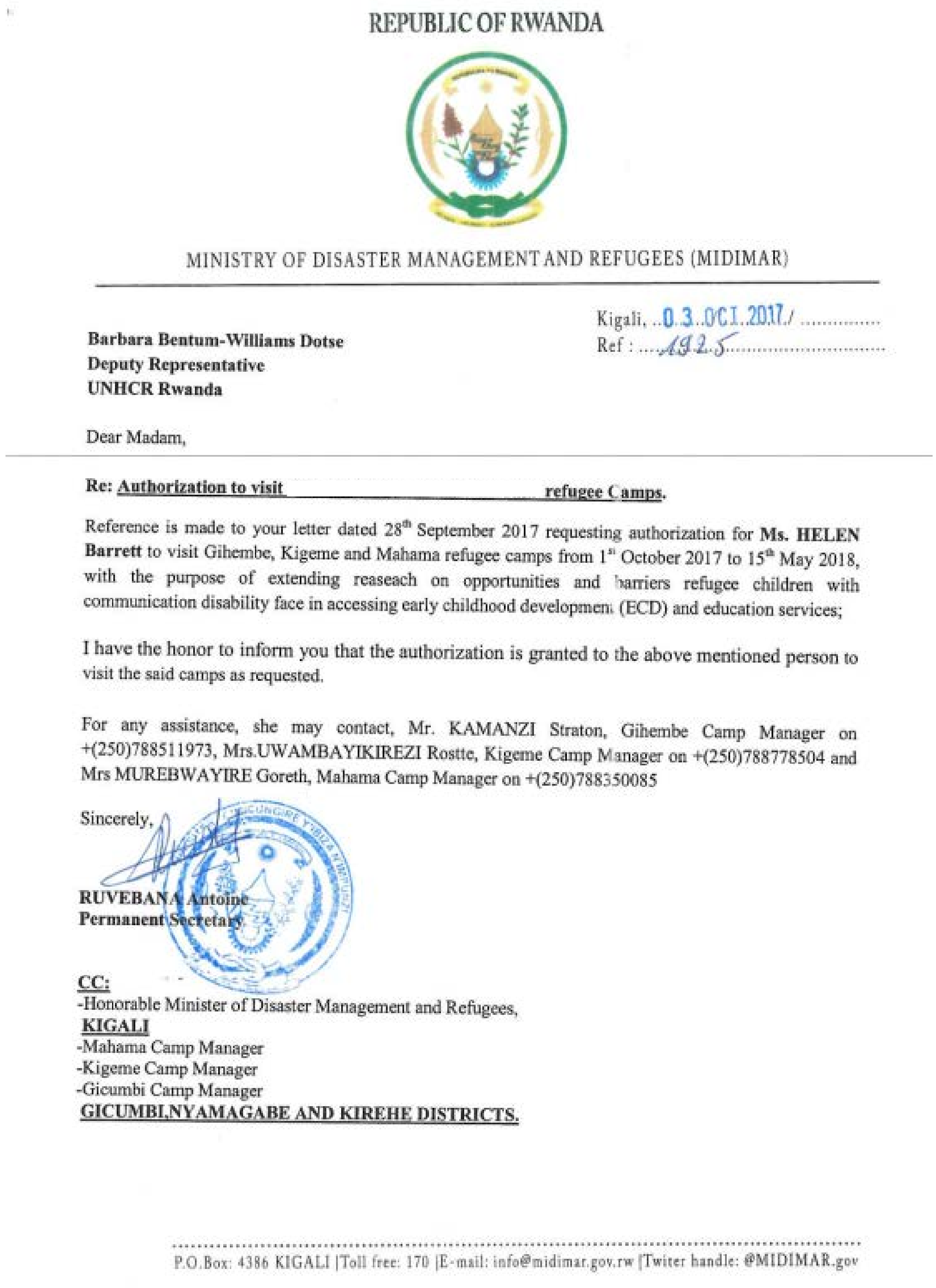
Sincerely,

Prof. Nelson Ijumba
Deputy Vice Chancellor for Academic Affairs and Research,
University of Rwanda

CC :
- Deputy VC- AF
- University Director of Research, Innovation and Postgraduate Studies

EMAIL: dvc.aar@ur.ac.rw P.O. Box: 4285 Kigali, Rwanda WEBSITE: www.ur.ac.rw

1.5 MINEDUC clearance



REPUBLIC OF RWANDA

MINISTRY OF DISASTER MANAGEMENT AND REFUGEES (MIDIMAR)

Kigali, ..0.3..OCT..2017./ ....
Ref : .....1925...............................

Barbara Bentum-Williams Dotse
Deputy Representative
UNHCR Rwanda

Dear Madam,

Re: <u>Authorization to visit</u> ______________ <u>refugee Camps</u>.

Reference is made to your letter dated 28th September 2017 requesting authorization for **Ms. HELEN Barrett** to visit Gihembe, Kigeme and Mahama refugee camps from 1st October 2017 to 15th May 2018, with the purpose of extending reaseach on opportunities and barriers refugee children with communication disability face in accessing early childhood development (ECD) and education services;

I have the honor to inform you that the authorization is granted to the above mentioned person to visit the said camps as requested.

For any assistance, she may contact, Mr. KAMANZI Straton, Gihembe Camp Manager on +(250)788511973, Mrs.UWAMBAYIKIREZI Rostte, Kigeme Camp Manager on +(250)788778504 and Mrs MUREBWAYIRE Goreth, Mahama Camp Manager on +(250)788350085

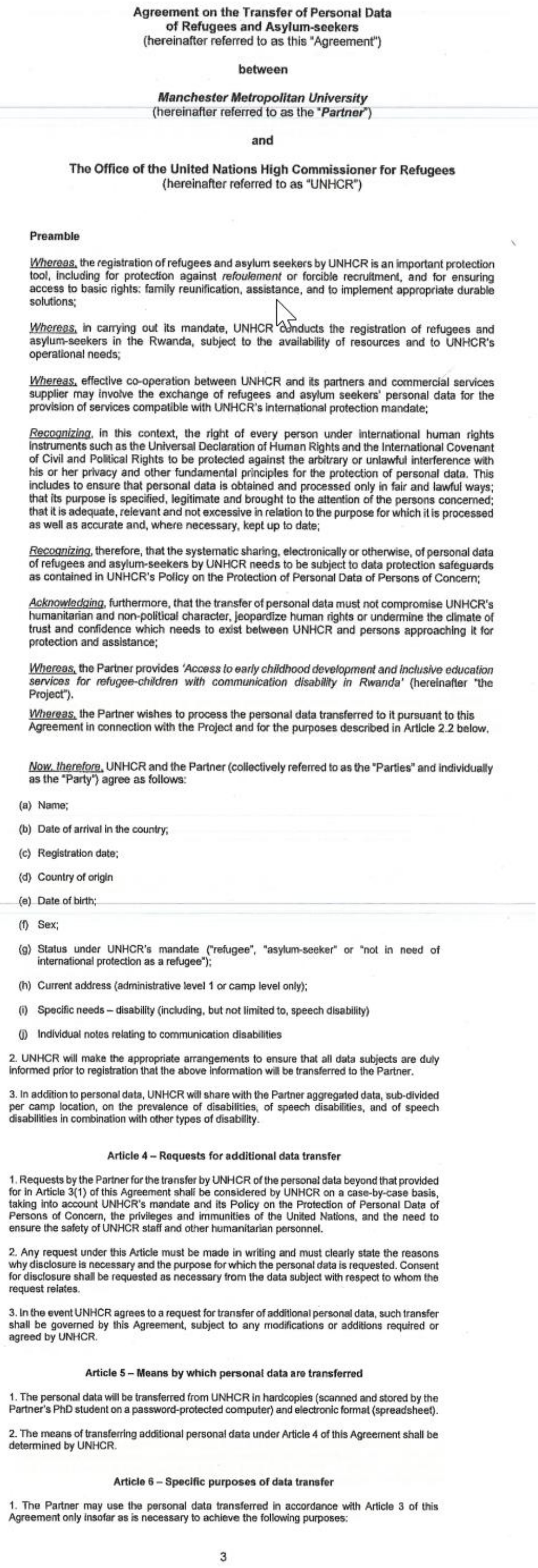
Sincerely,

RUVEBANA Antoine
Permanent Secretary

<u>CC:</u>
-Honorable Minister of Disaster Management and Refugees,
<u>KIGALI</u>
-Mahama Camp Manager
-Kigeme Camp Manager
-Gicumbi Camp Manager
<u>GICUMBI,NYAMAGABE AND KIREHE DISTRICTS.</u>

P.O.Box: 4386 KIGALI |Toll free: 170 |E-mail: info@midimar.gov.rw |Twiter handle: @MIDIMAR.gov

Appendix 2: Data sharing agreement



Agreement on the Transfer of Personal Data
of Refugees and Asylum-seekers
(hereinafter referred to as this "Agreement")

between

Manchester Metropolitan University
(hereinafter referred to as the "***Partner***")

and

The Office of the United Nations High Commissioner for Refugees
(hereinafter referred to as "UNHCR")

Preamble

Whereas, the registration of refugees and asylum seekers by UNHCR is an important protection tool, including for protection against *refoulement* or forcible recruitment, and for ensuring access to basic rights: family reunification, assistance, and to implement appropriate durable solutions;

Whereas, in carrying out its mandate, UNHCR conducts the registration of refugees and asylum-seekers in the Rwanda, subject to the availability of resources and to UNHCR's operational needs;

Whereas, effective co-operation between UNHCR and its partners and commercial services supplier may involve the exchange of refugees and asylum seekers' personal data for the provision of services compatible with UNHCR's international protection mandate;

Recognizing, in this context, the right of every person under international human rights instruments such as the Universal Declaration of Human Rights and the International Covenant of Civil and Political Rights to be protected against the arbitrary or unlawful interference with his or her privacy and other fundamental principles for the protection of personal data. This includes to ensure that personal data is obtained and processed only in fair and lawful ways; that its purpose is specified, legitimate and brought to the attention of the persons concerned; that it is adequate, relevant and not excessive in relation to the purpose for which it is processed as well as accurate and, where necessary, kept up to date;

Recognizing, therefore, that the systematic sharing, electronically or otherwise, of personal data of refugees and asylum-seekers by UNHCR needs to be subject to data protection safeguards as contained in UNHCR's Policy on the Protection of Personal Data of Persons of Concern;

Acknowledging, furthermore, that the transfer of personal data must not compromise UNHCR's humanitarian and non-political character, jeopardize human rights or undermine the climate of trust and confidence which needs to exist between UNHCR and persons approaching it for protection and assistance;

Whereas, the Partner provides *'Access to early childhood development and inclusive education services for refugee-children with communication disability in Rwanda'* (hereinafter "the Project").

Whereas, the Partner wishes to process the personal data transferred to it pursuant to this Agreement in connection with the Project and for the purposes described in Article 2.2 below.

Now, therefore, UNHCR and the Partner (collectively referred to as the "Parties" and individually as the "Party") agree as follows:

(a) Name;

(b) Date of arrival in the country;

(c) Registration date;

(d) Country of origin

(e) Date of birth;

(f) Sex;

(g) Status under UNHCR's mandate ("refugee", "asylum-seeker" or "not in need of international protection as a refugee");

(h) Current address (administrative level 1 or camp level only);

(i) Specific needs – disability (including, but not limited to, speech disability)

(j) Individual notes relating to communication disabilities

2. UNHCR will make the appropriate arrangements to ensure that all data subjects are duly informed prior to registration that the above information will be transferred to the Partner.

3. In addition to personal data, UNHCR will share with the Partner aggregated data, sub-divided per camp location, on the prevalence of disabilities, of speech disabilities, and of speech disabilities in combination with other types of disability.

Article 4 – Requests for additional data transfer

1. Requests by the Partner for the transfer by UNHCR of the personal data beyond that provided for in Article 3(1) of this Agreement shall be considered by UNHCR on a case-by-case basis, taking into account UNHCR's mandate and its Policy on the Protection of Personal Data of Persons of Concern, the privileges and immunities of the United Nations, and the need to ensure the safety of UNHCR staff and other humanitarian personnel.

2. Any request under this Article must be made in writing and must clearly state the reasons why disclosure is necessary and the purpose for which the personal data is requested. Consent for disclosure shall be requested as necessary from the data subject with respect to whom the request relates.

3. In the event UNHCR agrees to a request for transfer of additional personal data, such transfer shall be governed by this Agreement, subject to any modifications or additions required or agreed by UNHCR.

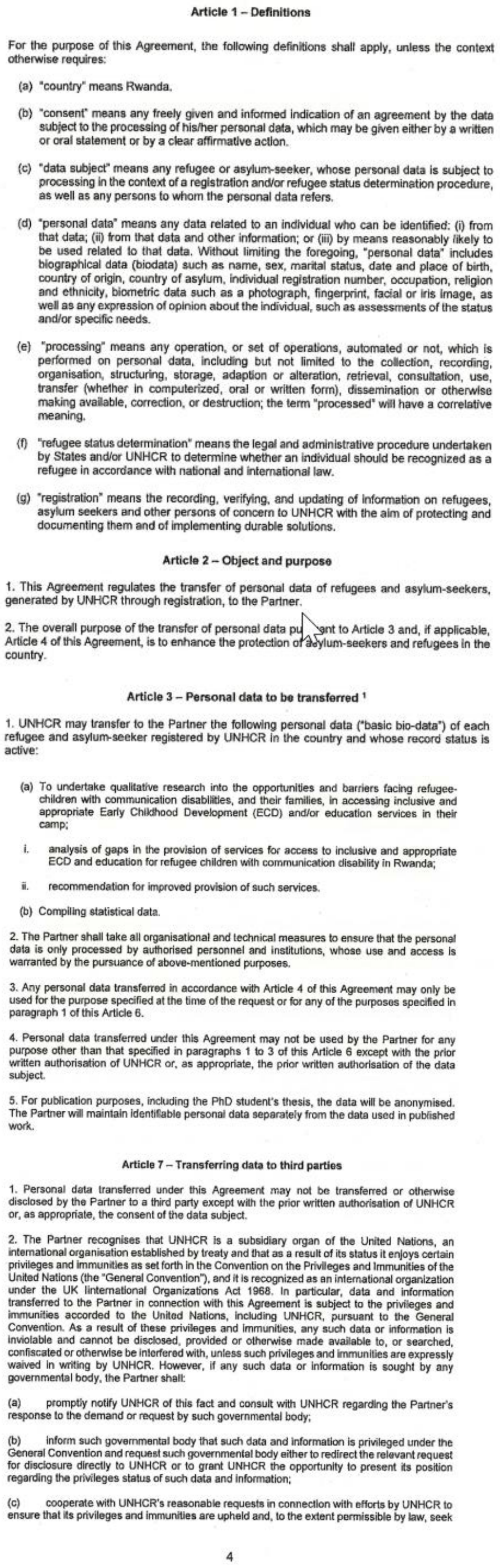
Article 5 – Means by which personal data are transferred

1. The personal data will be transferred from UNHCR in hardcopies (scanned and stored by the Partner's PhD student on a password-protected computer) and electronic format (spreadsheet).

2. The means of transferring additional personal data under Article 4 of this Agreement shall be determined by UNHCR.

Article 6 – Specific purposes of data transfer

1. The Partner may use the personal data transferred in accordance with Article 3 of this Agreement only insofar as is necessary to achieve the following purposes:



Article 1 – Definitions

For the purpose of this Agreement, the following definitions shall apply, unless the context otherwise requires:

(a) "country" means Rwanda.

(b) "consent" means any freely given and informed indication of an agreement by the data subject to the processing of his/her personal data, which may be given either by a written or oral statement or by a clear affirmative action.

(c) "data subject" means any refugee or asylum-seeker, whose personal data is subject to processing in the context of a registration and/or refugee status determination procedure, as well as any persons to whom the personal data refers.

(d) "personal data" means any data related to an individual who can be identified: (i) from that data; (ii) from that data and other information; or (iii) by means reasonably likely to be used related to that data. Without limiting the foregoing, "personal data" includes biographical data (biodata) such as name, sex, marital status, date and place of birth, country of origin, country of asylum, individual registration number, occupation, religion and ethnicity, biometric data such as a photograph, fingerprint, facial or iris image, as well as any expression of opinion about the individual, such as assessments of the status and/or specific needs.

(e) "processing" means any operation, or set of operations, automated or not, which is performed on personal data, including but not limited to the collection, recording, organisation, structuring, storage, adaption or alteration, retrieval, consultation, use, transfer (whether in computerized, oral or written form), dissemination or otherwise making available, correction, or destruction; the term "processed" will have a correlative meaning.

(f) "refugee status determination" means the legal and administrative procedure undertaken by States and/or UNHCR to determine whether an individual should be recognized as a refugee in accordance with national and international law.

(g) "registration" means the recording, verifying, and updating of information on refugees, asylum seekers and other persons of concern to UNHCR with the aim of protecting and documenting them and of implementing durable solutions.

Article 2 – Object and purpose

1. This Agreement regulates the transfer of personal data of refugees and asylum-seekers, generated by UNHCR through registration, to the Partner.

2. The overall purpose of the transfer of personal data pursuant to Article 3 and, if applicable, Article 4 of this Agreement, is to enhance the protection of asylum-seekers and refugees in the country.

Article 3 – Personal data to be transferred [1]

1. UNHCR may transfer to the Partner the following personal data ("basic bio-data") of each refugee and asylum-seeker registered by UNHCR in the country and whose record status is active:

(a) To undertake qualitative research into the opportunities and barriers facing refugee-children with communication disabilities, and their families, in accessing inclusive and appropriate Early Childhood Development (ECD) and/or education services in their camp;

i. analysis of gaps in the provision of services for access to inclusive and appropriate ECD and education for refugee children with communication disability in Rwanda;

ii. recommendation for improved provision of such services.

(b) Compiling statistical data.

2. The Partner shall take all organisational and technical measures to ensure that the personal data is only processed by authorised personnel and institutions, whose use and access is warranted by the pursuance of above-mentioned purposes.

3. Any personal data transferred in accordance with Article 4 of this Agreement may only be used for the purpose specified at the time of the request or for any of the purposes specified in paragraph 1 of this Article 6.

4. Personal data transferred under this Agreement may not be used by the Partner for any purpose other than that specified in paragraphs 1 to 3 of this Article 6 except with the prior written authorisation of UNHCR or, as appropriate, the prior written authorisation of the data subject.

5. For publication purposes, including the PhD student's thesis, the data will be anonymised. The Partner will maintain identifiable personal data separately from the data used in published work.

Article 7 – Transferring data to third parties

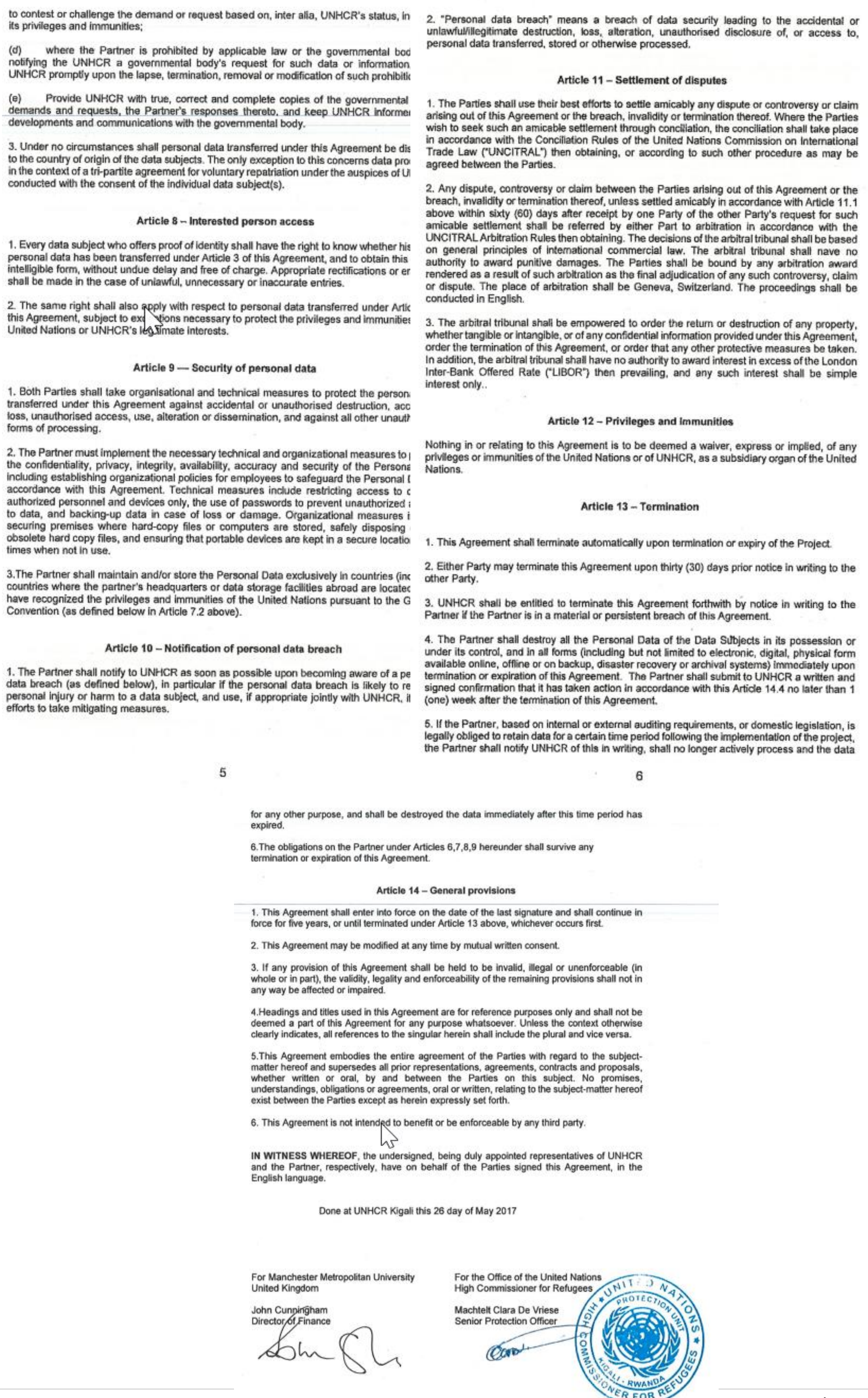
1. Personal data transferred under this Agreement may not be transferred or otherwise disclosed by the Partner to a third party except with the prior written authorisation of UNHCR or, as appropriate, the consent of the data subject.

2. The Partner recognises that UNHCR is a subsidiary organ of the United Nations, an international organisation established by treaty and that as a result of its status it enjoys certain privileges and immunities as set forth in the Convention on the Privileges and Immunities of the United Nations (the "General Convention"), and it is recognized as an international organization under the UK Iinternational Organizations Act 1968. In particular, data and information transferred to the Partner in connection with this Agreement is subject to the privileges and immunities accorded to the United Nations, including UNHCR, pursuant to the General Convention. As a result of these privileges and immunities, any such data or information is inviolable and cannot be disclosed, provided or otherwise made available to, or searched, confiscated or otherwise be interfered with, unless such privileges and immunities are expressly waived in writing by UNHCR. However, if any such data or information is sought by any governmental body, the Partner shall:

(a) promptly notify UNHCR of this fact and consult with UNHCR regarding the Partner's response to the demand or request by such governmental body;

(b) inform such governmental body that such data and information is privileged under the General Convention and request such governmental body either to redirect the relevant request for disclosure directly to UNHCR or to grant UNHCR the opportunity to present its position regarding the privileges status of such data and information;

(c) cooperate with UNHCR's reasonable requests in connection with efforts by UNHCR to ensure that its privileges and immunities are upheld and, to the extent permissible by law, seek



to contest or challenge the demand or request based on, inter alia, UNHCR's status, in its privileges and immunities;

(d) where the Partner is prohibited by applicable law or the governmental bod notifying the UNHCR a governmental body's request for such data or information, UNHCR promptly upon the lapse, termination, removal or modification of such prohibitio

(e) Provide UNHCR with true, correct and complete copies of the governmental demands and requests, the Partner's responses thereto, and keep UNHCR informe developments and communications with the governmental body.

3. Under no circumstances shall personal data transferred under this Agreement be dis to the country of origin of the data subjects. The only exception to this concerns data pro in the context of a tri-partite agreement for voluntary repatriation under the auspices of U conducted with the consent of the individual data subject(s).

Article 8 – Interested person access

1. Every data subject who offers proof of identity shall have the right to know whether his personal data has been transferred under Article 3 of this Agreement, and to obtain this intelligible form, without undue delay and free of charge. Appropriate rectifications or er shall be made in the case of unlawful, unnecessary or inaccurate entries.

2. The same right shall also apply with respect to personal data transferred under Artic this Agreement, subject to exceptions necessary to protect the privileges and immunities United Nations or UNHCR's legitimate interests.

Article 9 — Security of personal data

1. Both Parties shall take organisational and technical measures to protect the person transferred under this Agreement against accidental or unauthorised destruction, acc loss, unauthorised access, use, alteration or dissemination, and against all other unaut forms of processing.

2. The Partner must implement the necessary technical and organizational measures to the confidentiality, privacy, integrity, availability, accuracy and security of the Persona including establishing organizational policies for employees to safeguard the Personal accordance with this Agreement. Technical measures include restricting access to authorized personnel and devices only, the use of passwords to prevent unauthorized to data, and backing-up data in case of loss or damage. Organizational measures i securing premises where hard-copy files or computers are stored, safely disposing obsolete hard copy files, and ensuring that portable devices are kept in a secure locatio times when not in use.

3.The Partner shall maintain and/or store the Personal Data exclusively in countries (inc countries where the partner's headquarters or data storage facilities abroad are locate have recognized the privileges and immunities of the United Nations pursuant to the G Convention (as defined below in Article 7.2 above).

Article 10 – Notification of personal data breach

1. The Partner shall notify to UNHCR as soon as possible upon becoming aware of a pe data breach (as defined below), in particular if the personal data breach is likely to re personal injury or harm to a data subject, and use, if appropriate jointly with UNHCR, i efforts to take mitigating measures.

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2. "Personal data breach" means a breach of data security leading to the accidental or unlawful/illegitimate destruction, loss, alteration, unauthorised disclosure of, or access to, personal data transferred, stored or otherwise processed.

Article 11 – Settlement of disputes

1. The Parties shall use their best efforts to settle amicably any dispute or controversy or claim arising out of this Agreement or the breach, invalidity or termination thereof. Where the Parties wish to seek such an amicable settlement through conciliation, the conciliation shall take place in accordance with the Conciliation Rules of the United Nations Commission on International Trade Law ("UNCITRAL") then obtaining, or according to such other procedure as may be agreed between the Parties.

2. Any dispute, controversy or claim between the Parties arising out of this Agreement or the breach, invalidity or termination thereof, unless settled amicably in accordance with Article 11.1 above within sixty (60) days after receipt by one Party of the other Party's request for such amicable settlement shall be referred by either Part to arbitration in accordance with the UNCITRAL Arbitration Rules then obtaining. The decisions of the arbitral tribunal shall be based on general principles of international commercial law. The arbitral tribunal shall nave no authority to award punitive damages. The Parties shall be bound by any arbitration award rendered as a result of such arbitration as the final adjudication of any such controversy, claim or dispute. The place of arbitration shall be Geneva, Switzerland. The proceedings shall be conducted in English.

3. The arbitral tribunal shall be empowered to order the return or destruction of any property, whether tangible or intangible, or of any confidential information provided under this Agreement, order the termination of this Agreement, or order that any other protective measures be taken. In addition, the arbitral tribunal shall have no authority to award interest in excess of the London Inter-Bank Offered Rate ("LIBOR") then prevailing, and any such interest shall be simple interest only..

Article 12 – Privileges and Immunities

Nothing in or relating to this Agreement is to be deemed a waiver, express or implied, of any privileges or immunities of the United Nations or of UNHCR, as a subsidiary organ of the United Nations.

Article 13 – Termination

1. This Agreement shall terminate automatically upon termination or expiry of the Project.

2. Either Party may terminate this Agreement upon thirty (30) days prior notice in writing to the other Party.

3. UNHCR shall be entitled to terminate this Agreement forthwith by notice in writing to the Partner if the Partner is in a material or persistent breach of this Agreement.

4. The Partner shall destroy all the Personal Data of the Data Subjects in its possession or under its control, and in all forms (including but not limited to electronic, digital, physical form available online, offline or on backup, disaster recovery or archival systems) immediately upon termination or expiration of this Agreement. The Partner shall submit to UNHCR a written and signed confirmation that it has taken action in accordance with this Article 14.4 no later than 1 (one) week after the termination of this Agreement.

5. If the Partner, based on internal or external auditing requirements, or domestic legislation, is legally obliged to retain data for a certain time period following the implementation of the project, the Partner shall notify UNHCR of this in writing, shall no longer actively process and the data

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for any other purpose, and shall be destroyed the data immediately after this time period has expired.

6.The obligations on the Partner under Articles 6,7,8,9 hereunder shall survive any termination or expiration of this Agreement.

Article 14 – General provisions

1. This Agreement shall enter into force on the date of the last signature and shall continue in force for five years, or until terminated under Article 13 above, whichever occurs first.

2. This Agreement may be modified at any time by mutual written consent.

3. If any provision of this Agreement shall be held to be invalid, illegal or unenforceable (in whole or in part), the validity, legality and enforceability of the remaining provisions shall not in any way be affected or impaired.

4.Headings and titles used in this Agreement are for reference purposes only and shall not be deemed a part of this Agreement for any purpose whatsoever. Unless the context otherwise clearly indicates, all references to the singular herein shall include the plural and vice versa.

5.This Agreement embodies the entire agreement of the Parties with regard to the subject-matter hereof and supersedes all prior representations, agreements, contracts and proposals, whether written or oral, by and between the Parties on this subject. No promises, understandings, obligations or agreements, oral or written, relating to the subject-matter hereof exist between the Parties except as herein expressly set forth.

6. This Agreement is not intended to benefit or be enforceable by any third party.

IN WITNESS WHEREOF, the undersigned, being duly appointed representatives of UNHCR and the Partner, respectively, have on behalf of the Parties signed this Agreement, in the English language.

Done at UNHCR Kigali this 26 day of May 2017

For Manchester Metropolitan University
United Kingdom

John Cunningham
Director of Finance

For the Office of the United Nations
High Commissioner for Refugees

Machtelt Clara De Vriese
Senior Protection Officer

Appendix 3: Literature review final included papers

Code	Reference
LR1	Alborz, A., Slee, R., and Miles, S. (2013).
LR2	Ayazi, T., Swartz, L., Eide, A.H., Lien, L., and Hauff, E. (2015).
LR3	Battle, D. (2015).
LR4	Grover, S. (2007).
LR5	Karangwa, E. (2014).
LR6	Karangwa, E., Miles, S., and Lewis, I. (2010).
LR7	Krupar, A. (2016).
LR8	Marshall, J., Barrett, H., and Ebengo, A. (2015).
LR9	Miles, S. (2013).
LR10	Njelesani, J., Siegel, J., and Ullrich, E. (2018).
LR11	Pinnock, H., and Hodgkin, M. (2010).
LR12	Rose, R., and Shevlin, M. (2004).
LR13	Sagahutu, J.B., Tuyizere, M., and Struthers, P. (2013).
LR14	Talley, L., and Brintnell, S.E. (2016)
LR15	Trani, J.F., Kett, M., Bakhshi, P., and Bailey, N. (2011).

Appendix 4: Literature review analysis – codes, sub-categories and categories.

Code	Sub-category	Category
Communication impairment	SC1. Individual-level barriers to inclusive education access	**LRC1. BARRIERS TO ACCESSING INCLUSIVE ECD/EDUCATION**
Basic needs take priority	SC2. Family-level barriers to inclusive education access	
Family finances		
Parental awareness of education services		
Role conflicts for women		
Fear for safety		
Underestimation of child's ability		
Cultural/contextual understandings of education and disability	SC.3 Community-level barriers to inclusive education access	
Discriminatory attitudes and behaviours		
Conflict	SC4. Environmental barriers to inclusive education access	
Trauma and chaos		
Safe passage		
External service providers	SC5. Policy and service-level barriers to inclusive education access	
Policy implementation gap		
Temporary solutions		
Intersections	SC6. Additional challenges	
Lack of evidence		
Children who experience disability not in school	SC7. Human rights infringements	**LRC2. IMPLICATIONS OF ECD/EDUCATIONAL EXCLUSION**
Rights violations		
Protection and nurturing care		
Survival and futures		
Family assistance	SC8. Reduced potential for nation-building	
Participation and cohesions		
Peace		
Prosperity		
Resource efficiency		
Global	SC9. Policy and guidance	**LRC3. EXISTING POLICIES AND PRACTICES**
National		

humanitarian		
Collaboration	SC10. Existing practices	
Resourcing and commitments		
Rights based agenda	SC11. Commitment	**LRC4. WHAT IS NEEDED FOR BETTER INCLUSION?**
Inclusion to inform all work		
Legal standards		
Monitoring, evaluation, and learning (MEAL)		
Policy clarity		
Systems, tools, and processes		
Budgeting and financial resources	SC12. Investment	
Infrastructure		
Sensitisation and knowledge/skill development		
time		
Avoid assumptions	SC13. Listening and learning	
Flexibility		
Understanding of needs		
Locally led planning and decision-making		
research		
Family and community support	SC14. Collaboration	**LRC5. OPPORTUNITIES FOR INCLUSION**
Involve teachers		
Political will		
Skill sharing		
'Build back better'	SC15. Crisis-related opportunities	
Reflect and build on what exists		
Pilot new ways of working		
Post-emergency training opportunities		
Attitudinal change through IE		

Appendix 5: Communication disability screening tool

COMMUNICATION DISABLITY SCREENING TOOL

Verification clerks

Refer to community desk for risk assessment:

- Any person who **cannot talk at all** using spoken words (they are non-verbal) **over 2 years old.**
- Any person who **can use some words,** but not as expected for their age **over 5 years old.**
- Any person whose **speech does not sound clear** (slow, slurred, unclear sounds, stammer) or like others of their age.
- Any person who does **not understand questions** like others their age (may not respond / gives unusual answers).
- People with **disabilities that affect the way they talk** (physical e.g. cerebral palsy; sensory e.g. hearing impairment).
- **People who use other ways to communicate**: sign, gesture, facial expression, vocalizations, a combination of these.

Community desk officials

Ask person or carer and highlight / underline answer(s):

1. **Using [your/their] usual language, can [you/they]:**

   A) Talk to others using spoken words?
   1. No difficulty 2. Some difficulty 3. A lot of difficulty 4. Cannot do at all / Unable to do

   B) Talk clearly (words may be slow, slurred, not smooth, pronounced unclearly, voice may not be clear)?
   1. No difficulty 2. Some difficulty 3. A lot of difficulty 4. Cannot do at all / Unable to do

   C) Understand what other people say?
   1. No difficulty 2. Some difficulty 3. A lot of difficulty 4. Cannot do at all / Unable to do

IF ANY RED ANSWER(S) GIVEN ABOVE, GO ON TO Q2 & Q3

2. **Does [your / their] communication difficulty impact upon:**
   - A. Ability to socialize with other people (e.g. family / friends / new people) No A little A lot
   - B. Ability to access services (e.g. education, health, food, sanitation) No A little A lot
   - C. Ability to do things independently (children over 5 years and adults) No A little A lot

3. **Do [you / they] use any of the following to communicate? (Highlight all methods)**
   - A. Sign language (formal, learned at school / adult class)
   - B. Gesture (informal, designed by that person and / or their carers)
   - C. Writing or drawing
   - D. Pointing or looking at pictures or objects
   - E. Body language and/or facial expressions
   - F. Vocalization (noises including crying, shouting)
   - G. Other (note)

Code any red response as DS-SD and note comments in free text box

NB: A person may also have Hearing impairment / deafness: DS-DF, Physical disability: DS-PM / DS-PS, Mental disability (intellectual impairment / learning disability): DS-MM / DS-MS

ENSURE ALL DISABILITIES ARE CODED

Appendix 6: Phase 1 numerical data comparison tables (pre-mapping, post-mapping, post-verification)

6.1 Comparison data for Rwanda: Total refugee population (all ages), pre-mapping, post-mapping, and post-verification.

	Pre-mapping April 2017 (Data set 3)		Post-mapping September 2017 (Data set 4)		% Change pre-mapping to post mapping (Data set 3 -> 4)	Post-verification January 2020 (Data set 5)		% Change post-mapping to post-verification (Data set 4 -> 5)
Population	159,349		161,968		+1.64%	150,574		-7.03%
	Number registered	**% Population registered**	**Number registered**	**% Population registered**		**Number registered**	**% Population registered**	
DS-DF	318	0.20%	365	0.23%	+15.00%	428	0.28%	+21.74%
DS-MM	207	0.13%	309	0.20%	+53.85%	570	0.38%	+90.00%
DS-MS	216	0.14%	299	0.18%	+28.57%	-	-	-
DS-SD	135	0.08%	157	0.10%	+25.00%	210	0.14%	+40.00%
TOTAL CRID	876	0.55%	1130	0.70%	+27.27%	1208	0.80%	+14.29%

TOTAL NON-CRID	1884	1.18%	2188	1.35%	+14.40%	3283	2.18%	+61.48%
TOTAL DS	2760	1.73%	3318	2.05%	+18.49%	4491	2.98%	+45.37%

** DS - disability; DS-DF – hearing impairment/deafness; DS-MM – mental disability moderate; DS-MS - mental disability severe; DS-SD - speech impairment/disability; CRID – communication-related impairment/disability; CR-SE – Child with special educational needs*

6.2 Comparison data for Rwanda: Children <12 years old, pre-mapping, post-mapping, and post-verification.

	Pre-mapping April 2017 (Data set 3)		**Post-mapping September 2017 (Data set 4)**		**% Change pre-mapping to post mapping (Data set 3 -> 4)**	**Post-verification January 2020 (Data set 5)**		**% Change post-mapping to post-verification (Data set 4 -> 5)**
Population	54,928		56,127		+2.18%	57,390		+2.25%
	Number registered	**% <12s registered**	**Number registered**	**% <12s registered**		**Number registered**	**% <12s registered**	
DS-DF	13	0.02%	19	0.03%	+50.00%	29	0.05%	+66.67%
DS-MM	16	0.03%	36	0.06%	+100%	113	0.20%	+233.33%
DS-MS	40	0.07%	80	0.14%	+100%	-	-	-
DS-SD	17	0.03%	25	0.04%	+33.33%	31	0.05%	+25.00%
TOTAL CRID	86	0.16%	160	0.29%	+81.25%	173	0.30%	+3.44%

TOTAL NON-CRID	142	0.26%	319	0.57%	+119.23%	429	0.75%	+18.00%
TOTAL DS	228	0.42%	479	0.85%	+102.38%	602	1.05%	+23.53%
CR-SE	10	0.02%	10	0.01%	-50.00%	-	-	-

** DS - disability; DS-DF – hearing impairment/deafness; DS-MM – mental disability moderate; DS-MS - mental disability severe; DS-SD - speech impairment/disability; CRID – communication-related impairment/disability; CR-SE – Child with special educational needs*

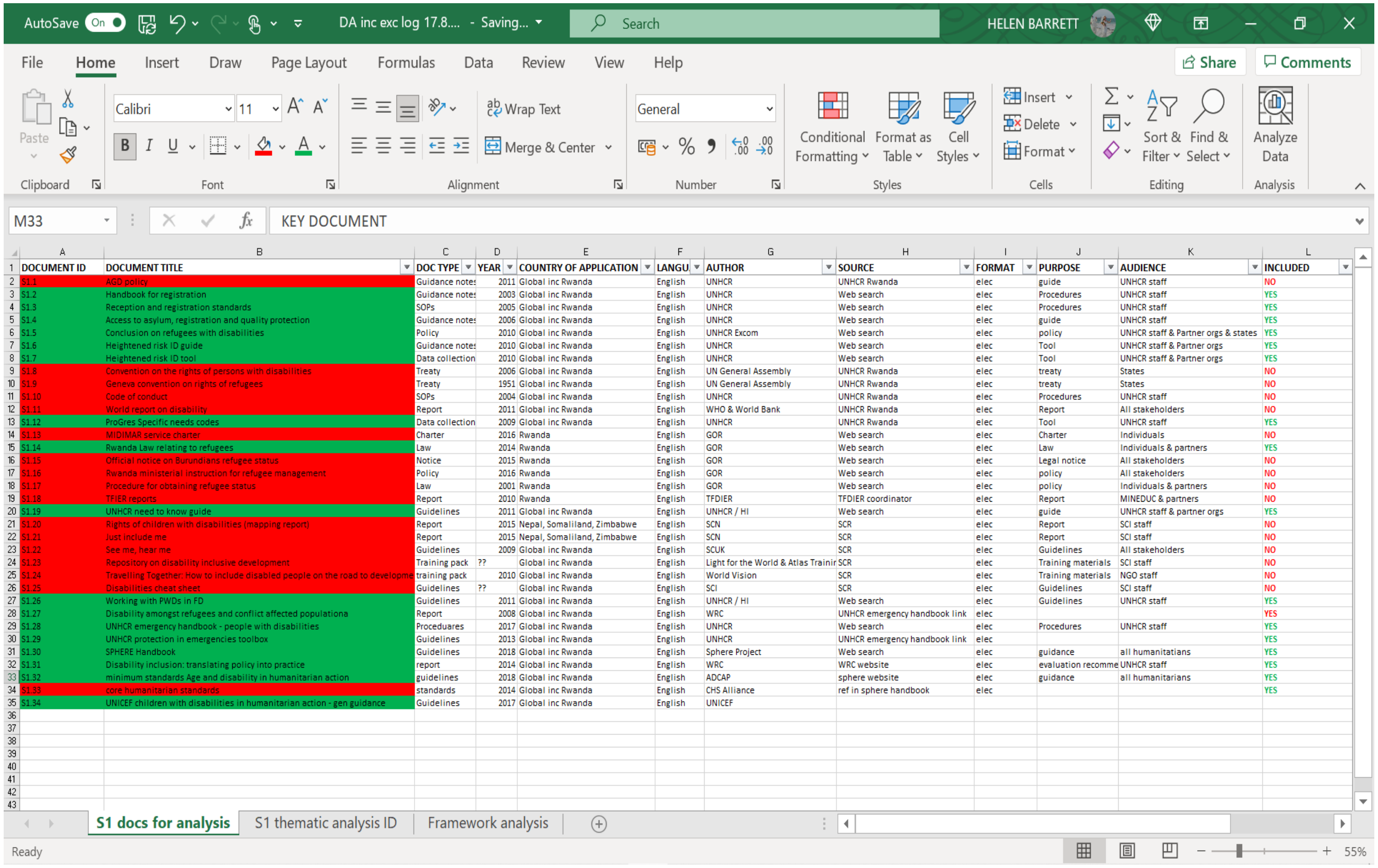
Appendix 7: Phase 1 document analysis search strategy and recording

7.1: Phase 1, data set 2: Document analysis search strategy

Document sources	Inclusion criteria	Exclusion criteria	Search window
Direct request -UNHCR Rwanda/ Geneva staff -Humanity and Inclusion Rwanda staff -Save the Children Rwanda staff -ADRA Rwanda staff **Specific website searches** -Government of Rwanda (MIDIMAR/ MINEMA) -UNGA -UNHCR -UNICEF -Handicap International/ Humanity and Inclusion -Save the Children -PLAN International -ADRA -Women's Refugee Commission -Sphere **Open web search (google search engine)** -See table X for search terms	**Publication date** -Published between January 2000 and December 2017 **Document type** -Treaties, conventions, charters -Policy/ guidelines -Data collection tools -Data recording systems -Guidance notes -Standard operating procedures -Meeting minutes including amendments to SOPs -Training manuals / toolkits documents -Reports **Applicability** -Globally applicable: -Including Rwanda -With reference to Rwanda: -Sub-Saharan Africa -East Africa -Great Lakes Region -Rwanda -Available in written English **Author** -Government of Rwanda (inc. MIDIMAR/MINEMA) -UN agencies -INEE	**Document type** -Opinion pieces -Research papers **Author** -Organisations/ individuals that do not work directly with refugees	January 2016 – June 2018

	-EENET -Sphere -Handicap International/ Humanity and Inclusion -Save the Children -Plan International -ADRA -World vision -WRC -Other NGOs working with refugees with impairments and associated disabilities, applicable to Rwanda **Refers to:** -Early childhood development AND/OR -Education services (all types) AND -Refugees/ displaced/ humanitarian/ emergencies AND -Impairment/ disability/ inclusion		
	Audience -Government -UN agencies -Humanitarian actors, including INGOs and NGOs.	**Audience** -Documents produced for general consumption	
	Publication language -Written English only		
	Format -Original documents in Electronic or hard copy	**Format** -Summary documents -Citations/references	

7.2 Document analysis spreadsheet example



DOCUMENT ID	DOCUMENT TITLE	DOC TYPE	YEAR	COUNTRY OF APPLICATION	LANGU	AUTHOR	SOURCE	FORMAT	PURPOSE	AUDIENCE	INCLUDED
S1.1	AGD policy	Guidance notes	2011	Global inc Rwanda	English	UNHCR	UNHCR Rwanda	elec	guide	UNHCR staff	NO
S1.2	Handbook for registration	Guidance notes	2003	Global inc Rwanda	English	UNHCR	Web search	elec	Procedures	UNHCR staff	YES
S1.3	Reception and registration standards	SOPs	2005	Global inc Rwanda	English	UNHCR	Web search	elec	Procedures	UNHCR staff	YES
S1.4	Access to asylum, registration and quality protection	Guidance notes	2006	Global inc Rwanda	English	UNHCR	Web search	elec	guide	UNHCR staff	YES
S1.5	Conclusion on refugees with disabilities	Policy	2010	Global inc Rwanda	English	UNHCR Excom	Web search	elec	policy	UNHCR staff & Partner orgs & states	YES
S1.6	Heightened risk ID guide	Guidance notes	2010	Global inc Rwanda	English	UNHCR	Web search	elec	Tool	UNHCR staff & Partner orgs	YES
S1.7	Heightened risk ID tool	Data collection	2010	Global inc Rwanda	English	UNHCR	Web search	elec	Tool	UNHCR staff & Partner orgs	YES
S1.8	Convention on the rights of persons with disabilities	Treaty	2006	Global inc Rwanda	English	UN General Assembly	UNHCR Rwanda	elec	treaty	States	NO
S1.9	Geneva convention on rights of refugees	Treaty	1951	Global inc Rwanda	English	UN General Assembly	UNHCR Rwanda	elec	treaty	States	NO
S1.10	Code of conduct	SOPs	2004	Global inc Rwanda	English	UNHCR	UNHCR Rwanda	elec	Procedures	UNHCR staff	NO
S1.11	World report on disability	Report	2011	Global inc Rwanda	English	WHO & World Bank	UNHCR Rwanda	elec	Report	All stakeholders	NO
S1.12	ProGres Specific needs codes	Data collection	2009	Global inc Rwanda	English	UNHCR	UNHCR Rwanda	elec	Tool	UNHCR staff	YES
S1.13	MIDIMAR service charter	Charter	2016	Rwanda	English	GOR	Web search	elec	Charter	Individuals	NO
S1.14	Rwanda Law relating to refugees	Law	2014	Rwanda	English	GOR	Web search	elec	Law	Individuals & partners	YES
S1.15	Official notice on Burundians refugee status	Notice	2015	Rwanda	English	GOR	Web search	elec	Legal notice	All stakeholders	NO
S1.16	Rwanda ministerial instruction for refugee management	Policy	2016	Rwanda	English	GOR	Web search	elec	policy	All stakeholders	NO
S1.17	Procedure for obtaining refugee status	Law	2001	Rwanda	English	GOR	Web search	elec	policy	Individuals & partners	NO
S1.18	TFIER reports	Report	2010	Rwanda	English	TFDIER	TFDIER coordinator	elec	Report	MINEDUC & partners	NO
S1.19	UNHCR need to know guide	Guidelines	2011	Global inc Rwanda	English	UNHCR / HI	Web search	elec	guide	UNHCR staff & partner orgs	YES
S1.20	Rights of children with disabilities (mapping report)	Report	2015	Nepal, Somaliland, Zimbabwe	English	SCN	SCR	elec	Report	SCI staff	NO
S1.21	Just include me	Report	2015	Nepal, Somaliland, Zimbabwe	English	SCN	SCR	elec	Report	SCI staff	NO
S1.22	See me, hear me	Guidelines	2009	Global inc Rwanda	English	SCUK	SCR	elec	Guidelines	All stakeholders	NO
S1.23	Repository on disability inclusive development	Training pack	??	Global inc Rwanda	English	Light for the World & Atlas Trainir	SCR	elec	Training materials	SCI staff	NO
S1.24	Travelling Together: How to include disabled people on the road to developme	training pack	2010	Global inc Rwanda	English	World Vision	SCR	elec	Training materials	NGO staff	NO
S1.25	Disabilities cheat sheet	Guidelines	??	Global inc Rwanda	English	SCI	SCR	elec	Guidelines	SCI staff	NO
S1.26	Working with PWDs in FD	Guidelines	2011	Global inc Rwanda	English	UNHCR / HI	Web search	elec	Guidelines	UNHCR staff	YES
S1.27	Disability amongst refugees and conflict affected populationa	Report	2008	Global inc Rwanda	English	WRC	UNHCR emergency handbook link	elec			YES
S1.28	UNHCR emergency handbook - people with disabilities	Proceduares	2017	Global inc Rwanda	English	UNHCR	Web search	elec	Procedures	UNHCR staff	YES
S1.29	UNHCR protection in emergencies toolbox	Guidelines	2013	Global inc Rwanda	English	UNHCR	UNHCR emergency handbook link	elec			YES
S1.30	SPHERE Handbook	Guidelines	2018	Global inc Rwanda	English	Sphere Project	Web search	elec	guidance	all humanitatians	YES
S1.31	Disability inclusion: translating policy into practice	report	2014	Global inc Rwanda	English	WRC	WRC website	elec	evaluation recomme	UNHCR staff	YES
S1.32	minimum standards Age and disability in humanitarian action	guidelines	2018	Global inc Rwanda	English	ADCAP	sphere website	elec	guidance	all humanitarians	YES
S1.33	core humanitarian standards	standards	2014	Global inc Rwanda	English	CHS Alliance	ref in sphere handbook	elec			YES
S1.34	UNICEF children with disabilities in humanitarian action - gen guidance	Guidelines	2017	Global inc Rwanda	English	UNICEF					

Appendix 8: Documents included in the phase 1 document analysis

Code	Reference
S1.2	UNHCR. (2003*). Handbook for registration: Procedures and Standards for Registration, Population Data Management and Documentation*. Geneva, UNCHR.
S1.3	UNHCR. (2005). *Procedural Standards for RSD under UNHCR's Mandate: Unit 3 - Reception and Registration in RSD Operations*. Geneva: UNHCR.
S1.4	UNHCR. (2006b). *UNHCR & International Protection Chapter 4: Access to Asylum, Registration and Quality Protection*. Geneva, UNHCR.
S1.5	UNHCR. (2010a). *Conclusion on Refugees with Disabilities and Other Persons with Disabilities Protected and Assisted by UNHCR No. 110 (LXI).* Geneva, UNHCR.
S1.6	UNHCR. (2008). *The Heightened Risk Identification Tool User Guide.* Geneva, UNHCR.
S1.7	UNHCR. (2010b). *Heightened Risk Identification Tool User Guide (Second Edition).* Geneva, UNHCR.
S1.12	UNHCR. (2006a). *Guidance on the Use of Standardized Specific Needs Codes*. Geneva, UNHCR.
S1.26	UNHCR & Handicap International. (2011). *Working with Persons with Disabilities in Forced Displacement. Need to Know Guidance 1.* Geneva, UNHCR.
S1.28	UNHCR. (2017b). *Emergency Handbook: Persons with Disabilities*. Geneva, UNHCR.
S1.29	UNHCR. (2013). *Protection in Emergencies Toolbox: Protection Checklists.* Geneva, UNHCR Division of International Protection; Division of Emergency Security and Supply.
S1.30	Sphere. (2018). *The Sphere Handbook: Humanitarian Charter and Minimum Standards in Humanitarian Response*. Geneva: Sphere Association.
S1.31	WRC. (2014). *Disability Inclusion: Translating Policy into Practice in Humanitarian Action.* New York, WRC.
S1.32	Age and Disability Consortium. (2015). *Minimum Standards for Age and Disability Inclusion in Humanitarian Action (Pilot Version).* London, ADCAP.
S1.34	UNICEF. (2017). *Including Children with Disabilities in Humanitarian Action – General Guidance.* New York, UNICEF.
S1.36	UNICEF. (2013). *Take us Seriously! Engaging Children with Disabilities in Decisions Affecting their Lives*. New York, UNICEF.
S1.42	UNHCR. (2009). *Inter-Office Memorandum No, 030/2009. Guidance on the Use of Standardized Specific Needs Codes*. Geneva, UNCHR.

Appendix 9: Phase 1 document analysis codes

Code	Sub-theme	Theme
1 RSD, initial registration, verification	1 Identification and registration processes, procedures, and safety nets	**1 IDENTIFICATION AND REGISTRATION IS A REFUGEE'S RIGHT**
2 Community-based ID activities		
3 Best interest assessment		
4 Rapid assessment		
5 Non-specific ID and registration		
6 Definition of disability	2 Disability identification and registration	
7 Categorisation of disability		
8 Special support during registration		
9 Distinguishing between ID and MH		
10 Communication disability		
11 Multiple disabilities		
12 Special educational needs		
13 Dignity and respect	3 Disability rights	**2 RIGHTS ARE THREATENED**
14 Non-discrimination		
15 Inclusion and equity		
16 Participation		
17 Service access		
18 Valuing contributions		
19 Accessible information		
20 Active discrimination/ exclusion	4 Violations of, and threats to, rights realisation	
21 Passive discrimination/ exclusion		
22 Invisibility	5 Barriers to inclusion	**3 EXCLUSION CONTRIBUTES TO PROTECTION RISK**
23 Negative attitudes and stigma		
24 Resource limitations		
25 Inaccessible services		
26 Children's access to services		
27 Dependency		
28 Discrimination	6 Heightened protection risk	
29 Exploitation		
30 Abuse		
31 Neglect and exclusion		
32 Children's heightened risk		
33 Referral to other agencies	7 Refugee-focused responses	
34 Referral to SLT		

35 Monitoring/ follow up		**4 THE NEED FOR MULTI-FACETED SUPPORT MECHANISMS**
36 Appropriate support		
37 Ensuring Access to services		
38 Consultation		
39 Awareness-raising/ advocacy	8 SP focused responses	
40 Training/capacity building		
41 Service providers addressing own prejudices		
42 Data disaggregation		

Appendix 10: Phase 1 document analysis expanded results: themes and sub-themes

Theme 1: Identification and registration is a refugee's right

Incorporating subthemes 1 and 2 (see table 21)

This theme describes the rights-based framework that governs identification and registration services for all refugees, including those with impairments and who experience disability.

Disability rights enshrined in the CRPD (UN General Assembly, 2006), and adopted in most documents, are inextricably interwoven with the refugee right to identification and registration. Realisation of both rights should result in equitable access to services for refugees who experience disability. Accurate documentation of disability 'status' and support needs are therefore acknowledged as crucial to ensuring service providers understand what accommodations and provisions may be required to provide accessible services.

Despite the documented commitment to identify and register refugees who experience disability by coordinating bodies, service evaluations highlight exclusionary practices that suggest refugees who experience disability may not be identified at all or may be unable to realise their right to accurate specific needs registration, impacting upon their access to protection services.

> *"Children and adolescents with disabilities are rarely included in assessments and other data collection exercises. Thus, humanitarian programmes may inadequately document and consider their needs" (S1.34: UNICEF, 2017: 15).*

Sub-theme 1: Identification and registration processes, procedures, and safety nets

Documents included in this sub-theme describe the different types of registration activities and processes available to refugees, including those aimed at capturing information potentially missed at initial registration, or in emergency situations. Some documents focus on one or more types of activity or process, whilst others make more general reference to all identification and registration services, from Refugee Status Determination (RSD), through to community-based ongoing registration activities. Many make explicit reference to the identification and registration of ‘refugees with disabilities’ and emphasise special measures that can/should be taken to ensure their timely and accurate identification.

Although reassuring to see such inclusive guidance, documents also report on the disabling exclusion that refugees with impairments continue to face. Their authors therefore encourage additional community-based and participatory assessments, preferably in collaboration with local and/or specialist disability-focused organisations, to identify and register anyone who may be missed at initial registration.

Sub-theme 2: Disability identification and registration

The rights-based definition of disability expounded in the CRPD (UN General Assembly, 2006) is used across most of the documents in the analysis. Some documents enhance the definition further, whilst others do not define the term ‘disability’ at all. Others demonstrate a more outdated, medically focused understanding of disability. This is evident in the omission of reference to the interaction of health conditions/impairments with the social and physical environment and the use of the word ‘suffers’ in relation to disability.

Discussions around ‘categorisation’ and ‘types’ of disability frequently overlap, or are confused with, the definition and categorisation of impairment, suggesting a lack of understanding and implementation of the globally accepted ICF framework in the operationalisation of the CRPD in humanitarian action (Bickenbach, 2011). The collection of accurate data is reportedly further hindered by a lack of staff skill to identify and ‘categorise’ disability upon registration (WRC, 2008).

Humanitarian organisations are advised to provide some special adaptations of identification and registration activities specifically for refugees who experience disability, including providing specialist support staff; fast-tracking; employing simplified procedures; and providing a covered waiting area, separate from others. This, by definition, means the refugees must self-identify as disabled before being registered, or are identified by attending staff identifying 'visible' impairments and 'picking people out' for special assistance, potentially exposing them to stigmatisation. In such cases, refugees with CIs may actively avoid being singled out and/or may be overlooked, unless the CI is part of a wider condition with more visible components.

Compounding these issues is the fact that communication is notably absent from the CRPD definition of disability, as well as its guidance for provision of services (e.g., habilitation/rehabilitation to respond to communication impairment and disability). This is reflected in many of the documents analysed in which a definition of CD is either absent, incomplete, or inaccurate. Despite this, the provision of accessible information is advised for those who may need it.

> *"Ensure people with disabilities and older people can access all important information and accommodate for people with vision, hearing, communication, mobility and literacy limitations and/or difficulties with processing information." (S1.32: Age and Disability Consortium, 2018: 15).*

Theme 2: Rights are threatened

> *"Exclusion of persons with disabilities during displacement can be inadvertent or purposeful: in either case, nevertheless, it is discriminatory" (S1.26 UNHCR and Handicap International, 2011: 4).*

Incorporating subthemes 3 and 4 (see table 21).

It is critical that, in situations of forced migration, refugee rights (UN General Assembly, 1951) and disability rights (UN General Assembly, 2006) are amalgamated. This principle is upheld in print by UNHCR and supporting humanitarian organisations.

Documents suggest that, at the intersection of being a refugee and being a person who experiences disability, lies elevated exposure to risks due to passive and active discrimination. This impacts upon the ability to realise refugee, disability, and human rights, including the right to accurate and timely registration.

Sub-theme 3: Disability rights

Documents issuing guidance on disability and inclusion, to humanitarian organisations (including those authored by UNCHR for their own staff, as well as more widely applicable advisory papers e.g., ADCAP, 2018; Sphere, 2018), generally align their guidance with the rights-based model of disability expounded by the CRPD (UN General Assembly, 2006). As such, the rights to equal (and, in some cases, equitable) social inclusion, participation, and service access are explained, alongside discussion of how to realise those rights through attending to the support needs of refugees who experience disability, whilst simultaneously acknowledging their capabilities and capacity to contribute to their communities.

> *"Response and preparedness programming should consider the capacities and needs of all persons with disabilities and make deliberate efforts to remove physical, communication and attitudinal barriers to their access and participation" (S1.30, Sphere 2018: 14).*

The need for service providers and communities to consult with refugees who experience disability, and value their suggestions and contributions, is considered key to achieving meaningful participation and rights realisation.

Additionally, the right to information is recognised as central to actualising the principle of non-discrimination and ensuring meaningful participation. With reference to identification and registration services, some documents cite a recognised lack of accessible information as a barrier to service access and participation and recommend provision of accessible communication methods as a strategy to remove this barrier and increase opportunities for inclusion.

> *"Ensure that information is accessible. Use appropriate forms of communication, and clear messaging. For example, use simple language to communicate with persons who have an intellectual disability, sign language for deaf persons, picture formats and visual demonstration for those who cannot hear well, and radio and spoken communication for those with visual impairments" (S1.26, UNHCR and Handicap International, 2011: 13).*

Despite this, documents lack detail on *how* to design and implement such strategies in context, to ensure inclusion and rights realisation, in the absence of specialist support.

Sub-theme 4: Violations of, and threats to, rights realisation

In stark contrast to the rights of refugees who experience disability, documents also reference the potential for violation of, or threats to, these rights. This group is known to experience active and passive discrimination which contribute to exclusion from services and restricted opportunities for participation, despite those rights being enshrined in global conventions, national laws, and organisational policies. Indeed, a circular situation appears to exist whereby refugees who experience disability are excluded because they cannot participate and cannot participate because they are excluded. In this scenario, realisation of human, refugee, and/ or disability rights, is compromised. This is particularly relevant for refugees who experience CD, as identification and registration activities are highly reliant upon verbal communication. Their refugee right to registration is threatened, alongside their right to equitable service access and participation, as enshrined in the CRPD (UN General Assembly, 2006), and defended by UNHCR:

> *"Persons with disabilities should have the same opportunity as other displaced persons to enjoy the full range of their human rights". (S1.26, UNHCR and Handicap International, 2011: 6)*

Theme 3: Exclusion contributes to protection risk

Incorporating sub-themes 5 and 6 (see table 21)

Documents describe how refugees who experience disability face a multitude of attitudinal, environmental, and institutional barriers to inclusion and participation. This contributes to elevated exposure to protection risk - the antithesis of the protective and rights-based global humanitarian agenda.

Sub-theme 5: Barriers to inclusion

The primary barriers to inclusion facing refugees who experience disability are identified and described across most documents, with the exception of those produced as overarching guidance without a specific disability focus. Barriers to service access arise from inaccessible infrastructure as well as inaccessible information and communications. Attitudinal and behavioural factors, such as stigma and active discrimination towards refugees with impairments from service providers and communities, interweave with environmental and institutional barriers, to create a complex web of limitations to participation.

For those who are dependent on family members or others to access services, stigma is acknowledged to increase isolation, further restricting autonomy and opportunities for participation.

> *"None of the above [family members] may wish to talk about persons with disabilities and/or other conditions of persons in the household if it is perceived as an embarrassment, taboo or stigma within the family or community". (S1.6, UNHCR, 2008: 4)*

It is particularly important to acknowledge this during identification and registration activities as refugees who experience disability may be purposefully hidden (UNHCR, 2010b). This may be even more significant for groups who are exposed to multiple protection risk factors, such as being a refugee minor, female, and/or of minority ethnic group, who experiences disability.

> *"They face multiple and compounding forms of discrimination, on the basis of disability but also on other grounds, which may lead to situations of exclusion". (S1.28, UNHCR 2017: 1)*

Sub-theme 6: Heightened protection risk

Barriers to identification, registration, service access and participation are acknowledged to contribute to further discrimination and directly heighten protection risk. Refugees who experience disability are known to be exposed to a higher risk of exploitation, abuse, and neglect, than their non-disabled peers – their isolation and dependency fuelled by their invisibility and limited opportunities to access humanitarian services effectively.

> *"Persons with disabilities are at particular risk because they may be invisible, and because they are less able to participate actively in decisions that concern them and are less likely to have their protection needs met." (S1.26, UNHCR and Handicap International, 2011: 4).*

Conversely, those with 'invisible' impairments, such as those affecting communication or cognition, may not be actively hidden by families because they are not visibly 'different', but may be just as likely to be passively hidden - having their needs overlooked and their ability to participate and access protective services compromised, resulting in disabling exclusion and increased risk.

> *"Persons with psychosocial and intellectual disabilities tend to be less identifiable than persons with physical and sensory disabilities. As a result, programmes are less likely to address their needs and registration procedures are more likely to overlook them" (S1.28 UNHCR, 2017: 3).*

Theme 4: The need for multi-faceted support mechanisms

Incorporating sub-themes 7 and 8 (see table 21)

Having identified the protection risks and rights infringements that refugees who experience disabilities face, several documents make recommendations for both meeting their specific support needs and enhancing inclusive practice. These recommendations follow the popular ’twin-track’ approach (DFID, 2000) whereby a split focus on providing specialist support, alongside empowerment strategies and improving access to mainstream services, is advised to enhance participation whilst ensuring individual support needs are addressed. The need to address the participation support needs of refugees who experience disability through both targeted responses to individuals and groups, as well as through service provider focused responses, demonstrates commitment to delivering a holistic approach to inclusion.

Sub-theme 7: Refugee-focused responses

Documents suggest that individual refugee needs relating to impairment and disability are to be met through several channels, including referral to specialist agencies (such as (re)habilitation services and medical facilities), ensuring mainstream services are accessible, and monitoring persons identified as experiencing disability, to ensure their inclusion and participation.

Crucially, the advice to consult with refugees who experience disability on all aspects of humanitarian assistance, from issues specific to their own support needs, to those that affect their families and communities, recognises their capabilities and values.

> *“Consult and involve persons with disabilities in decision making, programming, and leadership, giving them the means to voice their opinion and participate in the design, assessment, monitoring, and evaluation of activities”. (S2.26, UNHCR and Handicap International, 2011: 5)*

For those with communication support needs, participation in consultations can be challenging. However, Age and Disability Consortium (2018) advises service providers to:

> *"Use a range of accessible communication methods in consultation/engagement activities and train staff to support this (e.g., the use of pictures or photos, audio, large print, visual demonstrations, face-to-face explanations, clear/slower speech and simple language)". (S1.32 Age and Disability Consortium, 2018: 10)*

The 'twin track' approach is evident in the concurrent advice to refer people with communication support needs to DPOs/Older Persons' Organisations (OPOs) for specialist communication support (Age and Disability Consortium, 2018).

Sub-theme 8: Service provider-focused responses

Many recommendations focus on service provider-focused response, recognising that the individual's impairment is not the sole contributor to their disability experience. A multifaceted approach to improving service provider and community knowledge and skills related to disability, through sensitisation campaigns, advocacy, as well as more formalised training and capacity-building, is rooted in both the human rights and social models of disability. Knowing who needs support and what services they access, through data collection and disaggregation, is considered essential to providing appropriate support.

> *"The identification of children with disabilities and disaggregation of data by disability can inform design of inclusive programmes, response, and early recovery, and determine the extent to which children with disabilities are accessing services". (S1.34 UNICEF, 2017: 44-45)*

Interestingly, despite the acknowledgement that service providers and communities need increased capacity to respond appropriately to inclusion issues, only one document recognises that service providers are often members of the same communities to which they provide services and are affected by the same cultural interpretations of disability, including stigmatising and discriminatory attitudes, behaviours, and practices (UNHCR and Handicap International, 2011). Recognition of this is a crucial step towards being able to change the way services are delivered to refugees who experience exclusion and discrimination.

> *“Staff should make themselves aware of their own preconceptions or attitudes towards disability”. (S1.26 UNCHR and Handicap International, 2011: 4)*

Appendix 11: Research assistant training schedule

Access to inclusive ECD and education for refugee children with communication disability

Research Assistant Training: November 2017

Camp A	Wed 8th	Helen travels to field office
	Thu 9th	Full day RA training
	Fri 10th	Camp visit am, Helen returns to Kigali pm.
Camp B	Mon 13th	Helen travels to field office am, RA training am.
	Tue 14th	RA training am, Helen to Kigali pm
Camp C	Wed 15th	Helen travels to field office
	Thu 16th	Full day RA training
	Fri 17th	Camp visit am, Helen to Kigali pm

ITEM	**TIME** *(split into half days in camp B)*	**TOPIC**
1	9.00-9.30	Introductions and discussion about experience
2	9.30-10.30	Introduction to communication disability & the study
	10.30-10.45	**BREAK**
3	10.45-11.15	Qualitative research
4	11.15-12.15	Ethics in cross-cultural and multilingual research
	12.15-1.30	**LUNCH**
5	1.30-2.30	Participant recruitment
6	2.30-3.30	Data collection: roles and responsibilities of the researcher and RA (inc. translation)
	3.30-3.45	**BREAK**
7	3.45-4.00	What will happen to the data?
8	4.00-4.30	Revision of key points / Q&A
9	4.30 / 5.00	Close

Slide deck available upon request.

Appendix 12: Participant information sheet

12.1 Full – English

Participant Information Sheet

Access to inclusive early childhood development and education services for refugee-children with communication disability, in Rwanda

Invitation

I would like to invite you to take part in a research study. Before you decide you need to understand why the research is being done and what it would involve for you. Please take time to read the following information carefully. Ask questions if anything you read is not clear or would like more information. Take time to decide whether or not to take part.

This study will try to find out what challenges children with communication disabilities and their families face in receiving early childhood development and education services in Rwanda's refugee communities.

Communication disabilities are not easy to identify – they are often 'hidden' within other disabilities (such as intellectual impairment or hearing impairment) and are not visible to others. Children with communication disabilities are often not identified and do not receive the health, education and social services that they need and are entitled to.

What is the purpose of the study?

The purposes of the study are to:

- Find out how children with communication disabilities can be identified in refugee communities.

- Find out what challenges children with communication difficulties and their families face in getting the early childhood development and education services that they need and are entitled to.
- Develop recommendations for organisations providing early childhood development and education services, so that children with communication disabilities are enabled and empowered to participate equally.

This research study will contribute to the award of a doctorate degree (PhD) from Manchester Metropolitan University, UK

Why have I been invited?

I would like to conduct my research with children with communication disabilities and their families who live in refugee communities in Rwanda and with support staff involved in delivering childhood development and education services.

You have been invited to participate because you are:

1. An employed member of staff of UNHCR, MIDIMAR or their partner organisations, involved in refugee registration, validation, best interest assessment or community-based data collection
2. An employed member of staff of UNHCR, MIDIMAR or their partner organisations, involved in ECD and education service design and delivery
3. A member of a refugee disabled peoples' organisation or committee
4. A teacher, early childhood development worker or health worker delivering services to refugee children aged 2-12
5. A child aged 8-12 who has communication difficulties
6. The carer of a child, aged 2-12 who has communication difficulties

Children aged 2-12 and their carers have been identified as the target age group since communication difficulties are most noticeable from age 2 upwards when children begin talking and children should access childhood development and education services up to the age of 12 in Rwanda.

Staff and carers who take part must be over the age of 18 and with capacity to give informed consent for their own and / or their child's participation in the study.

Do I have to take part?

It is up to you to decide. I will describe the study and talk through an information sheet, which I will give to you. I will then ask you to sign a consent form to show you agreed to take part. You are free to withdraw at any time, without giving a reason, and this will not affect the way you receive services in the future.

What will happen to me if I take part?

Humanitarian organisation staff:

You will be asked to take part in between 1 and 3 group discussions and / or individual interviews. You are free to decline attendance at any time, without reason. The research study will be conducted in two phases over the period of approximately 1 year. Group discussions are estimated to last between 1-3 hours and individual interviews approximately 1 hour.

The topics covered will include:

- Your experience of registering / taking information from or about people with communication disabilities and their families
- Your understanding of communication disability
- Your experiences of working with people with communication disability

Interviews and focus group discussions will be audio-recorded with your permission. You are free to withdraw from the discussion if you do not agree to this. Pictures may also be taken and I will also ask you to consent to using those pictures e.g. in printed publications or on the internet. You may decline to have your picture taken and / or used and still participate.

Refugee committees / disabled peoples' organisations

You will be asked to take part in 1-3 group activities and / or individual interviews. You are free to decline attendance at any time, without reason. The research study will be conducted in two phases over the period of approximately 1 year. Focus group discussions are estimated to last between 1-3 hours and individual interviews approximately 1 hour

The topics covered will include:

- Your understanding of communication disability
- Your experiences of working with people with communication disability
- Your views about the opportunities and challenges that children with communication disabilities and their families face in accessing services within the camp or local community
- Your views about the opportunities and challenges that children with communication disabilities and their families face in accessing early childhood development and education services within the camp or local community

Interviews and focus group discussions will be audio-recorded with your permission. You are free to withdraw from the discussion if you do not agree to this and request to attend a non-recorded individual interview. Pictures may also be taken and I will also ask your consent to using those pictures e.g. in printed publications or on the internet. You may decline to have your picture taken and / or used and still participate.

Teachers / ECD staff / health workers

You will be asked to take part in 1-3 group activities and / or individual interviews. You are free to decline attendance at any time, without reason. The research study will be conducted in two phases over the period of approximately 1 year. Focus group discussions are estimated to last between 1-3 hours and individual interviews approximately 1 hour

The topics covered will include:

- Your understanding of communication disability

- Your experiences of working with children with communication disability
- Your views about the opportunities and challenges that children with communication disabilities and their families face in accessing early childhood development and education services within the camp or local community
- Your thoughts on how services could be improved to meet the needs of children with communication disability

I would also like to participate in observations at your place of work so that I can better understand your working environment and will ask your consent to do so.

Interviews and focus group discussions will be audio-recorded with your permission. You are free to withdraw from the discussion if you do not agree to this and request to attend a non-recorded individual interview. Pictures may also be taken and I will also ask you to consent to using those pictures e.g. in printed publications or on the internet. You may decline to have your picture taken and / or used and still participate.

Carers of children with communication difficulties

You will be asked to take part 1-3 group activities and / or individual interviews. There will always be another person present. You are free to decline attendance at any time, without reason. The research study will be conducted in two phases over the period of approximately 1 year. Focus group discussions are estimated to last between 1-3 hours and individual interviews approximately 1 hour.

The topics covered will include:

- Information about your child's communication difficulties, including any diagnosis or a description of the challenges and history of the condition.
- Your experience of caring for a child with communication disability in the camp - both positive and negative
- The opportunities your child has to access early childhood development (2-5 years) or education (4-12 years) services

- The challenges your child faces in accessing early childhood development (2-5 years) or education (4-12 years) services
- Your support networks / sources of information
- Your thoughts on how services could be improved to meet your child's needs

If at any time I need to collect video or audio recordings, or take pictures, I will ask for your consent to do so. If you consent to me taking pictures, I will also ask for your consent regarding how the pictures can be used e.g. in printed publications or on the internet. You may decline to have your picture taken and / or used and still participate.

Children with communication difficulties (8-12 years)

You will be asked if you would like to talk to me, but you do not have to agree. I would like to talk to you up to 3 times. If you do agree, there will always be another person with me and you can bring someone to support you. You can stop whenever you want to.

We will talk about:

- You and the way you communicate with your friends and family
- What you like to do / don't like to do
- Places you go
- What things are easy or difficult for you to do
- School or other activities that you do
- What you think about going to school – Do you want to go? What makes it easy or difficult for you to go?

I would like to make a recording of what you say to help me to remember. I would also like to take some photographs. I will ask you if you are happy with that. You can say no if you are not happy.

Expenses

Attendance at group meetings and individual interviews at a place other than your home, place of work or place you would normally be at the time (e.g. school, ECD centre) will include provision of refreshments and compensation for any transport costs incurred up to 5,000 RWF per person attending.

What will I have to do?

You will be asked to participate in one or more group discussions and individual discussions with me and my colleagues that focus on identifying / caring for and / or working with children with communication disability. These discussions will take place in a convenient location and you will be informed of the date, place and time at least one week in advance. You are free to decline attendance at any time.

During the discussions, you do not have to answer any questions that you do not want to or give any personal information if you feel uncomfortable about this. The information you do give will be recorded in writing and by audio recording (your consent will be sought for this) and will be anonymised. No identifying information will be used in any publications.

What are the possible disadvantages and risks of taking part?

It is possible that you may find some of the topics of discussion unpleasant or distressing. If this happens, you are free to withdraw and you will be given the contact information for counselling and support services that can help you.

What are the possible benefits of taking part?

I cannot promise the study will help you right now, but the information I get from the study will help to increase the understanding of the challenges that children with communication disability and their families face in refugee communities in Rwanda and contribute towards the improvement of services in the future.

What if there is a problem?

If you have a concern about any aspect of this study, you should ask to speak to me, Helen Barrett, and I will do my best to answer your questions. You can contact me on Rwanda 0782306695 or helen.l.barrett@stu.mmu.ac.uk

If you remain unhappy and wish to complain formally you can do this through Dr Julie Marshall at Manchester Metropolitan University. Julie can be contacted on j.e.marshall@mmu.ac.uk

For more serious complaints, you can contact the Manchester Metropolitan University research and innovation manager, ……………………. on………………………..

If you do not have access to telephone or email, a member of UNHCR staff can assist you to contact the relevant person named above.

Will my taking part in the study be kept confidential?

All information collected about you during the course of the research will be kept strictly confidential, and any information about you which leaves the university will have your identifying details removed so that you cannot be identified.

Your confidentiality will be safeguarded during and after the study. All data will be collected using hand-written notes and audio-recording. Any photographs will only be taken and / or used with your explicit permission.

The data will be stored safely by Helen Barrett, principal researcher, in the following ways:

- Interview and focus group discussion data will be anonymised and given a research code, known only to the researcher
- A master list identifying participants to the research codes data will be held on a password protected computer, accessed only by the researcher
- Hard paper/taped data will be stored in a locked cabinet, within locked office, accessed only by researcher and destroyed once the information has been typed / uploaded onto a password-protected computer.
- Electronic data will be stored on a password protected computer known only by researcher.

- The data will be used in this study only. If, after the study is complete, the data could to be used for future studies, further ethical approval will be sought from Manchester Metropolitan University ethics board.
- The data will be destroyed after 3 years after the project end-date (2025)
- Consent forms will be stored in a locked cabinet to which only the principal researcher holds the key.

Who will be able to access the data?

- Researchers within the team, supervisors and auditors will have access to anonymised data. Only the principal researcher will have access to the identifying master list.

What will happen if I don't carry on with the study?

If you withdraw from the study I will destroy all identifiable recorded interviews and data, but I will need to use any anonymised data collected up to the point of your withdrawal.

What will happen to the results of the research study?

The results of this research will be submitted to Manchester Metropolitan University as part of a PhD post-graduate qualification. The results will be documented in a thesis made available at Manchester Metropolitan University Library. A summary of the research findings will be made available to participants in both hard and electronic copy. Findings may also be published in academic journal articles, at conferences and meetings or by UNHCR and its partners.

You will not be identified in any report/publication unless you have given your consent.

Further information and contact details:

1. For more information about Rwanda's inclusive ECD and education policies, please visit http://www.migeprof.gov.rw/index.php?id=3 and http://www.mineduc.gov.rw/home/
2. Principal researcher: Helen Barrett helen.l.barrett@stu.mmu.ac.uk
3. Who to approach if unhappy with the study: Julie Marshall j.e.marshall@mmu.ac.uk

12.2 Plain language - English

Participant Information Sheet

Access to early childhood development and inclusive education services for refugee-children with communication disability in Rwanda

Invitation

I would like to invite you to take part in a research study. Please ask questions if you do not understand something or would like more information. Take your time to decide if you want to take part.

Why is the research being done?

Children who have difficulties talking or understanding others sometimes do not receive the services that they need to help them. I will try to find out what is easy and what is difficult for children with communication difficulties when they go to school or ECD centres. I hope services can be made better using the information I find.

Why have I been invited?

You have been invited to participate because you are:

7. An employed member of staff of UNHCR, MIDIMAR or their partner organisations, involved in refugee registration, validation, best interest assessment or community-based data collection.
8. An employed member of staff of UNHCR, MIDIMAR or their partner organisations, involved in ECD and education service design and delivery.
9. A member of a refugee disabled peoples' organisation or committee.

10. A teacher, early childhood development worker, or health worker, delivering services to refugee children.
11. A child aged 8-12 with a mild or moderate communication difficulty.
12. A carer of a child, under 12 years of age who has communication difficulties.

Do I have to take part?

No, it is your decision. If you decide not to take part, it will not affect you in any way.

You can decide to stop at any time without saying why.

What do I have to do to take part?

- I will ask you to take part in some group discussions and / or individual interviews with me. Discussions will last between 1-3 hours.
- The study will last approximately 1 year, and you may be asked to attend up to 3 discussions over that time.
- We will talk about your experience of communication disability and early childhood development or education services in your work / community or family.
- You do not have to answer any questions that you do not want to.
- I will write your answers down, but not your name, so no-one will be able to identify you.
- If I need to make a recording (audio / picture / video) I will ask you first.

Will there be any cost?

No. Discussion groups or interviews will be held either at your home or at a place that is easy for you to get to. If you have to travel, I will provide refreshments and transport costs up to 5,000 RWF per person.

Will people know that I took part?

No. Everything that you say will be recorded without your name on it so nobody knows who you are. All the information will be stored very carefully.

What if there is a problem?

If you have any questions or are not happy, you can contact:

- The researcher: Helen Barrett on Rwanda 0782306695 or helen.l.barrett@stu.mmu.ac.uk
- The research supervisor: Julie Marshall on j.e.marshall@mmu.ac.uk
- For more serious complaints, you can contact the Manchester Metropolitan University research and innovation manager, ……………………. on………………………

If you do not have access to telephone or email, a member of UNHCR staff can help you to contact the right person.

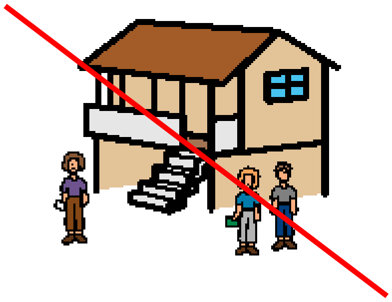
12. 3 Symbol supported – English

Manchester
Metropolitan
University

Participant Information Sheet

Children who have difficulty talking and understanding: Going to school

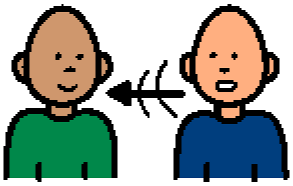
Children who have difficulties talking and understanding people sometimes do not go to school.



This is Helen

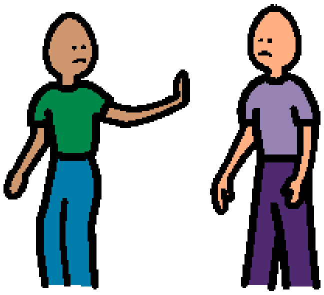
Helen wants all children to go to school

Helen would like to talk to you about going to school

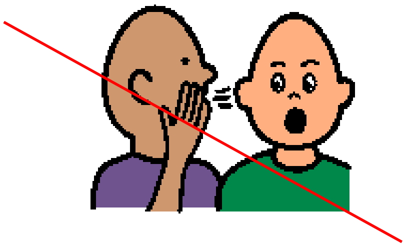


You do not have to talk

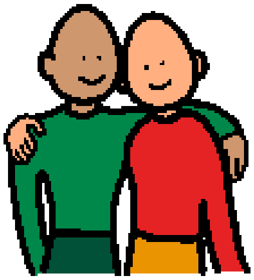
You can stop if you want to



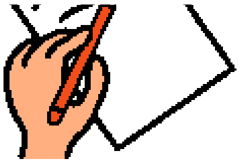
Helen will not tell anyone your name or what you say



You can bring someone with you



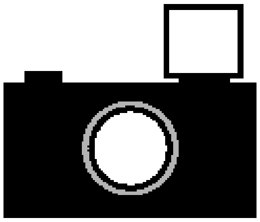
Helen will write what you say



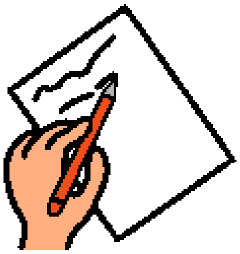
Helen will record what you say

Helen might take pictures

She will not show them to anyone in your community

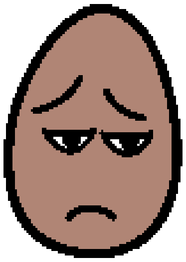


Helen will write a report. Other people will read the report.
Your name will not be in the report



If you feel sad or upset, you can talk to ……………….

You can keep this paper.



Appendix 13: Phase 1 participant demographics

13.1 Camp A participant demographic data

CAMP A	Gender *Identifies as:*			Age (years)				Experience				Total number
	Man	Woman	Other answer*	18-30	31-40	41-50	50+	< 1 year / not stated	1-5 years	6-10 years	10 years +	
Implementing organisations	2	3	0	2	1	0	2	0	5	0	0	**5**
Community volunteers	3	3	0	3	1	1	1	0	6	0	0	**6**
Refugee disability committee	4	3	0	0	6	1	0	3	4	0	0	**7**
Educators	3	3	0	1	4	1	0	0	6	0	0	**6**
TOTALS	**12**	**12**	**0**	**6**	**12**	**3**	**3**	**3**	**21**	**0**	**0**	**24**

**Transgender, non-binary, intersex, any other gender identification, or prefer not to say.*

13.2 Camp B participant demographic data

CAMP B	**Gender** *Identifies as:*			**Age**				**Experience**				**Total number**
	Man	**Woman**	**Other answer ***	**18-30**	**31-40**	**41-50**	**50+**	**< 1 year / not stated**	**1-5 years**	**6-10 years**	**10 years +**	
Implementing organisations	4	3	0	1	4	1	1	4	3	0	0	**7**
Community volunteers	4	0	0	1	0	1	2	0	4	0	0	**4**
Refugee disability committee	6	1	0	2	2	0	3	7	0	0	0	**7**
Educators	4	2	0	5	0	1	0	0	4	2	0	**6**
TOTALS	**18**	**6**	**0**	**9**	**6**	**3**	**6**	**11**	**11**	**2**		**24**

**Transgender, non-binary, intersex, any other gender identification, or prefer not to say.*

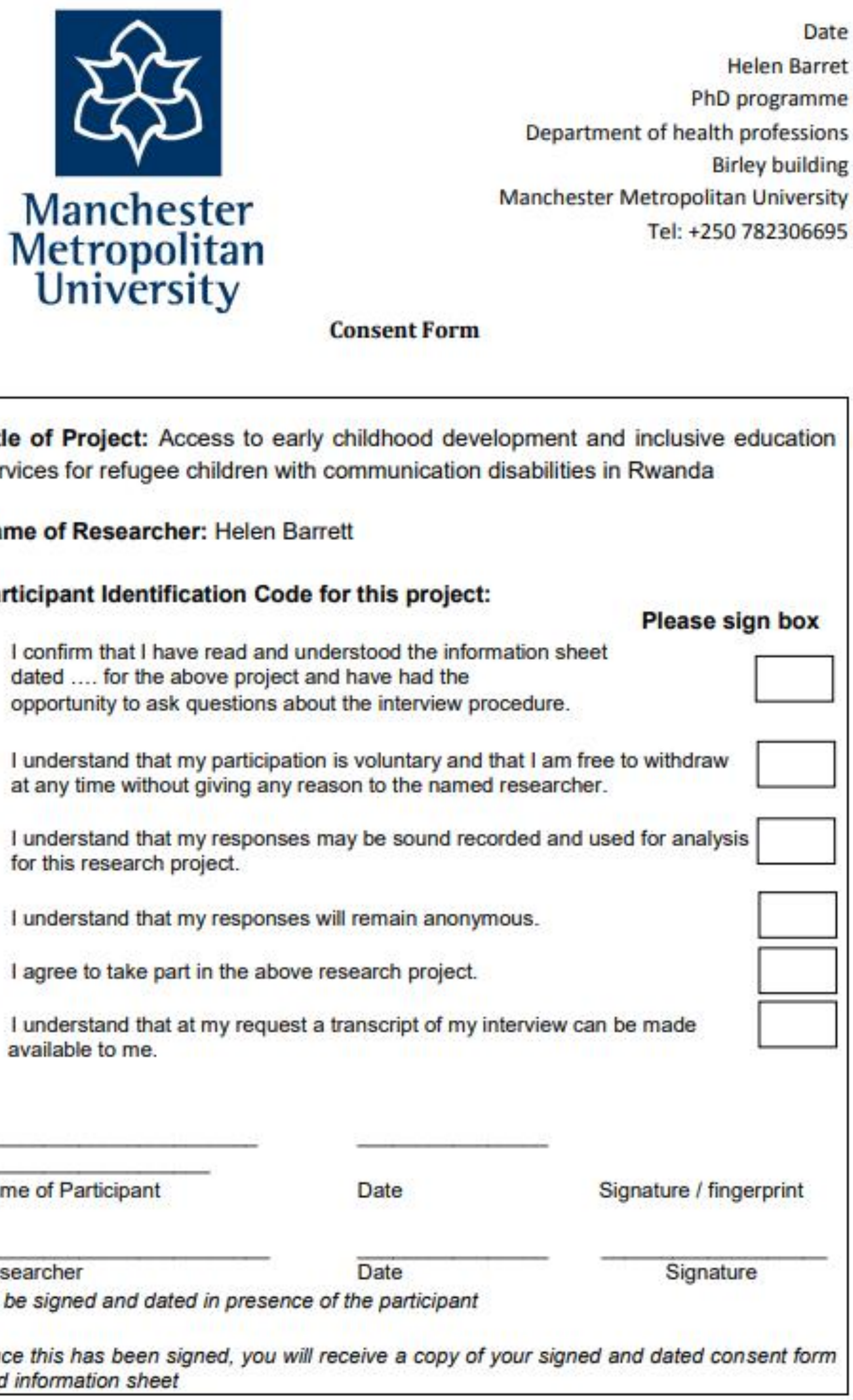
13.3 Camp C participant demographic data

CAMP C	**Gender** ***Identifies as:***			**Age**				**Experience**				**Total number**
	Man	**Woman**	**Other answer ***	**18-30**	**31-40**	**41-50**	**50+**	**< 1 year / not stated**	**1-5 years**	**6-10 years**	**10 years +**	
Implementing organisations	2	3	0	2	1	2	0	0	5	0	0	**5**
Community volunteers	6	2	0	2	2	3	1	2	4	1	1	**8**
Refugee disability committee	6	1	0	4	0	0	3	1	6	1	0	**7**
Educators	1	4	0	3	2	0	0	1	3	1	0	**5**
TOTALS	**15**	**10**	**0**	**11**	**5**	**5**	**4**	**4**	**18**	**3**	**1**	**25**

**Transgender, non-binary, intersex, any other gender identification, or prefer not to say.*

Appendix 14: Consent forms

14.1 Full - English



Manchester Metropolitan University

Date
Helen Barret
PhD programme
Department of health professions
Birley building
Manchester Metropolitan University
Tel: +250 782306695

Consent Form

Title of Project: Access to early childhood development and inclusive education services for refugee children with communication disabilities in Rwanda

Name of Researcher: Helen Barrett

Participant Identification Code for this project:

Please sign box

1. I confirm that I have read and understood the information sheet dated …. for the above project and have had the opportunity to ask questions about the interview procedure. ☐
2. I understand that my participation is voluntary and that I am free to withdraw at any time without giving any reason to the named researcher. ☐
3. I understand that my responses may be sound recorded and used for analysis for this research project. ☐
4. I understand that my responses will remain anonymous. ☐
5. I agree to take part in the above research project. ☐
6. I understand that at my request a transcript of my interview can be made available to me. ☐

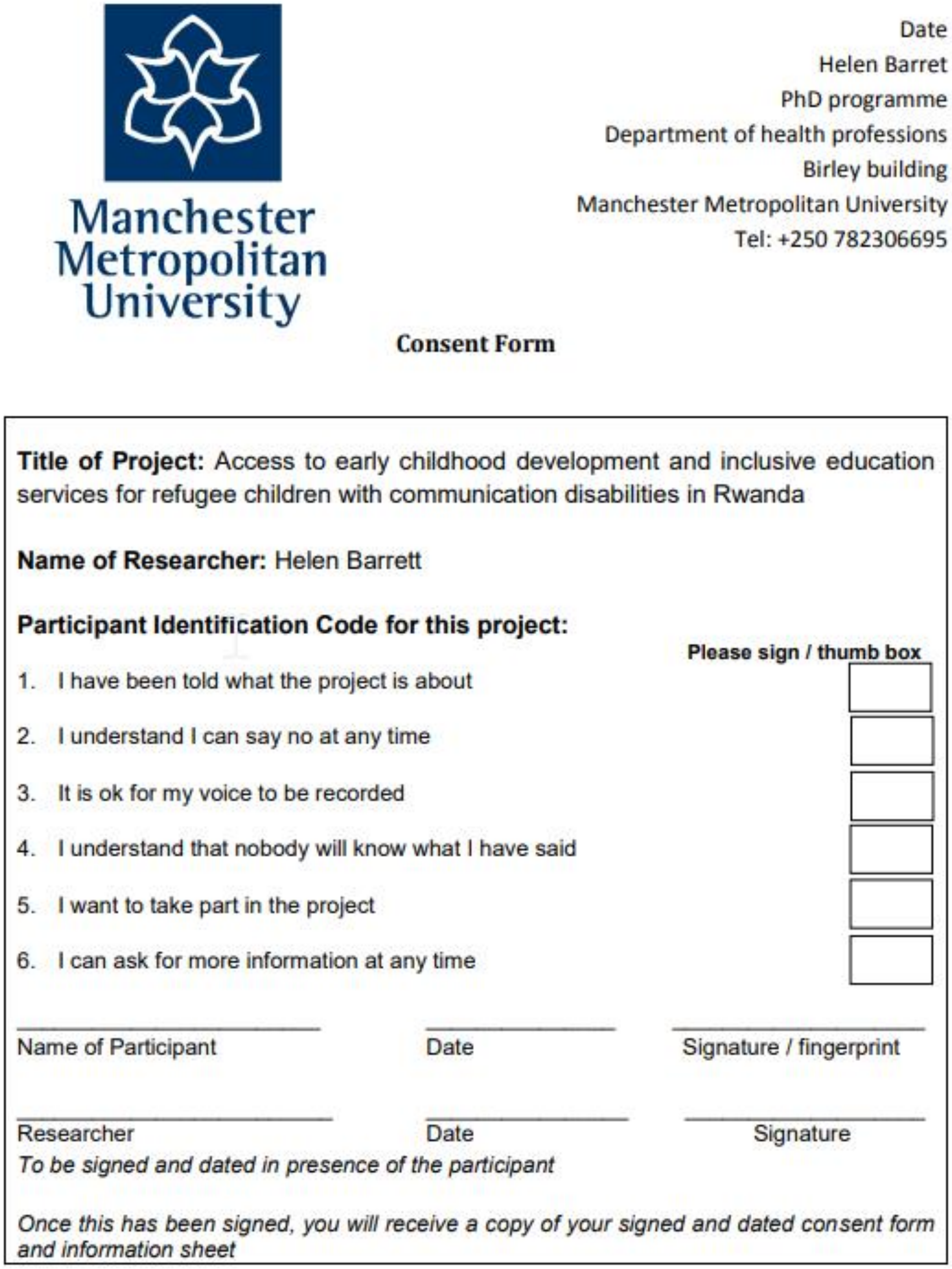
Name of Participant ____________________ Date ______________ Signature / fingerprint

Researcher ____________________ Date ______________ Signature ______________

To be signed and dated in presence of the participant

Once this has been signed, you will receive a copy of your signed and dated consent form and information sheet

14.2 Plain language - English



Manchester Metropolitan University

Date
Helen Barret
PhD programme
Department of health professions
Birley building
Manchester Metropolitan University
Tel: +250 782306695

Consent Form

Title of Project: Access to early childhood development and inclusive education services for refugee children with communication disabilities in Rwanda

Name of Researcher: Helen Barrett

Participant Identification Code for this project:

Please sign / thumb box

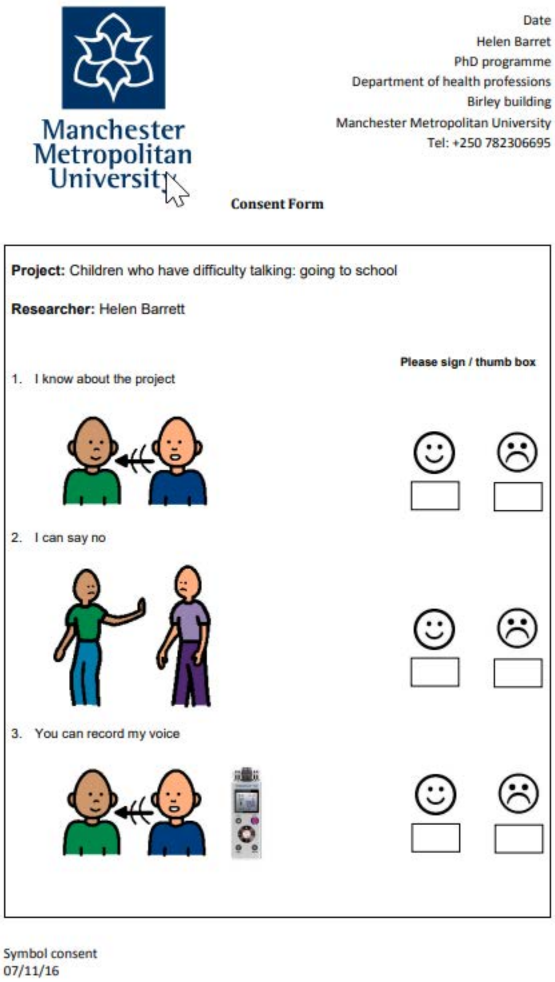
1. I have been told what the project is about ☐
2. I understand I can say no at any time ☐
3. It is ok for my voice to be recorded ☐
4. I understand that nobody will know what I have said ☐
5. I want to take part in the project ☐
6. I can ask for more information at any time ☐

Name of Participant	Date	Signature / fingerprint
Researcher	Date	Signature

To be signed and dated in presence of the participant

Once this has been signed, you will receive a copy of your signed and dated consent form and information sheet

14.3 Symbol supported – English



Manchester Metropolitan University

Date
Helen Barret
PhD programme
Department of health professions
Birley building
Manchester Metropolitan University
Tel: +250 782306695

Consent Form

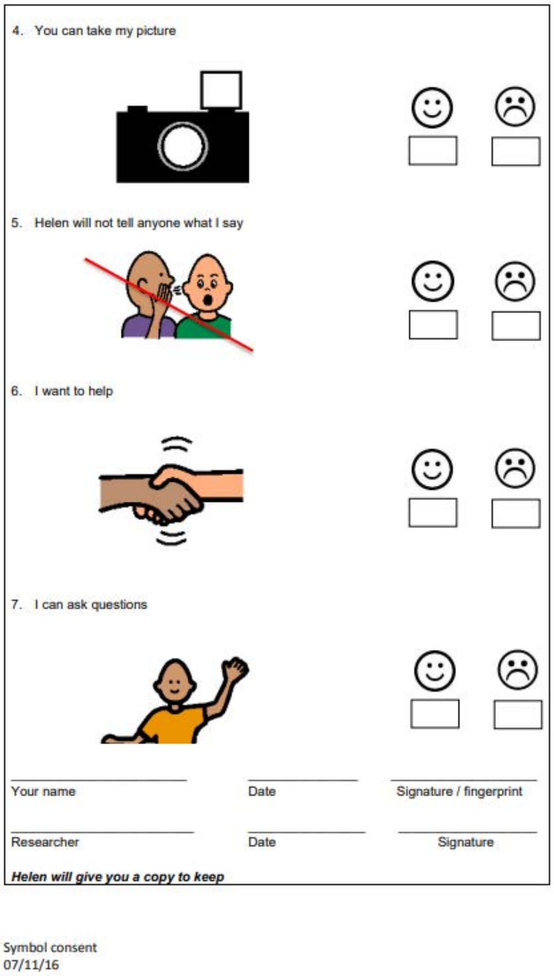
Project: Children who have difficulty talking: going to school

Researcher: Helen Barrett

Please sign / thumb box

1. I know about the project ☺ ☐ ☹ ☐
2. I can say no ☺ ☐ ☹ ☐
3. You can record my voice ☺ ☐ ☹ ☐

Symbol consent
07/11/16



4. You can take my picture ☺ ☐ ☹ ☐
5. Helen will not tell anyone what I say ☺ ☐ ☹ ☐
6. I want to help ☺ ☐ ☹ ☐
7. I can ask questions ☺ ☐ ☹ ☐

Your name ____ Date ____ Signature / fingerprint ____

Researcher ____ Date ____ Signature ____

Helen will give you a copy to keep

Symbol consent
07/11/16

Appendix 15: Example FGD/interview topic guide – Educators

STAGE 1 FOCUS GROUP TOPIC GUIDE

GROUP 3: Educators (teachers / ECD caregivers)

Objectives:

1. Describe the **tools and processes** used to **identify refugee-children with CI/who experience CD** in Rwanda.
2. Document the **self-reported understanding, behaviours and experience** of staff responsible for determining if children have CD.

Notes: Ensure interpreter(s) available. If more than one language needed, split the groups by language, if possible.

1. **Welcome**

2. **Introduction**

   My name is Helen and I am a Speech and Language Therapist from the UK. I've been living and working in East Africa for the past 10 years, and in Rwanda for the past 3 years. I work with people who have difficulties communicating that affect their everyday life. I have a particular interest in children who experience communication disability, and how it affects them as they develop.

   We know that many children have different types of difficulties with communication that affect their learning. We also know that communication impairments are invisible or hidden – people can't see them, so people with communication impairments are often overlooked in consultations, planning meetings, community events. I'm not going to talk too much about communication impairment and disability now, because I'd like us to talk about it as a group later.

We know, from the data we have, that refugees with communication impairment are not always known to service providers. This research is looking at how children with communication impairment can be identified and how we can make sure that they are included in ECD services and education, to make sure they fulfil their rights as children and go on to live as independent a life as possible.

The research is in 2 stages: the first is looking at how refugee children with communication impairment and disability are, or can be better, identified. The second will look at the experiences and needs of families of children who experience communication disability in relation to accessing ECD and education services, and of the service providers – ECD staff and teachers - to ensure more effective inclusion.

This focus group / interview forms part of phase 1 of the study on identification. I hope to learn more about how refugee children with CI are identified and the process used for registration or recording of their needs. I also hope to learn more about your experiences of working with people with communication impairment and your needs as staff in improving the tools and systems for identification and registration.

3. **Summary of what we are going to talk about today**
    - ECD and primary school services
    - Identification of impairment and disability – how, by whom, special services / referrals?
    - Challenges to registration / identification of impairment and disability.
    - Understanding of communication disability? What do you think it is?
    - Experience of communication disability
    - What do you / would you do if you find a child experiencing communication disability?
    - Suggestions for improvements in the system
    - Needs

- Any other discussion points

4. **Consent check**

   Everybody here today has been given information about the research project by …….RA…… and you have signed a consent form to say that you fully understand that:

   a. Your participation is voluntary
   b. That you can stop at any time, without explanation
   c. Everything you say will be fully anonymised and no quotes used will be directly traceable to an individual
   d. Personal information will be stored securely and separately from the transcripts of the discussion. I will be the only person with access to that information
   e. All recorded data will be destroyed immediately after it has been transcribed
   f. You will be given access to the published research, and a summary of findings, when the project ends

   In order to ensure confidentiality, everyone in this room needs to agree that whatever is said here today remains confidential between us all and that nothing discussed here today will be discussed outside of this group setting. Do we all agree?

   Check written consent obtained.

5. **Ground rules**

   In order to make the group work well, we all need to feel comfortable to **speak freely and honestly**. It's important that **everyone has a chance** to say what they feel is important and the everybody's contribution is valued. *RA* and I will **help to guide the discussion** so that we ensure we get the information we need for the research, but feel free to raise things that you feel are relevant.

   Please also be **respectful of other people's opinions and contributions**. It's ok to disagree, to debate and talk about different sides of a story, but please be mindful that peoples’ experiences and opinions do vary, and I am interested in hearing about different opinions and experiences.

I will guide the discussion in English and *RA* will translate into French / Kinyarwanda as needed. Please allow time for this to happen so that everyone in the room understands what is happening.

Any comments / questions?

6. **Sound check.**

   Before we begin, I need to do a **sound check** with the recorder. So please can we go around the room and introduce ourselves, one by one, then I will check I can hear you clearly.

FGD GUIDING QUESTIONS / PROMPTS

a. Tell me about what ECD / primary school services are available in the camp
    - What types of ECD services are there?
    - What age groups are involved?

b. How children are referred to ECD services / schools in the camp?

c. What happens if someone suspects a child has an impairment or learning difficulty?
    - Who makes the decision?
    - What process do you go through?
    - What tools are used?
    - Where is the information recorded?
    - What does this mean for the child?
    - Who uses the recorded data and what for?

d. Have you ever worked with a child with an impairment disability / suspected impairment?
    - What kind of impairment?
    - How did you identify their needs?
    - What did you do?
    - What was the outcome?

e. Have you experienced any challenges to identifying impairments / disability?
    - What about multiple impairments?
    - What do you do if faced with a challenge? Is there a process?

f. When I say 'communication disability', what is your understanding of it?
    - What are the features of communication disability?
    - Who does it affect and how?
    - What do you think its impact could be?

g. Do you have any experience of working with a child who has difficulties communicating? Either using or understanding language, or being unclear when they talk?
    - What did you do?
    - What would you do?
    - What did / would you do if that person was /were a child?

h. How effective is the system for identifying and registering communication impairment and disability?
    - What can be improved?

i. What are your needs as front-line workers to help improve your ability to identify and register children with communication impairment who experiences CD?

j. Any other points?

7. **Any questions?**

8. **Thanks and close**

Appendix 16: Phase 1 FGD coding results

16.1 Phase 1, data set 3

Thematic Network Analysis: Group 1 (implementing organisations)

Codes	Basic themes (BT)	Organising Themes (OT)	Global Themes (GT)
1 Types of registration	1 Registration is an ongoing and collaborative process	1 Accurate registration of refugee needs is the gateway to appropriate assistance	**1 INCREASED PROTECTION RISK AS REALITY FOR REFUGEES WHO EXPERIENCE CD**
2 Organisations collect information and report up			
3 Organisations have specific roles and make referrals			
4 Community role in ID and registration			
5 Vulnerabilities identified	2 Registration is for protection and assistance		
6 Registration is for assistance			
7 Refugee status			
8 “Disability is tricky”	3 Disability is complicated.	2 Refugees who experience CD are at risk of exclusion from specific needs registration	
9 Need for specialists			
10 Ill equipped to identify and respond to needs			
11 Disability is stigmatised			
12 CD is…	4 CD is acknowledged but poorly understood		
13 Caused of CD			
14 CD is not understood			
15 The need for sign language			
16 Registration systems are problematic for refugees who experience CD	5 STPs are inadequate for accurate disability registration		
17 Registration tools are problematic for 18 refugees who experience CD			
19 Recording multiple disabilities			
20 Prevalence of CD			

30 CD often missed	6 CD is under-identified	3 Refugees who experience CD are overlooked and vulnerable	
31 Refugees who experience CD are at increased risk	7 CD is associated with dependency and vulnerability		
32 Refugees who experience CD endure limited service access			
33 Refugees who experience CD have limited autonomy			
34 CD increases caring responsibilities			
35 Increasing awareness	8 Positive impacts of sensitisation and mobilisation	4 Building on a strong foundation	**2 COLLABORATIVE CAPACITY BUILDING TO ACHIEVE INCLUSION**
36 Changing attitudes and behaviours			
37 Improving service access			
38 Knowledge and skills	9 Service provider needs		
39 Current service gaps			
40 “We do what we can”	10 Service provider capacity		
41 Service providers have skills to build on			
42 Existing disability services			
43 Some refugees who experience CD use alternative and augmentative communication (AAC) methods	11 Capabilities of refugees who experience CD	5 Communities at the core	
44 “They can do everything”			
45 Refugees who experience CD need more communication methods			
46 Community volunteers represent refugees who experience CD	12 Community capacity		
47 Community roles in ID and registration			
48 Communities know their members			
49 Families are experts			
50 Knowledge and skills	13 Community needs		
51 Community empowerment			

16.2: Phase 1, data set 3

Thematic Network Analysis: Group 2 (community volunteers)

Group	Codes	Basic themes (BT)	Organising themes (OT)	Global theme(s) (GT)
G2: Community Volunteers	52. Registration types	14. Registration is an ongoing and collaborative process	6. Accurate registration of refugee needs is the gateway to assistance.	**3. REFUGEES WITH CI EXPERIENCE LIMITED PARTICIPATION AND ACCESS TO ASSISTANCE**
	53. Stakeholders work together			
	54. Registration is continuous			
	55. Registration is a refugee's right	15. Registration is for assistance		
	56. registration is effective			
	57. registration enables service access			
	58. partners and communities make referrals	16. Specialist partners have specific roles and responsibilities		
	59. ID and registration of disability			
	60. diagnosis of health conditions			
	61. protection			
	62. registration and orientation			
	63. Self-identity	17. Disability is perceived as a negative attribute	7. Identification and registration of refugees who experience CD is challenging	
	64. taboo and stigma			
	65. CD is invisible	18. CD is acknowledged but hidden		
	66. CD is….			
	67. "We didn't know what is CD"			

	68. Limited service provider understanding, skills and resources	19. Capacity and priorities		
	69. Priorities of refugees who experience CD			
	70. Need for specialists			
	71. SPs have some skills	20. What works: service providers	8. Improving upon existing good practice	**4. HARNESSING EXISTING RESOURCES & CAPACITY OF PARTNERS AND COMMUNITIES**
	72. mobilisation, sensitisation, and advocacy			
	73. service provider training			
	74. Inclusion	21. What works: communities		
	75. Families support each other			
	76. attitudinal and behaviour change			
	77. specific services for refugees who experience CD	22. ID and registration STPs can be improved		
	78. Community volunteer capacity building			
	79. Non-stigmatising language			
	80. Refugees who experience CD are capable	23. Refugees who experience CD are present and can contribute to society	9. Maximising capabilities to enhance inclusion and participation	
	81. Perceived CD prevalence			
	82. Needs of			

	refugees who experience CD			
	83. Assistance and care	24. Refugees who experience CD are dependent on others		
	84. Lack of autonomy			
	85. Impact on families			
	86. Futures			
	87. Socialisation and interaction	25. Refugees who experience CD face isolation		
	88. Limited service access			
	89. Mental health and disposition			
	90. Limited participation			

16.3 Phase 1, data set 3

Thematic Network Analysis: Group 3 (Educators)

Group	Code	Basic theme (BT)	Organising theme (OT)	Global theme (GT)
G3: Educators	91.ECD and school reg processes	26. Community-based registration functions as a safety net.	10.Registration STPs are insufficient for refugees who experience CD.	**5: REFUGEES WHO EXPERIENCE CD FACE STRUCTURAL AND HUMAN BARRIERS TO INCLUSION**
	92. Other community registration			
	93. SPs report to partners			
	94. Registration is not effective for RWCD	27. Registration of refugees with CI is challenging		
	95. Collaboration challenges			
	96. Disability is difficult			
	97. Reduced service access		11. Refugees with CI experience	

	98. Reduced participation	28. Refugees with CI face challenges across contexts.	disabling exclusion and increased protection risk.	
	99. Expressing needs			
	100. CD community challenges			
	101. CD home challenges			
	102. CD school challenges			
	103. Risk of abuse and neglect	29. Refugees with CI experience increased vulnerability.		
	104. CD is…			
	105. Negative attitudes, behaviours			
	106. Emotional / mental health impacts			
	Examples			
	CD is invisible	30. CD is acknowledged but difficult to identify.	12. Meeting the needs of refugees who experience CD is difficult.	**6. INCREASING STAKEHOLDER CAPACITY AND RESOURCING TO ADDRESS BARRIERS TO INCLUSION**.
	Perceived scale of the problem			
	SPs lack knowledge, skills, resources			
	We do what we can	31. Current provisions are not enough		
	SPs have specific roles			
	SL training and provision is too little			
	Referrals to specialists			
	Current services for RWCD			
	Community needs support and training	32. Service providers and communities	13. Holistic approach to	

	SPs need more support, training	need increased capacity to mainstream inclusion	addressing inclusion barriers,	
	Sign language	33. Specialist skills and services are necessary		
	Need for specialists and specialist services			
	RWCD and families need assistance	34 Refugees who experience CD need support to maximise their capabilities		
	RWCD need comm methods			
	RWCD are capable			
	Religion, hope			
	Families a experts			

16.4: Phase 1, data set 3

Thematic Network Analysis: Group 4 (Refugee disability committee - RDC)

Codes	Basic themes (BT)	Organising themes (OT)	Global themes (GT)
121. Registration is a process	35. Registration is an important process	14. Registration is the gateway to mainstream and specialist service access.	**7. REFUGEES WHO EXPERIENCE CD FAIL TO REALISE THEIR RIGHTS TO PROTECTION AND PARTICIPATION.**
122. Registration is important			
123. Registration is for assistance	36. Registration is to meet needs		
124. Referrals to specialists			
125. Service provider specific roles and responsibilities			
126. Collaboration for registration	37. There are multiple routes to registration.		
127. Community ID and registration			

128. Communities report up			
129. Registration can be inaccurate	38. Fallible disability registration STPs	15. Refugees who experience CD may not have needs registered accurately or at all.	
130. Registration tools are insufficient			
131. We don't know what happens to the data			
132. Registration of disability			
133. Community volunteers lack knowledge and skills			
134. Refugees who experience CD rely on others	39. Disability is difficult		
135. Some disability is invisible			
136. Disabled identity	40. Refugees who experience CD may choose not to register or access support		
137. Other priorities			
138. Stigma and shame			
139. Rights are violated	41. Potential rights abuses	16. CD can have negative impacts on all aspects of life as a refugee	
140. Risk of abuse, mistreatment, neglect			
141. Reduced service access			
142. Lack of autonomy			
143. CD is hidden			
144. Families			

145. Conflict	42. CD impacts individuals, families, and communities.		
146. Mental health, wellbeing, opportunities			
147. Community frustration			
148. CD is…	43. CD recognised but not well understood	17. Misunderstanding of CD and support needs	8. COMMUNITY-LED ADVOCACY TO DISMANTLE STRUCTURAL AND HUMAN BARRIERS TO INCLUSION
149. Trauma			
150. sign language			
151. perceived size of problem			
152. Current services for refugees who experience CD	44. Some services address some CDs		
153. Specialist provisions			
154. services are not enough	45. Services do not the meet the needs of refugees who experience CD		
155. Specific needs are neglected			
156. Sensitisation and mobilisation	46. Community plays a key role in ID, registration, and inclusion	18. Community empowerment and ownership can improve the participation and inclusion of refugees who experience CD	
157. Community follow-up			
158. Community advocacy			
159. Need for communication methods	47. Empowerment of refugees who experience CD		
160. Need to be known			

Appendix 17: Phase 2 document analysis search strategy

Document sources	Inclusion criteria	Exclusion criteria	Search window
Direct request -UNHCR Rwanda/ Geneva staff -Humanity and Inclusion Rwanda staff -Save the Children Rwanda staff -ADRA Rwanda staff **Specific website searches** -Government of Rwanda (MIDIMAR/ MINEMA) -UNGA -UNHCR -UNICEF -Handicap International/ Humanity and Inclusion -Save the Children -PLAN International -ADRA -Women's Refugee Commission -Sphere **Open web search (google search engine)** -See table 26 for search terms	**Publication date** -Published between January 2000 and December 2017 **Document type** -Treaties, conventions, charters -Policy/ guidelines -Data collection tools -Data recording systems -Guidance notes -Standard operating procedures -Meeting minutes including amendments to SOPs -Training manuals / toolkits documents -Reports **Applicability** -Globally applicable: -Including Rwanda -With reference to Rwanda: -Sub-Saharan Africa -East Africa -Great Lakes Region -Rwanda -Available in written English **Author** -Government of Rwanda (inc. MIDIMAR/MINEMA) -UN agencies -INEE	**Document type** -Opinion pieces -Research papers **Author** -Organisations/ individuals that do not work directly with refugees	January 2016 – June 2018

	-EENET -Sphere -Handicap International/ Humanity and Inclusion -Save the Children -Plan International -ADRA -World vision -WRC -Other NGOs working with refugees with impairments and associated disabilities, applicable to Rwanda		
	Refers to: -Early childhood development AND/OR -Education services (all types) AND -Refugees/ displaced/ humanitarian/ emergencies AND -Impairment/ disability/ inclusion		
	Audience -Government -UN agencies -Humanitarian actors, including INGOs and NGOs.	**Audience** -Documents produced for general consumption	
	Publication language -Written English only		
	Format -Original documents in Electronic or hard copy	**Format** -Summary documents -Citations/references	

Appendix 18: Documents included in the phase 2 document analysis

Document code	Author	Year	Title
S2.1	UNHCR	2015b	SOP: Urban refugees' access to education
S2.3	UNHCR and Handicap International	2011	Working with persons with disabilities in forced displacement. Need to know guidance 1
S2.4	INEE	2010a	Minimum standards for education: preparedness, response, recovery
S2.5	Handicap International	2015	Disability in humanitarian context: views from affected people and field organisations
S2.6	WHO & WB Group	2011	World report on disability
S2.7	UNGA	2006	Convention on the rights of persons with disabilities (CRPD)
S2.9	UNGA	2016	CRPD general comment 4
S2.10	UNGA	2015B	Thematic study on the rights of persons with disabilities under article 11 of the Convention on the Rights of Persons with Disabilities, on situations of risk and humanitarian emergencies Report of the Office of the United Nations High Commissioner for Human Rights
S2.11	UNICEF	2017	Guidance: Including children with disabilities in humanitarian action (Education).
S2.12	UNHCR	2017c	Left behind. Refugee education in crisis
S2.14	UNICEF	2014	Early Childhood Development in Emergencies: Integrated Programme Guide
S2.17	UNESCO	2015	Incheon Declaration– Education 2030: Towards Inclusive and Equitable Quality Education and Lifelong Learning for All.
S2.18	INEE	2016	Education in Emergencies: Including Everyone. INEE pocket guide to inclusive education Inter-Agency Network for Education in emergencies
S2.19	INEE	2010b	INEE thematic issue brief: inclusive education
S2.20	INEE	2010c	INEE pocket guide to supporting learners with disabilities
S2.21	INEE & Global Education Cluster	2011	Module 15: Inclusive education in emergencies

S2.23	Save the Children	2008a	Making Schools Inclusive: How change can happen. Save the Children's experience
S2.24	Age and Disability Consortium	2018	Minimum standards for age and disability inclusion in humanitarian action
S2.25	Plan international	2017	Planning for inclusion: How education budgets and plans target the most marginalized
S2.26	UNESCO	2001	Understanding and responding to children's needs in inclusive classrooms: A guide for teachers
S2.27	UNICEF & UNESCO	2007	A human rights-based approach to education for all
S2.29	Stubbs, S. (Atlas Alliance)	2008	Inclusive Education: Where there are few resources
S2.30	Save the Children	2016b	Inclusive education: What, why, and how: A Handbook for Program Implementers
S2.31	UNESCO	2009	Policy guidelines on inclusive education
S2.33	UNESCO	2000	World Education Forum Education For all Assessment: Education for all and children who are excluded
S2.34	Save the Children	2003	Education in Emergencies - A tool kit for starting and managing education in emergencies
S2.35	IDDC	2008	Discussion paper on access to quality educational activities for children with disabilities in conflict and emergency situations
S2.37	Save the Children	2017	Losing out on learning: providing refugee children the education they were promised
S2.42	UNICEF	2010	Core Commitments for Children in humanitarian action (CCC)
S2.43	United Nations	2016	New York Declaration for refugees and migrants
S2.46	Save the Children	2008b	Non-discrimination in emergencies training manual and toolkit
S2.47	Save the Children	2002	Schools for All: Including disabled children in education
S2.48	UNICEF	2007	The Participation of Children and Young People in Emergencies: A guide for relief agencies, based largely on experiences in the Asian tsunami response

Appendix 19: Phase 2 document analysis codes

Code	Sub-theme	Theme
1. Dependency	1. Disability leads to exposure to heightened risk in forced migration contexts	**1. EDUCATIONAL EXCLUSION EXACERBATES CURRENT AND FUTURE RISKS, FOR REFUGEE CHILDREN WHO EXPERIENCE DISABILITY AND THEIR COMMUNITIES**
2. Effects on households		
3. Humanitarian context magnifies disability-related risks		
4. Loss of services, facilities, and resources		
5. Poverty and disability		
6. Rights violations		
7. Attitudinal and behavioural barriers to inclusive education	2. Exclusion is multidimensional and pervasive	
8. Organisational barriers to inclusive education		
9. Legal and policy barriers to inclusive education		
10. Intersections		
11. Impacts of exclusion		
12. Crisis breeds opportunity to 'build back better'	3. Inclusive education contributes to inclusive futures	**2. INCLUSIVE EDUCATION UNDERPINS THE CREATION OF EQUITABLE, PEACFUL AND JUST SOCIETIES**
13. Education is a universal right		
14. Education is an investment in the future		
15. Education supports the realisation of other rights		
16. Inclusive education builds inclusive societies		

17. Inclusive education for protection, stability, and recovery		
18. Capacity building	4. Systemic change to achieve education for all	
19. Community focus		
20. Disaggregated data and needs analysis		
21. Dignity, resilience, and capacity		
22. Disability mainstreaming		
23. Generating and documenting evidence and learning		
24. Educational paradigm shift		
25. Specialist support		
26. Using existing resources		

Appendix 20: Phase 2 document analysis expanded results: themes and sub-themes

Theme 1: Educational exclusion exacerbates current and future risks for refugee children who experience disability and their communities.

Incorporating sub-themes 1 and 2 (see table 27).

This theme summarises information on the heightened exposure to current and future risks for refugee children who experience disability, derived from the documents included in the DA. At the intersection of their disability and refugee statuses lies pervasive discrimination, exclusion, and human rights violations, including a lack of access to appropriate education, that can have significant impacts across the lifespan. Systemic barriers to inclusion across communities, organisations, services, and legal entities combine to render refugee children who experience disability some of the most at-risk children on earth (S2.11: UNICEF, 2017).

> *"Exclusion from education, then, is not a single 'one-off' event in the lives of the children affected. Having no access to school, or access only to those that are ineffectual and harmful, needs to be understood as part of a pattern of systemic exclusion, one linked to other social, economic and political conditions which can, in effect, serve as proxy. The child who consistently does not go to school is also the child who consistently suffers from poor nutrition and health care, from inadequate water, sanitation, and shelter; who lives in a family with an unstable income and limited opportunities to participate; whose community is in conflict." (S2.33: UNESCO, 2000: 2)*

Ironically, documents suggest that out-of-school children (including those who experience disability) fail to access the protective benefits of an inclusive, community-based education. This includes: a physically and psychologically safe and protective environment; a supportive network of friends and advocates; access to information on personal safety and protection; lifelong learning and independence skills; as well as active participation in community life, and the peaceful restructuring of their community post-emergency. They fail to have their voices heard and their capabilities valued. Moreover, their classmates miss the opportunity to experience and appreciate diversity – a lesson with transformative potential.

Sub theme 1: Disability leads to exposure to heightened risk in forced migration contexts.

Documents reference an increase in a person's exposure to protection risks as an integral part of the disability experience in forced migration contexts. Risk exposure is further exacerbated by intersections with factors such as age and gender (older/younger persons and/or women/girls who experience disabilities in humanitarian contexts are exposed to heightened risk compared to other groups).

> *"Emergencies act as magnifiers of existing vulnerabilities – particularly in the case of groups already subject to discrimination…. For many, the burden of multiple discriminations severely affects their life chances both during and after an emergency". (S2.46: Save The Children, 2008: 8)*

The humanitarian context also increases opportunity for rights violations on a multitude of levels for all people affected, but particularly for high-risk groups with intersecting identities, such as children who experience disability. These rights violations include a lack of access to inclusive ECD and education services – a right enshrined in several global conventions, including the CRC (UNGA, 1989), the CRPD (UNGA, 2006) and the Convention on the Status of Refugees (CSR) (UNGA, 1951).

> *"Situations of armed conflict, humanitarian emergencies and natural disasters disproportionately impact the right to inclusive education" (S2.9, CRPD general comment. 2016: 6).*

The long-term implications of these rights violations in childhood cannot be overstated: Children who miss large periods of education often never return, impacting upon their ability to protect and provide for themselves and their families, now and in the future (S2.6, WHO & WBG, 2011).

> *"Children with disabilities are less likely to attend school, thus experiencing limited opportunities for human capital formation and facing reduced employment opportunities and decreased productivity in adulthood" (S2.6, WHO & WBG, 2011: 10).*

Sub-theme 2: Exclusion is multidimensional and pervasive.

Documents reference factors that contribute to disabling, multidimensional exclusion for children with impairments in humanitarian contexts. They face numerous barriers to participation across the globe although the exclusion they face from service access and community life can be more acute in some contexts, influenced by factors such as cultural understandings of the causes and nature of impairment and disability, religion, gender roles, and magnified by crisis and/or forced migration.

> *"Negative attitudes to disability are, arguably, the single biggest barrier to disabled children accessing and benefiting from mainstream education." (S2.47: Save The Children, 2002: 27)*

Documents attribute disabling exclusion to a complex combination of attitudinal and behavioural, environmental, organisational, legal/policy, and personal barriers to inclusion and participation. Refugees with impairments – especially children - are very often 'invisible', misunderstood, and actively and passively discriminated against as individuals and as a group - particularly in humanitarian contexts – resulting in disablement. Their invisibility means their voices are unheard, their support needs are unknown, and their human rights infringed upon. This precludes participation in community consultations and decision-making, further intensifying their invisibility and disablement (reflected in findings by Jagoe et al, 2021). Communication barriers exacerbate access and participation limitations.

> *"Many interventions only treat the symptoms of discrimination and do not deal with the root causes that result in those symptoms. The pressure to produce immediate and tangible results often leads to programs delivering goods and services that can be easily measured, but do not contribute to a sustainable solution beyond the program". (S2.30, Save The Children, 2016: 43).*

Theme 2: Inclusive education underpins the creation of equitable, peaceful, and just societies.

Incorporating sub-themes 3 and 4 (see table 27)

This theme describes the transformative potential of inclusive ECD and education on society, from the immediate effects on the individual and their family, to the future economic and social impacts on nations.

The documents included in this theme make the case for investment in inclusive education in humanitarian contexts as an investment in the future of children, families, and society. They advocate that the benefits of inclusive education cannot be overstated, particularly in humanitarian contexts, and specifically those involving forced migration. In these situations, children who experience disability are known to be overlooked and often fail to realise their rights on a multitude of levels (see sub-theme 2, appendix 20). Education is documented to foster dignity and participation and to provide opportunities for visibility and attitudinal and behavioural change amongst peers and community members. It also facilitates the realisation of other human rights, paving the way for a dignified and independent future. Critically, education for all (EFA) is purported to provide the opportunity for every child to play a role in the creation of equitable, peaceful, and just societies – the goal of Sustainable Development Goal (SDG) 16.

> *"Inclusive schools are able to change attitudes toward diversity by educating all children together and form the basis for a just and non-discriminatory society." (S2.31: UNESCO, 2016: 9)*

<u>*Sub-theme 3: Inclusive education contributes to inclusive futures.*</u>

A rights-based approach to inclusive education for refugee children who experience disability is at the core of contemporary humanitarian practice, especially at the humanitarian-peace-development nexus (HDPN – see chapter 2, section 2.3.3). Human, child, refugee, and disability rights now combine to form the backbone of educational provision, both in emergency and protracted forced migration situations, on paper. Access to EFA is also widely acknowledged to facilitate the realisation of other rights, whilst acknowledging that other rights need to be realised (such as basic survival needs met) before the right to inclusive ECD and education can be fulfilled.

Not only does inclusive education benefit individual children, but it is also considered to benefit wider society. Educating children with impairments with non-affected peers encourages understanding and acceptance of diversity which can reduce disabling exclusion and be carried forward toward the creation of future inclusive communities. UNGA (2016, document S2.9) describes education as:

> *"A means of realizing other human rights. It is the primary means by which persons with disabilities can lift themselves out of poverty, obtain the means to participate fully in their communities, and be safeguarded from exploitation. It is the primary means through which to achieve inclusive societies." (S2.9: UNGA, 2016: 4).*

Furthermore, education in emergencies and forced migration contexts is considered an important vehicle for physical and psychological protection during a crisis, as well as for reconciliation and peace building in situations of conflict. A lack of access to education does not simply affect an individual child, or group of children in the short term, but affects their ability to participate in building a sustainable and peaceful future for their community. The EFA agenda is therefore an investment in the future of peaceful and productive nations.

> *"Education gives refugee children, adolescents and youth a place of safety amid the tumult of displacement. It amounts to an investment in the future, creating and nurturing the scientists, philosophers, architects, poets, teachers, health care workers and public servants who will rebuild and revitalize their countries once peace is established and they are able to return. The education of these young refugees is crucial to the peaceful and sustainable development of the places that have welcomed them, and to the future prosperity of their own countries" (S2.12: UNHCR, 2012: 4).*

Although children who experience disability are known to be one of the largest groups of out-of-school children globally, particularly in the majority world and in situations of displacement, evidence suggests that crises present unique opportunities to develop inclusive education services, even where they did not previously exist.

> *"Groups that are often excluded, such as young children, girls, adolescents, disabled children, refugees and internally displaced persons (IDPs), can benefit from opportunities for education achievement. This can be a dividend of a crisis, resulting in improvements in access to and quality of education" (S2.4: INEE, 2010: 3).*

Sub-theme 4: Systemic change to achieve education for all.

EFA is a vision set out in the Incheon Declaration and Framework for Action (S2.17: UNESCO, 2015a) and bilateral, multi-lateral, and humanitarian organisations almost unanimously subscribe to its recommendations for achieving Agenda 2030 (UNDESA, 2015a). However, there is also a clear understanding that achieving EFA requires a fundamental change in conceptualising, operationalising, and monitoring the success of inclusive education services, particularly in humanitarian contexts. It is not sufficient to only change identification processes and techniques for children who experience disability, decrease negative attitudes and behaviours, or to increase funding and teacher capacity – all must change and be captured within, and driven by, inclusive policy, to achieve transformative inclusive education that is more than the sum of its parts. Crucially, the documents analysed note that communities must also support the concept of EFA for it to be successful.

> *"The barriers to inclusion can be reduced through active collaboration between policy-makers, education personnel and other stakeholders, including the active involvement of members of the local community, such as political and religious leaders, local education officials and the media". (S2.31: UNESCO, 2017: 14).*

In essence, a fundamental paradigm shift is required within the humanitarian education sector (covering emergency and protracted contexts), whereby the right to education for all children is underpinned by the belief that every child can learn and is valued for their unique contributions to society.

> *"The right to inclusive education encompasses a transformation in culture, policy and practice in all formal and informal educational environments to accommodate the differing requirements and identities of individual students, together with a commitment to remove the barriers that impede that possibility". (S2.9, UNGA, 2016: 3).*

The outcomes of a truly inclusive education are envisioned to translate into a world where all children realise their rights to education and protection; are valued and have their dignity respected; and can participate and contribute to the creation of equitable and just societies. This seems to be an almost insurmountable task, leading organisations advocating for improving inclusive education practice to reassure stakeholders of the importance of small steps forward.

> *"Inclusive education is a gradual process of change and improvement, not an over-night solution to all problems." (S2.21: INEE & Global Education Cluster, 2011, slide 15).*

To make the necessary changes to achieve true inclusion for every child, all stakeholders, from individuals to policy makers, must believe that inclusive education is not only a human right, but that it is of profound value to society.

> *"Inclusive education is part of a broader goal of working towards an inclusive society. It is not just about methods and systems, but is about key values and beliefs about the importance of respecting and valuing difference, not discriminating, and collaborating with others to create a more equitable world." (S2.29: Stubbs (Atlas Alliance), 2008: 112).*

Appendix 21: Phase 2 participant demographics

21.1 Demographic data for participants included in phase 2, data set 2: Camp A

CAMP A	**Gender *Identifies as:***			**Age (years)**				**Experience**				**Total number**
	Man	**Woman**	**Other answer***	**18-30**	**31-40**	**41-50**	**50+**	**< 1 year / not stated**	**1-5 years**	**6-10 years**	**10 years +**	
Educators	4	0	0	1	1	2	0	0	1	0	3	**4**
Implementing organisations	0	2	0	0	0	0	2	0	0	1	1	**2**
Carers	1	2	0	0	0	1	2					**3**
Refugee committee	2	1	0	0	2	0	1	0	3	0	0	**3**
Children	0	0	0									**0**
TOTALS	**7**	**6**	**0**	**1**	**2**	**3**	**5**	**0**	**4**	**1**	**4**	**12**

**Transgender, non-binary, intersex, any other gender identification, or prefer not to say.*

21.2 Demographic data for participants included in phase 2, data set 2: Camp B

CAMP B	**Gender** *Identifies as:*			**Age (years)**				**Experience**				**Total number**
	Man	**Woman**	**Other answer***	**18-30**	**31-40**	**41-50**	**50+**	**< 1 year / not stated**	**1-5 years**	**6-10 years**	**10 years +**	
Educators	1	0	0	0	1	1	0	0	1	0	1	**1**
Implementing organisations	0	0	0	0	0	0	0	0	0	0	0	**0**
Carers	0	2	0	2	0	0	0					**2**
Refugee committee	8	0	0	1	2	0	5	0	8	0	0	**8**
Children	0	0	0									**0**
TOTALS	**9**	**2**	**0**	**3**	**3**	**1**	**5**	**0**	**9**	**0**	**1**	**11**

**Transgender, non-binary, intersex, any other gender identification, or prefer not to say.*

21.3 Demographic data for participants included in phase 2, data set 2: Camp C

CAMP C	**Gender** *Identifies as:*			**Age (years)**				**Experience**				**Total number**
	Man	**Woman**	**Other answer ***	**18-30**	**31-40**	**41-50**	**50+**	**< 1 year / not stated**	**1-5 years**	**6-10 years**	**10 years +**	
Educators	1	1	0	2	0	0	0	0	2	0	0	**2**
Implementing organisations	1	1	0	0	2	0	0	1	1	0	0	**2**
Carers	0	2	0	1	1	0	0					**2**
Refugee committee	4	2	0	1	1	1	3	1	1	1	3	**6**
Children	0	0	0									**0**
TOTALS	**6**	**6**	**0**	**4**	**4**	**1**	**3**	**2**	**4**	**1**	**3**	**12**

**Transgender, non-binary, intersex, any other gender identification, or prefer not to say.*

Appendix 22: Phase 2 FGD coding results

22.1: Phase 2, data set 2 joint interview results: Group 1 - Educators

Codes	Basic themes	Organising themes	Global themes
1-Different disabilities	BT-1 Inclusive education is every child's right	OT-1 The disconnect between education rights and reality.	**GT-1 POLICY IS NOT ENOUGH: REALISING THE RIGHT TO COMMUNICATION-ACCESSIBLE EDUCATION, THROUGH FAMILY AND EDUCATOR SUPPORT**
2-Equality			
3-Rights			
4-Inclusive education policy and curriculum			
5-Number of CWD			
6-Teachers support inclusion			
7-Interactive approaches	BT-2 "We do what we can with what we have".		
8-Lesson adjustments			
9-Making own resources			
10-Motivating children			
11-Peer learning and support			
12-multi-sensory approaches			
13-Positive socialisation			
14-Something is better than nothing			
15-Doing special things			
16-We do our best			
17-Progression through education			
18-Severe disability			
19-Accessing support	BT-3 Delivering on inclusive education commitments is challenging		
20-Access to the curriculum			
21-Monitoring progress			

22-Children who experience CD need extra time			
23-Refugee integration in local schools			
24-Challenging environment			
25-Services are insufficient			
26-Social and emotional challenges			
27-Communication challenges			
28-Teacher burnout			
29-Not enough knowledge and skills			
30-Communication strategies	BT-4 Educators need tangible support on communication and inclusion	OT-2 Children who experience CD need holistic support systems to access education.	
31-Assistive devices			
32-Referrals			
33-Specialist devises			
34-Specialist support			
35-Special schools			
36-Need for communication skills training			
37-Need for materials			
38-Need for smaller class size			
39-Encouraging attendance	BT-5 Accepting and supporting children and families		
40-Families need support			
41-Making the child feel accepted			
42-Negative attitudes			
43-Sensitisation for acceptance			
44-Parental appreciation			
45- Social-emotional support			

22.2 Phase 2, data set 2 joint interview results: Group 2 – Implementing organisations (IOs)

Codes	Basic themes	Organising themes	Global themes
Implementing IE policy	BT-6 IOs as advocates for education rights	OT-3 IOs bridge the gap between inclusive education policy and implementation	**GT-2 STRIVING FOR BETTER: CELEBRATING SUCCESSES AND IDENTIFYING CHALLENGES TO EDUCATION RIGHTS REALISATION**
IO collaboration			
IO roles			
Numbers of school age children			
Rights to inclusive education			
Communication support	BT-7 Practical support for policy implementation		
Inclusion strategies			
Supporting educators			
Supporting learners			
Belief in capability	BT-8 Recognising a child's capabilities as a route to acceptance and inclusion		
Children who experience CD need life skills			
The need to be accepted			
Parent sensitisation and support			
Parents are fearful, depressed			
Children have to travel	BT-9 Bottlenecks to achieving communication accessible education	OT-4 Identifying barriers for targeted improvement in IE	
Children who experience disability are difficult to teach			
Facilities are temporary			
Financial limitations			
Lack of knowledge, understanding and			

skills on to support communication access			
Resource shift to emergency response			
Training needs			
Under-resourcing			
Segregation	BT-10 Specialist provisions can help and hinder inclusive practice		
Provision of assistive devices			
Children are assisted if ‘known’			
Supporting older children / young people			

22.3: Phase 2, data set 2 FGD and interview results: Group 3 – Carers

Codes	Basic themes	Organising themes	Global themes
Causes of CD	BT-11 Causes and nature of CD	OT-5 Life is more difficult when experiencing CD	**GT-3 WANTING INCLUSION, SETTLING FOR SEGREGATION**
Family communication strategies			
Other impairments			
Communication challenges	BT-12 CD causes difficulties with everyday life		
Frustrations			
Participation difficulties			
Segregated education may be better	BT-13 School failure	OT-6 Inadequate support fuels desire for segregated education	
Negative experiences in school			
Lack of progression through school			
CD is excluded from disability support services	BT-14 Insufficient services		

Communication support centres on sign-language			
The support that is there is not enough			
Abuse	BT-15 Negative community experiences		
Rejection			
Community misunderstandings			
Community support	BT-16 Communities are becoming more accepting	OT-7 Acceptance and support for inclusive futures	
We need a community centre			
Friendships are developing			
Desire for inclusion for future independence	BT-17 Inclusive education for independent futures		
Families need support for communication with their child			
Children need support to access education			
The desire for community-based inclusive education			
Small successes in school	BT-18 Recognising capabilities and potential		
Participation			

22.4: Phase 2, data set 2 FGD and interview results: Group 3 – RDC

Codes	Basic themes	Organising themes	Global themes
Fear and isolation	BT-19 Discrimination has negative impacts on children's lives	0T-8 Children with CI endure adverse and disabling life experiences	**GT-4 ACHIEVING EDUCATIONAL PARTICIPATION THROUGH STAKEHOLDER CAPACITY BUILDING**
Dropping out of school			
Falling behind / not progressing at school			
Abuse			

Stigma and shame	BT-20 CD is stigmatised and shunned by the community		
Alterity			
Disability is a 'calamity'			
School is not welcoming	BT-21 School life is difficult for children who experience CD		
Starting school late			
Educators don't know (enough) sign language	BT-22 School-based support does not meet communication accessibility needs		
Schools can't support children with CD			
Families see their child 'can do more'	BT-23 IE is challenging assumptions around capability.	OT-9 Inclusive education is improving community inclusion	
Communities see what children are capable of			
Play	BT-24 IE is increasing peer socialisation		
Communicating with peers			
Mobilisation helps get children in to school	BT-26 Changing attitudes and behaviours	OT-10 Change from inside and outside of the classroom	
Sensitisation to increase understanding and reduce stigma			
Assistive devices support learning	BT-27 Tangible and ongoing classroom support		
Early support is foundational			
Educators need guidance and support			
Teachers need LSAs			
Advocates need knowledge and skills	BT-28 Empowering advocates and educators		

Educators need to be empowered to support children			
Increasing community understanding and support			

Appendix 23: Phase 2 classroom observation codes

Codes	Sub-categories	Categories
Children find it difficult to engage	SC-1 Child engagement varies	**C-1 INCLUSION SUCCESS DEPENDS UPON THE BALANCE OF FACILITATORS AND INHIBITORS WITHIN THE CLASSROOM**
Competition for resources		
Children try their best		
Social interaction		
Educators use strategies to engage children		
School feeding programme		
Few, basic resources are used to their maximum potential	SC-2 Knowledge, skills, and resources affect inclusion success	
Understaffing		
Educator understanding of CD		
Teachers create their own basic resources		
Communication strategies		
Children who experience disability are welcomed and present		
Teachers try their best		
Children miss some education	SC-3 Educational environment affects inclusion success	
Physical inaccessibility		
Not enough space		
Large classes		
Poor light and acoustics		
Temporary structures		
Positive aspects of the classroom environment		

Appendix 24: Published work, conferences, awards, blogs, and posters produced during my PhD

24.1 Published work since commencement of study

Barrett, H., Marshall, J., Goldbart, J., & Bussien, N. (2023). Access to Early Childhood Development and Inclusive Education Services for Refugee Children with Communication Disability in Rwanda. In: EDS *The Handbook of Speech-Language Therapy in Sub-Saharan Africa*. New York: Springer.

Barrett, H., & Marshall, J. (2023). Participation, equity, and justice for people who experience communication disability in Rwanda: Achieving Sustainable Development Goal (SDG) 16. *International Journal of Speech Language Pathology.* 25(1): 136-140. Doi: 10.1080/17549507.2022.2140828

Staley, B., Fernandes, M., Hickey, E., **Barrett, H.,** Wylie, K., Marshall, J., Pillay, M., Kathard, H., Sowden, R., Rochus, D., Westby, C., Roman, T., & Hartley, S. (2022). Stitching a new garment: Considering the future of the speech–language therapy profession globally. *South African Journal of Communication Disorders,* 69(1): a932. Doi: 10.4102/sajcd.v69i1.932

Staley, B., Hickey, E., Rule, D., **Barrett, H**., Salter, C., Gibson, R., & Rochus, D. (2021) Speech-language pathology and ethical practice in global contexts. *International Journal of Speech-Language Pathology.* 23:1, 15-25, DOI: 10.1080/17549507.2020.1743358

Barrett, H., Marshall, J & Goldbart, G. (2019). Access to inclusive ECD and education services for refugee children with communication disability in Rwanda. *Forced Migration Review* (March edition). Oxford. https://www.fmreview.org/sites/fmr/files/FMRdownloads/en/education-displacement/FMR60_English_Education_2019_web_0.pdf

Marshall, J., & **Barrett, H.** (2018). Human rights of refugee survivors of sexual and gender-based violence with communication disability. International Journal of Speech-Language Pathology. (Open access) Doi: 10.1080/17549507.2017.1392608

Barrett, H., & Marshall, J. (2018). SLTs in disaster, emergencies and humanitarian response. *RCSLT Bulletin.* February edition.

Barrett, H., & Marshall, J. (2017). *Understanding Sexual and Gender-Based Violence Against Refugees with Communication Disability and Challenges to Accessing Appropriate Support: A Review of the Literature.* Communicability Global & Manchester Metropolitan University. Available online at: https://www.elrha.org/wp-content/uploads/2017/03/sgbv-literature-review-2.pdf Accessed 7.6.2023.

Marshall, J., **Barrett, H.,** & Ebengo, A. (2017). Vulnerability of refugees with communication disability to SGBV: Evidence from Rwanda. Forced Migration Review. (June): 74-76. http://www.fmreview.org/sites/fmr/files/FMRdownloads/en/shelter.pdf

Barrett, H. (2016). Applying theories of cultural competence to speech-language pathology practice in East Africa. *Journal of Clinical Practice in Speech-Language Pathology.* 18(3): 139-144.

Barrett, H., Turatsinze, F., & Marshall, J. (2016). Strategic Thinking Achieves Change. *RCSLT Bulletin.* July edition.

24.3 Publications about work I have been involved in since commencement of study

UNHCR. (2021). *Improving Communication Accessibility for Refugees with Communication Disabilities through Capacity Building - a Case Study from Rwanda.* Geneva, UNHCR. Available online at: Improving communication accessibility for refugees with communication disabilities through capacity building - a case study from Rwanda | UNHCR

24.3 Conference oral presentations

Barrett, H., Marshall, J., Goldbart, J., Karangwa, E., & Jayes, M. (2023). *Using Interpretive Description to Understand the Educational Access Needs of Refugee-children who Experience Communication Disability, in Rwanda.* Aukland, IALP. (August).

Barrett, H., Marshall, J., Goldbart, J., Karangwa, E., & Hughes, E. (2022). *Understanding the Educational Access Needs of Refugee-Children who Experience Communication Disability, in Rwanda: A Collaborative Mixed Method Study.* Manchester, Manchester Metropolitan University Postgraduate Researcher Conference.

Barrett, H., Marshall, J., Goldbart, J., Karangwa, E., & Hughes, E. (2021). *Understanding the Educational Access Needs of Refugee-Children who Experience Communication Disability (CD) in Rwanda - a Mixed-Method Study.* Online, SPA.

Barrett H., Marshall, J., Goldbart, J., Karangwa, E., & Hughes, E. (2021). *Using Interpretive Description to Understand the Educational Access Needs of Refugee-children who Experience Communication Disability, in Rwanda.* Manchester, Manchester Metropolitan University Communication Disability and Participation Research seminar Series. (May).

Marshall, J., Anwar, S., Muragijemariya, G., Mukagatare, C., & **Barrett, H.** (2021). *Meeting the Needs of Refugees who Experience Communication Disabilities in Rwanda - Learning from Three Collaborative Projects.* Online, RCSLT (October).

Kathard, H., Abrahams, K., Marshall, J., Stemela, U., Mallick, R., Selemani, C., Wylie, K., Harty, M., **Barrett, H.,** & Pillay, M. (2019). *Drivers of Educational change: Perspectives from Africa.* Taipei, IALP. (August).

Barrett, H. (2019). *The Challenges Faced by Families of Children Living with Complex Disabilities in Rural Rwanda.* Geneva, UNICEF Universal Child Grants Conference.

Barrett, H., Marshall, J., Goldbart, J., Hughes, A., & Karangwa, E. (2018). *Collaborating with Humanitarian Agencies to Improve Service Access for Refugees with Communication Disability, in Rwanda.* Kisumu, East African Conference on Communication Disability (July).

Marshall, J., **Barrett, H.** (2017). *Understanding Sexual and Gender-Based Violence (SGBV) against Refugees with a Communication disability, in Rwanda*. Glasgow, RCSLT (September).

Marshall, J., & **Barrett, H.** (2017). *Understanding Sexual and Gender-Based Violence Against Refugees with Communication Disability, in Rwanda*. Manchester, Manchester Metropolitan University Communication Disability and Participation Research seminar Series. (June).

Barrett, H. (2016). *"Umva": Challenges to Developing Cultural Competence for External SLTs in East Africa.* Dublin, IALP. (August).

Barrett, H. (2016). *Access to Early Childhood Development (ECD) and Inclusive Education (IE) Services for Refugee Children with Communication Disability in Rwanda.* Johannesburg, SASLHA. (October).

24.3 Conference poster presentations

Barrett, H., Marshall, J., & Goldbart, J. (2022). *Understanding the educational access and support needs of children who experience communication disability, in*

Rwanda's refugee communities: An interpretive description. Online, Professionals and Researchers in Early Childhood Intervention Inaugural Conference.

Barrett, H., Marshall, J., Goldbart, J., Karangwa, E., & Hughes, A. (2021). *Understanding the Educational Access and Support Needs of Children who Experience Communication Disability (CD).* Online, 4th International Developmental Pediatrics Association Conference (December).

Marshall, J., **Barrett, H.,** Mukagatare, C., & Muragijemariya, G. (2021). *Increasing Communication Access and Inclusion in Refugee Communities in Rwanda.* Online, SPA.

Barrett, H., Marshall, J., Goldbart, J., Karangwa, E., & Hughes, A. (2019). *Access to Inclusive Early Childhood Development (ECD) and Education Services for Refugee Children with Communication Disability in Rwanda*. Manchester, Manchester Metropolitan University Postgraduate Researcher Showcase.

Barrett, H., Marshall, J., Goldbart, J., Karangwa, E., & Hughes, A. (2019). *Access to Inclusive Early Childhood Development (ECD) and Education Services for Refugee Children with Communication Disability in Rwanda.* Brisbane, SPA.

24.4 Awards

Images of Research – 1st prize (Postgraduate researcher category – judges' choice) (2022). *'Invisible'.* Manchester Metropolitan University. Available online at: https://www.mmu.ac.uk/research/research-study/events/images#:~:text=This%20year%E2%80%99s%20winners%20were%3A%201%20Judges%E2%80%99%20Choice%20%28PGR%29%3A,Setterington%2C%20%E2%80%9CSafety%20Net%E2%80%9D%2C%20Faculty%20of%20Arts%20and%20Humanities Accessed 6.7.2023.

Research Student of the Year (2017). Manchester Metropolitan University Faculty Research in High Summer Conference.

24.5 Professional blogs

Barrett, H. (2021). *Language Matters: Why we Need to Rethink Disability Terminology.* Helen Barrett Inclusion. Available online at: https://www.helenbarrettinclusion.com/post/language-matters-why-we-need-to-reimagine-disability-terminology Accessed 6.7.2.23.

Barrett, H. (2019). *"They Sleep like Goats and No-one Cares": The Role of Social Protection in Promoting Dignity for People who Experience Disability.* Development Pathways. Available online at: https://www.developmentpathways.co.uk/blog/they-sleep-like-goats-and-no-one-cares-the-role-of-social-protection-in-promoting-dignity-for-people-who-experience-disability/ Accessed 6.7.2023.

Barrett, H., Marshall, J., Olifirovych, O., & Anwar, S. (2018). *Prevention is Better than a Cure.* Elrha. Available online at: https://www.elrha.org/project-blog/prevention-is-better-than-a-cure/ Accessed 6.7.2.23.

Barrett, H., Marshall, J., & Anwar, S. (2018). *The Voices of Experience.* Elrha. Available online at: https://www.elrha.org/project-blog/the-voices-of-experience/ Accessed 6.7.2023.

Barrett, H., Marshall, J., & Anwar, S. (2018). *A Call to Action.* Elrha. Available online at: https://www.elrha.org/project-blog/a-call-to-action/ Accessed 6.7.2023.