AN INVESTIGATION INTO THE PERCEPTIONS OF "OUTSIDER" CONTRIBUTIONS TO SUSTAINABLE SERVICES FOR PEOPLE WITH COMMUNICATION DISABILITIES, IN MAJORITY WORLD COUNTRIES.

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__Abstract__

Background Services for people with communication disability (PWCD) are extremely limited in Majority World countries. Speech and language therapists (SLTs) provide many services for PWCD, but in Majority World countries the number of SLTs is small. Outsider (foreign) SLTs have been involved in providing services for PWCD in Majority World countries. Little is known about insiders' (country nationals) and outsiders' preferences for outsider-involvement; whether outsider involvement in the development of services follows a common trajectory; or what best practice for outsiders in developing sustainable services for PWCD in the Majority World should be.

The aim of this study was to investigate the processes and perceptions of collaboration between insiders and outsiders, in developing services for PWCD in Majority World countries, with a particular emphasis on the contribution and roles of outsiders.

Methods A two-phase, exploratory, mixed-method study used ethnographic and survey case study approaches. In phase one, interviews, document analysis, and participant observation were carried out in Uganda. Phase two formed a pilot study using a written survey with participants from five Majority World countries. Data were analysed using content analysis, Thematic Network Analysis and descriptive statistics.

Results Ten thematic networks and three categories were generated from the two phases. Exploration of these resulted in 18 findings, which were integrated and synthesised to produce seven *key statements.* These key statements related to topics of power, roles, exchange, culture and development approaches.

Discussion and Conclusions This study has added to the knowledge base by revealing insiders' and outsiders' perceptions of challenges of their power, roles and cultural appropriateness; their need for fair exchanges of contributions; and the need for plans, flexibility and overall commitment to ensuring sustainability. The key statements showed insider preferences for outsider contributions and

provide valuable guidance for outsider involvement at different stages of collaboration.

Contents

List of tables and figures

Tables

Figures

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1   Introduction

1.1   Overview

This chapter introduces the study in three sections. 1.2 provides the background to the research, describing its purpose and importance and discussing important terminology. 1.3 states the aims and objectives. 1.4 describes the thesis structure and provides a brief summary of each chapter.

1.2   Description of the study

This study investigates key stakeholders' perceptions of outsider contributions to sustainable services for people with communication disabilities in Majority World countries. Communication disabilities (CDs) and swallowing disorders occur when a person's ability to communicate is affected by an impairment or by social and contextual elements (Hartley, 1998). The term people with communication disability (PWCD) describes the group affected by these problems. Speech and language therapy (SLT) is a specialist clinical service that provides specialist rehabilitation to PWCD (Wylie et al., 2016). Many Minority World countries have developed SLT as a way of meeting the needs of PWCD.

In Majority World countries, an estimated 225 million people have CDs or swallowing disorders (Rupert et al., 2015). Despite this, Majority World services for PWCD remain scarce. For over 30 years, stakeholders in Majority World countries have approached (or been approached by) Minority World organisations or individuals for assistance in supporting services for people with communication disabilities (Hartley and Wirz, 2002). This support has traditionally consisted of outsider agencies, often charities, posting outsider professionals to Majority World countries, typically for short periods of time. In many Majority World countries, this outsider intervention has historically been the only formal SLT service available to PWCD locally.

More recently, this outsider-based model of services has faced criticism from postcolonial theorists and SLT reformers alike. Such criticism interrogated the 'deep paternalism' of Minority World countries, with some outsider SLTs

questioning the fundamental compatibility of 'European' SLT methods in countries where 'service and education structures' were fundamentally 'different' from Minority World expectations (Robinson et al., 2003:322). Further criticism focused on the scale and sustainability of outsider-based service models.

In response to this criticism, there has been an observable recent trend towards a new model of outsider/insider interaction in a number of Majority World countries: a model which aims to build new country-specific and self-sustaining services for PWCD in Majority World countries through the sharing of skills and knowledge between insider and outsider groups. Services for PWCD in Uganda formed the context and setting to an initial phase of in-depth qualitative research. Uganda was selected as a setting for the initial phase of research based on access to a project, led by the researcher's Director of Studies, that provided mentoring and continuing professional development (CPD) to a group of newly qualified Ugandan SLTs. A second phase of research formed a pilot study exploring the applicability of the phase one findings in five other Majority World countries.

1.2.1 Purpose of the research

The purpose of the research was to address the research gap focusing on how (and how effectively) outsiders have contributed to services for PWCD in Majority World countries. The research gap regarding insider and outsider collaboration in developing services for PWCD in the Majority World is particularly problematic as such collaborations are becoming increasingly common, while very little knowledge of their challenges and successes exists or is being shared. There is a need to establish and share knowledge in this area, with the aim of finding best practice for outsiders.

The researcher's motivation to investigate outsiders' contributions to sustainable services for PWCD came from her personal and professional experiences. Her experience of being a carer to family members with communication disability motivated her to understand communication disability and ultimately train as an SLT, whilst retaining a holistic consideration of PWCDs' and carers' priorities. The specific focus on outsiders' contributions to sustainable services for PWCD came initially from the researcher's

undergraduate research project, in which she explored attitudes to communication disabilities in Jamaica. This first study was motivated by a family connection. Whilst researching, the low provision of SLTs and the challenges in expanding the service size became increasingly apparent. The researcher became curious as to the best ways of developing services where there are limited numbers of SLTs, and whether SLTs were the most appropriate people to meet service demand. Following her qualification as a SLT in 2012, the researcher became interested in ways of starting and developing sustainable services for PWCD in Majority World countries, particularly the questions of (a) whether such developments need to occur as part of a specific developmental sequence in a country's progression and (b) how outsiders can most effectively and most ethically contribute to such services.

1.2.2 A note on terminology

The terms *Majority World* and *Minority World* are used to describe a country's development-stage and geopolitical position. Coined by Bangladeshi social activist Shahidul Alam, these terms aim to reflect a world in which nations containing the majority of global population have the least access to the world's power and wealth (Stone, 1999). Crucially, this terminology does not assign a hierarchy, set system of development, or intrinsic value to either group. Though recognising a key problem with this terminology — its relatively recent coinage means it is not as familiar or rigorously-defined as pre-existing terms such as "Third" and "First world" or "Developing" and "Developed countries" — the researcher chose to use these terms precisely because they are not encumbered with the problematic connotations of the pre-existing terms but *are* still able to carry some of the meanings and definitions the older terms conveyed.

Key examples of rejected but relevant terminology are discussed below.

<u>First, Second or Third World Countries</u>

The terminology of First, Second and Third World Countries arose during the Cold War as a means to refer to countries by political affiliation. First World Countries referred to capitalist countries aligned to the American ideals of democratic free enterprise. Second World Countries referred to socialist

countries aligned to the Soviet ideals of economic communism. Third World Countries referred to countries that were not aligned to either, often seen as ideological battlegrounds in the struggle between capitalist and communist economic practice. Following the Cold War, the term Third World became associated with economically poor countries, often in a pejorative sense. The terminology has drawn particular criticism as its number-based system implies a hierarchy (with third being inferior to first). Following the disbanding of the Soviet Union, and the ensuing redundancy of Second World as an informative political label, there is a strong argument that the term Third World is both insulting and meaningless (Hurrell, 2013).

Global North and Global South

The terminology of Global North and Global South countries came to prominence in the late 20th century as an alternative to the hierarchical language of First, Second and Third Worlds. Unfortunately, this terminology carries the duel flaws of inaccuracy (as most practical definitions place Southern-situated countries such as Australia, Japan and South Korea in the Global North) and lack of clarity (in terms of what, aside from geography, qualifies a country for inclusion in each category).

Developed Countries and Developing Countries

This is the preferred terminology of the United Nations Development Programme (UNDP). The UNDP has clear classifications of countries and provides an annual rank of their development, classifying countries as Low, Medium, High or Very High according to its ranking system: the Human Development Index (HDI). The UNDP ranks development through measures such as the longevity, education and income of a country (Nielson, 2011). Despite these measures, the United Nations Development Programme (2009:21) itself notes that the classification of developed and developing countries is 'somewhat arbitrary.' Furthermore, there is an implied paternalism and superiority in the act of labelling one set of countries and cultures as "developed" (implying an end point of economic, political and social progress) and assuming that the progress of other countries and cultures must, or should, follow this model.

High Income and Low and Middle Income Country

This is the preferred terminology of the World Bank. The World Bank define four categories, Low-Income economies, Lower-Middle-Income economies, Upper-Middle-Income economies, and High-Income economies (The World Bank, 2018). This system, however, is only a measure of economic prosperity and does not divide countries into two clear groups.

OECD countries and non-OECD countries / rest of the world

This terminology denotes membership or non-membership of the Organisation for Economic Co-operation and Development (OECD). The OECD developed from the Organisation for European Economic Cooperation (which was established in 1948 to reconstruct European countries ruined from war (OECD, 2018)). The OECD has 35 member countries from Europe, North and South America, and Asia while the majority of the world's poorest countries are non-members. Though a useful indicator of relative global wealth and power, this terminology has the inherent problem of defining large groups of countries in terms of what they are not (as opposed to what they actually are). As such, it lacks rigour and clarity while simultaneously maintaining a Euro-centric worldview.

Defining the Researcher's Choice

In an effort to use terminology with both political sensitivity *and* meaningful definition, the researcher elected to use the terms Majority and Minority World, linking these to the existing classifications of economic development provided by the United Nations Development Programme. For this research, the researcher decided to use the term Majority World country to refer to a country that has their HDI distributed in the lower three quartiles (Low, Medium, and High HDI rankings), and use the term Minority World country to refer to a country that has their HDI distributed in the upper quartile (a Very High HDI ranking).

The following terms were coined. *Insider* refers to native (or locally trained) individuals or institutions operating in a particular country. *Outsider* refers to non-native individuals or institutions operating in a particular country.

Other terminology was considered. In place of insider, the words native, aboriginal, indigenous, autochthonous and local were considered; and for outsider, the words alien, foreign, expat, migrant/immigrant were considered. Many of these words were felt to have negative connotations, whilst some were felt to be unfamiliar and unclear. *Insider* and *outsider* were chosen as they were considered to have less emotive connotations, whilst being general enough to be readily understood by people.

The terms *insider* and *outsider* have occasionally been challenged during the Ugandan phase of this research (by both insiders and outsiders). Challengers usually raise one of two key criticisms: firstly, that the terms are not specific enough to fit a particular country's nationality; secondly, that the concepts themselves fail to convey the internal complexity and heterogeneity of each group. Although the terms have been open to change and exploration throughout the research process, a short response to each criticism seems appropriate here.

In response to the first criticism: the reason outsider and insider (as opposed to, say Ugandan and Non-Ugandan) have been selected for this research terminology is because the terms need to be robust and non-specific enough to hold-firm beyond the first phase of research, that is to say: they need to be applicable to systems of SLT outside a particular country and have an international use. They need to exist as generic terminology for the phenomena being looked at in both phases of research.

In response to the second criticism: the concepts of outsider and insider do *not* necessarily need to elucidate the diversity within each group. The terms only need to elucidate the *distinction between* the groups. In a world where so many Majority World country healthcare services are delivered (at least in part) by Minority World charities or interest groups, this distinction is crucial.

1.2.3 Anticipated challenges in conducting the research

A number of research challenges were anticipated. Firstly, based on the researcher's prior experience, limited availability of both general information about local services and published research was anticipated. To counter this,

the researcher had to consider specific search strategies for findings and accessing literature, and the use of grey literature throughout the study. This will be described in more detail in chapter 2.1.

Secondly, issues of practicality needed to be considered as part of undertaking research overseas. Due to resource constraints, it was not possible to collect data in person across all countries selected for the research. A survey was therefore developed to collect data for phase two. It was anticipated that it would be necessary to consider the accessibility of technology across different countries, particularly low bandwidth and limited computer access in certain locations. This will be described in more detail in chapter 5.3.

Finally, the close relationship of the Director of Studies to a CPD and mentoring project in Uganda and to the researcher's research was considered. The ethical considerations of this challenge and strategies used will be discussed in 3.3.

1.3   Aim and objectives

The research question asked: how have outsiders been involved in developing services for PWCD, and what were insiders' and outsiders' perceptions of their contributions?

This had one aim with five objectives.

Research aim:

To investigate the processes and perceptions of collaboration between insiders and outsiders in developing services for PWCD in Majority World countries, with a particular emphasis on the contribution and roles of 'outsiders.'

Objectives:

1. To explore and describe the process and history of the development of services for PWCD in Uganda.
2. To describe and explain insiders' perceptions and experiences of the contributions of outsiders and outsider support, to the development of services for PWCD in Uganda.
3. To describe and explain outsiders' perceptions and experiences of their contribution to the development of services for PWCD in Uganda.

4. To analyse and interpret insider/outsider collaboration and working practices.
5. To interpret and explain perceptions of outsider contributions in five Majority World countries.

1.4   Thesis structure

The thesis is presented across seven chapters. The study used a two-phase mixed method research design which, for clarity, the thesis structure follows.

Chapter one provides a background to the research, describes its purpose and importance, and discusses terminology. It states the aims and objectives, describes the thesis structure, and provides a brief summary of each chapter.

Chapter two provides the background and literature review. The background contextualises the study which allows for the literature review to draw on key historical and philosophical discussion. The literature review focuses on health and disability, health service development and services for PWCD in Majority World countries.

Chapter three details the methodology guiding the study. It outlines the methodological considerations and philosophy that underpin the study. It describes the methods chosen and justifies their selection in relation to the research objectives, the ethical considerations and approval processes.

Chapter four provides the first phase of research, an ethnographic case study in Uganda. The chapter presents the background, methods and procedures, results and discussion.

Chapter five provides the second phase of research, a pilot study using a survey case study approach. It presents the background, methods and procedures, results and discussion.

Chapter six synthesises the findings of both phase one and two to produce overall key statements, which are then discussed in relation to the literature.

Chapter seven concludes the key statements of the study. It discusses the limitations and provides a summary of the study.

1.5   Chapter summary

This chapter has provided an overview of the study, detailing both its purpose and importance. It has provided a definition of novel terminology used throughout the thesis, coined by the researcher, namely the terms *insider* and *outsider*. It has explained the aims and objectives of the study, and described the structure of the thesis as a mixed method, two phase study.

2   Background and literature review

2.1   Overview

This chapter comprises a background and literature review. The background information provides contextualising information to the area of study, drawing on key historical and philosophical discussion. The literature review critiques the literature concerning health and disability, health service development, and services for people with communication disabilities in Majority World countries, with a particular focus on the legacy of colonialism and the impact of individuals and agencies from Minority World countries on health services.

There is a lack of specific research looking at outsider contributions to services for PWCD in Majority World countries. As such, a decision was made to review literature from a range of sources. Both published and unpublished findings were considered for inclusion. This was to allow for the inclusion of articles in contexts where producing and publishing research may be more challenging. Therefore as well as primary and secondary literature, grey literature (such as theses, reports and publications with limited distribution, conference proceedings and government documents) was also included. This was hoped to reduce publication bias, whilst retaining a high standard of document quality for the review. Other forms of grey literature and tertiary documents were included for the specific country backgrounds in chapters 4 and 5, and for the document analysis. It must however, be acknowledged that the quality of the literature, particularly the research literature, may be variable, as not all of the studies reported had been through the peer review process.

It was anticipated that there would be low numbers of publications exploring all three main elements of the research nature and content: services for people with communication disability, Majority World countries, and outsider contributions. A decision was therefore made to include research from broader areas, including services for people with disability, findings in Minority World countries (for loose application/comparison to Majority World countries), and articles not focused on outsider support.

The overall structure of this chapter is as follows. 2.2 provides a historical overview of colonialism and its impact on today's Majority World countries (this is needed to contextualise the history of outsiders in Majority World countries). 2.3 examines and critiques five prominent development theories in relation to health service development. 2.4 focuses specifically on health services, reviewing health service history and development in Majority World countries. 2.5 focuses on disability in Majority World countries and in particular services for people with communication disability, concluding with an overview of outsider involvement in these services. 2.6 looks at communication disability, focusing on Majority World countries. 2.7 describes outsider contributions to healthcare services, specifically services for PWCD. 2.8 summarises and focuses these disparate areas of theory and history, exploring their relevance in Majority World countries today and their applicability to the study.

2.2   Historical overview of colonisation

When exploring or discussing healthcare systems and development in Majority World countries, especially in the context of these countries' relationships with Minority World countries, it is necessary to consider the influence and legacy of the colonial era: an era which began these countries' uneven relationship and continues to inform it to this day. Colonialism refers to the period of European expansion (between the early 16th and mid-20th centuries) in which European countries made concerted efforts to rule, and exploit the resources of, overseas territories (Lester, 2006).

The busiest period of colonial activity occurred in the final decades of the 19th century (Gorman, 2008). Intense competition between colonising powers in this period created what has come to be known as 'the scramble for Africa' (Gorman, 2008:83): a period which saw (among many other colonial acquisitions) the colonisation of Eritrea by the Italians, the Congo by the Belgians, Egypt by the British, and large swathes of West and Equatorial Africa by the French. It was during this period that the full economic potential of Africa's many natural resources (rubber, diamonds and other minerals) became apparent to European leaders; Belgium's King Leopold famously declared his wish to possess 'a piece of this magnificent African cake' (Shale, 2008:74) and took private ownership of the Congo free state. In November 1884, at the height

of this "scramble," German chancellor Otto von Bismarck hosted the Berlin Conference: a meeting of European powers which sought to prevent inter-European conflict by establishing agreed-upon spheres of influence in Africa, essentially dividing as-yet-unclaimed African territories between the European states (Gorman, 2008). Though the central locus of late 19th century colonialism was Africa, European expansion continued across the world, from British India to French Indochina. Lange et al. (2006) described four main forms of colonisation —categorised and summarised below.

Settler colonialism (in countries such as Australia and the USA) directly transplanted the coloniser's population, political system and culture into the colonised territory without regard for existing culture and social structures.

Direct colonialism (in countries such as Singapore and Jamaica) imposed governmental control over a colonised population without settling large numbers of the coloniser's population. This was common in colonies whose economic relationship to the colonising country was based on trade or plantation slavery.

Indirect colonialism (in countries such as Uganda and Kenya) allowed existing leaders and social structures to remain while extracting taxes and resources from the colonised countries.

Hybrid colonialism combined either indirect and direct approaches (as occurred in India, which was deemed too large to be controlled entirely through direct colonialism) or indirect and settler approaches (as occurred in South Africa, which saw limited European settlement alongside indirect colonial government).

2.2.1 British colonialism

Though colonisation was widespread among Western European powers, this study specifically focused on the British colonial project and the countries studied were all former British colonies.

At the start of the 20th century, Britain had become the dominant colonial power in Europe. By 1914, The British Empire occupied a quarter of the globe and encompassed 369 million subjects, more people than the entire population of

China at the time (Constantine, 1999). France, by way of contrast, boasted only 93 million colonial subjects and Germany 84 million (Constantine, 1999). Britain itself had a population of 16 million at the time (Hyam, 2010), one 20th of its global citizenry.

The British Empire was not a single, uniform entity ruled from London and driven by one unifying political imperative. Instead, Britain's colonialism varied so widely from colony to colony that it has been described as 'a loose aggregation of diffuse elements ... complex, endlessly uneven in its impact ... its name was diversity' (Hyam, 2010:21). In the main, the territories controlled by Britain were smaller (at least in population terms) than Britain itself: British Swaziland had a population of 2 million in 1914 (Hyam, 2010) and British Uganda: 3 million (Colonial Office, 1916). These small population sizes were optimum for direct and indirect forms of British Colonialism as they enabled long-distance colonial control through a relatively small colony-based civil service (Hyam, 2010). British India, in contrast, had a population in 1900 of 294 million people and a language-base of 179 main languages with almost 600 distinct dialects (Hyam, 2010).

According to Osterhammel (2010), the relationship between colonised societies and their European colonisers had three defining features. Firstly, the colonised society would have its natural development and culture disrupted (often halted) by the colonising power (Osterhammel, 2010). Secondly, the colonising power would seek to superimpose its own — significantly distinct — European cultural ideals and values onto the pre-existing culture (Osterhammel, 2010). Thirdly, this process would be viewed (at first by the colonising power, and later by many of those colonised) as a necessary element of a greater moral mission: a mission (both divine and secular) to replace pre-existing religion and 'civilise' native societies (Osterhammel, 2010:16).

2.2.2 The end of the colonial era

From 1900 to 1960, the European colonial project collapsed dramatically. The defeat of the axis powers at the end of WW2 saw both the punitive severing of both Germany and Japan's colonial empires — an act which demonstrated to the world the possibility of effective de-colonialisation — and the burgeoning of

independence movements within the colonies (Sheppard et al., 2009). The changing political landscape of the cold war era from the 1950s onward further benefitted these colonial independence movements in two key ways. Firstly: this new landscape forced European powers to focus their military and political resources on combating the perceived Soviet threat, and in the case of Britain, diverting these resources from on-going anti-independence military action in India, Malaysia and Kenya (Sheppard et al., 2009). Secondly: the promotion of world-wide free trade and political sovereignty now became a key policy in confronting the socialism of the USSR and its allies. By supporting independence-movements in the colonies, European powers could simultaneously spread an ideology of economic freedom and protect their former subjects from Soviet influence and agitation (Sheppard et al., 2009). In just over ten years, the number of colonies fell from 134 in 1950 to 58 in 1961 (Sheppard et al., 2009). At present, the United Nations' (2017) list of Non-Self-Governing Nations includes only 17 countries: all but one of which are settlement colonies with a population smaller than 50,000.

2.2.3 Imperialism, neocolonialism and postcolonial theory

Postcolonial theory refers to thought and discourse which seeks to analyse the continued legacy and impact of the colonial project following political independence (McLeod, 2013). Though the colonial project, in terms of direct rule and physical occupation of land, was effectively over by the end of the 20th century, postcolonial thinkers argue that the economic, cultural and infrastructural imbalances of the era still remain (Sheppard et al., 2009). The term "imperialism" (traditionally employed in reference to the direct occupation of other nations by European powers) was first used by Frantz Fanon, a key postcolonial thinker of the 1950s, to describe the continued economic and cultural domination of former colonial powers over former colonised nations (Cain and Harrison, 2001). For postcolonial theorists, the political independence gained by former colonies in the 20th century has not been matched by economic freedom. From this perspective, former colonies (operating in a global system established by, and designed to favour, former colonial powers) still run economies based on the production of primary commodities (such as cocoa and coffee) sold at prices determined by the richer, Minority World nations (Sheppard et al., 2009).

In 1961, delegates of the All-African People's Conference drafted the 1961 'Resolution On Neocolonialism' (Ghosh, 2016), introducing the term "neocolonialism" as 'the survival of the colonial system in spite of formal recognition of political independence in emerging countries which become the victims of an indirect and subtle form of domination by political, economic, social, military or technical means' (reprinted in Wallerstein, 1961:266).

2.3   Development Theories

The term "development" is used to 'describe, compare and manage processes of socio-economic change' in countries across the world (Breuer, 2015:online). Development theories offer explanations and interpretations of (a) what economic progress means in the context of developing societies, and (b) how such change can best be achieved. Each of the following theories (Modernisation Theory, Dependency Theory, World Systems Theory and Postdevelopment Theory) specifically consider the notion, and nature, of "development" in Majority World countries in relation to Minority World countries. While all development theories attempt to explain and interpret the process of economic development across societies, some (such as Modernisation Theory) seek also to provide a framework for successful development, while others (such as Dependency Theory) offer a critique of the power relationship between Minority World countries and Majority World countries. Though development theories are primarily socioeconomic theories, all have implications for healthcare services (discussed below). As this study is concerned with sustainable services and service development, the theories may help in understanding patterns of development.

2.3.1 Modernisation Theory

Modernisation Theory is a model of social and economic development which stems from three central propositions. One: that there exists a linear scale of societal development. Two: that this scale leads towards a capitalist model of progress. Three: that all countries sit somewhere on this scale. Modernisation Theory is an evolutionary theory of development: it posits a universal one-way model of progress (Friedmann and Wayne, 1977). Originally writing in 1960, Rostow (1991) defined the basic stages of development as:

1. <u>Traditional Society</u> can be identified by a pre-scientific worldview and low-level technological development; a clan-based social hierarchy with little social mobility; and an economy based almost entirely on agriculture. Traditional Societies are limited in terms of economic productivity. Such societies suffered from aspirational 'fatalism': no one expected to live a more productive, more comfortable, or more opulent life than their grandparents (Rostow, 1991:5).

2. <u>Preconditions for Take-Off</u> can be identified by the embrace of a scientific worldview and the translation of this worldview into technological-driven agriculture and industry. These Preconditions are explicitly tied to a capitalist agenda: requiring a move away from collectivism and (in its place) the emergence of individuals who take risks in pursuit of increased productivity or profit. These Preconditions can also be effected through external influence — through the 'invasions' of more developed societies (Rostow, 1991:6). Such invasions can be either active (as in the case of colonialism) or passive (as in the case of pervasive Western culture and its conflict with traditional values). As the adoption of a scientific worldview contrasts with the viewpoints of a Traditional Society, political turmoil and reactionary attitudes will be encountered and overcome at this stage.

3. <u>Take-Off</u> is the critical stage in the development of societies: the period in which tradition and resistance give way to modernizing forces. This is the point at which growth, rather than stagnation, becomes the economic paradigm of society. The Take-Off stage is always industrial in nature, exemplified by the British and Japanese industrial revolutions and the railway booms of Russia and Canada in the 19th century. There is an emphasis on the role of the private sector and an emerging entrepreneurial class.

4. <u>Drive to Maturity</u> reflects the post-industrial-revolution development of Western Europe. This is characterised by the broadening of a country's economy to include not just the heavy industries (coal, steel, railway engineering, etc.) but also chemical engineering and electrical manufacturing. A society Driving to Maturity strikes a balance between imports and exports, producing 'not everything, but anything that it chooses to produce' (Rostow, 1991:9). Crucially, countries Driving to Maturity may choose to trade or import

certain goods rather than pursue complete industrial autonomy, but — for these countries — such a decision will be an economic choice, not a necessity born of technological limitation.

5. Age of High Mass Consumption occurs when the income of an average citizen rises significantly above the essential cost of living. Essentially it is an age of disposable incomes. Here, economic activity is no longer merely essential to human survival, but a driver of leisure and choice. It is only during the Age of High Mass Consumption that a successful 'welfare state' can emerge, as a society will now have reached a level of economic stability sufficient to support such a system (Rostow, 1991:10).

A note on development beyond Stage Five

For Modernisation theorists, the Age of High Mass Consumption does not represent the absolute pinnacle of societal development. When Rostow was writing his Stages of Economic Growth at the start of the 1960s, mass consumption was an exciting new phase of economic development into which the societies he considered most developed were beginning to emerge (Rostow, 1991). Though Rostow examined and categorised the differences between what he considered the most developed societies (America, Europe and Japan) and least developed societies (including most of Sub-Saharan Africa), he posited that all societies — through the adoption of a capitalist, technocratic worldview — could reach an Age of High Mass Consumption.

Critiques of Modernisation Theory

In the 60 years since its conception, Modernisation Theory has been widely criticised. Each of its three central propositions (that there exists a linear scale of societal development; that this scale leads towards a capitalist model of progress; that all countries sit somewhere on this scale) have been questioned by postcolonial theorists and several competing theories (examined in detail below) have aimed to replace Modernisation Theory in relevance and prominence. Postcolonial theorist Walter Rodney took particular issue with the role of Minority World countries in the development of Majority World countries — as highlighted in Rostow's second stage of development (see above) —

seeing the role of Minority World countries as deliberately exploitative rather than benign and supportive (Rodney, 1972)

In criticising Modernisation Theory, however, one should be careful not to oversimplify Rostow's work which, through close reading, reveals itself as more nuanced and flexible than a quick summary of his five stages may suggest. Even when taking a linear and universal scale of development for granted, Rostow in a small way anticipates Dependency Theory (see 2.3.2) by acknowledging the tension and conflict engendered by 'modern economic activities, conducted for limited economic purposes by a colonial or quasi-colonial power' within an otherwise traditional society (Rostow, 1991:12). Modernisation Theory is an idealised model of benevolent capitalism: looking at the development path taken by Minority World countries and using this to project a similar path of development for Majority World countries. It is not an analysis of how Majority World countries and Minority World countries interact in practice.

2.3.2 Dependency Theory

In contrast to the capitalist optimism of Modernisation Theory, Dependency Theory posits that the postcolonial relationship between Minority World and Majority World countries is fundamentally rigged to prevent the development of Majority World countries and continue the economic exploitation of former colonial countries (James, 1997).

Dependency Theory operates on the twin convictions that (1) Majority World countries have been continually and actively exploited by Minority World powers, and (2) Minority World countries perpetuate — consciously or otherwise — this state of dependence. According to Dependency Theory, this state of continual dependence of Majority World countries is perpetuated through the activities of a number of Minority World agencies including 'multinational corporations, international commodity markets [and] foreign assistance' (Ferraro, 2008:60). From the perspective of Dependency Theory, charity given by Minority World countries to Majority World countries is not charity, but rather a form of 'reparation for injuries done in the past and continuing into the present' (Hartwick, 2009:94). Although charity may help treat

the symptoms of colonial exploitation, Dependency Theory maintains that only 'revolutionary transformation to a new global order' can effectively eradicate global inequality (Ferraro, 2008:60).

Although it did not rise to prominence (or get its name) until the mid-1960s, Dependency Theory stems from the work of two influential economists Raul Prebisch and Hans Singer both writing in the early 1950s, the dawn of the postcolonial era. Making specific reference to Latin America, they argued that, instead of strengthening their economies relative to Minority World countries, 'the opening of less [economically] developed countries to trade and investment has tended to inhibit their growth' (Ghosh, 2001:84). This interpretation (known as the Prebisch-Singer thesis) states that trade between the Minority and Majority World will always be economically weighted to favour the Minority World. This is because Majority World countries typically trade raw materials (commodities) or simple manufactured goods, whereas Minority World countries typically trade more complex manufactured goods (cars, technology, etc.). As the global economy grows, the relative value of Majority World country commodities are forced down by Minority World-controlled market forces. Due to these diminished commodity values, Minority World countries are able to purchase larger amounts of the same commodities without increasing their expenditure. This, in turn, exacerbates the economic gulf between the countries leading to ever-diminishing values for Majority World producers (Toye and Toye, 2003).

As Modernisation Theory (with its vision of exponential growth for all nations) gained traction in the 1960s and 70s, Dependency Theory drew on the work of Prebisch and Singer and combined it with the radical Marxism of South American theorists Fernando Cardoso and Enzo Faletto (Larrain, 1989). These Latin American writers expounded the idea that the postcolonial relationship between the Minority and Majority World was a continuation, as opposed to a break from, old colonial power-relations. The aim of the former colonial powers, Cardoso and Enzo argue, is not to improve the economic position of the Majority World country, but for the former colonial power to continue to exploit the Majority World country for economic gains (James, 1997).

One of the main exponents of Dependency Theory in the 1970s was the Guyanese scholar and activist Walter Rodney. Rodney politicised the term "underdevelopment," using it as active verb synonymous with "exploit." Minority World countries had, according to Rodney, wilfully "underdeveloped" less powerful societies through a process which was a 'capitalist, imperialist, colonialist exploitation … depriving the societies of the benefit of their natural resources and labour' (Rodney, 1972:14).

Rodney (1972) does not direct all his criticism at Minority World intervention, he also criticises African infrastructure, health and social care provisions and bureaucracy. However these are described as consequences of underdevelopment, as much as causes (Rodney, 1972).

Critiques of Dependency Theory

Critics of Dependency Theory point to a number of potential weaknesses in the dependency argument. Chief among these is the tendency of development theorists to focus on external factors (e.g., the role of Minority World countries in the developmental challenges faced by Majority World countries) rather than focusing on in-country problems and factors (Kiely, 1996). O'Brien (1975) points to lack of a clarity in the processes through which dependency theorists claimed Majority World countries were exploited. Caricaturing a central tautology in this idea of dependency, O'Brien (1975:24) stated that 'dependent countries [according to Dependency Theory] are those which lack the capacity for autonomous growth and they lack this because their structures are dependent ones.' Lall (1975) developed this line of criticism by arguing dependency theorists can not produce a definitive list of factors affecting "dependent" economies but not affecting Minority World countries. Furthermore, many critics of Dependency Theory point to the potential Marxist bias of many dependency theorists, challenging the idea (posited by Dependency Theory) that a capitalist system will inherently lead to the exploitation of Majority World countries by richer and more powerful former-colonial powers (Cubitt, 2014). In light of these criticisms, many contemporary development theorists view Dependency Theory as a flawed-but-useful model of understanding, choosing to 'move on from a dependency position, rather than totally discarding these ideas' (Cubitt, 2014:41).

Though Modernisation and Dependency theories dominated early development theory, several alternative models have risen in prominence in recent years: building on the foundations of Development Theory.

2.3.3 World Systems Theory

Acting as a bridge between the two dominant theories of development, World Systems Theory is an evolution of Dependency Theory, based on the work of the American sociologist Immanuel Wallerstein. Whereas Modernisation Theory emphasised a natural process of development within each society, World Systems Theory picks up from Dependency Theory and argues that (due to globalisation and the postcolonial interdependency of the world economy) the entire concept of unique societies (developing in parallel with each other) is no longer applicable to the world. Instead, World Systems theorists postulate that the entire, globalised world is most accurately regarded as one giant economic society: a single World System which is hierarchically arranged to protect the interests and wealth of former colonial powers (Peet and Hartwick, 2015).

Within this single economy, World Systems Theorists identify three main zones of economic activity. These are:

1. Zone One: The Core comprises countries which have accumulated vast amounts of capital. These states have complex and efficient systems of administration and international military might (Peet and Hartwick, 2015).

2. Zone Two: The Semiperiphery comprises countries with slightly smaller amounts of accumulated capital, deferential to Core countries in terms of economic and military might but more powerful on a global level than Peripheral countries (Peet and Hartwick, 2015). According to World Systems Theory, the existence of a semiperiphery is essential in creating the instability and political complexity necessary to prevent the Periphery from uniting against the inferior (in population terms) Core countries (Wallerstein, 1974, cited in Babones, 2012).

3. Zone Three: The Periphery comprises countries with low levels of wealth and underdeveloped infrastructure. In a non-globalised world, these states may well

be able to develop along the lines outlined by Rostow's (1991) Development Theory. But, because the Core continuously drains resources from Peripheral nations, these nations are unable to generate the surplus wealth needed to launch a programme of modernisation (Peet and Hartwick, 2015).

Tracing a very different history of modernisation to that provided by Modernisation Theory, World Systems Theory examines the rise of global capitalism from its 16th century European origins to the consolidation of power in (initially) Minority World countries and (latterly) multinational corporations (Peet and Hartwick, 2015).

Taking in the global scale of the interconnected Zones, World Systems Theory provides a history of global economic development which has (in the past hundred years) become weighted to benefit the Core at the expense of the Periphery. Only by understanding and overthrowing this fundamental imbalance of power (and the historical conditions which led to its creation) can Peripheral countries begin to develop equally (Peet and Hartwick, 2015).

A Critique of World Systems Theory

As with Dependency Theory, critics of World Systems Theory tend to target its Marxist leanings and economic assumptions. World Systems Theory does answer some of the key criticisms of Dependency Theory (see above) by fleshing-out the details of economic exploitation and nuancing the argument through the inclusion of the Semiperiphery level. Critics, however, argue that World Systems Theory still arrives at its conclusion through an implicit Marxist bias, providing no alternative strategy for improving the development of Majority World countries beyond the unlikely collapse of the global capitalist system (Pieterse, 1988).

2.3.4 Postdevelopment Theory

Postdevelopment Theory is a radical offshoot of Dependency Theory which, controversially, defines the idea of "development" as a racist and neo-imperialist ideology. For Postdevelopment Theorists the attempts made by richer countries to "develop" Majority World countries are 'at best … failed, or at worst … a hoax

designed to cover up violent damage being done to the so-called "developing world" and its people' (Thomas, 2000:3, cited in Ziai, 2007:4).

The seeds of Postdevelopment Theory were sown in the 1980s publications of the Columbian anthropologist Arturo Escobar and the Mexican writer Gustavo Esteva (Ziai, 2007:4) but the theory came to prominence with the publication of Wolfgang Sachs' "Development Dictionary: a Guide to Knowledge as Power." Essentially a Postdevelopment manifesto, Sachs (2010:xv) opens with a statement of intent:

> The idea of development stands like a ruin in the intellectual landscape. Delusion and disappointment, failures and crimes, have been the steady companions of development and they tell a common story: it did not work.

For Postdevelopment theorists, the very ideas which underpin both Modernisation Theory and the less radical interpretations of Dependency Theory (the importance of developing an industrial economy, the need to reproduce Western institutions as a gold standard of societal progress) are fundamentally racist, harmful, cultural imperialist exports which simultaneously assume the superiority of Western institutions and devalue the culture and lives of those living in Majority World countries (Ziai, 2007).

Even the term "underdevelopment" — explored in so much detail by less radical Dependency Theorists – was deemed irrelevant by the Postdevelopment theorists, who singled out the first use of the term (in President Truman's inaugural address as he set out his plan for US aid for "developing countries") as the single moment in which 'two billion people became underdeveloped … ceased being what they were, in all their diversity, and were transmogrified into an inverted mirror of other's reality: a mirror which belittles them and sends them to the back of the queue' (Esteva 1992:7, cited in Ziai, 2007:4).

A Critique of Postdevelopment Theory

For all its anger and righteousness against the development and modernisation programmes imposed on Majority World countries, several critics have accused

Postdevelopment Theory of the very racism it claims to stand against. Maiava and King (2007) claimed that — while criticism of external interference is often valid — postdevelopment theorists fail to recognise that development programmes can be internally initiated by individuals or organisations within Majority World countries. Relatedly, Postdevelopment Theory also fails to differentiate between effective, sustainable development and ineffective, unsustainable development. While it may well be true that some supposed development has a minimal (or even harmful effect) on Majority World countries, Postdevelopment Theory regards all development as harmful and suspicious (Maiava and King, 2007).

2.3.5 Implications of Development Theories for Health Services in Majority World countries

Although development theories are primarily concerned with economic development, the potential implications of each model on the development of healthcare services in Majority World countries are significant.

Modernisation Theory suggests that the process of industrialisation benefits all areas of society including welfare and healthcare (Rostow, 1991). If correct, this theory has implications for healthcare workers in Majority World countries. While Development Theory suggests that all countries will (eventually) achieve healthcare systems to match those of the Minority World, it also suggests that such levels of developed healthcare will remain unachievable until Majority World countries reach accompanying levels of financial and industrial development. Rostow provided a loose timeframe for the 5 stages of development: at least fifty years to complete the transition. It is only in the final stage of this process that Rostow claimed a welfare state could emerge and be successfully supported by a country's economy and infrastructure (Rostow, 1991). Applying these stages to the world of today, many Majority World countries appear to be in what Rostow (1991) would consider the initial stages of development: the "Traditional Society" or the "Preconditions for Take-Off." Sub-Saharan Africa, for example, is the least urbanised area of the world (Njoh, 2003).

While it is true that, in Majority World countries, more urbanised and industrialised areas have lower mortality rates and higher healthcare standards (Njoh, 2000), these disparities, may be better explained in terms of a country's colonial history (the uneven infrastructure and healthcare systems established by Europeans; the continued underdevelopment of the Majority World by richer countries; the geographical challenges of many Majority World countries; and the passing of colonial power to in-country elites) than as a fulfilment of Rostow's development theory (Njoh, 2000).

While Rostow's Modernisation Theory (1991) posits far-reaching benefits of industrial development (with urbanisation and expansion leading to better healthcare and welfare), rapid development and urbanisation projects in sub-Saharan Africa (and the ensuing housing and employment issues these developments created) have sometimes been seen to have the opposite effect: overstraining and reducing healthcare services (Njoh, 2000). In further contradiction of this aspect of Modernisation Theory, Frey and Field (2000) found an increase in industrialisation had no influence on rates of infant mortality.

Dependency Theory

The concept of intentional or malicious underdevelopment (the idea that the Minority World wilfully exploits and drains resources from the Majority World) has been applied more specifically to the relationship between Minority and Majority World countries in the delivery of healthcare. It can be argued that a practical, measurable form of "underdevelopment" — as described in Dependency Theory — can be observed in the way Minority World countries attract and "drain" skilled workers from Majority World countries to boost their own economies while weakening those of Majority World countries (also known as the "brain drain" effect). Literature on the effects of brain drain from the Majority World highlights a number of "push" and "pull" factors that serve as motivations for such emigration. "Push" factors include a lack of professional development opportunities and work pressures such as high caseloads. "Pull" factors include improved living conditions, improved working conditions, increased opportunities for career advancement and professional development (Kirigia et al., 2006).

Unfortunately, for the Majority World, there is an apparently cyclical nature to this "brain drain" effect (comparable to the Prebisch-Singer thesis described above), in which increased emigration levels worsen conditions for remaining professionals (contributing to increased caseloads and lessening the return of any training investment the country has made) in turn driving further emigration (Korte et al., 2003 cited in Stilwell et al., 2004:598)).

A number of writers suggest it may be unethical to actively recruit healthcare workers from the Majority World. As Kirigia et al. (2006:89) state, if the 'poaching of scarce human resources for health' continues, 'the chances of achieving the Millennium Development Goals would remain bleak.' If true, this statement has universal implications, particularly when considering how reliant some countries' are on health care support from foreign-born workers. This arrangement — though beneficial to the Minority World — contributes to underdevelopment because the cost of training is usually financed by the Majority World country (whether the undergraduate course is subsidised or if the students pay their fees directly). Even below the level of specialist training, a Majority World country would have invested in a person's general primary and secondary education, while Minority World countries reap the economic benefit (Raghuram, 2009). The work of Raghuram (2009) and Kirigia et al. (2006) does not, however, consider the continuing contribution of Majority World-born healthcare workers, who may still contribute to their native economies (e.g., by sending money back home to their families).

To combat the negative consequences of brain drain, writers such as Rizvi, (2006:181) outline a number of strategies Majority World countries can undertake to retain their educated professionals, such as guaranteed jobs on their return (if studying abroad), and 'bilateral and multilateral arrangements under which developed countries pledge not to recruit skilled people from the developing states,' or ensuring a period of commitment to working in a home country before a person can emigrate. The Commonwealth Code of Practice for the International Recruitment of Health Workers was ratified by the UK government in 2003 (Commonwealth Secretariat, 2003) to alleviate the unfair poaching of human healthcare resources by ensuring foreign-born health

professionals have contributed economically to their native countries before entering the Minority World country (Raghuram, 2009). The majority of Minority World countries have not, however, ratified this code (Raghuram, 2009).

2.4   Health and health services

Health is a complex and elusive concept (Brüssow, 2013; Brülde, 2000). One of the best-known definitions was published in the World Health Organisation's (WHO) 1948 constitution, first presented in 1946, defining health as 'a state of complete physical, mental and social well-being and not merely the absence of disease or infirmity' (World Health Organisation, 1946). This definition has drawn widespread criticism. The majority of criticism stems from the use of the word "complete" regarding the different areas of well-being, the changing health demographics of populations, and the use of the term "disease" (Huber et al., 2011). People with disease or disability may consider themselves healthy in spite of this definition (Bircher and Kuruvilla, 2014).

Although a number of alternative definitions or models of health have been posited against the WHO's definition, Callahan (1973:77) describes such attempts as a game of 'king of the hill, where the aim of all players is to upset the… WHO definition of "health."' Despite this, a number of alternative definitions or models of health have been suggested, with Frenk and Gómez-Dantés (2014) justifying the need for constant and continuous redefinition because of the complexities of health. One such model is the Meikirch Model of Health, developed by Bircher and Kuruvilla (2014). This model suggests a need to consider health as a balance between the demands of life, against individual potentials which are both biological and personally acquired. This model also explores this in the wider context of the environment and society.

The WHO (2018) defines health services as:

> all services dealing with the diagnosis and treatment of disease, or the promotion, maintenance and restoration of health. They include personal and non-personal health services. Health services are the most visible functions of any health system. Service provision refers to the way inputs such as money, staff, equipment and drugs are combined to allow the

delivery of health interventions. Improving coverage and quality of services depends on key resources being available; and how services are organized and managed. Equity in health outcome is the ultimate aim.

Health services are part of health systems, which are all the organisations and individuals involved where their primary focus is the promotion, restoration or maintenance of health (WHO, 2007).

2.4.1 Health services history in Majority World countries

The first types of health services were traditional medicines, provided by local healers. In many Majority World countries, local traditional medicine was practised before and as the first Europeans were entering and settling in countries. The first European health services in Majority World countries were typically introduced before and during the period of colonialisation by Christian Missionaries, with some of the earliest missionary hospitals dating from the early 1500s (Good, 1991). Missionaries in the 18th and 19th centuries often believed illness to be caused by exposure to local religions and culture (Mohr, 2009), and hospitals and clinics were built as a way of building connections with the local population in order to evangelise. During the 19th century, missionaries discouraged the local population from using traditional healers, which prevented them from accessing local medicine and diminished their cultural identity and self-esteem (Etherington,1987). As with missionaries blaming illness on the local culture, in 1883 Ghanaian traditional priests blamed an outbreak of whooping cough on a rejection of local beliefs (Mohr, 2009). Malowany (2000) argued that, in ignoring local knowledge and expertise, these missionary outsiders attempted to control the spread of disease only to make it worse.

East Africa (now present day Uganda and Kenya) under the Imperial British East African Company received their first medical staff in 1889, to look after the company (Beck, 1970). Under the Foreign Office, the numbers of medical staff increased at a slow rate due to a lack of physical infrastructure, low numbers of staff and reported poor skill of human resources (Beck, 1970). Interestingly at this time, many of the medical staff throughout British colonial Africa were from

India (Schräm, 1971), with around 200 Indian doctors in Kenya (Greenwood and Topiwala, 2015). The recruitment and use of Indian doctors was a practical choice, as they could be paid less than their British counterparts, and were cheaper than training African doctors (Greenwood and Topiwala, 2015; Schräm, 1971). However, the Indian authorities were reluctant to send their best medics, and instead sent those considered less effective practitioners (Beck, 1970).

Following the first medical training programmes in Sub-Saharan Africa under colonial rule, the number of medical schools increased most in the post-independence period (1960-1979) and the 1990s, with few new schools being developed in the 1980s (Mullan et al., 2011). A further difficulty with the development of health services followed Idi Amin's expulsion of Asians. This led to the loss of many doctors (Patel, 1972). Interestingly, in 2017, following a mass protest of government-employed doctors, the Kenyan government again took to advertising for the recruitment of Indian and Cuban doctors to plug the shortfall in care, and replace Kenyan doctors (Benjamin, 2017).

Specific health services or professions have developed at different rates. Health services in Majority World countries have generally begun with medical physicians and nurses as the first healthcare professionals. The missionaries began many of the first European-style hospitals and clinics, which still account for a high proportion of health services in Africa (Good, 1991). The development of other health care professions began before independence, in particular, the nursing profession expanded with university training programmes. In Egypt, higher education in nursing began in 1955 (Frenk et al., 2010). Where countries had not developed or had few nursing training courses, they offered alternative ways for the training of their population. In the 1950s, the Rhodesian government offered bursaries to encourage Rhodesians to train as nurses in South Africa for them to return after training (Masakure, 2012).

Following on from the roles of doctors and nurses, rehabilitative services generally emerged in the latter half of the 20th century in Majority World countries. Within Minority World countries, allied health professionals (AHPs), such as physiotherapists, occupational therapists and speech and language therapists are the most recently-developed professions and were not formally

developed (with dedicated and accredited training and education programmes) until the 1900s. Before this time, these professions were practised by unaccredited enthusiasts: some medically trained, others not (Paterson, 2008; Nicholls and Creek, 2006; Leahy and Supple, 2002). As these professions did not develop in Minority World countries at the same time or same rate, many of the first practicing AHPs trained abroad in other Minority World countries. This includes the first British occupational therapist, who trained in the USA while on holiday before returning to practise in Scotland (Paterson, 2008).

In Majority World countries, AHP services have been established more recently and in different ways. Physiotherapy in Majority World countries has often been developed following war, as evidenced in Cambodia (Dunleavy, 2007) and Afghanistan (Wickford et al., 2008), in response to the increased need of rehabilitation services. However, as much as war appears to have increased the necessity of services for people with disabilities (PWD) in some countries, instability has also impeded service development. The profession of physiotherapy began in Afghanistan in 1984 (Wickford et al., 2008), with a diploma training course that ran intermittently. However, this programme was suspended under the Taliban (Armstrong and Ager, 2006).

Allied health professions (AHP) services in Majority World countries have developed in a range of ways with small (often unrelated) pockets of services being developed in tandem (or in competition) by different groups in single Majority World countries with varying degrees of liaison and collaboration. Some AHP services are provided by outsiders (used to refer to non-native individuals or institutions operating in a particular country). Other AHP services have been established by insiders (used to refer to native individuals or institutions operating in a particular country) training overseas and returning to establish services and perhaps later, professional bodies, and/or education programmes. Some examples include SLT and audiology in South Africa in 1938 following the return of Professor Pierre de Villiers Pienaar from studying in Germany (Swanepoel, 2006); and occupational therapy in Uganda in the 1970s following Ugandan occupational therapists having completed training overseas, returning to practise in Uganda and establishing a training scheme in the early 1990s (Wilson, 1994).

How a profession develops, in terms of the types of personnel or training level, varies. Kay et al. (1994) focused on the profession of physiotherapy in East Africa, suggesting that the training of physiotherapy assistants, or other roles in physiotherapy below the qualification of BSc, had caused a number of challenges. This contributed to low pay, low status and hindered the growth of the profession. The authors also felt that degree level training would better equip practitioners for independent or isolated practice, which is a likelihood for many AHPs in Majority World countries, whilst also allowing for the appropriate training of CBR workers.

2.4.2 Structure of health services in Majority World countries

Health services can be categorised in terms of how they are funded. The main ways that healthcare is financed internationally (focusing mainly on public and private healthcare), and health system reforms and health policy internationally are outlined below.

Public healthcare

Public, or statutory, healthcare services are healthcare services provided by a country's government. Public healthcare can differ in the amount of services offered. It may provide limited specific or all health services. Public healthcare can be financed in different ways. In the UK, public healthcare is provided by the government and funded by taxation. In Germany, the majority of the population are covered by statutory healthcare, with health insurance being compulsory. Although public funding should allow healthcare to be more accessible to the population, some people in Majority World countries may choose to avoid public healthcare because of informal fees or perceptions of low quality (O'Donnell, 2007).

Universal Health Coverage (UHC) describes a system of publicly-funded or publicly-subsidised healthcare made available to an entire population (WHO, 2013). The UN included UHC as an aim of its Sustainable Development Goals (Pablos-Mendezet al., 2016). At present: 50% of health funding in low-income countries, and 30% of health funding in middle-income countries comes from 'out of pocket' payments, (Mills, 2014:553). This way of funding healthcare is

more likely to contribute to poverty, especially where illness is sudden or unexpected. Instead, Reeves et al. (2015) found that progressive taxation in Majority World countries is an important way of supporting UHC.

Private healthcare

Private healthcare is typically defined as healthcare provided by organisations other than governments where there is a direct cost to the service user. Private healthcare may be paid for directly by the user for the services they have received at the point of use, or via a persons' health insurance scheme if they have it. Private healthcare is used most often for outpatient services, which accounts for the majority of health spending in Majority World countries (Hanson and Berman, 1998).

Although Sekhri and Savedoff (2005) argue that private healthcare can be a successful way of serving those who are able to afford it (while relying on available public healthcare for those unable to afford it), there are a number of challenges related to private healthcare in Majority World countries. Zwi et al. (2001) found despite the high use of private healthcare in Majority World countries, it is often of varying quality, and is associated with inequality in both access and treatment.

Voluntary and informal healthcare

Healthcare services can also be provided for no fee by not-for profit enterprises. There is no agreed definition for informal healthcare services. However Sudhinaraset et al. (2013) completed a systematic review and used the criteria of informal healthcare providers as people who have no formal training (but may have informal training), were not regulated and collected payment directly from their clients. Informal healthcare workers undertake a wide range of roles, including traditional healing. Traditional medicine is also researched at several institutions in East Africa, with the profession registered in Tanzania (Msuya, 2016). The informal health care sector makes up a significant proportion of all healthcare services, particularly in Majority World countries, and is generally accessed more by the poor (Sudhinaraset et al., 2013).

There are many different ways countries can organise their health systems. The different ways of financing healthcare are not mutually exclusive, with many countries using a combination of the above approaches. UHC describes all people being able to receive the health services they need without incurring financial challenges from paying (Kieny and Evans, 2013). Although Minority World countries have higher levels of UHC than Majority World countries, Mills (2014) describes the complexity of comparing health systems across different settings: suggesting that successful services in one national context may not be practically or financially replicable in another.

Healthcare services in Majority World countries have not only had the challenge of less funding, but a greater burden of disease — which subsequently slowed countries' economic outputs as well as increasing the death rates and poor health rates among the population (Malowany, 2000). Furthermore, Majority World health services have developed at different rates, and have been shaped both by internal politics and outsider influence.

2.4.3   Health system structure and development

In terms of international health policy on health systems in Majority World countries, one of the most ambitious (and most contentious) projects to attempt to set and achieve a programme of international development was the Millennium Development Goals (MDG) project: a project developed by the United Nations (UN). There is disagreement about how the goals were first formulated. Tran (2012) and Kumar et al. (2016) describe the goals as developed quickly by a small group of mainly Minority World country members. However, McArthur (2014) disputes this. Regardless, the MDG commitment was accepted by all member states of the UN and each (at varying levels) committed to achieving the goals. It was the explicit aim of the MDG project that, through international co-operation, all goals would be achieved by the year 2015. Although the individual goals focused on many different areas of development, and comprised eight goals in total, no less than three of these goals (highlighted in bold below) focused *directly* on health service development. The eight goals where:

1. Eradicate extreme poverty and hunger
2. Achieve universal primary education
3. Promote gender equality and empower women
4. **Reduce child mortality**
5. **Improve maternal health**
6. **Combat HIV and AIDS, malaria and other diseases**
7. Ensure environmental sustainability
8. Develop a global partnership for development

Although some progress was made in meeting the project's health service objectives, none of the MDG were achieved universally. Progress in achieving goals, and the abilities of countries to complete goals, was uneven. Fundamentally, gross inequalities remained in poverty levels (disproportionately affecting Majority World countries more than Minority World countries, and thus placing a greater burden on these countries to meet goals) as well as internal inequalities between urban and rural areas, genders, and various ethnicities within individual countries (Kumar et al., 2016). Despite the fact that none of the MDG covered disability or services for people with communication disability (PWCD) directly, there are a number of factors within the goals that may impact on the incidence and prevalence of communication disabilities (CD) worldwide. For example, complications from diseases such as malaria may result in secondary CDs. From a more nuanced perspective, reduced child mortality rates could potentially increase the number of children being born with disabilities in general and CDs in particular — an effect which could increase the pressure on services for PWCD globally.

Throughout the MDG programme, there was concern over sub-Saharan Africa's ability to meet the health goals (Haines and Cassels, 2004). Easterly (2009) argued that the health-specific MDG were inherently flawed: setting arbitrary measures of success then condemning any shortfall as a failure (even if it contained significant progress). Furthermore, as the health-specific MDG were measured by averages, they ignored internal inequality (Haines and Cassels, 2004).

Following 2015, and the less-than-successful completion of the MDG project, the UN developed sustainable development goals (SDGs) to achieve progress across 17 main areas consisting of 169 targets. These aimed to improve lives, services and infrastructure across the world. The SDGs were developed from the MDG project (specifically where goals were not being sufficiently met) and augmented with the inclusion of new goals such as reducing deaths from road traffic accidents (WHO, 2015). One of these new goals (SDG 3: 'Ensure healthy lives and promote well-being for all at all ages') is of particular interest as it broadly relates to health service development. Despite an increased number of sub targets compared to the health-related MDGs, none are related directly to PWD or PWCD. Instead the targets focus on many similar areas to the MDG project such as reducing child and maternal mortality rates, and reducing disease such as HIV and AIDS, tuberculosis, malaria and tropical diseases. Both high, middle and low income countries are included in working towards SDGs (Kumar et al., 2016).

Most critiques of the SDGs note that a large number of the goals and targets are not quantified (Kumar et al., 2016), while others are explored in only vague detail. As an example: the SDG project's plan for dealing with infectious disease (including HIV/AIDS) contains no specific goals at all, merely a description of the problem. This is in stark contrast to the MDGs: which explicitly aimed to reverse the spread of the disease. It may be that, through this lack of detail, the authors and contributors of the SDG project aimed to avoid the potential embarrassment of missed targets that plagued the MDG project. It remains to be seen, however, whether this lack of explicit pressure to perform will lead to a laissez-faire approach to meeting goals.

2.5   Models of disability

Disability is understood and conceptualised in many different ways; there is no single universal definition (Officer and Groce, 2009; Grech, 2009). Although definitions of disability are controversial (Filmer, 2005), a number of organisations have put forward their own definitions. Among the most influential of these is the International Classification of Functioning, Disability and Health (ICF) by the WHO (2011:4), who defined disability as 'an umbrella term for impairments, activity limitations, and participation restrictions.' It refers to the

negative interactions experienced by people with health conditions with both personal and physical or societal factors (WHO, 2011). This definition from the WHO and the classification instruments developed have evolved over time (Bickenbach et al., 1999).

However, definitions of disability have been and are understood in different ways culturally. Perceptions and attitudes of disability can be influenced by many facets of a person's culture, including their age, and whether they live in urban or rural areas. Although definitions and conceptualisations of disability can be considered a 'western endeavour' (Grech, 2009:772), a western concept of disability will be used as a baseline to allow for a consistent understanding of the history of disability models. This section will focus on how disability has been understood within Minority World countries and briefly compare this with perceptions of disability in Majority World countries. This will better allow for discussion of disability (specifically communication disability) in Majority World countries, in relation to colonialism and theories of development in 2.6.

Disability has been historically, and culturally, understood in different ways. Within the field of disability studies, there are many different models of disability. Four main models of disability will be discussed. The oldest model of disability is the moral model (Kaplan, 2000). Moral models of disability are often rooted in religious interpretation. As such, different cultures may have different moral understandings of disability. Some moral models understand disability to be caused by an external actor or force to the person with disabilities, often because of sins or transgressions committed either by the person themselves, a family member, or a community member. As such, disability in some cultures is highly stigmatised by association of wrongdoing, and may lead to the persecution, mistreatment or exclusion of PWD from society. Within this context, treatment of disability would often be linked to the redemption of a PWD, with cures including prayer. Moral models of disability may stem from a particular culture, or be transported from one culture to another (as was the case with the early European missionaries described in 2.4.1). The understanding of disability in this way may have negative connotations. However, some cultures understand disability to be caused by an external force in a more positive way.

Here, disability may be viewed as resulting from a blessing, a gift, or a challenge for a PWD to overcome (Devlieger, 2005).

The medical model of disability developed alongside increased presence of modern medicine (Kaplan, 2000). The medical model of disability understands disability as resulting directly from an individual's body, and positions the person with a disability as someone to be treated or "fixed," by a doctor or medical professional (Llewellyn and Hogan, 2000). Criticism of the medical model stems from the placement of disability or problem with an individual with an impairment, and the potential of the person with disability to be stigmatised.

The social model of disability emerged as a counterpoint to the medical model. The social model of disability has its roots in the Union of the Physically Impaired Against Segregation, an organisation based on radical leftist principles (Shakespeare, 2006). The social model of disability views disability as a result of physical or environmental, social or attitudinal barriers experienced by a person. As these barriers are established or maintained by wider society, it is society that disables individuals, not physical or mental impairments (Hughes, 2010). Although many writers focus on the differences between the medical and social models of disability, many believe them not to be mutually exclusive. The social model acknowledges the use of appropriate medical intervention whilst calling for social change and equality (Hughes, 2010). However, Anastasiou and Kauffman (2013) argued that removal of the societal barriers alone would not remove disability. Indeed, one of the main weaknesses of the social model is that, for many people, the impairments have impacts on their lives, alongside disabling barriers from society.

The human rights model of disability comes from Convention on the Rights of Persons with Disabilities (UN General Assembly, 2007). This is a modern human rights treaty which views disability as socially constructed, created from the interaction between impairment and societal barriers (Degener, 2016; Kayess and French, 2008). Although there are some similarities with the social model, it differs in several main ways according to Degener (2016). These will be summarised below. The human rights model recognises the human dignity of PWD rather than describing what disability is; addresses human rights more

comprehensively; demands for PWD to be considered in theories of social justice; can include other aspects of disability politics; and offers solutions for change.

Aspects from the models may interact and intersect in different times, places or contextual situations (Devlieger, 2005). As disability is complex, writers such as Shakespeare (2006) have called for a new model of disability taking into account the dimensions of socio-political and medical: synthesising the existing approaches into a more holistic perspective.

Despite an improvement of human rights, PWD still represent the largest group of marginalised people in the world (Mercer and MacDonald, 2007). Regardless of how it is defined, PWD are more likely to experience poverty, as poverty can be a cause and effect of disability (Gathiram 2014). There appears to be a cycle of PWD experiencing less access to education and attainment, and therefore poverty (Filmer, 2008). Because of this, PWD represent a greater proportion of the population in Majority World countries. They are also less likely to receive protection, for example, in the form of human rights policies. Despite this, disability is a development issue that is often overlooked (Officer and Groce, 2009; Mitra et al., 2013).

2.5.1 Disability statistics

There is a lack of data about disability on an international level (Mitra and Sambamoorthi, 2014), with the available information mainly focusing on the prevalence of disability differing between Minority World countries and Majority World countries. Within Minority World countries there is generally greater availability of data on the prevalence of disability, with such information available both from clinical research as well as national censuses.

The WHO and World Bank (2011) calculated the international prevalence of disability to be 15.6%. This equates to over 1 billion people. Although disability prevalence calculations can vary, Mitra and Sambamoorthi (2014) calculated the percentage of PWD across a range of low, middle and high income countries and found it to be 14%.

Focusing on disability data from Majority World countries, Filmer (2008) conducted an analysis of surveys on disabilities across fourteen Majority World countries and found the prevalence of disability to be between one and two percent of the general population. Interestingly, even when different definitions of disabilities were used in different surveys in the same country (or when similar or the same definitions of disabilities are used) this does not necessarily produce different or similar results respectively (Filmer, 2008). Conversely, Mitra et al. (2011) analysed disability and poverty data across fifteen Majority World countries from the WHO survey and found the disability prevalence rate to vary substantially, with measures of 3% from Lao People's Democratic Republic to 16% in Bangladesh.

2.6 Communication disability and services for PWCD

People with communication disability (PWCD) are the population which is the focus of this study. Communication disability (CD) occurs when a person's ability to communicate is affected by an impairment or social and contextual elements which interrelate (Hartley 1998). CD can be primary (when a person's disabilities are specific to their speech and language difficulties) or secondary (when a person's disabilities coexist with, or is caused by, another condition: such as cerebral palsy, autism or stroke).

Services for PWCD refer to the specific rehabilitative services that PWCD access, or can access, in order to support their CD. This does not include general services that people without CD also use. As such, speech and language therapy (SLT) is a specific service for PWCD that is unique to their communication needs. SLT typically exists in both health and education systems (Law et al., 2002; American Speech-Language-Hearing Association, 2001) however this study will mainly focus on the development of the service within the health system of countries as SLT within education services typically develop later (Lindsay, et al., 2002).

SLT is a clinical service that provides specialist rehabilitation to PWCD for communication and swallowing disabilities (Wylie et al., 2016). Globally, the profession of SLT ranges in scope, having different titles, education and qualification levels. In the UK and Ireland, SLTs are currently trained to at least

undergraduate degree level in order to practise, with training courses at sixteen different institutions. As of 2017, there were nearly 17,000 SLTs registered by the Health and Care Profession Council (HCPC, 2017). In the US, the rehabilitative professionals who work with PWCD are called Speech and Language Pathologists and require either an undergraduate or Master's degree to practise the profession (Battle, 2006).

2.6.1 History of services for PWCD

In Minority World countries, some of the first services for PWCD were created for specific groups, such as deaf people or people with learning disabilities. Within the UK, the profession of SLT was preceded by people working in other roles including elocutionists and teachers of the deaf (Rockey, 1979), and as such, services for PWCD were often split between healthcare and education services (with both still playing a role in the support of PWCD). Such related disciplines, and others including medicine and phonetics gave the speech therapists of the time credibility (Duchan, 2012). The main focus of need at this time being on children who stammered (Robertson 1995). By the mid 1920s, there were two places in London that provided training in specific speech therapy methods (Duchan, 2012; Leahy and Supple, 2002). Two separate professional organisations representing speech therapists formed in the 1930s, conglomerating into CST in 1945, then RCSLT in 1948 (Stansfield and Armstrong, 2016; Robertson, 1995). Entry into the profession was by way of Diploma of Licentiateship, before the first university degree programme was accredited by RCSLT, with the whole profession gaining graduate entry in 1985 (Robertson, 1995).

SLT perhaps faces greater challenges in the development of services in Majority World countries compared to other AHPs because of its language-specific nature. Unlike the professions of occupational therapy and physiotherapy (whose general principles are not specific to one language) shared development of the SLT profession between countries is complicated by the necessity to develop language-specific assessments and interventions. In Majority World countries, the profession of SLT has developed in different ways, typically through one of the following routes (or a combination of both): outsider (foreign) SLTs being the first professionals in country; insider (native) individuals

train abroad and return to practise in-country. These second approach is described below, with outsider approaches detailed in section 5.5.

Individuals may make a personal decision to go abroad to train as an SLT. Before training courses have been established in a country this may be the only way to become an SLT. Training abroad may be undertaken to initially become an SLT, however where training programmes exist up to an undergraduate level, an SLT may choose further postgraduate study to develop their skills. People may also be encouraged to train abroad where there is sponsorship for them to attend a training programme then return to their country to practise, as seen from Brunei, Zimbabwe and Singapore (Marshall et al., 2001). Often there are links or partnerships between universities which serve to increase health professionals (Domsch, 2012).

Marshall et al. (2001) suggested that this way of learning may not be appropriate to the own cultural context of such trainees and, as such, insiders training abroad would potentially choose to either stay in their country of education or (if they returned home) not be able to practise in the public health sector of their home country due to the differences in context. Conversely, Molrine and Drayton (2013) found that (excepting practice involving some specific client populations such as people with craniofacial disorders) all of the Trinidad and Tobago SLTs (who had all received education abroad) felt that their eduction had been appropriate, or at least adaptable, to a Trinidad and Tobagonian context. There are models of education developed to help international students have chances to do well (Chang, 1992) however, where insiders have been trained by outsiders, they still have to consider how they can make practice most appropriate (Pickering and McAllister, 2000).

2.6.2 Communication disability service structure

Services in Minority World countries are structured in different ways in order to try to meet the needs of PWCD. SLT is one service for PWCD, which is more commonplace in Minority World countries than Majority World countries (Wylie et al., 2016). In Majority World countries, typically the first services for PWCD use a medical model. Developing from this, SLT services are often hospital-based and part of departments such as ENT.

Majority World countries often have many challenges in developing services for PWCD. One problem with applying specialist healthcare knowledge in Majority World countries is that, even where sufficient facilities and knowledge enable accurate diagnosis of communication disabilities, effective treatments are still often beyond the financial means of PWCD. Wirz and Lichtig (1998) examined the diagnosis and treatment of audiological impairments in Sao Paulo, Brazil. Though free-to-access assessment clinics existed, they found the majority of hearing impaired children could still not afford hearing aids. Even with a number of programmes focused on the distribution of hearing aids from Minority World countries to Majority World countries, supply is still unable to match demand, meaning that — even with accurate diagnoses — a large proportion of CDs still go untreated.

Even where treatment is available, such as in Thailand, there are many reasons PWCD do not access such support. Prathanee et al. (2010) found that Thai people with cleft lip and palate may not be referred to SLT services for three reasons: a lack of awareness of the support available; a belief that surgical intervention will solve all related difficulties; and prohibitive travel costs. Even in South Africa, which has a relatively high number of SLTs for a Majority World country, Jordaan and Yelland (2003) suggested that a dearth of sufficiently trained interpreters may still prevent PWCD from accessing available services.

One way in which Majority World countries try to increase services for PWCD is the use of community based rehabilitation (CBR). CBR was initially developed to respond to the lack of disability services in Majority World countries (Kendall et al., 2000), and is defined by International Labour Organization, United Nations Educational, Scientific and Cultural Organization and WHO (2004:2) as a:

> strategy within community development for the rehabilitation, equalization of opportunities and social integration of all people with disabilities. CBR is implemented through the combined efforts of disabled people themselves, their families and communities, and the appropriate health, education, vocational and social services.

The production and distribution of the manual "Training disabled people in the community" (Helander et al., 1983) allowed for the training of lay persons in rehabilitation, special education, vocational training and other related disciplines (Finkenflügel et al., 2005), which in turn increased the number of CBR workers.

Due to financial and resource deficit, Wirz and Lichtig (1998) identified a significant need for CBR workers in providing appropriate and sustainable support for PWCD and their families. However, a challenge of CBR is to make sure adequate links are made and maintained between health services and PWCD locally. Often this role requires practical and effective delivery of healthcare in the absence of specifically trained professionals. McConkey et al., (2000) found parents were effective as trainers in disability and developed training manuals for parent groups to use in Africa and elsewhere which could be replicated across Majority World countries.

Despite the prevalence of CBR workers across Majority World countries, CBR fails to meet the needs of PWCD (Wylie et al., 2016). Whatever the specific challenges of each situation, CBR workers, by necessity, need to be trained to deal with a wide spectrum of disabilities. Nganwa et al. (2013) showed that many CBR workers in Majority World countries were not currently trained to provide sufficient intervention for PWCD. More extensive training, however, brings its own financial toll on Majority World country governments.

One of the dangers of judging health service development in Majority World countries by equivalent standards in Minority World countries is the tendency to see Minority World countries' health services as a gold standard of design, efficacy and achievement. In reality, common health service problems (including low staff numbers, long waiting lists, lack of research, and uneven distribution) are also widespread in Minority World health services. Focusing on services for PWCD: it should be noted that even in Minority World countries (where services for PWCD are typically more developed than in Majority World countries) services for PWCD experience difficulties. SLT is a relatively new profession in all contexts, and many models of service delivery are used globally (Glykas and Chytas, 2004). In the UK, children from lower socioeconomic groups are more

likely to have poorer language skills compared with children from higher socioeconomic groups (Lee, 2013), and children from some ethnic minorities face greater prevalence of CDs (Strand and Lindsay, 2012). Cochrane et al. (2016) found SLTs working with Indigenous Australians with CDs cited a number of barriers in offering SLT to the population. In many Minority World countries, people who are from low economic statuses or ethnic minorities are both disproportionately affected by CDs and comparatively underserved in terms of support (Hersh et al., 2015).

Both Minority World and Majority World countries experience challenges to their own health systems, including uneven distribution of professional personnel, and disparity of their skill mixes (Frenk et al., 2010). Health services in Majority World countries, however, are more likely to be affected negatively by this, which is further compounded by poor health profiles in terms of disease (Travis et al., 2004). It should be noted, however, that although writers have stated the progress of SLT and other AHPs has occurred at a slower rate in Majority World countries compared to Minority World countries (Thomas, 2013), this assessment generally does not acknowledge the relative newness of the professions, or the challenges that professions face initially in Minority World countries.

Many health system problems affecting PWCD in Minority World countries are in fact shared with Majority World countries. Even where Minority World countries have higher numbers of SLTs, rural areas are often significantly underserved, reflecting the situation in many Majority World countries. In these cases, some Minority World countries have developed ways of adapting to these challenges in the use of tele-rehabilitation (Theodoros, 2012). This model of service delivery could also be used in Majority World countries, however the literature shows limited awareness and knowledge of this way of providing such intervention (Mars, 2011) and limited use in Majority World countries.

2.6.3 Prevalence of communication disability

As with general disability prevalence data, there are challenges in the collection and interpretation of data on the prevalence of CDs. Amongst countries that have relatively developed SLT services and some available data on prevalence

of CDs, there is variability in the terminology used, how the CDs are classified and how they are measured (Enderby and Philipp, 1986). Furthermore, large scale epidemiological research has high costs (Pinborough-Zimmerman et al., 2007).

Another challenge is that the assessments used in Minority World countries are often developed to be used with certain languages, often designed for monolingual populations. Even within Minority World countries, this means there are populations who cannot be assessed equally using standardised assessment. This further contrasts with the distribution of languages spoken globally, where the majority of the population speak more than one language (Tucker, 1999). As many assessments are based on normative data from Minority World countries, research in Majority World countries often discusses how assessments have been culturally adapted for research purposes. Translation of assessment items may not be an appropriate way of adapting resources as linguistic structures between languages differ greatly (Carter et al., 2003). However Carter et al. (2012) adapted UK assessment resources to be used on a Kigiryama speaking population in Kenya, who were already identified as having or being at risk from language impairment, and found their adaption process to have strong measures of reliability. Other approaches to adapting assessments include re-norming assessments. Tchoungui Oyono (2016) used a French speech and language assessment to assess French speaking Cameroonian children to develop Cameroon norms and assess the prevalence of speech and language disorders and found 17.1% of Cameroonian children aged 3-5 have a speech and language disorder. However this approach is still vulnerable to cultural and linguistic bias (Tchoungui Oyono, 2016).

In terms of estimating the possible numbers of PWCD in the Majority World, there are some further difficulties. Poverty is a factor that has been linked to communication disabilities in Minority World countries (Locke et al., 2002). As poverty is greater in the Majority World, this may further cause differences in the proportion of prevalence of communication disability globally. There may also be variability in the causes of secondary CDs further complicating the ability to estimate rates of CD between countries. This is due to different health risks or complicating factors in other countries. For example, populations in Majority

World countries may face increased prevalence of secondary CDs from conditions or factors not commonly seen in Minority World countries. In Majority World countries, road traffic accidents are more common (Hyder et al., 2016) and are increasing (Tulu et al., 2017), which contribute to a high proportion of disability in these countries (Patel et al., 2016; Hyder et al., 2016). Majority World countries also have increased rates of diseases, such as cerebral malaria, meningitis and HIV (Paget et al., 2016; Carter et al., 2003) which can also cause CD.

Despite difficulties, a number of researchers have aimed to calculate the prevalence of PWCD. Within Minority World countries, the prevalence of CDs has been estimated to suggest that 6% of British children have CD (Law et al., 2003). When using direct assessment, 14.7% of Australian children aged 4-5 were found to have receptive language difficulties (McLeod and Harrison, 2009). Keating et al. (2001) found that 1.7% of Australian children aged 0-14 had speech disorders, with different prevalences for specific age groups within this range. However, these studies are not representative of the population of PWCD as a whole, largely focusing on children only, or specific age groups of children, and may only focus on specific areas of communication. Some researchers measure and report different aspects of CD separately, for example, the prevalence of speech disability and the prevalence of language disability (McKinnon et al., 2007). However, there is a large amount of comorbidity, which will not give an overall accurate measure of communication disability as a whole (Tseng et al., 2015).

Where parents or teachers report the prevalence of CD, this is likely to be greater than when it is assessed directly (McLeod and Harrison, 2009). This has implications for measures of CD prevalence as Bornstein and Hendricks (2013) found that across Majority World countries the rate was consistent at around 14% when this was self-reported.

Within Majority World countries, Rupert et al. (2015) estimated that 225 million people have CDs or swallowing disorders from secondary conditions. However, on an international scale, although there is some similarity amongst prevalence estimates in Minority World countries, equivalent information about the number

of PWCD in Majority World countries is scarce (Wylie et al., 2013), with many countries not specifically including communication disabilities as a type of disability in household surveys (Filmer, 2005). Despite difficulties relating to estimating the population size, Hartley and Wirz, (2002) suggested that between 38% and 49% of PWD in Majority World countries may have CD. Estimates indicate that by 2025 the population of PWCD in Majority World countries will be 190.5 million (Hartley, 1998). Despite the challenges of obtaining epidemiological data on the prevalence of CD, there is a clear need to reduce the burden of CD in Majority World countries (Olusanya et al., 2006).

Although little epidemiological data on communication disabilities in Majority World countries is available for the general population, many researchers have conducted SLT caseload reviews to explore the breakdown of communication disorders. Aremu et al., (2011) reviewed referrals to an SLT unit in North Central Nigeria and found the majority of clients to be children aged 0-15, with most children being referred aged 0-5. The most common diagnosis for all clients was deaf-mutism (57.5%), then speech delay (21.2%). Within the population of PWCD receiving support on an Indian paediatric SLT caseload, the most prevalent difficulties were auditory, language and speech difficulties (affecting 62%, 24% and 14% respectively (Devadiga et al., 2014)).

Comparatively, Broomfield and Dodd (2004) calculated the incidence of different CDs within a paediatric SLT caseload in the UK. The most common difficulties were speech sound difficulties, receptive language difficulties and expressive language difficulties (affecting 29.1%, 20.4% and 16.9% respectively). However, rather than reflecting differences in the type of CD prevalent across different countries, these studies may instead reveal the likeliness of people accessing SLT between Minority World countries and Majority World countries.

In terms of the need for epidemiological data on the prevalence of CD, there is disagreement in the field over whether statistics are the most useful or appropriate way of supporting services for PWCD (McAllister et al., 2013). Although collecting data on the epidemiology of CD may help inform service delivery and the selection of service models (Enderby and Pickstone, 2005), it may be less of a priority for an SLT service consisting of low numbers of

personnel where time and resources may be limited, evidenced by already high caseloads.

2.7   Outsider approaches to services for PWCD in the Majority World

There are many ways in which outsiders may work to support services for PWCD in Majority World countries. However, as there is limited specific research looking at outsider approaches to services for PWCD in Majority World countries, this section will also draw on research relating to outsiders working in Medicine and Nursing in Majority World countries. This section identifies and critiques the different approaches of outsider working, which have been coined by the researcher as direct roles, indirect roles, and partnerships.

1.   Direct Roles

Direct roles have been classified as any role in which an outsider delivers services to PWCD in a hands-on, face-to-face fashion. Given the legacy of the early medical missionaries (see 2.4.1), these roles have, until recently, been the most common form of outsider contribution to services for PWCD in Majority World countries. Many medical or nursing outsiders work in direct roles. Here, the literature typically describes groups of professionals who are linked as part of a wider project or cohort (Alimoglu et al., 2016). There is, however, also some record of these professionals operating as lone workers (Rankin, 2002). In contrast, outsiders who support services for PWCD working in direct roles are often lone workers, perhaps even the only person in that role in the country, or, if there are existing equivalent local personnel, as part of a small team or network. Here the researcher has further classified outsiders by the time length of their contribution to services for PWCD as the short-time frames often associated with outsider support are often linked to different ways and challenges of working. Bauer (2017), criticising the literature on medical volunteering, notes cleft lip and palate surgery repair teams face complications during and post surgery from a lack of full medical history that may result in death, and that international teams often do not follow up care with speech and language therapy. For the purpose of this study, time frames have been defined as: long-term, medium-term and short-term.

Long-term outsiders are often immigrants (or "expatriates") from Minority World countries who participate in a Majority World country's healthcare practice after moving to that country, for at least one year. Anecdotally, in SLT, this role has often been undertaken by women whose partners have moved to a Majority World country for work purposes. Although immigrants can have a significant impact on services for PWCD, their work may not be sustainable, particularly when disconnected from a wider health system. A lack of a connection to an overseeing professional body may also mean that their work is rarely regulated or recorded (and, as such the positive and negative impacts of their work cannot be fully assessed).

Medium-term outsiders are defined as Minority World health professionals operating in a Majority World country for between three months and one year, often on fixed-term appointments. Some medium term outsiders are orchestrated by larger NGOs and charities (although other medium term outsiders are self-funded) and often work on a rotational basis: working on a specific contract in a Majority World country before being replaced by a new outsider. In this situation, medium-term outsiders are typically provided with a small living allowance for their services: distinguishing them from unpaid volunteers. Examples of medium-term lone workers in action include a number of NGOs who send SLTs to under-served countries, typically Majority World countries.

Short-term outsiders are outsiders who work in a Majority World country for less than three months. Some short-term outsiders may work for a very short period of time (as little as a single day) or aim to combine holiday or travel with work. Some outsiders may also be voluntourists. A voluntourist is an individual from a Minority World country (commonly a pre-qualified or undergraduate student who lacks practical experience) who takes the opportunity (provided by a number of organisations and schemes) to combine 'global health experiences' (McCall and Iltis, 2014:287) with holiday or tourism activities abroad. Some universities also offer students the opportunities to work abroad as part of the university's established links or programme. However, there are questions and uncertainty about the best way for outsider students to be prepared for work overseas (Trembath et al., 2005).

As well as attracting many of the same criticisms as those generally of the direct roles model (in the assumption that prospective student SLTs, under-qualified students or recent graduates can contribute more to Majority World country services than locals; inefficiency; in the short periods volunteers typically spend in-country), voluntourism attracts additional criticism. Hickey et al. (2012) has described some of the problems of voluntourism within SLT, and included that that the primary benefits are not reaped by the countries in which voluntourists serve but by the voluntourists themselves who benefit in terms of experience and kudos (which can be used to enhance CVs or university applications). This imbalance in benefits also extends to the voluntourists' home countries: voluntourism opportunities are often more widely available to people from upper-middle class backgrounds (Sherraden et al., 2008) which, in turn, has a damaging effect on diversity within Minority World countries' health professions. Furthermore, Kelly et al. (2015:4) described how lots of the benefits are revised to focus on 'soft' gains rather than harder or more concrete gains. However, Hickey et al. (2012) found that where there is a balance between altruistic and self-enhancing motivations — or where there is an opportunity for personal support, supervision and appropriate training from qualified healthcare professionals — voluntourism may contribute to services for PWCD in Majority World countries.

Although a lone worker approach is widespread in direct outsider roles in Majority World countries (and has the obvious advantage of injecting Minority World healthcare expertise directly into Majority World countries), there are disadvantages to this approach. Firstly, this model tends to be capital-centric: isolating services to the area where they are based. In Uganda, for example, Robinson and Tumweheire (2002, cited in Barrett, 2010) calculated that 90% of the PWCD seen by the Kampala-based SLT volunteers from VSO lived within a 15 km radius of the service's point of delivery. This meant over 98% of Ugandans with disabilities were geographically isolated from potential SLT assistance (Hartley and Wirz, 2002). Secondly, this model does not encourage any growth in knowledge or expansion of local services. Because lone workers are exclusively Minority World experts, little knowledge is passed on to local health professionals: creating a culture of dependence without a reciprocal

transfer of skills and knowledge. Finally, this model is inefficient. Because lone workers tend to operate on temporary appointments, any cultural or medical knowledge that they gain while on appointment in the Majority World country is lost when their individual appointments end.

2.   Indirect roles

Outsider roles are termed as those where the main focus of the role is not direct clinical intervention, but the training and education of people in Majority World countries. In Medicine and Nursing, this has been a common approach to increase service provision and "upskill" or train local professionals, with Chu et al. (2009) noting various forms of training levels and programmes in different disciplines internationally. Within services for PWCD, this may also be to different levels, such as training people to become SLT assistants, for the specialist training for CBR workers, or to SLT level by developing SLT training programmes. Indirect roles developed from the need to make SLT in Majority World countries more sustainable.

The approach of an outsider SLT training insiders as assistants has occurred in many Majority World countries. Wirt et al. (1990) described the training of 5 Cleft Palate SLT assistants using a specific programme of training. Other insider assistants may learn in the role while working with outsider SLTs.

Courses such as the BSc in Communication Therapy in Malta have been developed. Where there is a low number of locally trained SLTs, students may also have placements abroad or staff partake in exchange programmes (Grech, 2001). Pierce (2012) described the training of SLTs in Peru and described one route being a distance learning course. However difficulties with existing low numbers of SLTs in Peru, especially in rural areas, led to a lack of clinical support and supervision, often causing a lesser service quality from distance learners. Recent research from Antony et al. (2016) has shown the potential of using video recordings of SLTs discussing principles of SLT with a CBR worker to train other CBR workers. Such training approaches have also been used successfully with CBR workers, teachers and families in Guyana (O'Toole and McConkey, 1995).

Many approaches for services for PWCD may be working simultaneously and be complementary, for example, SLTs offering specific focused advice for CBR workers. Such a mix of skilled professionals working with non-specialists helps to provide a rich and contextually appropriate service for PWCD.

Potential problems of direct and indirect outsider roles

Drawing on Hickey et al.'s (2012) critique of voluntourism, there are a number of problems which may affect outsiders working individually in any role in supporting services for PWCD. These are:

Lack of pre-departure training:

Training is an important aspect for preparation for any overseas work (Hickey et al., 2012). Without sufficient training, individual workers may be unaware of the culture and history of the host country they are entering: an unintentional ignorance which may create barriers for effective therapy (described in the next potential problem, lack of cultural safety). Proficiency in local languages is not common among SLTs working in Majority World countries. While complete fluency may be an unrealistic expectation (especially in countries with many official languages), knowledge of the linguistic structures in local languages is useful for any SLT intervention.

Lack of cultural safety:

According to Hickey et al. (2012), volunteers and others need to reflect on their own knowledge, skills and experience and not to consider their skills to be superior to the insiders they are working with. Outsiders should be careful not to disrupt established support systems, especially when they are only in the country for a short period of time (Hickey et al., 2012). Such reflection is also crucial for client safety, especially when they are inexperienced or ill-qualified to undertake activities (Hickey et al., 2012).

Neocolonialist practices:

Neocolonialism (as discussed in 2.2.3) can be defined as any exploitative or systematically unequal relationship between a former colony and a former colonial power. Coloniality describes ways of thinking, feeling or association with domination, which continue after independence (Adams et al., 2018). To

prevent neo-colonialism and coloniality in services for PWCD, it is important to ensure that the host country is the primary beneficiary of any outsider intervention (Hickey et al., 2012). To achieve this, an outsider may need to work with an interpreter or cultural guide to add context and holism to service users' communication needs. Due to the history of colonialism, an outsider (even when conscious of avoiding neo-colonialist practices) may still — to a person in the host country — represent superiority either financially, culturally, experientially or in terms of the worth of their contributions.

Ethical considerations

Given the comparatively-looser (or unwritten) healthcare guidelines of many Majority World countries, outsiders are often able to mix healthcare practice with personal beliefs (e.g., religious beliefs) in a way that would not be allowed in the UK. Furthermore, Pierce (2012) described US-based SLTs working for the volunteer organisation Peacecorps, where, volunteers were encouraged to use their professional SLT training even though Peacecorps provides no specialist SLT support.

Difficulties upon re-entry:

Whilst working in Majority World countries, volunteers often fail to maintain links with the sending organisation or host country's workers (Hickey et al., 2012). This can lead to difficulties re-adjusting on their return to the Minority World. Hickey et al. (2012) also considered the support needed for volunteers on completion of their volunteering.

Outsiders may work in either direct or indirect roles, or a combination of both incorporating training alongside direct clinical work.

Three: Partnerships

The previous two approaches of outsiders working to support PWCD in Majority World countries (direct and indirect roles) describe individuals working in Majority World countries. The trend of outsider working encompasses a wide variation of working practices from the use of SLTs from Minority World countries in covering local service shortfalls (Hanchanlert et al., 2015) to larger scale projects. Partnerships are another way in which outsiders may work to

develop services in Majority World countries. The model of partnerships for insiders and outsiders to collaborate by sharing expertise and resources to learn together has become increasingly prevalent in health (F.A. Jones et al., 2013). Binagwaho et al. (2013) described an example of how this approach is also used to create benefits at both clinical and academic levels and also to enable research collaborations. As there is limited literature looking at the use of partnerships to develop services for PWCD, partnerships in health more generally will be discussed. F.A. Jones et al. (2013) looked at the benefits and costs at three levels: individual; institutional; and national. Costs (or negatives) included: the financial costs of collaborating; the need to find cover and the effects of finding cover; reputational damage to the perception of both the UK partner institute or the UK as a whole; Threats to health and security such as stress or burnout and culture shock; and the loss of opportunity such as annual leave or promotion/career effects.

Writers such as Musoke et al. (2016) described partnerships as a way of having a more equal relationship, balanced on both sides. However, in terms of exploring the benefits, the literature tends to focus on those of outsiders (Crawford et al., 2017). Guidelines are written from the point of view of outsiders, rather than how both sides work together. Hague et al. (2015) note that there is limited assessment on the benefits of partnerships to both insiders and outsiders, however they continue to focus on the benefits to outsiders only, particularly to individuals and the NHS. Perhaps this is a way of justifying the sending of outsiders despite challenges of partnerships such as limited or uncertain funding.

Looking at the benefits of outsiders from health partnerships, (Jack et al., 2015) found that outsiders who had been involved in a palliative health degree programme felt their teaching/educating skills and clinical skills had improved, as well as gaining personal development (such as travel). Within SLT, Pickering and McAllister (2000) have been two of many voices describing how international experience has improved their understanding of cross cultural issues at home.

Aside from outsider benefits, the literature often describes strategies for best practice. Musoke et al. (2016:16) included strategies such as 'building partnerships with various stakeholders for example MOH, health facilities and local health authorities that can be sustained.' They did not, however, say whether this is something they have done, or indeed if this has been successful. Kelly et al. (2015) described the need to develop frameworks to assess the benefits of partnerships and their effectiveness.

Regardless of the overall approach, whether through direct or indirect individual roles, or through partnership roles, the literature does highlight some areas for outsiders to consider for best practice in Majority World countries. Authors such as Johnson and Hitchens (2011) have stated that models of intervention should not define practice or approaches in other countries and call for culturally appropriate working. Similarly, outsiders need to consider the power relationships at play not only from being an outsider, but also as a healthcare professional. Many cultures and people in Majority World countries may be more compliant to medical professionals (Domsch 2012), which may reduce their power in a clinician-client relationship. Furthermore, working approaches need to be sustainable. There are examples of NGOs stopping the sending of professionals (Nganwa et al., 2013), or ending partnerships which damage the sustainability of contributions. One example of an NGO ending a partnership prematurely can be seen in Zambia (Beneke, 2016). However, often collaborations are not well documented, and it is unknown how many end before completion.

The literature showed a need to explore how services for PWCD in Majority World countries had developed with outsider support as there is both limited information showing how this happened. This is needed to document the challenges and successes of collaborative working practices. A focus on both insiders' and outsiders' perceptions of outsiders' contributions allows for the consideration of how both feel regarding outsiders' collaboration, particularly when outsiders' typically remain the focus in the literature. Therefore the aim of the study was:

To investigate the processes and perceptions of collaboration between insiders and outsiders in developing services for PWCD in Majority World countries, with a particular emphasis on the contribution and roles of 'outsiders.'

This aim was to be achieved by five research objectives:

1. To explore and describe the process and history of the development of services for PWCD in Uganda.
2. To describe and explain insiders' perceptions and experiences of the contributions of outsiders and outsider support, to the development of services for PWCD in Uganda.
3. To describe and explain outsiders' perceptions and experiences of their contribution to the development of services for PWCD in Uganda.
4. To analyse and interpret insider/outsider collaboration and working practices.
5. To interpret and explain perceptions of outsider contributions in five Majority World countries.

2.8 Summary

This chapter provided an overview of colonialism and development theories, and reviewed the literature on health services, specifically services for PWCD in Majority World countries. Five decades from the collapse of the European colonial project, the impact legacy of colonialism can still be felt in health services Majority World countries globally. It was outsiders who replaced traditional methods of healing with a westernised (and Christianised) healthcare model, and it was often outsiders who continued to promote this model in the decades following de-colonialisation (however well-or poorly-suited this European model may be in the context of each country). Precise records of health services in Majority World countries (especially at a national level) are often hard to obtain, and accurate estimates of disability-prevalence and country-specific needs are even scarcer. As a result, services can be difficult to target and even harder to deliver, especially when aimed at PWCD (of whom even less data is available) as there may be challenges with co-ordination. Delivery is complicated by the varying aims and approaches of outsider collaborators: some of whom seek to provide extremely localised services, while others commit to grander projects before withdrawing support. In many cases,

multiple outsider agencies will attempt to deliver similar services without sharing resources or expertise (leading to duplication: both of services and of mistakes). Other outsiders focus on their personal gains rather than optimum service for PWCD in country. The research aim was justified and described, and the research objectives were outlined. The next chapter will explore the methodology underpinning this research in relation to the aim and objectives.

3   Methodology

3.1   Introduction

This chapter outlines the methodological considerations and philosophy that underpin the study. It describes the methods chosen and justifies their selection in relation to the research aims and objectives, the ethical considerations and approval processes. In terms of structure, section **3.2** describes the philosophical approach; section **3.3** discusses the ethical considerations; section **3.4** discusses research quality; and section **3.5** gives a summary of the chapter.

As the research was conducted in two phases and used different methods and procedures, these are detailed separately in each phase. Therefore, chapter 4 describes the methods and procedures used in phase one, and chapter 5 describes the methods and procedures used in phase two.

The design of this research was selected to meet the research aim most effectively. The aim was: "To investigate the processes and perceptions of collaboration between insiders and outsiders in developing services for PWCD in Majority World countries, with a particular emphasis on the contribution and roles of 'outsiders.'" This aim was to be achieved by five research objectives:

1. To explore and describe the process and history of the development of services for PWCD in Uganda.
2. To describe and explain insiders' perceptions and experiences of the contributions of outsiders and outsider support, to the development of services for PWCD in Uganda.
3. To describe and explain outsiders' perceptions and experiences of their contribution to the development of services for PWCD in Uganda.
4. To analyse and interpret insider/outsider collaboration and working practices.
5. To interpret and explain perceptions of outsider contributions in five Majority World countries.

With this in mind, this chapter firstly focuses on the philosophical approach, providing a detailed discussion of the epistemology, theoretical perspective,

methodological approach and methods used in gathering and analysing the data according to the research objectives (Crotty 1998) in relation to both phases of the research.

3.2   Philosophical approach

All research is guided by underlying philosophical perspectives: perspectives personal to the researcher informing their approach to the process, from the research topics selected to the methods used. There are different ways of describing a researcher's research philosophy and it is important to provide an account of it for transparency. Terminology can be confusing as writers use differing definitions to describe the foundations of the philosophy of research (Hammersley, 2007). For clarity, Crotty's (1998) definitions of terminology have been used to detail the researcher's approaches and perspectives in line with the research study question. Crotty (1998:3) detailed the four elements of research as:

> 1. Epistemology - 'the theory of knowledge embedded in the theoretical perspective and thereby methodology.'
>
> 2. Theoretical perspective - 'the philosophical stance informing the methodology and thus providing a context for the process and grounding its logic and criteria.'
>
> 3. Methodology - 'the strategy, plan of action, process or design lying behind the choice and use of particular methods and linking the choice and use of methods to the desired outcomes.'
>
> 4. Methods - 'the techniques or procedures used to gather and analyse data related to some research question or hypothesis.'

Some writers may also include ontology as a foundation of research. However, Crotty (1998) stated that ontology is concerned with the study of being (and the realities of this) and as such sits at a similar level to epistemology but informs the theoretical perspective. Whilst ontological perspectives are not discussed in further detail, they may be mentioned indirectly in terms of their alignment with

epistemological perspectives. Although some researchers advocate that philosophical approaches should be followed strictly, other researchers advocate flexibility in research (Johnson and Onwuegbuzie, 2004). Crotty (1998) recognised the particular associations between specific epistemology, theoretical perspectives, methodology and methods, but did not, however, propose rigid adherence to these as a philosophical approach.

3.2.1 Epistemology

Epistemology is the philosophy of the theory of knowledge. It concerns the relationship between what is known and the knower: looking at how things are known and what can ultimately make or count as knowledge (Tuli, 2010). Within this, there are many different positions and the position selected informs the theoretical perspective taken in the research. There are three main branches of epistemology — objectivism, constructivism and subjectivism. These will be outlined briefly, and one will further be justified for its relevance to the study.

Objectivism holds that social phenomena and its meanings exist independently of social actors (Bryman, 2012). Social phenomena — behaviour and events, and their meanings or interpretations — exist externally to people. Objectivism is closely associated with realism, which considers that reality is directly observable and independent of perception.

Subjectivism holds that there is no one objective or external truth, and that knowledge is subjective, where meaning is imposed on the subject (Gray, 2004). It regards all opinions and outlooks on a topic as having an equivalent truth value. Some researchers describe this equivalence as a flaw (Ratner, 2002). However, in terms of research, the researcher's subjective position and that of participants can be integrated (Chmiliar, 2010).

Constructivism holds that meanings are constructed by humans as they engage in the world (Crotty, 1998). Such meanings, according to constructivism, are active and in an ongoing state of revision (Bryman, 2012). Constructivism believes there are many different interpretations of events or actions, and, although some interpretations may be more useful than others for a particular situation, there is no single truth, as each interpretation is bound in context

(Crotty, 1998), being intertwined in both objectivity and subjectivity at once (Crotty, 1998). With this in mind, individuals are entwined with their culture. Each person's culture is something that is both pre-existing *and* constantly in the process of being re-understood and re-imagined (Crotty, 1998).

Constructivism is generally understood as being associated with a relativist position — which fundamentally posits there to be multiple constructed views of phenomena (Mays and Pope, 2000). To Guba and Lincoln (1994) this meant multiple interpretations of social phenomena and, therefore, realities of equal worth and validity (where constructions have been created by trustworthy and competent interpreters), even across different identities. Constructivism considers the researcher and research subject to be interactively linked — meaning findings are created as the research takes place (Guba and Lincoln, 1994).

The researcher's epistemological position for this study best fits that of constructivism as it allows for consideration and interpretation of multiple perspectives, rather than arriving at one overall "true" reality (as in objectivism). There are similarities between subjectivism and constructivism, however, the researcher is interested in *how* perspectives are constructed and the possible differences in and between insider and outsider perspectives: holding that this will allow for an understanding of outsiders' contributions.

3.2.2 Theoretical perspective

Crotty (1998) stated that discussion of a researcher's theoretical perspective provides a statement of the researcher's assumptions about the research. Three main theoretical perspectives will be described — positivism, pragmatism and interpretivism — before providing an explanation of the researcher's theoretical perspective. Although there are more than the three theoretical perspectives described below (such as more critical approaches of postmodern or feminist theoretical perspectives), it is beyond the scope of this study to define them all. These three have therefore been discussed to give context to mixed methods research, while still providing the most relevant to this study.

Positivism is used widely within the field of science. It is a theoretical perspective that uses a scientific method of observation (Crotty, 1998) and assumes that only what can be directly experienced through rigorous scientific observation should be posited.

Pragmatism is a theoretical perspective that considers the practical problems of social research: it draws focus to the nature of research questions or aims and how research is interpreted (Feilzer, 2010). Pragmatism is closely aligned to mixed methods research. Pragmatism is focused on the question of how best to answer the research questions or aims, therefore, pragmatic research often uses multiple methods of data collection and interpretation and is less concerned with the apparent contradictions of set epistemological or theoretical perspectives on method selection. Although a pragmatist paradigm did not guide the perspective or influence how the research was conducted, *pragmatic reasoning* (focusing more on practical, sensible and realistic approaches over theoretical approaches) allowed for such flexibility. A pragmatic approach was used to identify the four elements of research that were most relevant in order to best answer the research aim.

Interpretivism is an epistemology that requires researchers to understand the subjective meaning of social action (Bryman, 2012). It is often contrasted with positivism: a position historically more aligned with the classical sciences but often applied to the social sciences. Some researchers believe that certain epistemologies are fundamentally in opposition and cannot be mixed. As interpretivism is the perspective that most closely aligns with the researcher's philosophical position, this will be described in greater detail.

There are three main approaches to interpretivism: symbolic interactionism, phenomenology and hermeneutics, however for clarity, the two most relevant to addressing the research aim (hermeneutics and phenomenology) will be described.

Hermeneutics is the study of the understanding of communication, activities and artefacts particularly in relation to other cultures or time periods (Hammersley, 2006). It originated from the discipline of the study of religious texts, focusing on

the interpretation of scripture (Kakkori, 2010). The discipline of hermeneutics dates back to ancient Greek times, but it has since been used as an approach for studying and understanding other areas, where the goal is not to arrive at religious interpretation (Crotty, 1998). Within hermeneutics, *ordo essendi* (the way things are), *ordo cogitandi* (the way we perceive things), and *ordo loquendi* (how we speak about things) are all linked and influence each other (Crotty, 1998). Hermeneutics looks at aspects relating to the text, not just to the text itself. This includes the 'intentions and histories of authors' (Crotty, 1998:91). Because of this, hermeneutics aims to give a deeper understanding than even, perhaps, the text's original author possessed. It does this by looking at implicit and often hidden intentions of the author and making these explicit to show greater meaning (Crotty, 1998).

Crotty (1998) identified the main first two proponents of modern hermeneutics as Schleiermacher and Dilthey. Schleiermacher (1809) described the art of interpretation as the construction of all the necessary conditions to enable understanding. This included both the grammatical and psychological components of the text (referring to the analyses of text in terms of the language used), and the consideration of the text in terms of the author's life history, arriving at the motivation of the author (Warnke, 1987). These two components of hermeneutics are complementary, and allow an interpreter to be transformed into the author, allowing for full understanding. However this resulting transformation was later critiqued by Gadamer for overstating this at the expense of grammatical interpretation (Warnke, 1987).

Dilthey's work built on that of Schleiermacher's, viewing the reading or interpretation of text as a role as creative as the corresponding author (Jasper, 2004), where the social and historical context of the author is the main source for understanding (Crotty, 1998). Dilthey viewed *Erlebnis* (life experience) as having commonalities that were universal across both cultures and time periods (Jasper, 2004). This is done by the interpreter re-living the author's experience, through transposition or empathy (Thiselton, 1992), using the hermeneutic circle. The hermeneutic circle is a metaphor that refers to the need to understand both the smaller parts and the whole piece. An understanding of

each helps to inform greater understanding of the other. It is a circular understanding process (Kinsella, 2006).

Phenomenology looks at understanding a person's subjective experiences (Braun and Clarke, 2013). Essentially the researcher aims to see things from a participant's perspective. It requires the researcher to suspend their culture to allow for the researcher to be able to obtain this perspective. Although an individual's culture influences and gives human meaning to reality, phenomenology states that it restricts a researcher's perspective to one subjective account of human meaning. Therefore, as a method, phenomenology requires researchers to 'bracket' and set aside their existing knowledge and assumptions, while being aware of their existence (Crotty, 1998:83; Smith 2007). This should result in the researcher being able to experience and interpret what is directly experienced without adding or implying additional meaning (Crotty, 1998:79), ultimately arriving at the 'true' phenomena. There are numerous types of phenomenology (Dowling, 2007). The most prominent of these is descriptive phenomenology (also referred to in the literature as transcendental phenomenology), which was developed by Edmund Husserl. It aims for the 'rigorous and unbiased study of things as they appear in order to arrive at an essential understanding of human consciousness and experience' (Dowling, 2007:132).

Hermeneutic phenomenology was developed by Martin Heidegger, a former student of Husserl. Heidegger's hermeneutic phenomenology was later further developed by other philosophers, such as Gadamer. As with phenomenology, it looks at the lived human experience, with emphasis placed on creating meaning and understanding from experiences (Laverty, 2003; Sloan and Bowe, 2014). However, phenomenology and hermeneutic phenomenology differ in their approaches of exploring lived experiences, with phenomenology concentrated on the understanding of beings or phenomena, and Heidegger's hermeneutic phenomenology concentrated on *Dasein*, which translates as the *mode of being* (Laverty, 2003; McConnell–Henry, et al., 2009). Many researchers have combined hermeneutic and phenomenology approaches for research**,** particularly in the field of health research, however at times "hermeneutics" and "phenomenology" are used as interchangeable terms in

describing the research process in the literature, which has contributed to confusion within this area of interpretivism (Dowling, 2004).

The combining of hermeneutic and phenomenology into a single complementary theoretical perspective has been critiqued (Kakkori, 2010), with critique centred on the lack of clear distinction between the different types of phenomenology (which is a wider criticism of phenomenology as a whole). Although there are differences between the two perspectives of hermeneutics and phenomenology, there are also a number of similarities or shared assumptions that are complementary (Laverty, 2003).

In relation to the research aim, use of hermeneutic phenomenology allowed for not only the description, but interpretation of experiences and observations. At a methodological level, rather than bracketing culture and experiences, hermeneutic phenomenology allowed for their use and reflection in the research process (Laverty, 2003). Although some researchers have advocated for hermeneutic phenomenology being either a method (Fagerberg and Norberg, 2009) or methodology (Ajjawi and Higgs, 2007; Harris, 2016), the researcher believes there is a subtle, yet important distinction in hermeneutic phenomenology as a theoretical philosophy that serves to inform methods.

As previously briefly mentioned, research philosophy and epistemology terms are used differently and often have looser subsets based on researchers' interpretations and philosophies. However, using Crotty's (1998:3) descriptions of the foundations of research, this considers hermeneutic phenomenology to neither be 'techniques or procedures used to gather and analyse data related to some research question or hypothesis,' nor a 'strategy, plan of action, process or design lying behind the choice and use of particular methods and linking the choice and use of methods to the desired outcomes.'

Another criticism of hermeneutics and phenomenology is that they are often described as lacking a critical component (Ricoeur, 1975). Criticality refers to any research that aims to challenge or disrupt existing or mainstream knowledge, particularly in relation to knowledge that is perceived to cause inequality or oppression (Muncie, 2006). However, neither hermeneutics or

phenomenology in isolation or hermeneutic phenomenology aim for critical understanding. Furthermore, the research aim was to investigate perceptions in an area that is lacking research, where it was reasoned critical approaches would not be complementary in terms of understanding the research area in relation to theories of development, or aiming to alter power dynamics.

Through the theoretical perspective of interpretivism, both hermeneutics and phenomenology were felt to offer an important lens. Firstly, hermeneutics allowed understanding to be gained, rather than provide an overall authoritative account of a subject (Kinsella, 2006). Hermeneutics allowed for the examination and consideration of the broader context of textual data in order to provide a rich overview. The hermeneutic elements of interpreting both the grammatical and psychological elements of the texts and the hermeneutic circle allowed for an in-depth and empathetic understanding of the perceptions of the development of PWCD in Majority World countries. Secondly, phenomenology was an appropriate approach to help ground the research in the phenomenon of "outsider contributions." Together, an interpretivist hermeneutic-phenomenological philosophy allowed for focus on the subjective experiences of the phenomena of outsider contributions to services for PWCD of individuals and groups, and provided an explanation of how individuals and groups experience this through their own narrative (Kafle, 2013). Practically, a hermeneutic phenomenology philosophy further allowed for the researcher's reflections to be included alongside information directly from participants and other sources (Laverty, 2003).

3.2.3 Methodology

Methodology refers to the research strategy (Crotty, 1998). It concerns the design of research — whether it is qualitative, quantitative or mixed methods; how research is conducted (e.g., whether the design is single or multi method); as well as the particular strategy or strategies within the design (Saunders and Tosey, 2013).

Quantitative, qualitative and mixed methodology

Traditionally, there have been two broad research methodologies: quantitative and qualitative. Quantitative counts and measures, in order to answer questions

such as "how many" or "how much," often in order to confirm or reject a hypothesis. It is closely aligned to the epistemological position of objectivism and theoretical perspective of positivism (Matthews and Ross, 2010). In contrast, qualitative methodology answers questions of "what" and "how." It often aims to explore, classify and "develop" rather than to test hypotheses. Data are often related to individual human perspectives, experiences or behaviours. It is strongly associated with constructivism and interpretivism.

Both methodologies have been used to examine healthcare in global settings. Some researchers believe that the two approaches are fundamentally incompatible (Salvador-Carulla et al., 2014). However, a third approach is the mixed methodology approach. This relatively new approach operates from the 'central premise… that the use of quantitative and qualitative approaches in combination provides a better understanding of research problems than either approach alone' Creswell and Plano Clark (2007:5). Creswell and Plano Clark (2011) outlined the development of mixed methodology research from the 1950s onwards. In contrast to Creswell and Plano Clark, other researchers have stressed the incompatibilities of quantitative and qualitative methodologies, which stemmed from how researchers saw each methodology as influenced from differing epistemological and theoretical paradigms (Glogowska, 2011). However methodologists such as Johnson and Onwuegbuzie (2004) see mixed method research as an equal to quantitative and qualitative methodologies, and a methodology in its own right: one which acknowledges the differences while appreciating the similarities between both traditional approaches.

Today, mixed methods research has gained acceptance and popularity with researchers and is often associated with pragmatism. Mixed methods research is common in health service research (O'Cathain et al., 2008; Salvador−Carulla et al., 2014; Johnstone, 2004), as it can present a more comprehensive overview than either of the single methodologies alone (Wisdom et al., 2012). As mixed methodology has become increasingly accepted and used, authors have also identified using multiple qualitative methods in one study as constituting a mixed method approach, with mono or multi-method, simple or complex methodologies also being used (Saunders and Tosey, 2013). The use

of more than one qualitative method of data collection in phase one, and the mixed methods survey used in phase two of this study, are part of the overall mixed methodology adopted in this research.

Justification for using multiple mixed methodology in this research

Some epistemologies and theoretical perspectives may be closely associated with specific methods and methodologies, however there are no fixed "rules" as to how research philosophy may influence methodological decisions (Bryman, 2012). Within the context of mixed methods research, this also explains how phases of research can be underpinned by the same overarching theoretical perspectives but differ in terms of data collection. As this was the case in this study, both constructivism and interpretivism have been used to inform quantitative approaches (Bryman, 2012).

Ultimately, a multiple mixed methodology was deemed to be the most appropriate way of achieving the research aim, allowing for both the in-depth understanding, and the statistical understanding, to meet all the research objectives. The research aim was broken into five objectives, each with either a qualitative or mixed methodology component (see Table 3.1).

Table 3.1 Research questions and data analysis used

Research objective	Methodology
1.To explore and describe the process and history of the development of services for PWCD in Uganda.	Qualitative
2. To describe and explain insiders' perceptions and experiences of the contributions of outsiders and outsider support, to the development of services for PWCD in Uganda.	Qualitative
3.To describe and explain outsiders' perceptions and experiences of their contribution to the development of services for PWCD in Uganda.	Qualitative
4. To analyse and interpret insider/outsider collaboration and working practices.	Qualitative
5. To interpret and explain perceptions of outsider contributions in five Majority World countries.	Qualitative and Quantitive

The specific research methods selected to respond to each objective will be detailed in the methods section, from section 3.2.4 onwards. Within the multiple

mixed methodology used, phase one used an entirely qualitative methodology, to provide in-depth country specific data. This data were used to inform the mixed methodology of phase two.

Within mixed methodology research, designs vary amongst researchers based on their disciplines and classification of methodology (Teddlie and Tashakkori, 2009). However, Creswell and Plano Clark (2011) described four basic designs based around the order of what type of data are needed first, summarised below:

1. Convergent parallel design - where both qualitative and quantitative research is conducted simultaneously.
2. Embedded design - where one type of research (quantitative or qualitative) is supplementary to the other type of research.
3. Explanatory sequential design - where the initial phase is quantitative and is followed by qualitative research.
4. Exploratory sequential design - where an initial phase of qualitative research is used to prepare for a follow up phase of quantitative research.

Rationale for a two phase, exploratory sequential design
The decision to split the research into two distinct phases and rationale for selecting the specific methods for each phase of the research will be described. Description of the procedures for each method will be described in 4.3 and 5.3.

As mentioned above, the two-phase, mixed methods approach allowed for both the in-depth analysis of a detailed case study (phase one) and a wider comparative study of five other countries (phase two). Furthermore, due to the dearth of previously-available research (and the difficulties of gathering in-depth data on a global scale), this approach also offered a practical solution. Practically, a mixed methodology allowed for the selection of the most appropriate and practical methods to respond to the research aim. The methods are further discussed in section 3.2.4. of this chapter (in which the specific methods chosen will be detailed and justified).

Ethnographic case studies represents data collection which draws on both a traditional ethnography (to describe the perspectives of members of a culture, which is commonly associated with methods of participant observation, although other methods are also used); and case study (which focuses more on telling the story of the subject of research, and is less bound to a specific methodology).

There has been a debate in academic literature concerning the similarities and distinctions between ethnographic and case study approaches. White et al. (2009) argued the approaches are essentially comparable, while Suryani (2008) identified crucial incompatibilities, including the immersive and non-immersive roles of the researcher, for each method. In order to best to explain the ethnographic case study, it is necessary to first define what is traditionally understood by basic ethnographic and case study approaches.

One: The ethnographic approach

Derived from the Greek words *graphē* (meaning writing) and *ethos* (meaning nation, or culture), ethnography literally is the qualitative attempt to 'write or represent' a particular culture or cultural phenomenon through immersion and observation of the culture in question (Parthasarathy, 2008:online). Ethnographic research always involves some aspect of observational research fieldwork (Brewer, 2000) and its particular aims are well summarised by Parthasaranthy (2008:online):

> Ethnographers look for patterns, describe local relationships (formal and informal), understandings and meanings (tacit and explicit), and try to make sense of a place and a case in relation to the entire social setting and all social relationships. They also contextualise these in wider contexts: e.g. the wider economy, government policies, etc.

Two: The case study approach

Although united in its essential desire to 'seek… a full, rich understanding (verstehen) of the context [being studied]' (Willis, 2007:240, cited in White et al., 2009:21), the case study is a much less ideologically-driven research tool than

traditional ethnography. Stake (2005:443, cited in Yin, 2014:17) defined the key motivation of case study research as an 'interest in the individual case, not [in] the methods of inquiry used.' Using this definition, the work of a case study researcher is more pragmatic than that of an ethnographer: focusing on telling the story of a particular case rather than strictly conforming to an acknowledged methodology.

For this reason, case study research need not necessarily include such ethnographic essentials as fieldwork (Yin, 2012) and, provided it maintains a focus on bringing the story of a particular individual, culture or phenomenon to light, a case study approach need not even be qualitative in its methods at all (Yin, 2012). In terms of the case, this was an SLT service in Uganda.

Synthesis: The ethnographic case study approach

A third approach, the ethnographic case study approach, is a synthesis of the previous approaches. It takes the ideological and methodological framework of ethnography, (considered by many researchers to provide 'the best opportunity to collect current, reliable, complete and specific data to answer the relevant questions' Suryani (2008:124)) and combines this with the practical and pragmatic aims of the case study approach (in which data collection is possible even when direct access to participants and lengthy research periods are not always possible). The ethnographic case study approach aims to produce the most robust case studies possible under restricted data-gathering conditions. Parthasarathy (2008) described ethnographic case studies as contrasting with ethnography in that they can be conducted over shorter time spans and explore more specific areas of interest to generate hypothesis. Similar to, but distinct from, a purely ethnographic approach, the ethnographic case study approach benefited the research in two key ways:

1. On a practical level, the ethnographic case study approach allowed for the in-country data collection over a relatively shorter time-span (just over four weeks spent in Uganda in total) than pure, immersive ethnography would have allowed.
2. The ethnographic case study approach allowed the phase one findings from Uganda to be more easily and usefully contrasted with the non-

ethnographic, non-immersive, phase two findings from other Majority World countries.

This methodology was chosen as appropriate to phase one of this research for several reasons. Firstly, as there were limited data in this area (see chapter 2) an ethnographic case study approach allowed the researcher to identify areas which were considered important by those with direct, first-hand experience. Secondly, as outsider work in Majority World countries was provided by a diverse array of individuals and organisations with varying aims, an ethnographic case study provided an opportunity to explore 'expressive information not conveyed in quantitative data about beliefs, values, feelings, and motivations that underlie behaviours' (Berkwits and Inui, 1998:195). Finally: through ethnographic techniques, such as participant observation, the aim was to obtain an understanding of the day-to-day working relationships between outsiders and insiders in delivering services to PWCD in Uganda: an understanding which was hoped to reveal nuances of the Ugandan model that would be hard to attain from quantitative research. In conducting an ethnographic case study, three data collection methods often associated with the ethnographic approach were used (Schensul and LeCompte, 2013): document analysis, semi-structured interviews and participant observation.

Within the study, the immersive aspects of the phase one investigation were not practical in other Majority World countries (due to limitations of time and of financial resources). Although these phase two case studies did not include the 'ethnographic staple' of fieldwork (Yin, 2012:17), they maintained the same focus on bringing the cultural phenomenon of outsider/insider collaboration to light using a mixed methodology. For the phase two pilot study, case study survey research was used, which used a mixed methods design consistent with the overall epistemological approach. Case study survey research administers a survey to a case (in this instance, five countries) which is either the whole population or a sample within this, to describe characteristics of the population sampled (Chmiliar, 2010). This design was consistent with Stake's definition of a case study as research which is primarily concerned with 'the individual case, not the methods of inquiry used' (Stake, 2005:443, cited in Yin, 2014:17). Table

3.2 summarises the use of methods and methodology by each phase of the study.

Table 3.2 Research phases

Phase	Methodology	Methods
1	Ethnographic case study	1.1 Document analysis 1.2 Interview 1.3 Participant observation
2	Case study survey research	2.1 Survey

3.2.4 Methods

This section details the rationale behind the selection of the methods used for both phase one and phase two. The process and procedures of each method will be described in the relevant sections in chapter 4 and chapter 5.

Document analysis

Document analysis is a 'systematic procedure for reviewing or evaluating documents' (Bowen, 2009:27). A range of documents can be used to explore themes and to contextualise meanings (Braun and Clarke, 2013). To address the first research objective (exploring and describing the process and history of the development of services for PWCD in Uganda), a document analysis of relevant archival documents was undertaken. The documents detailed the history of outsider/insider collaboration in the development of services for PWCD in Uganda.

Document analysis was selected to provide a detailed historical context to the provision of services for PWCD in the country. This scope provided a historical overview, contextualising the perceptions and experiences of interview participants (both insiders and outsiders). It was also anticipated that the document analysis would help provide some perspectives on how and why services for PWCD started in Uganda, including the influence of outsiders: providing a descriptive iterative review. The document analysis used data sources that were in the public domain to provide a snapshot of services for PWCD in Uganda.

<u>Semi-structured interviews</u>

Interviews are a data collection method involving the researcher asking participants questions (Davies, 2006). Semi-structured interviews are considered in-depth, allowing the participant to respond to open questions. They are typically based on a pre-developed interview guide which allows the interview to remain focused as well as ordering topics and questions in a logical way (Jamshed, 2014). They are commonly used by health professionals and in health research (Whiting, 2008). To address the second research objective (describing and explaining both outsiders' and insiders' perceptions and experiences of outsiders of their contribution to the development of services for PWCD in Uganda), semi-structured interviews were chosen in order to encourage a participant-focused process and to allow the concerns of the individual participants to become the key topics of the research (Braun and Clarke, 2013). A topic guide was developed prior to interviews to guide the interview process.

<u>Participant observation</u>

Participant observation has a long-standing association with ethnographic approaches and anthropology (Tedlock, 1991). Participant observation is an immersive form of research in which the researcher embeds themselves in a social setting, gathering information through in-situ questioning and observation (Bryman, 2012). For this research, participant observation provided a lens through which the researcher understood the opinions expressed in the semi-structured interviews. These observations focused on interactions between insiders and outsiders, which occurred as part of a project providing continued professional development for East African SLTs which is described in more detail in chapter 4.2.11.

<u>Survey</u>

The method used for the phase two pilot study was self-completion survey. Self-completion survey is an instrument that uses pre-compiled questions for participants to respond to in order to complete the instrument. Surveys have been used extensively in health service research and, more specifically, surveys have been successfully used to profile SLTs who provide services for PWCD in Majority World countries (Wylie et al., 2018). The survey was distributed to five

Majority World countries. The procedure of phase two, including country selection, will be described in more detail in chapter 5.3.

Phase one and two synthesis

Following the analysis and production of findings for both phases, phase one and phase two were synthesised. There are many approaches for the combining of data, such as meta-analysis (for quantitative analysis) and meta-synthesis (for qualitative analysis) (Urquhart, 2010). As a predominately qualitative study, meta-synthesis was used. Timulak (2009:591) stated that the principle of a qualitative meta-analysis was to 'provide a concise and comprehensive picture of findings across qualitative studies that investigate the same general research topic.' Therefore, this study used the findings from each phase of research for synthesis to arrive at key statements about the perceptions towards outsiders in Majority World countries.

3.3.   Ethical Considerations

Ethics are a set of moral principles that guide behaviour and influence how activities are conducted. Ethical issues exist in all research (Orb et al., 2001). As such, ethical considerations are a fundamental aspect of any research project. Thinking specifically about research in Majority World countries, there have been discussions about the ethics of conducting clinical research in Majority World countries (Edejer, 1999; Emanuel et al., 2004). This section describes the broad ethical considerations taken for the study, before describing specific ethical considerations linked to the research methods in chapters 4 and 5.

Ethical approval

Ethical approval was granted by Manchester Metropolitan University in February 2014. Ethical approval was also sought in Uganda from Makerere University and the Uganda National Council for Science and Technology (UNCST). Approval from Makerere University was granted in July 2014, and UNCST approval request was submitted in March 2014 and the study was approved in January 2015. (See appendix 1 for all ethical approvals).

<u>Confidentiality</u>

All participants' right to privacy and confidentiality was maintained through the anonymisation of individual names and some organisation names. Records of all participants were anonymised and stored securely on a password-protected computer. Confidentiality was also maintained throughout the data collection periods. Due to the countries' unique situations and small population of the participants involved in both phases of research, there was the potential for deductive disclosure (Kaiser, 2009). In the event of there being a potential lack of confidentially, it was decided that data could either be edited or removed, whilst retaining the substance of the data, to protect participants. As the Director of Studies (DoS) personally knew some of the participants, it was decided that in these cases the DoS would not see data from these participants, and in place the other research supervisors would have had access to these if necessary.

3.4   **Research quality**

Because positivist epistemology has historically been the dominant and more established approach, concepts of research quality have traditionally been based on quantitative concerns and terminology, namely reliability and validity (Golafshani, 2003). Reliability is essentially defined as the repeatability of research: the consistency with which a study could be re-mounted by another researcher with similar or identical results (Braun and Clarke, 2013). Validity is defined as the accuracy of measurement in research: how accurately a study reflects the reality of its research subject (Braun and Clarke, 2013).

However, within qualitative research the appropriateness of these terms is debated (Mays and Pope, 2000) as they are grounded in positivism and objectivism epistemology. For example, to ensure reliability, it is crucial to minimise the influence of the researcher, and ensure measurement tools not be influenced by the researcher, participants or the research context (Braun and Clarke, 2013). In their place, Lincoln and Guba (1985) introduced the concepts of credibility, transferability, dependability, and confirmability to foster the trustworthiness of research. Lincoln and Guba's (1985) four concepts are summarised as:

Credibility: Does a study show what it claims to show? Do the results capture the reality of its research subject?

Transferability: Does a study have universal applications? Can its findings remain useful in other contexts?

Dependability: Can a study be repeated with similar or identical findings?

Confirmability: Are the results of a study free from researcher bias?

Within mixed methods research, Bryman (2006) suggested quality criteria can be:

1. Convergent: which uses the same criteria for qualitative and quantitative components
2. Separate - which uses different and operate criteria for qualitative and quantitative components
3. Bespoke - in which new criteria are created for mixed methods.

Although the use of bespoke quality criteria would have helped to incorporate quantitative and qualitative data, and would have left the option of putting greater emphasis on the qualitative data, convergent criteria was selected. As the quantitative component of the study was relatively small, convergent criteria were judged to be more grounded and aligned in the researcher's overall interpretivist theoretical perspective (Bryman, 2006). As the qualitative component of the overall research study significantly outweighed the quantitative component, Lincoln and Guba's (1985) measures of quality were used as a framework to guide the rigour and evaluate quality.

3.4.1 Enhancing research quality

As described above, Lincoln and Guba (1985) suggested a number of ways to promote trustworthiness and rigour in their seminal work. The suggested techniques will be outlined, with a description of how the researcher used the techniques to enhance the research quality. Firstly, for ensuring rigour in

attaining credibility, Lincoln and Guba (1985) suggested the following techniques:

<u>Prolonged engagement</u>

This refers to the researcher taking sufficient time in order to understand the phenomena in question. Lincoln and Guba (1985) suggested that, over time, a researcher should blend into the setting with participants. This means that any participant observation field notes should be generating new observations, rather than the researcher's preconceptions. The researcher should also build trust and rapport with participants: essential to successful interviews.

During the interview data collection process, the researcher needed to be able to respond to challenges from both 'defensive' participants (who act defensively when threatened by research) and 'conventional' participants (who value research and are keen to contribute) (Goldman and Swayze 2012:232). At several points during data collection, participants had questions or expressed concerns about the nature of the research (such as the use of terminology). Here, they were invited to discuss alternatives and challenges. Interview topic guides were shared with participants, with the aim of putting participants at ease and also to signal professionalism to the participant (Goldman and Swayze, 2012).

While any interview or interaction is always grounded in both people's identities, some interviews may be more influenced by age, gender, nationality and race issues than others. Some of these factors may contribute to a power imbalance (Goldman and Swayze, 2012). In the case of interviewing professionals with high status, the researcher's strategy for rapport building was to assume a subordinate, deferential position within the interview rather than challenge them and potentially threaten the relationship and interaction. Assuming a lower status allowed the researcher to ask questions that may have been more challenging to ask if the researcher assumed (and was considered to possess) a higher status.

Triangulation

Lincoln and Guba (1985) suggested three levels of triangulation to improve credibility: triangulation of method, triangulation of sources, and triangulation of analysts.

Triangulation of method

Through the use of mixed methods, several methodical frameworks were applied to the research. Although the use of multiple and mixed data collections can aid overall corroboration, any measures to do so should be grounded within the overall context of the research (Barbour, 2001). Rather than triangulation, within qualitative research, this might be better considered as complementary perspectives or findings. In the case of non-complementary or contradictory findings these can co-exist within the principles of relativism (Barbour, 2001). Combining methods will also provide more viewpoints / perspectives of the phenomenon being researched (Barbour, 1998). The use of multiple mixed methods was relevant and the most appropriate way to answer the research aim.

Triangulation of sources

Lincoln and Guba (1985) suggested using a range of different sources from different times and settings to strengthen rigour surrounding a study's credibility. For this study, a range of sources were used for the document analysis. For the participant observation and interviews: participants were observed and interviewed in different settings, and across time (the in-situ research for phase one was conducted over a whole year in two separate visits to Uganda).

Triangulation of analysts

Lincoln and Guba (1985) suggested using multiple analyses and multiple analysts to review findings, to ensure a lack of researcher bias. This was approached during the supervision process, when the researcher intensively discussed and examined the themes of the research to allow for further interpretation and debate.

Peer debriefing

In a similar vein to their Triangulation of Analysts, Lincoln and Guba (1985) also suggested Peer Debriefing as a technique for promoting rigour: using conversation to discuss and explore elements of the research 'implicit within the inquirer's mind' (Lincoln and Guba, 1985:308). Once again, the researcher used supervision sessions to provide peer debriefing.

Negative case analysis

Negative case analysis, according to Lincoln and Guba (1985), is the conscious search for outlying or contrary themes within the data as a balance against implicit researcher bias. The researcher demonstrated this technique in two ways. Firstly (through document analysis), the researcher was able to examine many contradictory versions of events in order to build a timeline of services for SLT in Uganda. Secondly, when analysing interviews, the researcher consciously searched for, identified and included contradictory segments between different interviewees.

Member checks

Furthermore, Lincoln and Guba (1985) suggested Member Checking (the checking of data, results, findings or conclusions with either the original participants or other group members) as a final method of ensuring rigour in terms of a study's credibility. Although not achieved formally, the researcher approached member checking throughout the research process by exploring, discussing and clarifying the themes and findings with the key participants she was in contact with as part of a clinical support group for Ugandan trained SLTs using Whatsapp and collaborative papers with Ugandan trained SLTs (Sowden and Musasizi, 2017; Sowden et al., 2016).

The second of the four quality measures that Lincoln and Guba (1985) suggested is transferability. Lincoln and Guba (1985) suggest using in-depth description of a phenomena as a method of providing enough cultural context to ensure research is understood enough for its results to be applicable in other settings. The researcher's use of multiple methods for phase one of the research allowed for a rich description of the phenomena. These findings were then used to create the phase two survey (which, in turn, allowed for testing the transferability of results in other contexts: in this case, other countries).

The third of the four quality measures suggested by Lincoln and Guba (1985) is dependability. In order to promote dependability, Lincoln and Guba (1985) suggest a process of External Auditing (having the research examined by a secondary researcher who is not invested in the original project). Again, as part of the supervisory process the researcher was able to benefit from the external support of a team of researchers, aiding this distancing process.

The fourth quality component that Lincoln and Guba (1985) suggested is confirmability. There are several techniques suggested to promote confirmability.

<u>Triangulation</u>

As well as enhancing credibility, Lincoln and Guba (1985) suggested that Triangulation should also be used to enhance confirmability (the separation of a study free from researcher bias). As discussed above, the study used three degrees of triangulation: triangulation of method, triangulation of sources, and triangulation of analysts (see above for details).

<u>Reflexivity</u>

Alongside Triangulation, Lincoln and Guba (1985) suggested a reflexive approach: a researcher's of continual self-reflection, particularly regarding the researcher's own perceptions, positions and potential prejudices. Practically, the researcher engages in self-critique and appraisal, and explanations of their experiences in how they did or did not influence the process of research (Dowling, 2007).

Whereas some theoretical approaches require a researcher to aim to suspend their cultural beliefs and influences (often referred to as bracketing, as described in 3.2.2), this is considered problematic in a hermeneutic phenomenology approach. Instead of bracketing, hermeneutic phenomenology allows a researcher to embrace and reflect on their own perspectives (Crist and Tanner, 2003). Reflexivity is important because it not only allows personal insight to add to the research, but declaring preconceptions reduces the likelihood of bias in research (Malterud, 2001). In this study — particularly

considering the legacy of colonialism — it was important to be continually reflexive as the researcher collected and interpreted data. Wall et al. (2004) describe how keeping a reflexive diary can assist the researcher in having a reflexive orientation, and so the researcher used this as a tool to aid understanding of their own position and interpretation of the issues raised in the research (see appendix 2 for excerpts). The researcher was aware that, by her own definition, she was an outsider, and aware that this affected her experiences with participants and the data collection process (as mentioned in the section on prolonged engagement in this chapter, which will be discussed more extensively in appendix 13).

The researcher reflected on the data produced from both participants and documents to consider the possible threats to validity (Jupp, 2006). This included reflection on the researcher's own position, including her age, gender, profession as an SLT, outsider status, and relation to the mentoring project in Uganda (to be described in 4.2.11).

In summary, the researcher used a number of strategies in order to enhance the research quality and rigour. Formal and informal discussion with participants and supervisors supported the research quality. Discussions with key participants supported member checking, where the researcher sought to clarify findings with a range of key participants in order to enhance rigour. Supervision gave the researcher time to discuss data, themes and findings to member check, as well as providing opportunities for external auditing and promoting credibility and dependability. The use of several mixed methods and data sources, supervisory discussion, and triangulation, further enhanced rigour, transferability and confirmability. Use of a reflexive diary assisted confirmability by giving the researcher the opportunity to develop her insights as well as state her beliefs, preconceptions and experiences, to reduce bias. Actively looking for contradiction within data sets and across the different data sets and findings allowed for negative cases to be explored. Rapport building, using open conversation with participants, allowed for the researcher to become accepted in order to collect accurate observations.

3.5   Summary

To conclude this chapter, the researcher's approach is shown in Table 3.3.

Table 3.3 Philosophical approach

Epistemology	Constructivism	
Theoretical perspective	Interpretivist (hermeneutic phenomenological)	
	Phase 1	**Phase 2**
Methodology	Ethnographic case study	Pilot study: Case study survey research
Methods	1.1 Document analysis 1.2. Interview 1.3. Participant observation	2.1. Survey

This shows the researcher took a constructivist approach; an interpretivist hermeneutic phenomenological theoretical perspective; used a two phase, case study (using both ethnographic case study and case study survey research approaches) multiple-mixed methodology; and used the methods of participant observation, interviews and document analysis for phase one and survey for the phase two pilot study.

This chapter has outlined the research aims, with the study's philosophical assumptions, including the epistemology, theoretical perspective, methodological approach and methods. It justifies the use of a two phase, mixed method research study. The next chapter will discuss the first phase of research in terms of the case setting, methods used, results and discussion.

4   Phase one: ethnographic case study - Uganda

4.1   Overview

This chapter describes the phase one study. It gives an overview of the ethnographic case study in Uganda: describing the country setting and the specific services for PWCD in terms of their history and modern day availability in section **4.2.** Section **4.3** describes the specific aims and objectives for phase one and the methods used. Section **4.4** focuses on the phase one results. Section **4.5** presents a discussion of the phase one results. This chapter concludes in section **4.6** with the chapter summary.

4.2   Phase one country background

The Republic of Uganda's most recent Human Development Index (HDI) ranking is 0.456, positioning the country at 161 out of 187 countries and territories — low in the UN's human development category (United Nations Development Programme [UNDP], 2013). The following sections provide an overview of Uganda as a nation, covering geography, history, demographics, economic background and describing Uganda's health and education systems. For more in-depth information on these areas, see appendix 3.

4.2.1 Country geography

Uganda is a land-locked East African country, bordered by South Sudan, Kenya, Rwanda, Tanzania, and the Democratic Republic of the Congo.

4.2.2 A brief history of Uganda

In pre-colonial times, the area covered by present-day-Uganda comprised many autonomous ethnic groups, from the monarchical Bantu-speaking cultures of Lake Victoria to the chiefdoms and non-centralised societies of the East and North (Amnesty International, 1989). In 1884 the area was annexed by the British Empire, who used the colony to grow and export cotton (Reid, 2017). The country's name, Uganda, derives from a British mis-pronunciation of the Bugandan tribal kingdom (Reid, 2014).

Uganda gained independence from Britain in 1962, experiencing political turbulence and shifting regimes until current president Yoweri Museveni gained

power in 1986, reinstating democracy and overseeing a period of relative stability (Central Intelligence Agency (CIA), 2014). Through participation in the International Monetary Fund's Economic Recovery Programme, Uganda has secured approximately $700 million per annum in international aid and investment since 1991 (CIA, 2014).

4.2.3 People and population

Uganda has a population of 34.6 million (Uganda Bureau of Statistics, 2016) with an additional refugee population from South Sudan, the Democratic Republic of the Congo, Burundi, Somalia and Rwanda, which in 2017 totalled more than 1 million people (UN High Commissioner for Refugees, 2017).

Uganda is a multi-lingual society with 63 languages / dialects stemming from three language families - Bantu, Sudanic and Nilotic (Mukama, 2009). The two official languages are English and Kiswahili, though Ugandans typically use many languages with varying proficiency (Mpuga, 2003). In 1995, Uganda recognised Ugandan Sign Language as an official means of communication used by 25,000 people, typically in urban areas (Lutalo-Kiingi, 2014).

The people of Uganda identify themselves as originating from 19 main ethnic groups (Otiso, 2006). The largest ethnic groups in Uganda are Baganda (16.5%); Banyankore (9.6%); Basoga (8.8%) Bakiga (71%); Iteso (7.0%); Langi (6.3%); Bagisu (4.9%); Acholi (4.4%); Lugbara (3.3%) (Uganda Bureau of Statistics, 2016). Over 99% of Ugandans identify as religious: Catholicism (39.3%), Anglican Protestantism (32%), and Islam (13.7%) comprise the largest groups (Uganda Bureau of Statistics, 2016).

4.2.4 Economy

Although rich in natural resources (minerals and oil) Uganda's main economy is agriculture, which employs 80% of the working population (CIA, 2014). 69% of the population depend on subsistence farming as their main source of livelihood (Ugandan Bureau of Statistics, 2016). Despite this, only 10% of the land is considered to have a high production (Otiso, 2006). 0.5% of the Ugandan population have professional occupations (Ugandan Bureau of Statistics, 2016).

Although markers indicate a decrease in poverty since 2002 (Daniels and Minot, 2015), Uganda has a high poverty rate, with a household income of $US 1 per day for 34% of the population (CIA, 2014). Child labour continues to exist in Uganda despite significant recent legislation to limit its practice (Bureau Of International Labor Affairs, 2016). Child labour is most prevalent in agriculture. Currently, 30% of Ugandan children aged 5-14 are estimated to be engaged in child labour (Bureau Of International Labor Affairs, 2016).

4.2.5 Politics

Uganda's highest political office is President. Free elections were introduced by President Yoweri Museveni in 1996. Despite this ostensible democracy, Amnesty International's 2017 International Report identifies current human rights violations in Uganda including restriction of political freedom, unlawful killings by security forces, and the suppression of LGBT rights events (Amnesty International, 2017). Under the influence of American Evangelical Christianity (Gettleman, 2010), Uganda has aggressively criminalised and punished homosexuality. Ugandan Minister for Ethics and Integrity, James Nsaba Buturo, has been quoted as saying, 'homosexuals can forget about human rights' (Gettleman 2010:online). The government's 2014 Anti Homosexuality Act affects people seeking healthcare (Beyrer, 2014): a potential disaster in a country where 14% of gay men are HIV positive (UNAIDS, 2014).

4.2.6 Infrastructure

According to the World Bank, Uganda spends 11% of its GDP on infrastructure development (Ranganathan and Foster, 2012). Uganda has relatively well-developed sanitation, power generation and water infrastructure, but other areas (including transport infrastructure and road maintenance) are still underfunded and under-developed (Ranganathan and Foster, 2012). The rural / urban divide is stark. Agricultural workers are often required to walk miles every day across gravel tracks, in order to trade and earn a living (World Bank, 1995). In terms of access to technology, the majority of Ugandans (55%) access news and information by radio, with only 7.3% accessing news and information through the internet (Ugandan Bureau of Statistics, 2016).

4.2.7 Education

Though traditional education has long existed in Uganda (Kristensen et al., 2003), formal education was introduced by Christian missionaries in the 1880s (Ssewamala et al., 2014) and schools were established in the early 20th century (Ojijo, 2012). The Catholic missionaries who ran these schools exclusively targeted the children of Ugandan chiefs in order to advance the influence of Christianity (Ojijo, 2012). The British expanded education in 1924 but narrowed the curriculum to focus on vocational and community skills: a shift many colonial historians have interpreted as racist and subordinating (Uchendu, 1979, cited in Ojijo, 2012).

In 1997, Uganda launched a policy of universal primary education (UPE), guaranteeing seven years of primary education to all children (Ssewamala et al., 2014) and raising literacy levels to 77.2% (Ugandan Bureau of Statistics, 2016). Universal secondary education (USE) was introduced in Uganda in 2007 (Ugandan Bureau of Statistics, 2016). In spite of this, Uganda has some of the highest student-teacher ratios globally (Deininger, 2003) and 13% of children, disproportionately girls, are still unable to access UPE (Ugandan Bureau of Statistics, 2016) as a result of rural poverty and poor infrastructure (Ssewamala et al., 2014).

At the tertiary level, universities in Uganda experience a number of challenges. Following the developments of UPE and USE, universities have had to rapidly expand over a period of a single decade (Otiso, 2006). Otiso (2006:8) noted that challenges to tertiary education included 'poor student supervision, inadequate funding for classrooms, dorms, sewerage and other infrastructure, equipment and libraries.'

Unfortunately, Uganda's schools for people with disabilities (PWD) do not meet the minimum educational standards of the Ugandan Education Standards Agency (Kristensen et al., 2006). The majority of schools for PWD are boarding schools, whose long distances from students' communities often reduces the contact with families (Kristensen et al., 2006). Furthermore, many children with disabilities do not attend school at all (Kristensen et al., 2006), for example: only 2% of Deaf children attend school (Miles et al., 2011).

4.2.8 Health

Uganda has a high infant mortality rate of 56/1000 (CIA, 2018), a maternal mortality ratio of 343/100,000 (African Health Observatory and WHO, 2016) and life expectancy at birth was 54.4 for males and 57.3 for females (CIA, 2018).

As with education, the health sector in Uganda suffered during the politically turbulent 1970s and 1980s (Zaramba, 2006). Under Museveni's rule, the Ugandan government introduced user fees and began channelling foreign aid money into the health sector (decisions which raised concerns about PWD's access to services and the potential of donors influencing health policy and spending (Tashobya et al., 2006)). Addressing concern from aid organisations regarding spending and administrative problems, Museveni's government re-structured the health service in 2001, dividing it into separate state and private sectors (Zaramba, 2006).

Uganda operates a multi-tier system for healthcare access, designed to deal with minor health problems locally while passing more complex cases up to an appropriate level (Kavuma, 2009). In practice, however, this system often breaks down through geographical obstacles, lack of resources and localised corruption (Kavuma, 2009). The restructuring has also caused a dearth of state-sector doctors (Kavuma, 2009) a reduction in the availability of medicine for state-sector patients (Xu et al., 2006), and the charging of illegal fees to state-sector patients (Nassaska, 2015). This, alongside a large demand for healthcare and a long waiting list at the national hospital, Mulago, has led to an estimated 50% of health services in Uganda being delivered privately (Nassaska, 2015).

Although Beyrer (2014) advocates for NGOs to not withhold or reduce aid in response to a recipient-country's human rights record, many institutions (including the US government) announced a withdrawal of healthcare funding in 2014 following Uganda's homophobic policy announcements (Butagira, 2014).

4.2.9 Disability

Uganda is considered to have relatively progressive laws concerning disability compared to other countries in sub-Saharan Africa (Yeo and Moore, 2003). Internationally, Uganda has signed legislation advocating for the rights of PWD, including the 2008 UN's Convention on the Rights of Persons with Disabilities (Abimanyi-Ochom and Mannan, 2014; Hartley et al., 2005).

Estimates on the incidence of disability in Uganda vary. The 2014 census indicated that 13.6% of the Ugandan population over the age of 5 has a disability (Ugandan Bureau of Statistics, 2016), whereas the Ugandan Bureau of Statistics and ICF international (2012) suggested that 19% of the Ugandan population have a disability. Using the population recorded by the Ugandan 2014 census of 34.6 million, this would indicate that between 4,705,600 and 6,574,000 Ugandans as having a disability. Prior to the 2001 restructuring of health services in Uganda, Wilson (1994) reported an increase in disability, particularly cognitive disabilities, because of failing immunisation programmes and a reduction in safe birthing practices.

The National Union of Disabled Persons of Uganda (NUDIPU) formed in 1987 in response to the lack of involvement and representation of PWD in the planning and execution of programmes designed to benefit them. Previously, programmes were typically performed through charitable ventures and separated PWD from their communities (NUDIPU, year unknown). NUDIPU brought together PWD and sought to challenge this top-down model of working, which resulted in over 47,000 PWD obtaining employment within the Ugandan government (Yeo and Moore, 2003).

4.2.10 Communication disability in Uganda

Communication disability in Uganda is not widely recognised. There is limited public and political awareness (I. Jones et al., 2013; Hartley, 1998). Attitudes to PWCD in Uganda vary but they are often stigmatised. I. Jones et al. (2013) discussed with two PWCDs their experiences of having acquired communication disability (CD). Here they reported being laughed at because of their disability, being perceived as having mental illness or being perceived as having the flu (I. Jones et al., 2013).

As briefly discussed in chapter 2, there is limited data regarding the prevalence of CD in Majority World countries (Wylie et al., 2013). There are general estimates for the incidence of CD in Uganda. Hartley and Wirz (2002) suggest that between 38% and 49% of all disabled people in Majority World countries may have CD. Using the previously mentioned estimated prevalence of disability of 4,705,600 as a lower estimate and 6,574,000 as an upper estimate, this would suggest that between 2,498,120 and 3,221,260 people in Uganda may have a communication disability.

4.2.11 Services for PWCD

There are limited services for PWCD within the Ugandan healthcare system (Barrett, 2010). Awareness and understanding of CD is also limited (I. Jones et al., 2013). In the absence of services and support, PWCD may be restrained within the family home, or sent away to family in rural areas (Baptist Missionary Society, 2015). Little has been written about PWCD and their carers' use of traditional medicine services, however Hartley et al. (2005) reported people with disabilities, including CDs, changed health worker or traditional healer when their disabilities failed to improve. Services for PWCD include SLT, as well as alternative or complementary services. This includes other health services such as occupational therapy, and special education schools. In Uganda, there is a high prevalence of CDs caused by diseases such as cerebral malaria; infections such as measles, meningitis and HIV/AIDS; and trauma from road traffic accidents, assaults and war (Jochmann, 2006; Alcock and Alibhai, 2013).

Starting in 1986, the main SLT service in Uganda was delivered by the UK NGO Volunteer Services Overseas (VSO) who supplied outsider SLTs (typically one at a time on a rotational basis) to Uganda's capital, Kampala (Barrett and Marshall, 2013). The first SLTs were based in Kyambogo, with later SLTs typically based at Mulago hospital, the National Referral Hospital in Uganda. This arrangement was typical of Majority World countries' services at the time which tended to rely on imported Minority World countries' therapists. Barrett (2010:2) reported that many Ugandan stakeholders felt this mode of delivery made SLT services 'inaccessible to the vast majority of the Ugandan population.' Robinson and Tumweheire (2002, cited by Barrett, 2010:6)

calculated that 90% of the PWCD seen by SLTs lived within 15 km of Mulago Hospital in Kampala. Due to this rural / urban division, over 98% of Ugandans with disabilities are geographically isolated from potential SLT assistance (Hartley and Wirz, 2002).

An alternative model to encourage sustainability was suggested in the early 2000s. To engage with local stakeholders, a two-day workshop took place to address topics such as the needs of PWCD, who would be the appropriate professionals to work with PWCD, and how best professionals could be trained to work with PWCD (Robinson et al., 2003). Here, stakeholders discussed the training of SLTs and CBR workers to work at different levels to improve access for PWCD; whether an SLT course should have international accreditation; and what educational level professionals should be trained to (e.g., Diploma, Bachelor's or Master's) (Robinson et al., 2003). Following the stakeholder workshop, the Ugandan government pledged to employ the trained professionals to work with PWCD (Robinson et al., 2003).

An SLT Bachelor's degree course was eventually established at Makerere University, the oldest Medical School in East Africa (Kiguli-Malwadde et al., 2006), with training provided by insiders (Ugandan lecturers in other disciplines) and outsiders (SLTs). Documents cite the first intake of students in 2008, and their graduation in 2012 (Barrett and Marshall, 2013). The Ugandan SLT course received students from across East Africa, with several students from neighbouring Rwanda, Kenya and Tanzania. In 2010 another stakeholder workshop explored how services for PWCD could be structured within the health and education sector, resulting in recommendations for government (Barrett and Marshall, 2013). In 2011, a mentoring project began (lead by the researcher's Director of Studies), offering support to the development of sustainable services for PWCD. This aimed to support Ugandan trained SLTs through CPD opportunities (Rochus et al., 2014).

4.3   Phase one objectives and methods

Chapter 2 discussed the rationale for the country setting for the first phase of research. Chapter 3 justified the specific methods of data collection used for this

phase. This section outlines phase one of this study, which considers how SLT education and services are viewed by insiders and outsiders in Uganda.

The overall aim of this phase of research was to investigate the processes and perceptions of collaboration between insiders and outsiders in developing services for PWCD in Uganda, with a particular emphasis on the contribution and roles of 'outsiders.' In this first phase of the research, the methodology of ethnographic case study was used (as described in chapter 2) to respond to the four research objectives seen in Table 4.1.

Table 4.1 Phase one research objectives and data collection

Objective		Data collection
1	To explore and describe the process and history of development of services for PWCD in Uganda.	• Document analysis • Interviews
2	To describe and explain outsiders' perceptions and experiences of their contribution to the development of services for PWCD in Uganda.	• Insider interviews
3	To describe and explain outsiders' perceptions and experiences of their contribution to the development of services for PWCD in Uganda.	• Outsider interviews
4	To analyse and interpret insider/outsider collaboration and working practices.	• Participant observation

4.3.1 Method 1: Document analysis

As documents can provide background information and historical insight (Bowen, 2009), document analysis was selected to best respond to the first research objective. This provided historical overview and contextualising information to aid the interpretation of the interview results (from both insiders and outsiders) and participant observation (Bowen, 2009). Although document analysis is a method commonly used in qualitative research, there is often a lack of transparency and variability in the descriptions of the procedures used, and no systematic rules to the approach (Altheide et al., 2008; Elo and Kyngäs, 2008). As such, both Elo and Kyngäs' (2008) and Hsieh and Shannon's (2005) procedures for content analysis were used as a guide to inform the researcher's procedure for the analysis of documents.

Procedure

Relevance of documents was guided by the first research objective: to explore and describe the process and history of the development of services for PWCD in Uganda. Both manual and electronic searches were used to identify potentially relevant documents which included published and accessible documents and grey literature (unpublished or published documents that have limited distribution, McAuley et al., 2000) in the public domain. Some documents had also been identified as being potentially relevant during the literature review stage (and from the identification of potential participants for interviews): these were kept for their potential inclusion in the analysis.

Searches were repeated over a 15 month period from May 2016 to August 2017. Search terms were limited to English only. To address the first research objective, specific key words were used to allow for the focused identification of potentially relevant documents. Using truncation, the key words used in combination as search terms were: *Uganda*; s*peech and language therap** and synonyms such as *speech therapy, SLT, speech and language pathol* SLP; communication disability* and similar terms such as *speech and language delay/ disorder/disability.* The following databases were selected for use: ERIC, CINAHL, PubMed, Google Scholar and Google.

Wright et al. (2015) noted a lack of guidance on the optimum selection for search databases. As such, combination of databases were used to search for specific types of documents. ERIC, CINAHL and PubMed were used to identify peer-reviewed articles in the field of health and education. Google scholar and Google were used to access more general "grey literature" documents such as conference reports and NGO annual reviews. Published and peer-reviewed articles were searched for on academic databases. The RCSLT's Bulletin was also searched from the online available editions (2003-2017). Titles and abstracts were examined for relevance. If the contents of documents met the criteria of describing Uganda plus either speech and language therapy (and synonyms), and communication disability (and synonyms), they were included for analysis. Grey literature was searched using the search engine Google. The first 30 pages of each Google search were explored to locate potentially

relevant sources to allow for the focused search of documents. As with the academic search, titles and introductory content of search results were read and included for analysis if they included Uganda and either speech and language therapy, and synonyms, or communication disability, and synonyms.

The manual literature search was conducted on a personal collection of documents regarding PWCD in Majority World countries belonging to the Director of Studies. This consisted of published and peer-reviewed articles and grey literature. These documents were read for the same key terms and inclusion criteria described above. Inclusion of both manual document searching and general web searching aimed to reduce publication bias (McAuley et al., 2000).

As the literature review revealed low numbers of documents relating to the topic area of outsider support for services for PWCD in Uganda, the inclusion worked on the basis of relevance to the topic. As such, all types of documents were considered, regardless of date. This was because searches were not expected to yield results prior to 1980, and earlier documentation was unexpected yet would have been new information based on the existing narrative of services for PWCD in Uganda. Only English-language documents were included. Duplicate or near-duplicate documents were excluded. Where documents were near duplicates, the first published or produced document would be included. Where documents had been published but had become inaccessible, authors and publishers were written to ask for permission to access documents for use in the research.

Documents

The resulting documents eligible for analysis were textual documents that described services for PWCD in Uganda, and outsiders' contributions to these. The aim was to focus on the topic of outsiders supporting services for PWCD in Uganda. Data were included from a number of different types of secondary sources in order to represent the range of perspectives. Secondary documents were predominately from outsider perspectives and efforts were made to include insider authored documents where possible. Data sources consisted of: academic journal articles; annual reports; university policy documents;

newsletters; national policy documents; project reports; university recruitment materials; volunteer adverts; NGO documents; webpages; blogposts.

<u>Ethical considerations</u>

Documents were in the public domain. Both webpages and blogs were assessed to consider the privacy level (Eastham, 2011). Furthermore, the names of specific individuals mentioned in these documents were not disclosed in the write-up or discussion, nor were individuals identifiable.

<u>Analysis</u>

All documents were analysed using content analysis. Content analysis is the most typically used approach for analysis of documents and is consistent with an ethnographic methodology (Bryman, 2012; Altheide, 1987). Content analysis can be either quantitative or qualitative. Hsieh and Shannon (2005) identified three main types of qualitative content analyses: conventional, directed, and summative. According to Hsieh and Shannon's (2005) descriptions:

Conventional Content Analysis is useful where there is limited literature or theory. It is an inductive approach, in which the researcher is immersed in the data. It avoids a preconceived coding framework or schedule. Instead, the researcher familiarises themselves with the text, making note of their initial thoughts. This process continues and the thoughts are used to develop a coding scheme. These codes are then arranged into categories of related and linked meanings. Finally, categories group codes into "clusters."

Directed Content Analysis is best used for describing a phenomenon where there is existing literature or theory, and allows for the validation or extension of a theory. It uses a coding framework which is developed from the existing theory and applied to the text. Where the codes from the framework cannot be applied to text, a new code is then assigned.

Summative Content Analysis uses an initial word/phrase search and count to calculate the frequency of the words/phrases in a text, as well as interpret the context and ways in which they are used.

Conventional content analysis was identified as being the most appropriate analysis approach for these data due to the relatively small amount of literature relating to Ugandan services and the lack of a clear existing theory about these services. Conventional content analysis has been used by a number of researchers (Blundell, 2012; Benner, 2013) for the analysis of documents, and allowed for a richer understanding of the phenomenon Hsieh and Shannon (2005).

Coding strategy

Documents were first categorised into types and numbered. Using an inductive approach, all texts were read to make note of first impressions and ideas. After all texts had been read, notes were used to create a coding schedule developed from key words and concepts from the texts and the researcher's interpretation and reflection on the documents (Hsieh and Shannon, 2005). This coding schedule was applied to all the texts. The texts and documents were analysed critically and skeptically (considering what was *not* mentioned in the texts, what was implied, and potential underlying themes or subtext (Rapley, 2007)). This approach was important as Rapley (2007:115) noted: 'descriptions are never neutral but produce a specific version or understanding of the world.' Once all texts were coded, codes were arranged into subcategories and categories organising by meaning.

4.3.2 Method 2: Interviews

As outlined in 3.2.4, semi structured Interviews were selected as the most appropriate method of data collection to respond to the second and third research objectives.

Participants

Inclusion criteria was guided by the second and third research objectives: to interpret insiders' perceptions and experiences of the contributions of outsiders and outsider support to the development of services for PWCD in Uganda; and to interpret outsiders' perceptions and experiences of their contribution to the development of services for PWCD in Uganda. Therefore inclusion criteria of participants was people who had experience of services for PWCD in Uganda, both insiders and outsiders. Insiders were defined as Ugandan nationals,

outsiders were defined as non-Ugandan nationals. Insider participants needed either to have worked or trained as part of services for PWCD with outsiders, or be parents or carers to have been a recipient of such services. Outsiders needed to have worked in services for PWCD in Uganda. Furthermore, participants needed to be competent enough in English to speak and take part in an interview (as a first or other language), and able to give voluntary fully informed consent.

<u>Sampling</u>

Purposive sampling was used to sample participants who were representative of the target population. The planned sample size was 30 (15 insiders, 15 outsiders).

Within this sample number, there were specific target groups of desired participants: aiming to capture the diversity of different roles in the target population. Table 4.2 shows the target populations and planned sample size for both insiders and outsiders.

Table 4.2 Participant interview sample

Insiders	Sample size	**Outsiders**	Sample size
SLTs	3	SLTs	9
Student SLTs	3	SLT Mentors of SLT graduates	3
University SLT programme staff	3	NGO coordinators involved in SLT programme	3
NGO coordinators involved in SLT programme	3		
Carers of PWCD who had received SLT	3		

These groups were chosen to reflect the different individuals involved within the development or reception of services for PWCD in Uganda, and the relative sizes of each groups' population. More outsider SLTs were planned for the sample as their roles included clinically practicing and lecturing on the SLT programme. The total planned participant size was appropriate due to small

target population sizes and the fact that this research was for a PhD (for which a medium-sized sample was likely to suit the time constraints, while still providing enough data to analyse effectively (Baker et al., 2012). Flexibility was allowed for, as the sample size was to be responsive to emerging data and the possibility of previously unknown participants coming to light. For example: although visiting practitioners were not part of the planned target groups, this group emerged following the beginning of the interview process and was later included.

In keeping with the ethnographic case study methodology, ethnographic principles were used to determine sample size. Ethnographic research often aims to reach a point of data saturation: a point at which sufficient participants have been observed or interviews carried out, that no new themes emerge (Guest et al., 2006). Sample size is often a factor in achieving saturation, as is the diversity of the population (Mason, 2010). Although the small sample size could have appeared to preclude saturation, the sample formed a relatively large proportion of the population of insiders and outsiders, considering the small number of potential participants involved in SLT services in Uganda.

Recruitment

Participants were recruited for interviews in four ways. All participants received participant information sheets (PIS) and an interview topic guide (ITG) which described interview topic areas (see appendices 4 and 5).

1. Direct contact. An outsider-led CPD training event for SLTs and allied professionals was hosted in a Ugandan University. Here, the research was introduced and interviews were arranged and scheduled. Participants had the opportunity to ask questions about the research.

2. Direct contact. Email was used to contact potential participants who were identifiable (and contactable) online due to their public roles in relation to services for PWCD in Uganda.

3. Snowballing. Potential participants were asked to suggest and identify other potential participants who met the inclusion criteria. PIS and ITG were given to

the initial participants to pass on to potential participants. Following contact with new potential participants, interviews where then offered and arranged.

4. Via gatekeeper. A participant from the CPD training acted as a gatekeeper. A PIS and ITG appropriate for parents or carers (see appendices 4 and 5) were given to the gatekeeper who identified and accessed potential participants who were parents and carers of PWCD. The PIS and ITG were developed for participants with limited literacy skills. For these individuals, the PIS was also read out to participants.

After providing PIS to potential participants, all participants were given a minimum of 24 hours before they were contacted again by phone or in person to ask if they wanted to continue. If, after this period of consideration, participants still wanted to take part in the research, consent forms were signed (see appendix 6) prior to interviews (either in person for face to face interviews, or digitally for phone or Skype interviews).

<u>Ethical considerations</u>
Issues of power were important to consider as an outsider. Although there are potential difficulties in using gatekeepers to access participants (Sixsmith et al., 2003), this measure helped to minimise potential coercion to take part in the research as a result of power dynamics between themselves and an outsider researcher. One participant from the CPD training session acted as a gatekeeper to recruit and gain consent of parents or carers of PWCD.

Furthermore, the researcher's Director of Studies (DoS) knew a number of people involved in supporting services for PWCD in Uganda through her role as the project lead on the mentoring project described in 4.2. It was important to ensure participants did not feel obliged to take part in the research. Participants were given PIS and reminded of their right to not take part in the research.

Informed consent was achieved by providing details of the research, how data was to be collected, and how it was to be used in a clear and comprehensible way to potential participants (Sanjari et al., 2014).

The provision of ITG gave participants an overview of the topic areas to be explored and aimed to reduce the power discrepancy between the roles of interviewer — participant (Allmark et al., 2009). As described in 3.3, measures were undertaken to ensure participant confidentiality. This included anonymisation of all interview data.

Data collection procedure

Interviews were scheduled to take place in venues which were convenient and safe for both the researcher and participant. MMU lone worker policy was followed (MMU, 2006). Interviews took place across a number of settings, including a University campus, participants' homes and participants' children's school. The majority of the interviews with insider participants took place in Uganda, with one interview with a Ugandan participant conducted from overseas over the telephone. Two insider participants wanted to be interviewed in person together and this wish was respected. Outsider interviews took place face-to-face in Uganda or in the UK, or over Skype. Semi-structured interview data were collected over a 15 month period from March 2014 to June 2015.

Both insider and outsider interviews were scheduled to last approximately an hour and followed the same procedure. The interviewer used topic guides (see appendix 5) to allow for focused and structured questions to lead to purposeful conversations about outsiders' contributions to sustainable services for PWCD in Majority World countries. Interviews were structured to begin by thanking the participant for their time, and then reading through the purpose of the interview and interview facts. Participants were again reminded of their right to withdraw at any time. Following this initial information, recording began using a dictaphone (Olympus Vn-731pc). Brief notes were made to follow up interviewees' comments in further detail, so as to not interrupt the flow of the interviews. On completion of each interview, participants were asked if they had any further comments or questions for discussion then thanked again for their participation.

Audio files of the interviews were uploaded onto the researcher's password-protected laptop then deleted. Audio files were played using Quicktime (version v10x) and transcribed verbatim into a Pages document (version 5.2). Where

speech was unintelligible after 5-10 listens it was not transcribed and marked by "XXX" in the transcript. Paralinguistic features such as body language, gestures and tone of voice were added (in brackets) to accompany the transcription for face to face interviews. Participant names and identifying information were not transcribed to maintain confidentiality. Where participants wanted to speak off the record, conversations were not transcribed or used as data (so as to respect participants' wishes). This happened in two interviews.

Data analysis

Thematic network analysis (TNA) was identified as the most appropriate method of analysis. The method of data analysis needed to be consistent with the overall philosophical approach of the research. Qualitative analysis is used to interpret data and themes to aid the understanding of the phenomena being explored (Sargeant, 2012). A number of analysis protocols were considered.

Thematic analysis is an umbrella term for method for the identification, analysis and reporting of patterns in data (Braun and Clarke, 2006). There are different types of thematic analysis: inductive, theoretical, experimental or constructive (Braun and Clarke, 2013). Although thematic analysis is commonly used in qualitative research, there is a lack of information and agreement about what it is and how it is done (Vaismoradi et al., 2013). Thematic network analysis (TNA) is a method for analysing data to arrive at themes ordered in a hierarchy of web like constructions called networks (Attride-Stirling, 2001). This method of analysis was developed as an interpretive tool, with clear procedures which may be lacking in other types of thematic analysis (Attride-Stirling, 2001). TNA was selected as an appropriate approach because, as a novice researcher, TNA offered a transparent approach for the analysis of data, which would in turn enhance replicability of the research.

Following the complete transcription of interview data, the Pages document was exported into NVivo (version 10.2.2). Each transcript was then was read and re-read to allow for the familiarisation of the text, then analysed according to the 6 stages of TNA. The process of the TNA approach used is summarised below using the stages described by Attride-Stirling (2001):

1. Coding

Separate coding frameworks were devised for both insider and outsider interview data. These were created using recurrent topics from the data following familiarisation with the texts. Codes from the framework were then applied to sections of the transcript: sometimes passages, sometimes just a few words, depending on the content. Insider data were coded first, following the first visit to Uganda.

Subsequently, the remaining insider interview transcripts were collected during the second visit to Uganda, and were coded following their collection. The outsider interview transcripts were coded following the collection of the outsider interview data set. Analysis of insider and outsider transcripts followed the same process: each transcript was read from beginning to end in order to familiarise the researcher with the text so as to devise a coding framework. Each data set was worked on in this order following an inductive approach to TNA — allowing the coding framework to use recurring issues from the participants' transcripts.

2. Theme Identification

Once all data were collected and coded, basic themes were identified by reading the text for each code, and abstracting themes from the identification of underlying patterns and structures. Themes were then refined to be specific and unique, whilst being general enough to represent ideas from many codes.

3. Network Construction

Basic themes with shared features or similarities were grouped into linked networks. These were then arranged into organising themes, by grouping similar basic themes and naming the organising theme on the issues described by the basic themes. Global themes were deduced by summarising the assumption of the linked organising themes. These themes were then organised into "webs" to produce each thematic network. The texts from each basic theme were read to check representation by each organising and global theme.

4. Network description

Each of these networks were described: a process involving a re-reading of the original text through the lens of the newly constructed networks, interpreting with a particular eye to emerging patterns.

5. Summary of the thematic network

At this stage, each network was summarised: with each network's main themes, patterns and motifs identified and illustrated.

6. Interpretation

Finally, the emergent themes and patterns from each network were brought together and reviewed in light of the original research objectives.

Transcripts were imported into NVivo which was then used to facilitate coding of each transcript. Due to the large number of codes generated, for both insider and outsider interviews, the NVivo codes were explored and grouped manually, using pen and paper. This low tech option was also used to enable basic themes to emerge and to construct the network.

Insider and outsider data were analysed separately, as initially more insider interviews were completed. As part of the supervisory process, a sample of quotes and themes were discussed with the supervisory team and compared with the researcher's analysis. Following separate analysis, insider and outsider results were synthesised as part of the discussion (section 4.5).

4.3.3 Method 3: Participant observation

The third research objective was achieved through engagement on a mentoring project the DoS was leading (described in 4.2.11). This objective was addressed using participant observation. Merriam (1988) described participant observation as an appropriate method of data collection when situations are directly observable. Opportunities to engage in participant observation were limited and therefore this was a comparatively small data set (compared with both sets of interview data and the documents from the document analysis), but was nonetheless felt to offer a valuable additional perspective.

As part of the mentoring project, CPD activities of classroom-based training and practical clinical training were observed (these settings are described in more detail below). Observations were unstructured but organised in a template to separate direct observations of actions, such as dialogue and behaviour, and the researcher's initial interpretations. It was decided to use unstructured observations as this approach was again in line with the epistemological and theoretical philosophy of the research and researcher worldview. Mulhall (2003) noted that unstructured observation is often wrongly associated with thoughtlessness or a lack of rigour, especially from a positivist perspective. However unstructured observation, like unstructured interview, aims to avoid influence of predetermined thought. The aim of these observations was to explore and analyse insider and outsider collaboration and working practices.

Participants

As in the previous approaches, insider participants needed to have worked in, or received, services for PWCD with outsiders. Insider recipients of services for PWCD needed to either be a parent or carer or PWCD over the age of 18. Outsiders were people who had worked in (or were involved with) services for PWCD in Uganda. Furthermore, participants needed to be English speakers (as a first or other language) and able to give informed consent.

Sample

Opportunity sampling was used to sample the target population. Attendees of the CPD training event for SLTs and AHPs working in East Africa were invited. Insiders were East African nationals, outsiders were foreign nationals.

Recruitment

Participants were recruited either directly by the researcher or with the help of a gatekeeper. For the classroom based observations, on the first day of each of the two visits' field situation, the researcher told all attendees about the research and Participant information sheets (PIS) were then distributed (see appendix 4). For clinical based observations, the gatekeepers (an employee in one of the two settings) identified and approached potential participants (three PWCD, parents or carers) to offer invitations, distribute PIS and gain consent of

PWCD for the field situation of practical clinical work. Participants had the opportunity to ask questions about the research.

Ethical considerations

There were a number of ethical considerations of the participant observation method that mirrored considerations of the interview method. As with the interview method, it was important to consider issues of power as an outsider and to minimise the potential for coercion. This was addressed by the use of a gatekeeper to access, recruit and gain the consent of PWCD or their parents/ carers.

As the mentoring project was organised by the researcher's DoS, there was some duality of roles while conducting observations. As with the interviews, it was crucial that participants did not feel obliged to take part in the research. Participants were given PIS and reminded of their right to not take part in the research. Informed consent was achieved by using PIS for all potential participants. Two PIS were distributed: one for both insiders and outsiders, one for participants with limited literacy skills. Information on these sheets was also read to participants in order to ensure understanding. Participant consent was sought and confirmed through participant consent forms (see appendix 6). Participants were aware of their rights to withdraw at any point from the research.

Although transparency with participants had the potential for observation bias (Schwartz and Schwartz, 1955), it was a deliberate ethical decision to inform all participants of their involvement in the study, thus overt participant observation was the preferred method. As an outsider in terms of the research and in terms of not being a full group member, the potential for observer bias may have been diminished. Throughout the participant observation, participants had the opportunity to ask questions about the research, and were aware of their right to withdraw at any stage. Anonymisation of data was ensured by avoiding participants' names in field notes, and instead assigning each participant a code.

<u>Data collection procedure</u>

Both sets of observation included CPD training, consisting of both classroom-based training and practical clinical training with clients with CDs.

The first set of participant observations was completed during the first field visit to Uganda by the researcher. This observation took place over five days of CPD training delivered by two outsider SLTs, to 13 attendees (Ugandan, East African or outsider SLTs or health professionals). Observations were completed of both classroom-based training in a local university, and practical clinical training in a local hospital. Here the practical clinical training was with clients with dysphagia.

The second set of participant observations was completed during a second field visit to Uganda. This observation consisted of five days of CPD training delivered by one outsider SLT to seven attendees (Ugandan, East African or outsider SLTs or health professionals). Observations were completed of both classroom-based training at a local university, and practical clinical training with children with PWCD in both school and nursery settings. Here the practical clinical training was with insider and outsider SLTs working with school and nursery aged children with CDs. Observations from these settings allowed for the dynamics of both training roles and practical intervention roles to be observed. A total of four different settings were part of the participant observation across the two visits and can be seen in Table 4.3.

<u>The researcher role in participant observation</u>

Junker (1960, cited in Merriam, 1988) described four main approaches a researcher can take when collecting participant observation data. These approaches comprise: Complete Participant (in which the observer is a fully fledged, undercover member of the group being observed); Participant as Observer (in which the observer is a fully fledged member of the group under observation but the group is aware of the observer's activities); Observer as Participant (in which the observer's participation in the group is subordinate to her activities as observer); and Complete Observer (in which the observer has no active role in the group, often being physically hidden from the participants).

As she was unknown to the majority of participants prior to the commencement of research (and therefore not a fully fledged group member), the researcher for this study classed herself as an 'Observer as Participant': a role which allowed the researcher to both observe and interact with participants.

Table 4.3 Participant observation

	Type of CPD	Days	**Insiders**	**Outsiders**
Visit 1	Classroom-based training	5	10	4
	Clinical CPD in hospital	1	13	3
Visit 2	Classroom-based training	2	7	2
	Clinical CPD in school or nursery	2	7	2

Participant observation materials

Audio or visual recording of observations were avoided as this was felt to be too distracting. Instead, observations were written. An observation template was devised to organise observations and serve to prompt to record the setting, the participants, the activities and interactions (Merriam 1988). This allowed for a rich range of information to be recorded detailing setting, participants, and the specifics of interactions and activities. This helped the researcher move from descriptive observations to more focused and finally selective observations (Angrosino and DePerez, 2000). During classroom-based training, the researcher typically sat away from attendees when making field notes, apart from when included in activities with the attendees (such as giving out papers and practising clinical assessments in groups). In the clinical CPD training sessions, the researcher typically sat with attendees to take part in the arranged activities (assessing PWCD in small groups and giving feedback to attendees).

Field notes

Field notes from both visits and scenarios were handwritten in a notebook. An observation framework was used to help record the researcher's observations.

This used a small table layout to separate direct speech, observations and interpretations (see appendix 7). As the focus of the participant observation was insider and outsider collaboration and working practices, the field notes recorded the following information: *who* was being observed (by assigning participant numbers to refer to each group member); the *type* of observation (an observable action, such as speech, body language or movement); *what* was observed (direct quotations from participants, and records of their other activities such as using phones or leaving the room); and the researcher's *initial interpretations* of the observations (such as perceived group member frustration). In addition to recording participants' activities, details of the settings were also recorded: descriptions of the rooms, the participants, how people were arranged (e.g., mapping seating positions), in order to help contextualise the data (Merriam, 1988). Where direct quotations were used, every effort was made to capture what was said verbatim. Only directly observed behaviour (such as participants' speech and actions) were analysed. The initial researcher's reflections were used to contextualise information. When the researcher had an increased participant role in the group — and live field notes were unable to be taken — these notes were instead made during less active periods or at the end of the day. Both sets of field notes produced from the participant observations were typed up on to a password protected computer following each visit to Uganda.

Analysis:

Thematic Network Analysis (TNA) was selected for the data analysis of the participant observation data. TNA was once again consistent with the epistemology and theoretical philosophy of the research and researcher. Use of the same analytical framework as the interview data would also allow for closer comparison and integration of the interview and participant observation results.

Written field notes were typed into separate Pages documents for each one day session, and exported into NVivo. Direct quotes and descriptions from the field notes were open coded according to Attride-Stirling's (2001) process for TNA to build thematic networks (as described in 4.3.2). This allowed for the interpretation and exploration of the data, as well as allowing for closer

comparison with the networks produced from the interview data. From here, the same process of TNA as described in 4.3.2 was followed to analyse both the participants' direct speech and actions. Where the researcher's reflections had been recorded at the time of observation, this was used to guide the interpretation and analysis.

4.4 Results

This section of the chapter presents the results of each data set. Firstly the document analysis, then insider interviews, outsider interviews and participant observation.

4.4.1 Document analysis results

A total of 74 documents were included in the analysis. Documents were each numbered D1-74 in the analysis (see appendix 8). Table 4.4 provides an overview of the document types used. This also provides detail of author affiliation (insider or outsider, or a combination).

Table 4.4 Document analysis data

Type of document	Number in category	Author affiliation (insider, outsider, collaboration or unknown)			
		Insider	Outsider	Collabora tive	Unknown
Conference report	2	-	-	2	-
University policy documents	8	8	-	-	-
Newsletter	2	-	2	-	-
National policy document	1	1	-	-	-
Project report	5	1	4	-	-
University recruitment leaflet	1	-	-	1	-
Volunteer adverts	12	-	2	-	10
NGO documents	6	-	6	-	-
Webpages	10	6	4	-	-
Blogposts	4	-	4	-	-
Journal articles	11	-	11	-	-
Bulletin articles	12	1	10	1	-
Total number of documents	74	16	43	4	10

19 codes were developed from the document sources following the collapsing of similar codes and excluding codes that were not relevant to the research objective. These codes were grouped into six sub categories, which were themselves grouped into three categories: "Moving forward," "SLT roles," and "Taking the lead."

Table 4.5 Summary of document analysis codes, subcategories and categories

Code	Subcategory	Category
1. Diversity and life in Uganda	1. Ugandan context	1. Moving forward
2. Communication disability in Uganda		
3. Inclusion in policy		
1. Experiences of PWCD	2. PWCD want and need improvements in their living standards	
2. Goals for PWCD		
1.Outsider skills and experience	1. Outsider working	2. SLT roles
2. Specific outsider roles		
3. Outsider perception of their contributions		
4. Outsider motivation		
1. Need for Ugandan SLTs	2. Insiders' roles	
2. Collaborative roles and power		
1. Organisation relationships	1. Nature of services — individual, community and professional	3. Taking the lead
2. Justification of SLT need		
3. Individual help		
4. Alternatives and group effort		
5. SLT history		
6. Planning and development models		
1. Systemic needs	2. Development needs	
2. SLT profession needs		

4.4.1.1 Category 1: Moving forward

The first category covers the development of services for PWCD within the Ugandan context. This category groups three subcategories together which give an overview of the setting of Uganda, both in terms of the lifestyle, culture and

diversity of the population as a whole, and more specifically for PWCD. This category has two subcategories.

Subcategory 1: Ugandan context

This describes the importance of the overall context of Uganda. It provides a background to describe life for PWCD within a setting where services are limited, and how they are seen and treated in society. This subcategory has three codes.

Code 1: Diversity and life in Uganda

This code describes life in Uganda. It shows a variety of lifestyles, both in the different cultures and ethnicities within Uganda, and in the differences between rural and urban settings. Linguistic diversity was often seen as a further hindrance to PWCD. Contextual country information was used to orientate the reader to the specific challenges SLTs and PWCD face. Documents often described the need for equality-of-access to SLT services. Nationwide SLT distribution was a favoured goal; shock was often expressed at the capital-focused approach. The overall context was often described in negative terms, with a focus on poverty and a lack of infrastructure, services and accessibility — often in direct comparison to Minority World settings and resources (typically the UK). Documents often sought to alert readers to the authors' concern over the lack of SLT in Uganda.

> *D22. "Problems identified for practice in the region centred around… the rich diversity of the region. It is not uncommon for children to speak three to four languages"*

Code 2: Communication disability in Uganda

This code describes and explores the prevalence of CD in Uganda, and Ugandans' knowledge regarding PWCD. Topics covered by this category include the prevalence of disability in Uganda and awareness of CD / PWCD. Authors often expressed concern regarding knowledge and awareness of PWCD in Uganda. They focused both on the public, and on health and education professionals, highlighting the effects of a lack of knowledge in terms of developing services for PWCD.

> *D47. "These challenges leave communities such as those in Uganda with very few people knowing about autism, who are left with no choice but to rely on traditional or non-evidence based approaches to define, diagnose and manage it."*

Code 3: Inclusion in policy

Existing context for disability inclusion policy was described for PWD in government documents. Documents described barriers in achieving increased rights of PWD and made recommendations for how increased rights could be achieved. Although these documents generally did not make reference to either PWCD or CDs specifically in their entries, CD is a disability and this absence may be indicative of how CD is understood or prioritised in Uganda.

> *D13. "Government and Civil Society Organizations should collaborate to uplift the plight of Children with Disabilities through Special Needs Education, the collaboration will help to reduce duplication of services, planning and budgeting for the needs of Children with Disabilities."*

Subcategory 2: PWCD want and need improvements in their living standards

This subcategory explores the present situation for PWCD in Uganda, along with hopes for improvement in the situation. This subcategory has two codes.

Code 1: Experiences of PWCD

This code describes life for PWCD in Uganda, and the consequences of societal perceptions. Many Ugandans are reported to view CD as a curse or punishment, often leading to negative, discriminatory or exclusionary treatment. Bullying and harassment can be severe: resulting in children with CD leaving school. Adults were mocked and excluded. Documents were written by both outsiders, and insider PWCD as seen in the exemplar quote:

> *D16. "My academic progress was hampered by stammering and I am currently laughed at, denied sales orders, and not invited to important meetings."*

Some documents written by outsiders occasionally used language such as "victims" to describe PWCD, and framed SLT in the position of "saving" PWCD. Documents made frequent reference to PWCD being more likely than other members of society to experience abuse. They also noted the high level of stigma associated with PWCD in Uganda.

<u>Code 2: Goals for PWCD</u>

This code explores goals set in documents for PWCD in Uganda. Both outsiders and Ugandans with CD documented the need to raise awareness of CD. Authors described a need for careful sensitisation of communities to combat negative attitudes. At a national level, they described a need to raise awareness with stakeholders and policy makers. Awareness raising was seen as one way of improving quality of life and empowerment for PWCD.

Direct SLT was considered to empower PWCD in two ways. Firstly: through clinical improvement. Secondly: through connecting clients and carers in an informal support group. Though limited, this may suggest that support groups offer considerable value, especially where services are lacking. The active inclusion of PWCD in projects and planning was described in several documents as increasing their representation and stake-holding. This may suggest some collaboration is being developed using a "bottom-up" approach.

> *D15. "People with communication disabilities and their family members have been empowered by involvement"*

4.4.1.2 Category 2: SLT roles

The second category explores how SLTs saw their roles practically. As outsiders were the first SLTs in Uganda, they had a longer working history and more experience to reflect on. Documents (written mainly by outsiders) described their feelings towards insiders: commending their bravery in helping to establish a new profession. Finally, this category covers the nature of collaborative roles. This category has two subcategories.

<u>Subcategory 1: Outsider working</u>

The first subcategory describes outsiders' arrival in Uganda, their day-to-day roles, and the challenges they faced. Documents varied in describing these roles. Some favoured a one-to-one approach with clients. Others favoured awareness raising projects involving the public, health or teaching professionals; or the training of Ugandan SLTs. This subcategory has four codes.

<u>Code 1: Outsider skills and experience</u>

Whilst some organisations had specific minimum work experience requirements for outsider SLTs, other documents revealed outsiders were working in Uganda while still students (as part of a gap year) or as newly qualified SLTs. There was considerable variation in experience levels, and often a discrepancy between what Ugandan organisations or outsider NGOs requested in job descriptions and what they received. Documents varied in the level of experience requested. Though organisations often asked for a degree and post-qualification work experience, many outsiders appeared in Uganda on self-organised trips as newly-qualified or as student SLTs.

D.21 "Speech therapists - currently people with experience is preferable"

Adverts generally focused on practical skills (language ability, professional flexibility) over SLT skills and qualifications. Some adverts referenced the need for outsiders to learn local languages. Outsiders' personal webpages and blogposts often reflected on these language barriers without describing strategies or practices for navigating this issue. Flexibility was described as an important trait for outsiders — both individually and collectively — which may suggest that local-language proficiency is viewed by outsiders as beneficial, but not essential. Not learning local languages may reflect the relatively short time many outsiders spend in Uganda.

<u>Code 2: Specific outsider roles</u>

This code describes the roles requested of, and undertaken by, outsiders. Roles varied, from direct service delivery and management; to indirect roles training SLTs; to working out-of-country fundraising to support SLT services (both

insider- and outsider-led). Outsiders often detailed ways in which they supported both qualified Ugandan SLTs, and the developing profession. Although roles were generally related to experience or expertise, some organisations advertised roles or activities not normally associated with SLT in the UK. For example, some organisations required outsider SLTs to participate in wound care and other interventions associated with nursing.

Many documents refer to volunteer SLTs in Uganda. Volunteer status varied greatly between different organisations associated with outsider SLTs with some receiving a salary, other SLTs working for free, and some SLTs paying to volunteer. Different "types" of volunteer had different roles ranging from observing, to active involvement with PWCD. Length of time spent in roles also fluctuated from one week to a requested working commitment of several years. Overall, longer-term outsiders were seen as better able to make lasting, meaningful contributions to services for PWCD.

> *D29. "We'll ask you to commit to 12 - 24 months to make a sustainable contribution to our development goals."*

Code 3: Outsider perception of their contributions

Outsider authors perceived their role and experience in varied ways. Most described their commitment abroad as an "exciting adventure," where they "gave" or "sacrificed." Many were proud of their work. Outsiders typically talked about what they personally gained or learned in Uganda (detailing personal experiences or improved clinical skills) without detailing what they had contributed. Many authors made reference to "Africa" in general instead of "Uganda" specifically. Organisations and individual writers varied in their perceptions of outsiders working in Uganda. Some organisations highlighted the non-clinical or non-working aspects of being an outsider in Uganda, such as their day-to-day life or leisure activities. Such organisations typically asked outsiders to contribute financially to their time in Uganda. Leisure activities were detailed as supporting PWCD in some cases. Some documents used language evocative of travel writing.

D50. "I have had the opportunity to learn first hand about one incredible organization that is made up of some hard working, caring and creative people who are making a difference here in Kampala"

Code 4: Outsider motivation

Outsiders had varying motivations for working to support services for PWCD in Uganda. Not all authors who were writing from personal experience documented their personal motivations explicitly; those that did described a range of motives from wanting to "help" PWCD or seeing communication as part of a person's humanity, to explicitly religious callings.

D51. "…To be able to convey the love of Jesus we need to be able to communicate"

Subcategory 2: Insiders' roles

This subcategory describes how outsiders viewed both Ugandan SLTs and the Ugandan public, and how their views informed collaboration with Ugandans. This subcategory has two codes.

Code 1: Need for Ugandan SLTs

Outsider authors were generally positive and supportive of insider SLTs: praising them individually and as a profession. Outsiders described Ugandan SLTs as courageous in starting a new profession, often expressing a sense of paternalistic pride. Documents make reference for the need for Ugandan SLTs. Job descriptions made reference to desired proficiency in Ugandan languages (appearing to indicate a preference for Ugandan SLTs). Outsider praise may relate to particular challenges of completing the first course. It may also be self-congratulatory: reflecting on the outsider individuals and organisations who have collaborated in training the graduates.

D12. "After three years of dedicated study, unlimited enthusiasm, and the courage to pursue a profession that few people have heard of in Africa, the first 12 East African–trained SLTs completed their studies in December 2010[1]."

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[1] Completed their studies in 2010, with graduation taking place in 2011.

<u>Code 2. Collaborative roles and power</u>

These data describe the nature of collaboration between insiders and outsiders. Documents reveal outsiders' approval of networking as a tool for providing contacts and support. Some authors indicated they or others were unaware of the number of SLTs in Uganda. Where insiders and outsiders directly collaborated, their roles and responsibilities varied. Outsiders often took senior roles, and were often referred to in the texts as "experts." One document, however, made reference to teaching roles being taken by both insiders and outsiders. Where documents referred to insider/outsider collaboration, they described outsiders taking a facilitatory role. Insiders often wrote testimonial documents, describing how they had benefitted from outsider support.

In group collaborations, documents noted that insider organisations contributed as hosts, whereas outsider organisations often contributed sponsorship.

> *D17: "supplemented by other experts in the field of speech and language therapy and development"*

4.4.1.3 Category 3: Taking the lead

The third category explores how individuals and organisations have taken the initiative to develop SLT services. Schemes and developments have been initiated by many different individuals, groups and organisations within Uganda — justified, in each case, by the perceived need for services for PWCD. This category has two subcategories.

> <u>Subcategory 1: Nature of services — individual, community and professional</u>

This subcategory covers available and desired services for PWCD in Uganda. It encompasses ideas about how SLT has developed, potential alternatives to SLT or SLT services, and possible future changes in developing services for PWCD. This subcategory has six codes.

<u>Code 1: Organisation relationships</u>

Partnerships were described as specific relationships between individuals and organisations, both for insiders and outsiders. Authors typically thanked or acknowledged the backing they had received from NGOs — indicating supportive relationships. Some NGO documents acknowledged their partners and volunteers, which gave the impression of more equal relationships.

> *D32. "[The volunteers'] commitment and dedication to our partner organisations, our joint development goals and to [NGO] have been unwavering"*

Documents that detailed the development partnerships or working relationships tended to be authored by outsiders. Such authors described which partners had been involved at which level in each partnership, but none of the documents detailed the actual beginning of a partnership, or the origins of institutional relationships.

In terms of the NGOs' relationships with individuals, NGO roles and obligations varied depending on organisational aims. Organisations saw the individual / organisation relationship in varying terms: from, "commitment-financial" to "purchaser-seller." Some documents placed the expected working responsibilities of outsiders in comparison with the NGO's "return" contribution. This was seen in the volunteer job descriptions which boasted a paid salary. Here the outsiders' key contribution was the length of their commitment; the NGO's contributions being training, professional support, and pension contributions. Other documents described the relationship as "financial contributor" on the part of the outsider, with the NGO detailing leisure, travel and hospitality facilities available in exchange. This latter model was generally seen in the documents of organisations offering voluntourism opportunities (see 2.7.1). Some outsider-written documents made reference to their authorship as part of an obligation to their associated organisation.

Other organisational relationships were also important to both individual insider and outsider SLTs, and to NGOs with whom they were in partnership. Organisational support was seen as essential to ensure the long-term success

and overall sustainability of the collaborative development of services for PWCD. Some documents made reference to organisations providing support to the development of services in their noted attendance at meetings and their contributions.

Where potential challenges within organisations had been identified — such as institutional agreed restrictions for certain posts that were likely to affect the employment of SLTs within the university (including age or qualification barriers) — stakeholders called for greater flexibility from the partner organisation, providing examples of flexible approaches used in other health departments. This was suggestive of different needs from different partners, and that even with increased equality within some partnerships, they may each have different terms to dictate.

<u>Code 2: Justification of SLT need</u>

This code describes the need and priority for SLT, how SLT was seen to "work," and the need for SLT to be appropriate to Ugandan PWCD. As somewhat explained in the earlier category "Ugandan context," there is a high number of PWCD unable to access SLT services. Documents revealed a lack of awareness about professionals and services that could support PWCD, and indicated that there was a need for SLT.

Documents described the role of an SLT: what they do and who they can work with. Often the role of an SLT preceded the need for support of PWCD in the documents, essentially giving an idea of support options before PWCD are considered or detailed. This was typically done by conference reports which explored how the profession of SLT could be developed. SLT was seen as working but also being the superior means of helping PWCD.

Documents used statistics regarding the prevalence of CD to highlight the importance and need for SLT. Despite this "need," some authors described how replicating the number of SLTs per capita in Minority World countries may not be feasible. However, authors of personal blogs, typically reporting their work with PWCD, spoke of progress and the positive impact of their work. Some

documents saw significance in having SLT in Uganda. As a needed service, it was also seen as a flagship for the region.

> *D2. "The acceptance and integration of SLT into Uganda's health and education systems will ensure the profession becomes well-established and self-sustaining, ensuring Uganda is the leading light in East Africa for SLT service-provision, development and training."*

Code 3. Individual help

This code describes how some parents or carers of PWCD have tried to arrange support on an individual basis. This included many approaches and strategies. Some sought help internationally, with a parent visiting or living in another country to access support for their child. Some aimed to create a centre in which a therapist could support other PWCD. Some placed personal adverts with the aim of either recruiting an SLT to work one-to-one with their child or with the aim of arranging international sponsorship for their child. These adverts were often placed with or by NGOs and distributed to organisations such as Communication Therapy International or local Ugandan publications.

> *D28. "The next skill set we are looking to fulfil would be that of a speech therapist…What I propose is to offer a 3-6 month placement"*

Parents who sought support for their child abroad typically described numerous trips to different countries, both to neighbouring Majority World countries and Minority World countries. Individual help was also sought by organisations. Some NGOs requested financial assistance in the form of sponsorship of children with disabilities, including CDs. Here documents referenced examples of children with communication or swallowing disabilities that had been helped in this way, and supporting further financial support for the future.

Code 4. Alternatives and group effort

As an alternative to SLT, where SLT and individual help was inaccessible to PWCD or their carers, groups came together to support services for PWCD.

The primary barriers to accessing SLT described in the documents were awareness, financial and geographical. Documents noted that aside from the cost of SLT directly, Ugandan PWCD and their carers experienced indirect costs in attending SLT, such as travel, and loss of earnings. This was typical for Ugandans who lived rurally or outside of the capital or urban settings. Where Ugandans were able to attend SLT, this was often for an assessment and advice only, as the expense of attending further therapy appointments was too great. Some authors highlighted the risks and disadvantage of PWCD not receiving adequate support. As such, barriers affected how insiders would develop alternative services or support. Some authors described the other approaches that PWCD and their parents/carers had tried to improve their communication. This included traditional approaches such as visiting a local healer, or praying. However documents noted both that the PWCD were often skeptical of these solutions, and when they ultimately did not improve, were often sent away to live with family in rural settings.

One association developed by Ugandan PWCD was described as a support group — giving counselling, advice and therapy tools — relying on financial donations and campaigns to raise running funds. As well as seeking financial resources, another document made reference to how the same group was requesting both dictionaries and atlases to support PWCD. The group used dictionaries as a means of language learning, and atlases to help Ugandans explore the possibility of working abroad. The group noted how some of the members had subsequently gone on to seek employment internationally.

There were also examples of parents or carers, who — following the awareness of having a child with CDs — formed NGOs to help both their own children and others with CDs. Often groups of individuals sought to improve services for a particular client group, rather than all PWCD. Again, in these instances, parents were often specifically motivated by the disability or condition affecting a person they knew with CD. Aside from alternatives or alternative arrangements to SLT in Uganda, other authors asserted that the improvements and solutions for PWCD should come from or needed to come from society as a whole first.

One association developed by PWCD described their goal of becoming self-reliant as individuals. This association encouraged Ugandans with PWCD to be creative and flexible in creating their own jobs where employment opportunities were limited by acquiring management skills, and forging links with businesses to sell their wares. Another group developed by PWCD revealed how their distribution of hearing aids had profound impact upon their members' lives, in some cases giving members their independence:

> D33. *"he received a customised hearing aid…This has enabled him to start working as a mason and he says he couldn't be happier. He is now planning to learn how to weld and to drive a car."*

<u>Code 5. SLT history</u>

This code covers Ugandan SLT development as reported by the documents analysed. This includes the history of SLT in Uganda, as well as more recent developments including the first Uganda SLT course and the first Ugandan SLT graduates. It also documents the broader development of SLT within East Africa as a whole.

Outsider organisations have placed SLTs to work in Uganda since the 1980s, although it is difficult to find records from the different organisations of how long these placements lasted, and whether there were any "gaps" in sending SLTs where services were therefore not available.

A move away from this style of service delivery was noted by one outsider organisation. An SLT training course was identified as a more sustainable approach and was developed, which was described as starting in 2008. Documents tracking the number of graduates from the course are inconsistent, with estimates but no consensus on the final numbers. The first Ugandan SLTs were described as "pioneers," and there were a number of articles celebrating their success and achievements written by outsider organisations. The first Ugandan SLTs were also celebrated in the annual reports of partnering organisations, who hailed their successes as being among the organisation's highlights. Documents frequently made reference to the SLT course being

unique in Uganda and the East African region. Success appeared to be measured in the number of Ugandan SLTs.

> D19. *"The first and only degree course in Speech and Language Therapy in East and Central Africa"*

SLT students came from other East African countries, where SLT was also considered a need. Following graduation of the first SLTs, insider SLTs have gone on to work within Uganda, and other East African countries. Documents show that throughout outsiders' involvement of supporting services for PWCD in Uganda, they have sought to raise the awareness of SLT amongst the Ugandan public. This can be seen through university recruitment materials describing the role and responsibilities of an SLT, as well as documents describing how outsider SLTs sought to raise the awareness of the profession of SLT within the appropriate government ministries. Although this is one way the service has developed, many organisations favour the model of sending individual outsider SLTs.

<u>Code 6. Planning and development models</u>

This code refers to the planning approaches for services for PWCD in Uganda. Conference reports described the work around planning and development that had occurred so far, including the successes, whilst highlighting the next steps needed to further SLT within Uganda. Many documents described the need for alternative models of service deliveries (from Minority World countries) as the replication of such models were inappropriate and had limited use. Documents made reference for the need for sustainability. Documents described the present state of SLT within Uganda and the plans for increasing the sustainability. Despite acknowledging that outsider support would be reduced, allowing for insider SLT to take over, documents were often ambiguous or contradictory about when and how this would practically happen.

> D2. *"to plan for handover from expatriate volunteers to national staff within the next five years"*

<u>Subcategory 2: Development needs</u>

This subcategory refers to the different development needs identified in the documents. Documents described systemic needs in terms of personnel, as well as the needs of the SLT profession. This subcategory has two codes.

<u>Code 1. Systemic needs</u>

This code describes the overall staffing and systemic needs for the Ugandan services. This was most prevalent in conference reports and national policy documents. Documents referred to the need for an increase in professionals (both SLTs and AHPs) to work as part of services for PWCD. Responding to low numbers of special education teachers, specialist training programs were incentivised, however this did not significantly increase the number of specialist teachers working with PWCD. As well as a need to increase the number of allied health professionals, there was a general need to up-skill other professionals to be able to identify CDs. There was also a need for governmental support for the profession. This included the need for registration within the Allied Health Professions Council.

> *D2. "Ultimately, the Ministries of Health, Education and Public Service work quickly to ensure the profession becomes integrated into the health and education systems and that positions for SLTs are created and funded across the country."*

<u>Code 2. SLT profession needs</u>

This code describes the needs of the SLT profession in Uganda. Following the graduation of the first Ugandan SLTs, an association was established to represent the professional body of SLTs. CPD was cited as important for Ugandan SLTs following qualification. One way this had been received was from outsider-led development work and funding. One document called for CPD in the form of a Master's degree in Speech and Language Therapy, as no opportunities for this existed in East Africa. For clinical SLT work, there were multiple references to the need for resources generally, as well as a need within this for culturally appropriate resources.

> *D43. "The…University Speech and Language Therapy Programme is cash-strapped, one year after its launch. The programme needs sh72m[2] if the pioneer students are to complete their studies."*

> *D12. "Any donations of books, equipment, or funds are always very gratefully received"*

4.4.1.4 Summary

To summarise the content analysis, the three categories describe how services for PWCD have developed and continue to evolve. Three key findings were drawn from the document analysis results. Firstly, although services for PWCD have increased and improved, PWCD continue to face many challenges in their lives. PWCD and their parents or carers reported a lack of awareness over their own disabilities; a lack of awareness on the part of the general public and health professionals; stigma, mistreatment or exclusion by others; limited support services; and difficulties accessing services. Outsider authors of documents typically introduced the situation for PWCD in Uganda and framed SLT as a solution, or, less commonly, used the situation for PWCD to justify their therapy and reason for being in Uganda. Insider authors typically described a similar situation for PWCD but also discussed the need for better treatment and independence within society. Although SLT was mentioned by insiders, less emphasis was placed on this, perhaps because awareness and availability of support services were limited. SLTs (both insiders and outsiders) expressed the need to raise awareness of CDs and advocate for the rights of PWCD and — or be their "mouthpiece" where it is hard for them to raise their needs at a societal level — especially where PWCD describe their on-going challenges.

Secondly, insiders and outsiders had similar but different roles. Outsiders reflected on their specific skills and expertise, perceptions of their roles, and their motivations. Outsiders who worked to train Ugandans — either working on the degree programme or training assistants at the main hospital — described their involvement in supporting services for PWCD through the development of

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2 Approximately £22,008 in 2009 (Xe, 2017).

the first Ugandan SLTs and first Ugandan SLT services. Employment advertisements referred to dual roles of running the degree programme and completing clinical posts. Documents described developing job descriptions for SLT posts. There was flexibility to the descriptions, with different job descriptions for working in either health or education settings. Experience levels were recommended for SLTs to reach different "band" levels, with increasing responsibilities. Points for action were listed at the end of one document, with steps to be undertaken such as submitting job descriptions to the AHPCs and MoH, MoE and MoPS and the national referral hospital. One reason for the variation of roles may be because this was not a way outsiders were used to working (based on their "home" roles within the profession). For example: outsider SLTs may have had little experience in strategic planning roles.

Finally, insiders and outsiders developed services for PWCD in multiple ways. Services for PWCD had been developed at both an individual level and at an organisational level. Services included both specific therapies (such as SLT) and alternatives (such as support groups and religious or spiritual interventions). Some PWCD and their families had developed support groups, others had bought-in a private SLT or established centres that helped with rehabilitative therapy (generally the former had been done by Ugandan insiders; the latter by either outsiders and insiders). A number of organisations had provided and developed SLT services within Uganda.

Ultimately many insiders and outsiders have taken the initiative to develop services for PWCD, with different actors often working independently of each other. Services have not evolved in a streamlined or linear way. Consequently, there was often limited information about existing services, with different PWCD, SLTs or health professionals unaware of other individual SLTs or their services. Where there was a lack of knowledge of existing services, this led to fragmented or duplicated services.

4.4.2 Insider interview results

The results from the insider interview data relate to the second objective: To describe and explain insiders' perceptions and experiences of the contributions of outsiders and outsider support, to the development of services for PWCD in Uganda. Interview data were also used to provide information for the first objective which was to explore and describe the process and history of development of services for PWCD in Uganda.

In total, interviews were completed with 14 participants. Table 4.6 shows the number of participants interviewed, by insider role. Demographic details will be presented separately to maintain participant anonymity. Of the fourteen participants, eight were male, four were female. Participants' age range was from 21 to 58 years, with 8 participants not disclosing their age. Their highest education levels ranged from school leaver to Master's degree. In total, 748 minutes of insider interviews were transcribed.

Table 4.6 Insider interview participants

Insiders	Target number of Interviews	Interviews completed
SLTs	3	3
Student SLTs	3	3
University SLT programme staff	3	3
NGO coordinators involved in SLT programme	3	2
Carers of PWCD who had received SLT	3	3
Total:	15	14

The insider interview data were analysed using thematic network analysis to produce themes. 24 basic themes were produced, which were grouped into eight organising themes and three global themes (see Table 4.7). The three global themes are "Mother-child relationship," "Shared values" and "The Ugandan context." The first two global themes respond to research objective 2, and the final global theme responds to research objective 1.

Table 4.7 Summary of insider basic, organising and global themes

Basic themes	Organising themes	Global themes
1. Outsiders leave	1.Unstable support	1. Mother - child relationship
2. Commitment and involvement		
1. Need for relationships	2. Developing relationships	
2.Extended support networks		
1. Need for new outsider role	3.Outgrowing outsider contributions	
2. Ugandan independence		
1. Age	1. Ideal outsider	2. Shared values
2. Language		
3. African outsiders may be better suited		
4. Flexibility		
5. Motivations		
1. Cultural rules	2. Culture	
2.Insiders not sharing cultural differences with outsiders		
3. Negotiate cultural differences		
1. Superior knowledge	3. Outsider status	
2. Outsider value		
1. Life in Uganda is different and hard	1.Coordination and infrastructure challenges	3. Developing sustainable services
2. Infrastructure		
3. Registration of SLT		
4. Awareness of CD		
1. How SLT emerged	2. Sustainable services	
2. Need for services for PWCD		
3. Planning and coordination		
4. Un/certainty		

4.4.2.1 Global theme 1. Mother - child relationship

This global theme concerns how insiders see their relationship with outsiders. Throughout the insider data set, the idea of outsiders being seen as maternal figures, and the Ugandans being seen as children, was prominent. This metaphor was often used to be complimentary towards the outsider — essentially being respectful of this parental role and appreciative of the support. Outsiders were always seen in a maternal role, however Ugandan's described

themselves as a "developing child" — initially as very dependent on the "mother," but increasing in independence and needed to make their own mistakes as a child, before tensions arose between the roles of insiders and outsiders similar to a frustrated teenager and mother. One participant summarised the later relationship succinctly by describing it as "pulling ropes" — similar to a tug of war as tensions arouse for power. This was suggestive of a perception of outsiders initially having more power and responsibilities than insiders; with a feeling that there should be a midpoint exchange in power and responsibilities; with insiders eventually taking charge. This also suggested an element of this exchange being "natural."

> *UG15: "I agree we need to work towards being independent but independence you can't just let a… child be independent completely. You let them do some things on their own you know to learn allow them to make some mistakes but still getting help… and that help for speech therapy is really needed"*

The first insider global theme focused on relationships between insiders and outsiders. Six basic themes were categorised into three organising themes. Table 4.8 shows the basic themes identified and their arrangement into organising themes for the first global theme. Insiders suggested that relationships between insiders and outsiders are the fundamental basis for collaborative work. As such, good relationships were needed to withstand the challenges of working in Uganda and suggested a focus in the development and maintenance of relationships against threats to relationships.

Table 4.8 Insider global theme 1. Mother - child relationship

Basic themes	Organising themes	Global themes
1. Outsiders leave	1. Unstable support	1. Mother - child relationship
2. Commitment and involvement		
1. Need for relationships	2. Developing relationships	
2. Extended support networks		
1. Need for new outsider role	3. Outgrowing outsider contributions	
2. Ugandan independence		

<u>Organising theme 1. Unstable support</u>

Outsiders and their support were perceived as transient and subject to flux and change. Outsider support was often viewed as inconsistent as outsider individuals and organisations tended to operate for brief periods of time in Uganda before moving elsewhere. As such, outsider support was often seen as inconsistent and unsustainable. Outsiders had developed a reputation for a lack of serious commitment.

<u>BT1. Outsiders leave</u>

Insiders viewed outsiders and their support as time-limited. Outsiders were often described as coming for a specific time frame (a few weeks, a few months) to do some teaching or training. However this often created a lack of continuity and, as such, short-term working was often seen as disruptive or negative to insiders (although there could be room for outsiders to visit on a short-term basis, particularly if a skill set was missing). Insiders also applied the long-term preference for outsider organisations — including the NGO that had been supporting the Ugandan SLT course, which insiders felt should have supported the SLT programme for longer. Despite this, insiders often expressed the need to compromise due to the difficulties in recruiting outsiders.

> *UG17: "take… swallowing disorders I think [it takes] seven months but then they did it in three weeks… It was hectic"*

<u>BT2. Commitment and involvement</u>

Insiders saw outsiders as lacking commitment in supporting SLT within Uganda on both an individual and an organisational level. Insiders perceived individual outsiders as having a lack of commitment when they did not actively contribute to the development of services and, at times perceived outsiders as instead causing complications for the insiders.

> *UG1: "a few would come to see how the programme works having heard from others' [you] can see, [and] can bring a few resources'… some of the resources that were brought were not culturally appropriate…. they would give a lot of advice, 'maybe do this do that' [but were] not committed enough to support…it wasn't so helpful"*

As part of a perceived lack of commitment, insiders described how some outsiders did not make a practical contribution to the development of services for PWCD whilst in Uganda. Despite this, insiders felt that there was always potential for outsider contributions to make a difference. Insiders talked about other ways in which outsiders were able to make contributions, such as financial legacies, or resources.

UGPWCDI3 "At any point, any help helps"

The topic of "commitment" was a sensitive issue for some participants who did not want to discuss this in detail, even "off the record." The consequence of the perceived lack of commitment of organisations meant that Ugandan SLTs felt unsupported, particularly where they felt NGOs had broken their support commitments.

Organising theme 2. Developing relationships

Having a wide network of insiders and outsiders was seen to increase the amount of support available to insiders. As well as enhancing and increasing the number of people in a support network, a wide network appeared to provide greater potential to increase the likelihood of future opportunities for jobs, further study, and resources.

BT1. Need for relationships

The need to develop good relationships was seen as important for potential clinical collaborations and peer support. Good relationships appeared to reduce anxieties by providing support networks. Where insiders experienced a challenging relationship in trying to make links with other SLTs, they still sought to develop relationships with other professionals. Some participants thanked the researcher during the interviews for conducting research in Uganda, hoping the research would improve conditions for PWCD. Aside from minimising challenges, good relationships also seemed to have an added positive effect of allowing individuals to form close friendships. As part of developing good relationships, there was a need to make outsiders or partners feel welcome, wanted and supported.

UG18: "If you're in a situation like this, when you feel improvements are not there, is not there, your salary is late, you're not getting enough -- sometimes all you need is somebody to say 'I care … you are important … look, you are doing a great job, look at how many children have benefited from you' Just the encouragement… a letter, maybe a call"

BT2. Extended support networks

The need to network was important to insiders. Extended support networks were seen as important in terms of developing the service regionally with other organisations and institutions, as well as for creating links with other countries. Generally insiders sought to network with both insiders and outsiders, valuing a wide network of people. Some insider SLTs sought to work with their peers for supervision or CPD.

UG17: "we are putting up an association of students so that we can get in touch with other people in touch with other courses of African speech therapists"

Organising theme 3. Outgrowing outsider contributions

There was a common perception that a gradual transfer (from dependence on outsiders to Ugandan independence in leading services for PWCD) was a natural process of development. Outsiders were still needed, but insiders felt that Ugandans should come to lead the establishment, development and operation of services in Uganda.

BT1. Need for new outsider role

Insiders felt outsiders were needed, but their roles should be redefined. All insiders felt that outsider support needed to continue in some form. Insiders felt that outsider support had generally been useful, and in the case of the SLT course, ultimately a significant part of enabling insiders to become SLTs. Some were concerned about the current situation of having no outsider support for the SLT course following the withdrawal of NGO support. Views varied about the suitability of the SLT course in being able to train Ugandan SLTs without the planned phasing-in of Ugandan support. Examples of what new outsider roles

could and should look like included continual professional development; support for further qualification; and developing resource materials. CPD / supervision was seen as an important role for outsiders as there were no senior insider SLTs in Uganda.

> *UGPWCDI3: "And now this is our person she has learnt that she absolutely knows what she is doing and she gets input from teachers and the mentor is the mentors who come from the UK and this lady who help her keep her on her toes and keep widening her"*

Further education opportunities, particularly the need for a Master's Degree, was something that insiders felt outsiders needed to address and support. Completing research and providing resources were considered a further way that outsiders could support SLTs in Uganda. One participant had an idea that both insiders and outsiders could form a network to provide resources to the Ugandan SLTs: through liaison, the insiders could order equipment for the outsiders to bring on their next visit to Uganda.

BT2. Ugandan independence

Rather than having either continued and constant outsider support or none at all, insiders felt that there should be a gradual exchange in power and guidance. This would give Ugandan SLTs time to develop their experience and take on the outsider responsibilities, and was what many Ugandan SLTs felt was the planned arrangement, and therefore should have happened. However, insiders discussed a need to become independent. Often they reflected how there was a culture of dependency in Uganda. Regardless of the agreed timescale detailing the support from outsider organisations, one insider SLT felt that the continued presence and input of outsiders often had unintentional negative effects:

> *UG1: "they seem to have developed a dependency…on the foreigners so that has deprived them of the opportunity of developing"*

Other insiders, in contrast, were more equivocal about the withdrawal of outsider support. Some felt that independence had come too soon, and would

have negative consequences for services for PWCD in Uganda. Insiders felt that insiders should be in charge for determining the future of services for PWCD in Uganda. For some participants, this seemed related to general ideas of Ugandan independence, as well as fundamental ideas about outsider SLTs not being entirely culturally competent to work in Uganda.

4.4.2.2 Global theme 2. Shared values

The second global theme is about how insiders value the importance of shared values. Generally, insiders felt outsiders with similar values to their own were better able to contribute more effectively to the development of services for PWCD. The three organising themes focused on how there may be cultural differences in values or attitudes — and in how insiders and outsiders are perceived — but there is a need to be treated equally or fairly.

Table 4.9 Insider global theme 2. Shared values

Basic themes	Organising themes	Global themes
1. Age	1. Ideal outsider	2. Shared values
2. Language		
3. African outsiders may be better suited		
4. Flexibility		
5. Motivations		
1. Cultural rules	2. Culture	
2. Insiders not sharing cultural differences with outsiders		
3. Negotiate cultural differences		
1. Superior knowledge	3. Outsider status	
2. Outsider value		

Organising theme 1. Ideal outsiders

There was a preference for outsiders with certain qualities, skills, or experiences. Insiders perceived outsiders to typically share specific qualities: volunteers for example were often young, and reflect the SLT profession of their native country (e.g., in the UK, the SLT profession is largely made up of white, female personnel). Insiders perceived outsiders to generally have a higher

status in Ugandan culture. Similarities in culture (for example, shared languages) were perceived as advantageous.

BT1. Age

This theme describes insiders' perception of outsider age and experience. Younger outsiders were often seen as immature: unready for the responsibilities or lacking the commitment to contribute in Uganda.

> *UG14: "we had a very very young speech therapist who was a bit kind of unstable that she stuck it out she did her two years but she was a bit unreliable sometimes and probably not as mature as you would've wanted"*

One participant expanded on this to discuss the potential for tension between relatively young outsider lecturers and older Ugandan students.

BT2. Language

Outsiders came from many different countries to work in Uganda to support services for PWCD. Insiders focused on the difficulties of understanding outsiders' spoken English based on both theirs and the outsiders' language proficiency, and the outsiders' accent. Although English is spoken in Uganda, it is typically learnt as an additional language. When outsiders did not speak English as a first language, this difficulty intensified.

> *UG18: "And of course it is always their accent … when you think about 'foreigners' or "outsiders" accents must have something… We're getting people from everywhere, um, and some who are not even using English, who do not have English as their first language. Ugandans have learned English as their weaker language and for many [it's] a second language."*

BT3. African outsiders may be better suited

Insiders felt that outsiders from within Africa potentially shared more culture with Ugandans, and were therefore better suited to supporting services for PWCD in Uganda than outsiders from Minority World countries were. Although African outsiders were generally felt to be better suited to working in Uganda, one

participant felt that some African outsiders were reluctant to be involved in supporting services for PWCD.

> *UG2: "but if someone is from an African country it is actually easier because you understand the language…they relate easy because they automatically know what is available"*

BT4. Flexibility

Insiders found certain personality traits and attitudes of outsiders easier to work with or better to collaborate with when working in conjunction to develop services for PWCD. Ugandans described their culture as friendly and non-confrontational. Insiders described a need for outsiders to be flexible and respectful. Insiders described outsiders who they felt to be less successful based on their attitude. Although some outsiders might have initially struggled to gel with their insider counterparts based on personality differences, it was felt they would generally eventually settle in with the team.

> *UG13: "they were free with us so you find that you understand and it would make us free to ask them questions and maybe to interact very well…they were flexible"*

BT5. Motivations

Insiders talked about their own motivations for working to support services for PWCD, and what they thought outsiders' motivations were to support services for PWCD in Uganda. Insiders perceived that insiders and outsiders had different motivations (there were also differences based on different insider roles). There were a range of motivations for insiders, including being motivated to work as SLTs as it was a new profession; settling to train as an SLT due to not getting into another course; and wanting to work with a specific client base. Comparatively, insiders' perceptions of outsiders' motivations centred on their reasons for working in Uganda, rather than their reasons for working with PWCD. Despite several insider cohorts now having graduated, and regardless of motivations, many used language to suggest that their training had been uncharted and experimental.

UG2: "we didn't know how it really meant to be a pioneer we had so many challenges here and there even the university didn't know about the course so we were really guinea pigs"

In some cases, insiders described outsiders as having different motivations for working with PWCD from themselves. When insiders described their perceptions of their own volunteering, it was described as work. However perceptions of outsiders' motivations for volunteering, were described in charitable or terms — such as "giving" and "sacrifice" Travel was felt to be a motivating factor for outsiders. Some insiders felt that outsiders used working abroad to enhance their work experience.

Insiders also discussed how some outsiders did not have an initial motivating reason to support services for PWCD in Uganda, as they had not come to Uganda to work in that capacity. These outsiders were perceived to have taken a role in supporting services for PWCD once they were already in-country. One participant described the effects of working with outsiders who were volunteering with an outsider NGO which apparently offered voluntourism-like packages. The outsider NGO had apparently dissuaded the outsider volunteers from working with insiders by withholding leisure activities for outsiders if they did. This insider perceived differences in motivations resulted from the NGO perceiving collaboration to take more time than lone working by outsiders, and thus resulted in less profit for the organisation.

Organising theme 2. Culture

The second organising theme describes cultural differences (both amongst different ethnic groups in Uganda, and between Ugandans and outsiders) and suggests how these cultural differences may be negotiated.

BT1. Cultural rules

This theme is about how insiders perceived outsiders. Outsiders were seen as being able to better navigate Ugandan society because they were not bound by Ugandan cultural rules. Insiders talked about Ugandan culture not being homogenous, with different ethnic groups having their own culture. In a multi-ethnic society they felt it was difficult to be aware of all the customs and were

anxious of offending others. Insiders often contrasted this with outsider culture. Outsiders were seen as having more freedom and ability to do what they wanted. Clinically, this meant outsiders were more able to specialise or pursue further CPD training.

> *UG15: "here it's a lot of respect your elders you don't ask about your elders you don't question why your boss or whatever people say about you er and yet I think for you guys I mean you have the right to question what someone is doing if you don't think it's right"*

<u>BT2. Insiders not sharing cultural differences with outsiders</u>

Insiders described how they personally and professionally found life within Uganda challenging because of the different cultures. Some insider SLTs described language problems because they did not speak the local language, or they were not comfortable working in other languages. This often had consequences for their clinical practice. Some Ugandans discussed the difficulties from not disclosing personal challenges (e.g., relating to external pressures affecting their work) and difficulties relating to understanding training information. One example of cultural differences that insiders did not share with outsiders was that in some Ugandans' cultures, it was considered rude to look in their mouths.

> *UG17: "because for us now in Uganda if I told this person [of a certain ethnicity] to open [their] mouth [they] would really be embarrassed on [their] side but then on my side…it's embarrassing on my side and also embarrassing like now I am embarrassing [them]"*

Not disclosing these challenges was typically due to embarrassment and shame. Due to the status of the teaching roles held by outsiders, insiders felt uncomfortable sharing what would or would not be appropriate in a clinical setting in Uganda. This meant that a portion of the teaching they received had not been culturally appropriate, and outsiders were unaware of this. Resultantly, outsiders may not only have been unaware of specific examples of cultural differences, they may also have been unaware of the "culture" of insiders not sharing information with, or correcting someone of, a perceived higher status.

Insiders noted that having shared aspects of identity helped to mitigate some of the overall cultural differences between insiders and outsiders. However, addressing aspects of culture that were not shared, insiders discussed the need for both groups to compromise, and the need for outsiders to be patient with Ugandans and Ugandan ways of life — such as different attitudes to time-keeping, expectations of financial compensation for attending training, and Ugandan work procedures. The most commonly discussed cultural difference related to attitudes around time-keeping. Insiders described how they felt the majority of outsiders found it hard to adapt to the flexible attitude to time-keeping, and that the few outsiders who had more laid back attitudes to time-keeping were more desirable. Insiders also felt structural or bureaucratic issues were not always understood by outsiders, who could be frustrated by the culture. One insider felt that there could be difficulties in the way insiders and outsiders understood training. In Uganda, people who attend training are often financially compensated by the training course "per diem" for being absent at work, and often insiders' viewed training or contact with outsiders as a way of making money. However, some outsiders instead offered training or supervision with no such compensation. This may have been because of differences between insiders and outsiders, such as insider SLTs having multiple jobs and more responsibilities, or differing attitudes to who is responsible for a new professions' CPD.

Overall, insiders felt that where there are cultural differences, that both insiders and outsiders need to adapt and respect each others' culture. However, cultural differences were not always apparent to outsiders, with insiders not always making outsiders aware of appropriate behaviour or the culture of Ugandans. During an interview with two insiders from different ethnic groups, participants demonstrated some of the cultural differences. Insiders described how they would not bring up cultural differences with outsiders.

UG17: "no we don't tell them that! (laughter)"

Insiders described the challenges and frustrations when outsiders had not adapted to the cultural differences, or offered inappropriate therapy strategies for male SLTs or family members to use. One student SLT reported that advice from outsider SLTs to sit on the floor and sing or play with a child would be culturally unusual and inappropriate for many Ugandans and especially for males. Where outsiders' methods were culturally appropriate, insiders would "pick" these methods for use; and where deemed culturally inappropriate, insiders would "pick" principles of the theory or method and adapt it for their own practice. This "skill picking" happened without insiders telling outsiders.

> *UG1: "I pick from people the volunteers and foreigners"*

Organising theme 3. Outsider status

The third organising theme in this global theme describes different notions of status in Uganda. Outsiders generally held a higher status than insiders, with insiders perceiving outsiders to have superior knowledge and resources. Outsider-provided services were seen as preferential to services offered by insiders.

BT1. Superior knowledge

Insiders described how they, or other Ugandans, viewed outsiders as superior or as a standard to aim for. Often insiders viewed services for PWCD in Minority World countries as aspirational or needed in Uganda. In the example below, a parent described some of the services for PWCD that she was aware of in Minority World countries and expresses the belief that, if these were available in Uganda, services for PWCD would be improved.

> *UGPWCDI1: "If they could do that, oh my goodness we would be so OK. we would be very good. Because I know in the western world, mzungu (laughter) I know they have such such uh such um arrangements in schools right?"*

Although outsider knowledge was typically seen by insiders as superior, one insider discussed the idea of reconciling Ugandan traditional beliefs with ideas from "western" SLT. They described how they were concerned that a number of

their Ugandan colleagues had beliefs about the causes of communication disabilities that were not founded in evidence based practice. The same participant gave examples of different understandings of the cause of CDs. In this example, they discussed how they reconciled their previous beliefs with knowledge from the SLT course.

> *UG1: "I think the thing of the moon I also believe it then but when when we when we went on this course I noticed that there is no link between the moon and the stammering and I mean I can say that I was wrong…I don't know… how can I wrap it up?"*

BT2. Outsider value

Insiders felt that outsiders were held in higher esteem than insiders. Insiders often talked about PWCD or their families having a preference for outsider SLTs, often believing their skills to be more authentic. As a consequence of the differences in status of insiders and outsiders, some insiders described examples of having worked with or in the same clinic as an outsider, and Ugandan PWCD or their parents / carers would choose intervention with the outsider instead of the insider, or be more accepting of the outsider's recommendations.

> *UG1: "[insiders] respect someone from overseas because we expect overseas they have better training better facilities so someone can be trained better than a person who trained from here…I have noticed that it makes it hard for me in speech therapy"*

For some, this perception had the consequence of causing insiders to feel substandard compared to outsiders, lowering self-esteem and self-confidence. Alternatively, one insider commented on this difference as making them feel validated because they perceived no difference in how they and outsiders perform SLT, therefore must be as "good" as the outsider.

4.4.2.3 Global theme 3. Developing sustainable services

The third and final insider global theme is about the context of Uganda. It draws on the specific challenges within health, the health system and the country.

There are two organising themes, "Coordination and infrastructure challenges," and "Sustainable services."

Table 4.10 Insider global theme 3. The Ugandan context

Basic themes	Organising themes	Global themes
1. Life in Uganda is different and hard	1. Coordination and infrastructure challenges	3. Developing sustainable services
2. Infrastructure		
3. Registration of SLT		
4. Awareness of CD		
1. How SLT emerged	2. Sustainable services	
2. Need for services for PWCD		
3. Planning and coordination		
4. Un/certainty		

Organising theme 1. Coordination and infrastructure challenges

The first organising theme is about challenges within Uganda in terms of the way of life for Ugandans, the infrastructure of Uganda as a whole, the profession of SLT, and challenges experienced by PWCD. These challenges affected insiders and outsiders in their ability to provide services for PWCD.

BT1. Life in Uganda is different and hard

Insiders talked about Uganda being a "developing country" and how many Ugandans live in poverty. The consequences of low income often contributed to problems attending SLT lectures, work or therapy sessions. Bureaucracy was also described by insiders as being different in Uganda and contributing to difficulties. This included the difficulty of establishing an SLT course.

> *UG14: "we didn't really understand the steps so it took a long long long [time] …and it went on and on and on and it's not just the steps, it it's the personality, a lot of it is just powerbrokering… so it's just doing your homework before you start something like this… find out who are going to be the personalities are going to be the roadblocks in that process in African academics circles there is a lot of egos"*

Other effects of poverty included challenges to outsiders in experiencing a different way of life or relative hardship, as well as the overgeneralisation by outsiders of people living in poverty. Poverty, rural living, and a lack of awareness affected Ugandan PWCDs' access of SLT services. Services provided by insiders and outsiders were still in limited availability. One insider felt the expansion of services to rural settings was important as rural dwellers are less aware of what support is available, however, insiders expressed their concerns that this situation was unlikely to change in the near future despite personnel increases.

> *UG3: "um if you are in the rural setting um I must tell you the first person you would get in contact with is the rural health centre and… if you're lucky enough you might find someone who has ideas about existence of SLT services now… You cannot be lucky"*

BT2. Infrastructure

Although networks had been formed, insiders found it difficult to keep in contact with other insiders working in the country, and outsiders working locally and abroad, because of the challenges of Ugandan infrastructure. This included difficulties with phone and internet connections as well as transport and education. Difficulties with Ugandan infrastructure often made sharing the support and information challenging even when contacts or services existed. This made contact, such as mentoring, between insiders and outsiders difficult.

> *UG5: "phone calls it is expensive, then internet you may not say or relay or the messages the way it's supposed to be"*

BT3. Registration of SLT

Insiders discussed the situation of policy and registration of the SLT profession, with a lack of consensus regarding whether or not the profession had been registered by the Ministry of Health. This suggested confusion and concern about the lack of policy and registration. This may indicate challenges in navigating new structures, particularly where these had not been defined, and rather than being supportive, were barriers for practising. One of the consequences of SLTs practising without official registration was that SLTs were

not paid as SLTs. SLTs were paid the same salary as their previous occupation, which often meant SLTs were underpaid, as well as not recognised. As such, many of the insiders described working as an SLT as part-time and undertaking SLT work when they could within their "main" job, or as an additional job. They believed that outsiders' ability to work was affected by the lack of registration, and at times dissuaded outsiders from working in Uganda.

> *UG3: "you can get a lot of bureaucratic things which I guess is also everywhere in the world they need to be registered they need to have the practical level they need to be officially admitted and they need to play work permit and blah blah blah! I think that is too much to handle for them… it's too much for them they would rather do what they came here for"*

BT4. Awareness of CD

Insiders discussed how SLT is a new profession in Uganda, and previously there was little someone could do, clinically, about having a CD. Ugandan SLTs explained how they had been previously unaware of the profession and services for PWCD. Services provided by insiders and outsiders had allowed for change. As awareness of CD increased, this led to improvement to the lives of PWCD.

> *UG2: "the current situation is that the service the service is evolving rapidly, parents are now bringing out their children out of the homes that is the interesting story"*

Despite advances, awareness of CDs remained low. This means that PWCD and carers continued to be stigmatised in Ugandan society. Against this, many SLTs and family members of PWCD were working to see PWCD treated equally.

> *UG16: "So stop abusing them and undermining them treat them generously…"*

UGPWCDI1: "I will say he can do this, and do this. So instead, they are not feeling sorry for him 'Let me help him', no, he can help himself."

Organising theme 2. Sustainable services

The second organising theme in this global theme reflects insiders' views on the need for sustainable services for PWCD in Uganda.

BT1. How SLT emerged

Some insiders discussed the history and evolution of SLT in Uganda. Challenges of the initial mode of working prevented the development of a sustainable service. Although insiders did not describe the current situation as sustainable, the perceived change in the outsider-led delivery approach was viewed as a move towards sustainability.

UG14: "they had a little service that has been going on for like 10 years when I joined that there was no sustainability strategy um the training was kind of ad hoc I felt "well why don't we developed a diploma or a degree course"

BT2. Need for services for PWCD

There are low levels of awareness of CD and difficulties in accessing SLT services. In seeking help for CD, other services may be used. This includes the church, support groups, traditional healers, other health services or professionals and educational services. However, insiders feel there is a need to address the lack of services for PWCD with SLT services provided by insiders and outsiders. A former university programme staff member described the worth of having SLT in terms of empowering other health professionals.

UG15: "it's kind of like you feel helpless but now we know where to refer them [but] I'm not sure that's the same situation most doctors in our country can possess"

BT3. Planning and coordination

This theme describes how there is a need for all stakeholders to plan and coordinate together to enable sustainable services. Insiders discussed feeling

that the NGO supplying SLTs did not have SLT as a priority, despite sending staff over several decades and supporting the development of an SLT programme. They talked about the process of the involvement of the NGO ending prematurely, with some participants describing how they felt their work was not appreciated by the outsider NGO. There was a perceived need for long-term commitment of both the NGO to SLT (which called for the appreciation of SLT), and the NGO to the insiders. The NGO had agreements with recipient organisations in Uganda that they would support some of the costs of the outsiders. However, the recipient organisation (the university) struggled to meet this agreement. Insiders felt that this damaged the sustainability of services for PWCD.

> *UG19: "Why did you pull about like this? You are the same people who killed the sustainability"*

This also applied to the planning and support from Ugandan organisations and government. Insiders felt the course needed investment, both in terms of increasing the resources, as well as support for admission fees to increase the number of Ugandan student SLTs. Insiders described how — although they needed investment — it was culturally inappropriate to "beg" or ask for money. However if money was offered, it would be gratefully received. Training as an SLT was already seen as a risk in terms of being a new profession, but this was exacerbated for students who had to risk personal finances in paying for course fees. This had led to low numbers of students in some cohorts.

> *UG13: "we went through six but other three were dropped out before they start the course because it was so expensive and they didn't know that the whole time"*

BT4. Un/certainty

This theme is about the future of Ugandan services for PWCD. Insiders discussed their hopes and fears for the profession, challenges and possible solutions. Insiders felt uncertain about the future of SLT in Uganda. Due to the lack of policy and registration for the SLT profession, the associated risks and insecurity mean that some insiders regretted training as SLTs. This also

contributed to the fears among student SLTs that they would struggle to find a job.

> *UG17: "that's my biggest worry… so [SLT is] not really yet here in Uganda um getting a job won't be easy… it will be hectic because people they don't know about speech therapy"*

One insider felt that there was a threat of people "masquerading" as SLTs, which would devalue the profession. However, some insiders were optimistic that in the future services for PWCD would improve as a whole. Insiders were also optimistic about the increased numbers of SLTs in Uganda, and felt that support could come from inside Uganda by the government supporting their employment. Some insiders felt that current links with outsider organisations were good for the future, and were also optimistic for further future links. Insiders considered the ways in which insider contributions could be strengthened to improve services — including both individual and government contributions. Without outsider support, insiders believed they could still work to raise awareness of PWCD and reduce the stigma that they experienced. One Ugandan SLT considered how there were difficulties affecting the SLT profession globally, not just within Uganda. As such, they hoped collaboration internationally would help strengthen services for PWCD everywhere.

> *UG5: "I think what you need to do is er I know that speech and language therapy has a lot of very many challenges both in Africa and the rest of the world So I think we need to work as a team we need to share whatever we have in terms of knowledge skills so that we can fight these challenges together"*

4.4.2.4 Summary

In summary, the three global themes explored insiders' perceptions of outsiders and their contributions to services for PWCD. This resulted in four main findings. Firstly, insiders viewed outsiders' contributions as being largely related to the specific roles of outsiders, however variables such as their age, skills and experience were also important. Insiders discussed how outsiders' roles influenced their contribution. Insiders talked about different roles of outsiders:

practicing SLT; lecturer; trainer; funders; observers, and how these different roles were often linked to different levels of contribution and the "potential to make a difference." Insiders felt that roles of lecturer or trainer were most needed for sustainable services for PWCD. There was a need for practicing outsider SLTs, however insiders felt that these needed to work in conjunction with the insiders. Some insiders felt that non-visiting or short-term outsiders could be involved through redefining roles. In terms of outsider roles that made little or no contribution, insiders felt both observers and voluntourists fit into this role. Interestingly, there was disagreement among the insiders about the level of outsider skill level needed for outsider roles. There was a split in preference between specialist SLTs and generalist SLTs. Within an educational or training role, it may be that outsiders need specialist knowledge of conditions and interventions. Within a clinical role, that there are specific client groups that require specialist expertise such as cleft lip and palate. Conversely, an outsider SLT may be unlikely to have a specialised client group for their caseload due to challenges in accessing services. Therefore generalist skills may be of greater use. Ultimately a mix of expertise is needed.

Secondly, insiders viewed outsiders as having a higher status, regardless of their skills or experience levels. Insiders described the difference in status between insiders and outsiders. They described how in Uganda, outsiders or "mzungu" were seen as having a higher status. The first SLTs in Uganda were outsiders, and with the development of an SLT programme and CPD training, outsider SLTs were in lecturing or training roles. This has meant that within the profession of SLT, outsiders have generally had a higher status.

Thirdly, insiders viewed outsiders' contribution as not always culturally appropriate, however insiders would pick and choose from the offerings available from outsiders. Insiders discussed the cultural differences both within Uganda and between Ugandans and outsiders. Insiders described the existence of many different ethnic cultures in Uganda, and as such, there were many different cultural rules for groups. Insiders described how this was often challenging for them to navigate. Furthermore, insiders discussed how as a whole, Ugandan culture sought to avoid conflict and confrontation. As part of this, when outsider support was either not culturally appropriate to the culture of

individual insiders, or to Ugandans as a whole, they would not tell the outsiders but instead described how they would "pick" outsiders' ideas. This included both ideas that were already culturally appropriate (which would be selected instead of other ideas), and those that were not (where the insider would "pick" and adapt the idea for appropriate practice). Insiders described "skill picking" as something they did not share with outsiders.

Fourthly, Insiders viewed outsider support as unstable and transient. Insiders discussed how they and other insiders perceived outsider support. They described how they often knew that the amount of support was time limited, in which case they knew support would come to an end. However, there were typically gaps in between outsider support. Where different individuals or groups of outsiders were involved, the support was often uncoordinated. This caused challenges for outsiders in terms of repetitive training that some insiders felt did not advance their skills (e.g., outsiders often provided training to raise awareness of CD). However, even when support was planned and coordinated, insiders were aware of support ending prematurely. This happened at both in individual and organisational level. At an individual level, outsiders sometimes had to leave their roles early due to personal issues; at an organisational level with NGO support ending prematurely.

4.4.3. Outsider interview results

Outsider interview results related to the third objective: To describe and explain outsiders' perceptions and experiences of their contribution to the development of services for PWCD in Uganda. Interview data was also used to provide information for the first objective which was to explore and describe the process and history of development of services for PWCD in Uganda.

In total, nine outsider interviews were completed. Table 4.11 shows the participants interviewed by outsider role. To maintain anonymity, demographic data are discussed separately from the data in Table 4.11. Of the nine participants, eight were female, one was male. Where participants gave their ages, these ranged from 36 to 56. Their highest education level ranged from BSc to PhD. Three groups of the initial planned target populations of outsiders

were interviewed: SLTs (who worked in Uganda in clinical roles); SLT mentors (who worked indirectly with Ugandan SLTs); and NGO coordinators. Visting supporting staff involved in the mentoring programme (non-SLTs) were later also included as a target population due to low participant numbers in the groups of NGO coordinators and SLT mentors. In total, 831 minutes of outsider interviews were transcribed.

Table 4.11 Outsider interview participants

Outsiders	Target number of Interviews	Interviews completed
SLTs	9	5
SLT Mentors of SLT graduates	3	1
NGO coordinators involved in SLT programme	3	1
Visting supporting staff	0	2
Total:	15	9

The outsider interview data were analysed using thematic network analysis (Attride-Stirling, 2001) to produce themes. 24 basic themes were produced, which were grouped into eight organising themes and four global themes. This section explores the results by the four global themes: "Relationships," "Reconciling Ugandan control and outsiders' expertise," "Development approaches" and "Embedding services in context."

Table 4.12 Summary of outsider basic, organising and global themes

Basic themes	Organising themes	Global themes
1. Support networks	1. Building relationships	1. Relationships
2. Being wanted and included		
1. Authority	2. Threats and challenges to relationships	
2. Relationship breakdown		
1. Transition period	1. Idealism and realism	2. Reconciling Ugandan control and outsiders' expertise
2. Reconciling ideals with concerns		
3. Uncertainty about future services for PWCD		

Basic themes	Organising themes	Global themes
1. Identity	2. Colonial history	
2. Roles		
3. Being useful		
1. Flexible planning	1. Process	3. Development approaches
2. Power		
3. Change is slow		
4. Acceptance of scale of challenge		
1. Country comparisons	2. Similarities and uniqueness	
2. Responsive evolution of services		
1. Uganda is a Majority World country	1. Contextual factors	4. Embedding services in context
2. Bureaucracy, fraud and corruption		
3. Prioritisation		
4. Health infrastructure		
1. Severity of conditions	2. Service challenges	
2. Access inequality		
3. Awareness of CD		
4. Profession needs		

4.4.3.1 Global theme 1. Relationships

The first global theme discusses how outsiders perceived relationships. In particular it shows how (for outsiders) relationships were seen to be built and developed between individuals, not groups of people, and the need for balance and equality between individuals to form good relationships.

Organising theme 1. Building relationships

This organising theme describes how outsiders felt relationships needed to be developed and sustained. Outsiders often described the advantage of having some kind of relationship or acquaintances in Uganda already and how positive working relationships were crucial when working in Uganda to develop services for PWCD.

Table 4.13 Outsider global theme 1. Relationships

Basic themes	Organising themes	Global themes
1. Support networks	1. Building relationships	1. Relationships
2. Being wanted and included		
1. Authority	2. Threats and challenges to relationships	
2. Relationship breakdown		

BT1. Support networks

Support networks were described as important. Outsiders often described times when they were not supported by others, although they felt such help should have occurred and would have been useful. Outsiders described the importance of establishing and maintaining positive and supportive relationships between insiders and outsiders. Outsiders often saw Ugandan contacts as a way of giving them support or access.

OU1: "you need to have a very good support network [you] need to have somebody… that you can talk to who can give you good advice you need to have a key Ugandan [like I had] you know it was easy for me"

Key Ugandan contacts typically seemed to be Ugandans with high status, particularly in terms of career. Outsiders rarely described times they were supported by insiders (other than by those in a key Ugandan role). One outsider described finding the client cases that they saw in Uganda distressing. In this instance, they received peer support from an outsider. Outsiders occasionally described the need for Ugandan SLTs to support each other.

BT2. Being wanted and included

Outsiders discussed the need of feeling wanted and included. When outsiders felt they were excluded by insiders from working with them, outsiders found it confusing or upsetting.

OU10: "I always felt like, welcome and the possibility of, of being involved um, the, and it, and you do genuinely have knowledge and information

that's useful too. That's a really nice feeling to know that you've got stuff to say that will help"

One outsider discussed instances of when there was no mutual respect between insiders and outsiders which caused difficulties. Some situations resolved after mediation, however this did not always improve situations. Incidents of bullying or harassing behaviour were described by some outsiders, which led to weakened relationships. In these cases, it appeared a small but vocal group of insiders excluded or rejected relationships with outsiders.

> *OU1: "she started getting anonymous texts nasty texts from the students saying she was rubbish and what are you doing here"*

One key way of making outsiders feeling wanted and included was by insiders and outsiders being respectful of each other. This was a fundamental foundation on which to build relationships.

Organising theme 2. Threats and challenges to relationships

This organising theme describes some of the threats and challenges to relationships that outsiders perceive. This included challenges at both an organisational and individual level.

BT1. Authority

Relationships often deteriorated as a consequence of differences or overlaps between the roles of insiders and outsiders, and the understanding of how these should be performed. As the first SLTs in Uganda, outsiders' roles had largely been self-made and had developed over time. Between insiders and outsiders there was some disagreement noted about roles and responsibilities. A lack of clear authority and poorly defined roles led to relationships breaking down.

> *OU11: "There was a lot of preciousness… about expertise and about role and about function"*

Outsiders discussed specific instances of working relationships breaking down, often within groups, but also as individuals. Reflecting on examples of disharmony, outsiders noted that they — or other outsiders — found it challenging to "play the game," and the potential of not doing this to fracture relationships beyond repair.

OU11: "this was a very dysfunctional team"

4.4.3.2 Global theme 2. Reconciling Ugandan independence and outsiders' expertise

The second global theme describes how outsiders recognised the strengths of Ugandan SLTs. However, outsiders expressed concern over insiders' abilities to be fully independent from outsider support, chiefly because of a lack of clinical experience. Outsiders were uncomfortable with the potential of their own work to be associated with Uganda's colonial history. Outsiders acknowledged a desire for specific things or milestones to have occurred, but had not been achieved and were not currently possible. Outsiders aimed to reconcile this need by accepting the reality of the present situation.

Table 4.14 Outsider global theme 2. Reconciling Ugandan control and outsiders' expertise

Basic themes	Organising themes	Global themes
1. Transition period	1. Idealism and realism	2. Reconciling Ugandan control and outsiders' expertise
2. Reconciling ideals with concerns		
3. Uncertainty about future services for PWCD		
1. Identity	2. Colonial history	
2. Roles		
3. Being useful		

Organising theme 1. Idealism and realism

This organising theme describes outsiders' often-held ideal that Ugandan SLTs were better suited to work and take the lead in delivering Ugandan SLT services. In reality, however, outsiders felt Ugandan insiders were not yet

experienced enough for this to be completely successful. This doubt was directed at the Ugandan profession as a whole, the SLT course specifically and individual SLT clinicians.

BT1. Transition period

Outsiders felt there should have been a gradual transition and handover of outsider support. This mainly focused on the unplanned withdrawal of support of the main NGO providing outsider SLTs to work on the course. However, for a variety of reasons this did not happen. The majority of outsiders described how the support from the outsider organisation was planned to gradually reduce over a five year period to allow for Ugandan sustainability. There was disagreement amongst the outsiders over whether the NGO had prevented a transition period. The majority believed that a memorandum of understanding had been signed (guaranteeing a longer commitment and staggered transition from the NGO), however one outsider claimed this memorandum of understanding had not been signed. Outsiders felt that a lack of transition had threatened the sustainability of the SLT course and, in turn, the profession as a whole.

> OU11: *"If you can imagine running a course here … with initial graduates…it would be limited… relying heavily in what you'd been taught, um, and you wouldn't have time… to be reading more widely and finding out about things that you weren't taught that you might bring into your teaching"*

This theme explored outsiders views that Ugandan SLTs need to be independent from outsider support in order for the Ugandan SLT service to be sustainable.

BT2. Reconciling ideals with concerns

This theme explored how outsiders had difficulties reconciling the ideal of a Ugandan SLT and Ugandan SLTs leading change, with their concerns about the changes that the Ugandan SLTs were making. Outsiders had specific concerns about how services and Ugandan SLTs were developing, as well as specific ideas of what they felt insiders should do to lead change. This included activities

and ways of working such as raising awareness with the public or other health professionals; the need for research and normative data on Ugandan PWCD; working with PWCD to develop the service in line with their needs; and strengthening the profession by obtaining recognition. Outsiders recognised that Ugandans needed to have ownership and responsibility of the service. Outsiders felt that Ugandan SLTs provided a more appropriate service for Ugandan PWCDs. This could be seen by descriptions of it being an "African version of SLT," and therefore "good".

> *OU6: "yeah I'm pretty sure they don't want any outsider support…[it] gives the impression that they now want to own it for themselves which is fair enough really"*

BT3. Uncertainty about future services for PWCD

This theme explored how outsiders were anxious or uncertain about the future of services for PWCD in Uganda. Outsiders were largely uncertain about the future of the profession, particularly in relation to the sustainability of the Ugandan SLT programme. This uncertainty was felt by outsiders still working in Uganda, and those who had left. When describing the future, outsiders typically used optimistic language such as "hope" while simultaneously indicating differences in what they hoped for, and what they thought would happen in reality.

> *OU1: "You know some of the students are committed [to] speech therapy and it is their future and it is going to be their career and they're going to be turned out without being able to practice properly as a speech therapists… that really is very very sad"*

Organising theme 2. Colonial history

This second organising theme in this global theme discusses how outsiders were aware of the colonial history of Uganda and of comparisons of this to their work today. Outsiders were uncomfortable with the history of colonialism, and were keen to avoid practice that continued (or was associated with) its legacy.

<u>BT1. Identity</u>

This theme explored the differences between insider and outsider identities. Though outsiders never felt like full members of Ugandan society, there were both positive and negative dimensions to this. Outsiders felt they typically had a higher status than Ugandans, and were seen as having more power. However this meant they had to be careful not to misuse their power. This aspect of identity was seen as a consequence of colonial history. It also allowed them to break cultural norms for therapy and suggest interventions for the clients' benefit that may be considered culturally strange. Outsiders often felt that they were not the best person to work with Ugandan PWCD because of their outsider status, and described anxiety when working as an outsider. They had to consider the most appropriate ways of working in conditions where there was little support, with CDs of which they perhaps had limited or no experience, and consider how their clinical expertise could be culturally appropriate, avoiding working in a way that was culturally imperialistic. Outsider relationships with insiders were often compared using a mother / child analogy.

> *OU1: "she started talking about colonial times and breastfeeding babies…and I I didn't know if I was the mother that was breastfeeding or I was the baby being breastfed… breastfeeding the baby and the baby and the baby biting the mother…and I thought 'oh I'm the mother here and I'm being bitten by the baby'…and then she start talking about colonial input and mzungus"*

<u>BT2. Roles</u>

This basic theme relates to how outsiders saw their and Ugandans' roles. Outsiders were perceived as "experts" in SLT. Insiders were perceived as outsiders' "cultural guides." This suggests a divide in power based on perceived expertise, as insiders were always basing their understanding of SLT from outsiders' views. There was no suggestion of if and when there would be an exchange of power and roles, or ability for insiders to not only have their existing cultural expertise, but clinical expertise.

> *OU9: "it needs to be collaborative with the outsiders bringing knowledge of speech and language therapy services of how things should run and*

what a gold standard is or what the end goal is umm but then also having the insider side of knowing understanding that culture"

<u>BT3. Being useful</u>

Outsiders attempted to reduce the differences between roles and status and to allow for more fair and equal exchanges and relationships. One approach was to ensure that outsiders coming to Uganda *were* actually highly skilled, adaptable and experienced, and therefore could be genuinely seen as having more clinical expertise than insiders. This was seen as preferable to outsiders who were perceived as not highly skilled, but were nevertheless endowed with a higher status than insider counterparts. In this way, perhaps outsiders felt relatively less uncomfortable when treated better than their insider counterparts: at least they were "better" than other, less useful, outsiders.

OU1: "you [need to] have considerable experience and knowledge and something to offer"

This meant that outsiders needed to evaluate their overall ability to contribute to services for PWCD in Uganda. Insiders felt long-term workers were more desirable overall in all contexts and working roles. Exceptions (for short-term work) occurred when there were specific skill sets missing from existing SLTs where a specialist SLT would be able to offer short-term but focused training. Some outsiders talked about discouraging short-term volunteers as they found their presence disruptive. Some outsiders also asked the researcher how she could be part of offering something useful to insiders.

4.4.3.3 Global theme 3. Development approaches

The third global theme concerns the different approaches to developing a service. There were core components needed for development, such as key drivers of change with specific personality traits and skills. Outsiders discussed the need for a customised SLT service that would be similar in a broad sense to the development of SLT services in other countries, but not the same in that each country has a different approach and focus in implementation.

Table 4.15 Outsider global theme 3. Development approaches

Basic themes	Organising themes	Global themes
1. Flexible planning	1. Process	3. Development approaches
2. Power		
3. Change is slow		
4. Acceptance of scale of challenge		
1. Country comparisons	2. Similarities and uniqueness	
2. Responsive evolution of services		

Organising theme 1. Process

This organising theme describes the process in developing a new service. Clear planning is crucial in the first instance, while it is also necessary to be both flexible and patient in the development process and to be transparent about the aims, capabilities and limitations of any service.

BT1. Flexible planning

Outsiders perceived a need for services for PWCD and the SLT degree programme to be planned appropriately before they are implemented, whilst allowing for flexibility to respond to unexpected emergent needs. There was a tension between the need for thorough planning and flexibility, where both were needed. Flexibility was crucial in the development of a new service in being able to respond to unforeseen needs and challenges. This was particularly important when there was a lack of control and availability over the resources needed. Clear scope of what the overall goal of the service was, and clarity over what it was able and unable to provide and deliver was needed for transparency. Goals needed to be realistic to minimise wasting resources and effort. Flexibility was also needed from organisations in authority positions.

> OU14: _"What you have to be prepared for is that either you get a lot of setbacks, or it doesn't last because the funding gets cut and then you think cor, what's the point of that?"_

<u>BT2. Power</u>

This theme describes how individuals with power have been the main agents in developing services for PWCD in Uganda. Although these "powerful" individuals included many of the outsiders, this also included several key insiders. The power of individual insiders and outsiders was typically related to their role within an organisation, and when there were organisational challenges or a lack of support, these individuals often lost the power, ability and involvement to develop services for PWCD.

> *OU7: "I think partly through the interests of one of the doctors in the ENT department - I think he has a relative who had seen a speech and language therapist I think he was quite keen in pushing forward to something more sustainable"*

<u>BT3. Change is slow</u>

This theme concerns the overall process of development in terms of implementing change. Outsiders described how outsider SLTs were thought to have been working in Uganda since the mid 1980s. One believed that SLTs may have been working in Uganda before this, as the hospital (built in 1962) had a room for "speech and language therapy" in the hospital's original signage fixtures. Moving from a point of having no service to the first trained SLTs takes time and hard work, with both successes and mistakes being an inevitable part of this process. Outsiders acknowledged that change and development was a time-consuming process. As such, there was a need for patience and resilience. Outsiders often reconciled this by accepting that there was a need to start somewhere, and that the process of development was not a direct, streamlined path.

> *OU11: "I know how long these things take over time".*

<u>BT4. Acceptance of scale of challenge</u>

This theme explored how outsiders perceive many difficulties in "making a difference." Difficulties were based on both on being an outsider (with language and cultural differences), coupled with the existing challenges that insider SLTs faced: lack of services and personnel, lack of awareness, and a lack of

resources. Although these challenges affected outsiders' ability to make a difference, outsiders felt that their support was still able to make a difference specifically to the individuals with PWCD that they worked with. However, often this was contrasted as a success against the challenges of trying to make a large difference. These difficulties were often described as "patching" by outsiders. This highlighted a need for coordination of services for PWCD.

> OU9: *"It's very what's the, what's the phrase? Band Aid-y"*

Organising theme 2. Similarities and uniqueness
The second organising theme in this global theme concerned shared development features of any service for PWD. Whilst this included SLT services, some outsiders noted similar services within Uganda pre-dated SLT as a profession, and wondered if there would be a similar movement through development. Here, an outsider compared the development of an occupational therapy (OT) training course that developed in the 1990s to the SLT course.

> OU6: *"I mean the difference with the OTs is that they managed to get their profession established… we were hoping that we would follow in their footsteps really…. that period of time where outsider help was shut down… maybe that is part of the natural progression of things, maybe that is what has to happen"*

BT1. Country comparisons

This basic theme described how, although similarities existed between Ugandan services and those of other countries, there was a limit to the usefulness of such comparisons. This was due to differences in the overall context: demographics, politics, and geography. Outsiders also discussed the differences within countries' services, such as different or increased proportions of different CDs or client groups from other settings. Outsiders often drew comparisons between Ugandan services and services in the UK, acknowledging the challenges still faced by UK services and changes within the British SLT profession. Many outsiders compared the profession's development across East Africa. Although they were pleased that other countries in East Africa were developing services, they were often frustrated that Uganda was

falling behind other countries' progress, despite a promising start and lots of effort.

> OU13: *"I mean there's all sorts of things that don't work out very well in this country"*

<u>BT2. Responsive evolution of services</u>

This basic theme concerned the importance of not transplanting the service models of other countries to Uganda, and the need for the service to be strong and appropriate to the local cultures in its own right. Outsiders talked about different outsider approaches, with some considered less appropriate then others. However, ultimately, insiders were seen as a way of the service becoming more appropriate and able to respond to the specific needs of the country.

> OU1: *"[other outsiders] came here wanted to such a course here and it was just totally inappropriate and it was really mzungus yeah mzungus of the worst kind coming in and setting up the worse kind of project… they didn't even know there was a speech therapy course in Uganda… this was a proposal to set up a new course completely… at [the same University]… so you'd have two speech therapy courses"*

4.4.3.4 Global theme 4. Embedding services in context

The fourth and final outsider global theme described the overall context of Uganda as outsiders saw it. It comprised two organising themes, which explored the varied challenges to the profession, the need for groups or organisations rather than individuals to prioritise SLT, and the need for services to improve for all Ugandan PWCD.

<u>Organising theme 1. Contextual factors</u>

Contextual factors considers the setting of Uganda as a country and some of the challenges of working within it. Contextual factors groups together four basic themes.

Table 4.16 Outsider global theme 4. Embedding services in context

Basic themes	Organising themes	Global themes
1. Uganda is a Majority World country	1. Contextual factors	4. Embedding services in context
2. Bureaucracy, fraud and corruption		
3. Prioritisation		
4. Health infrastructure		
1. Severity of conditions	2. Service challenges	
2. Access inequality		
3. Awareness of CD		
4. Profession needs		

BT1. Uganda is a Majority World country

This first basic theme described the context of Uganda as a Majority World country in terms of its development status. Outsiders acknowledged the context of working in Uganda as being different from working in a Minority World context. This context acted as a backdrop to explain the challenges filtering down from the general infrastructure, health infrastructure and within SLT. The majority of outsiders explored the need for Ugandan PWCD to be included in society and have increased rights. One outsider went further and linked the need for PWCD to have improvements to employment opportunities so as to help bolster Uganda's economy.

> _OU14: "Uganda is gonna have this problem of very uh disparate and diverse communities all over the place, very poor emotionally, poor infrastructure to get between them, you know, um even basic health is gonna be a challenge"_

BT2. Bureaucracy, fraud and corruption

This second basic theme described the perception of the levels of bureaucracy, fraud and corruption in Uganda. Outsiders described how these challenges appeared in many government and national settings, and within NGOs. Despite these challenges, outsiders felt they were able to achieve some successes:

> _OU11: "it's quite an achievement to be able to [establish an SLT course] within their highly bureaucratic, regimented university system"_

174 of 450

<u>BT3. Prioritisation</u>

One challenge often discussed by outsiders was the cultural difference in attitude to training and meetings, and receiving expenses for attending them. Although outsiders did not always agree with this practice, it was generally accepted and respected. However outsiders noted that on occasion they thought that the compensation asked was inappropriate.

As well as outsiders considering the overall priorities of the health service, outsiders also stated that even for PWCD and their families, that SLT is likely to be a lower priority than other health care. Although outsiders understood this, they noted that PWCD would continue to face challenges until they were supported by services.

> *OU14: "most of the emphasis is on stopping the malaria…. obviously you can use that in lots of   different contexts… But of course it does mean that you're always gonna have a very marginalised proportion of the population who've had malaria and have got these deficits"*

<u>BT4. Health Infrastructure</u>

Outsiders viewed the challenges of Uganda's health infrastructure as a whole. A lack of allied health professionals, SLTs, and services for PWCD contributed to weaknesses. As such, many viewed SLT in Uganda to be built on weak foundations. They discussed how it would have been beneficial for the sustainable development of SLT if the infrastructure was more developed, however, they balanced this against a need to start somewhere. There was a tension of beginning a service where infrastructure and other services were lacking, which begged the question of is there a right way to start services?

> *OU14: "we all know, don't we, that Uganda's history over those 50 years: it's been a huge struggle. So, you know, trying to set up a health service in this kind of situation is like, you know, mindblowing*

<u>Organising theme 2. Service challenges</u>

The second organising theme in this global theme described challenges to services for PWCD. Services for PWCD needed to improve for all Ugandan PWCDs. The theme described a need for increased geographical presence for services (to increase access) and a need for increased awareness of CDs and services that can support PWCD. The theme also described the specific needs of the SLT profession.

<u>BT1. Severity of conditions</u>

This theme described how services for PWCD and SLT needed to provide for all PWCD, from people with mild to severe difficulties. Outsiders often described how the CDs in Uganda were often severe or moderate. Outsiders felt that a service needed to be able to work for all the PWCDs, regardless of the severity.

> *OU14: "Because [Ugandan SLTs] have got a massive great soup of people…what proportion of these people have got severe problems? Moderate problems?"*

<u>BT2. Access inequality</u>

This theme explores how there was inequality amongst PWCD in accessing services. Factors affecting access included: location, as there were fewer SLTs working in rural settings (though SLT numbers were also low in urban areas); direct costs of treatment; and indirect costs of treatment (such as travel, loss of earnings). Some outsiders aimed to improve accessibility for Ugandans by working for free or re-investing money from private practice into the SLT service.

> *OU8: "Uh, I suppose it's effectively like private patients but I don't … I never charge anybody… if it's um NGO crowd that can afford to pay they're willing to make a donation to our organisation"*

<u>BT3. Awareness of CD</u>

This theme described the lack of awareness of both CDs, and services for PWCD in Uganda. Although awareness of CDs in some areas may have

improved, as a whole, awareness amongst the general population and potential referrers or sign-posters was at a low level.

> *OU9: " there was still stories of like a little boy he had been locked up by his parents because he had cerebral palsy and they didn't understand what that meant or in their culture"*

BT4. Profession needs

Outsiders felt that the profession of SLT had a clear need for continued development. This included the recognition of SLT as a profession and appropriate policy, as well as the provision of employment opportunities for SLTs. Outsiders felt that one way to strengthen and safeguard the profession was to obtain recognition of the profession. Outsiders had worked to try and achieve the recognition of the profession within relevant regulatory settings, and to create government employment positions. However, a lack of recognition meant that there were a number of difficulties in practicing as an SLT in Uganda. For example: whilst some Ugandan SLT graduates were able to work as an SLT, a number of them returned to previous jobs and tried to incorporate SLT into these jobs or additional private work, or even move abroad to work as an SLT. Supportive measures were crucial for the sustainability of the profession.

> *OU1: "all those who were clinical officers went back to their clinical officers post… and tried to do whatever speech therapy they could there but they were still employed as clinical officers they weren't recognised as speech and language therapists"*

4.4.3.5 Summary

These four global themes describe how outsiders perceived their contributions to services for PWCD. In summary, four main findings were produced. Firstly, outsiders discussed the colonial history of Uganda. They were aware of their privileged status in Uganda and typically uncomfortable with it. They were aware that outsider-status carried certain privileges and opportunities: being able to navigate the political structures with relative ease, and able to suggest therapy techniques that were seen as unconventional in Uganda. Outsiders

described how they were not the most appropriate people to work with PWCD in Uganda, and that insiders were. Although outsiders viewed Ugandan SLTs as ultimately more appropriate for working with PWCD in Uganda, outsiders were concerned that insiders were unready to work in lead roles such as lecturing. Roles between insiders and outsiders were divided; outsiders viewed outsider roles as providing clinical expertise, and insider roles as providing cultural expertise.

Secondly, though outsiders viewed themselves as having relationships with both insiders and outsiders, there were different focuses in these relationships. Outsiders saw their relationships with other outsiders as based in friendship and personal support. Whilst some outsiders did mention receiving personal support and friendship from insiders, their relationships with insiders were generally discussed in terms of providing strategic support to the development of services for PWCD.

Thirdly, outsiders felt the model of development approach used was directly related to the quality and sustainability of their contribution. Outsiders were keen to describe the need for a custom approach for Uganda, rather than the replication of approaches used in the UK, and often critiqued other outsiders for not altering their approaches to therapy to reflect the different context.

Finally, outsiders viewed the ability to make a practical difference as important. Though a minority of outsiders felt a difference could be made through indirect outsider roles such as fundraising, the majority of the outsiders interviewed viewed "making a difference" as contributing in a direct role such as training, lecturing, or clinical work. The same majority of outsiders felt that outsiders who wanted to observe or only be involved for a very short time (e.g., for a few days as they passed through the country) had a negative effect, with many outsiders describing how they actively discouraged such attempts from other outsiders. Such offers of support were seen by outsiders as disruptive, as well as undermining the importance of the profession.

4.4.4 Participant observation results

The final method of data collection for phase one used participant observation to achieve the objective to analyse and interpret insider/outsider collaboration and working practices. A total of nine insiders and two outsiders were observed once, with five insiders and two outsiders observed twice. Participants were insiders and outsiders. Outsiders were both trainers and attendees of the training; insiders were attendees of the training. Observations took place all day across each training day, and included both training activities and non-training events such as lunch.

Table 4.17 Insider and outsider participants for participant observation

	Type of CPD	Days	Insiders	Outsiders
Visit 1	Classroom-based training	5	10	4
	Clinical CPD in hospital	1	13	3
Visit 2	Classroom-based training	2	7	2
	Clinical CPD in school or nursery	2	7	2

10 days of participant observation were completed resulting in 42 pages of field notes. Insider and outsider data from the field notes were coded separately to produce separate themes and networks. The data from the participant observations resulted in two global themes. The first global theme "Togetherness" concerned insider data and comprised three organising themes and eight basic themes. The second global theme "Support" concerned outsider data and comprises four organising themes and nine basic themes. The development of separate thematic networks for insiders and outsiders is useful for a comparison of the ways they collaborate.

For each global theme, exemplars will be used to illustrate the basic themes. Exemplars will consist of both examples of what participants said (illustrated with quotation marks) and examples of what participants did (illustrated using brackets).

Basic Themes	Organising Themes	Global themes
1. Participation and engagement	1. Participation brings unity	1. Togetherness
2. Group formation		
3. Helping outsiders		
4. Power		
1. Cultural differences	2. Cultural confusion	
2. Language confusion		
1. Clinical fear	3. Negotiating needs	
2. Need for career advice		
1. Culturally appropriate examples	1. Minimising cultural confusion	2. Support
2. Explanation of style		
1. Encouragement	2. Supportive behaviours	
2. Promoting positive learning experience		
3. Ensuring understanding		
1. Power dynamic	3. Outsiders as leaders	
2. Agenda		

4.4.4.1 Global theme 1. Togetherness

The insider global theme "Togetherness" described group working. The diversity of people from different backgrounds with different learning needs appeared to contribute to challenges in group working. It comprised three organising themes which are described along with their associated basic themes.

Table 4.19 Insider participant observation basic, organising and global themes

Basic themes	Organising themes	Global themes
1. Participation and engagement	1. Participation brings unity	1. Togetherness
2. Group formation		
3. Helping outsiders		
4. Power		
1. Cultural differences	2. Cultural confusion	
2. Language confusion		
1. Clinical fear	3. Negotiating needs	
2. Need for career advice		

<u>Organising theme 1. Participation brings unity</u>

This organising theme is about participation as a crucial basis for collaboration. Participation helped to bring both insiders and outsiders together, regardless of whether they were attendees or trainers.

<u>BT1. Participation and engagement</u>

The first basic theme described how insiders participated or engaged with outsider-led tasks, and demonstrated this to show support of the outsiders. Some insiders participated by engaging in the tasks. At times it appeared to the researcher that some insiders appeared to ask the outsider trainers questions to make up for other people's non-participation. Sometimes insiders appeared to participate by asking the outsider something that they had some existing knowledge in already. The researcher interpreted this as the insider knowing the answer but wanting reassurance or perhaps praise. The example below shows an insider SLT asking the outsider SLT trainer a question about the clinical impacts of a visual impairment on dysphagia.

Insider SLT: "I'd like to ask what is the relevance of vision to eating and swallowing"

Some insiders did not always give the impression of participating fully. One way this was indicated was the use of mobile phones to text or take phone calls, and the use of iPads to read news during classroom-based training and during clinical interactions. At other times, some insiders did not complete the tasks set by outsiders. Other non-engagement was also noted through insiders sleeping through activities.

Insiders were sometimes prompted by outsiders to focus and engage in the activities. On these occasions, insiders would typically re-engage in activities. Insiders appeared to use humour to defend themselves or diffuse the tension from their lack of full participation. On other occasions, when prompted to engage in group tasks, some insiders paraphrased the activity description as a statement to contribute, which appeared to frustrate some outsiders. This example shows an insider responding to both insider and outsider SLTs in a

small group activity where the group was tasked with how to assess a clients' dysphagia.

Insider SLT: "What if we assess him, how is he feeding?"

BT2. Group formation

Insiders appeared to come together both as a group of insiders and as a group with insiders and outsiders. One way insiders appeared to do this was by building rapport through the use of humour, or friendly teasing. The example below shows the result of an outsider asking for a culturally appropriate example, but mispronouncing it.

Insider SLT: (giggled at outsider's pronunciation of 'poshol')

Other times insiders appeared to praise or ask other group members for information to gain an opinion or agreement to gain consensus and create group harmony.

Insider SLT: "That's great how are we doing?"

BT3. Helping outsiders

Some insiders tried to support outsiders in their roles. Sometimes this was explicit, with insiders offering direct help. Sometimes insiders appeared to be aiming to support an outsider, but the wider group dynamics made this difficult. For one observed task, an outsider was put in a leadership role of a group of insiders and outsiders. Here the insider in the leadership position (insider SLT 2) appeared to want to complete the task, however other insiders in the group appeared to be working at a lower ability (here an example from insider SLT 1). An outsider then appeared frustrated with both insiders, perhaps perceiving both insiders to be working at a lower level, despite the insider group leader trying to help.

Insider SLT 1: "Yes a secure assessment yes we would need both"
Insider SLT 2: "Do we need that first?" (facilitating, negotiating)
Outsider SLT "Yes we do that first." (seems frustrated)

Insider SLT 2: "So the medical then the case history" (Trying to be explicit to move task along)

BT4. Power

This basic theme described how power relations worked within the group. This was typically demonstrated by insiders correcting or undermining others. In this first example, an insider asserted their position by acting as an authority to a small group of insiders and outsiders. This was for a classroom practical exercise.

Insider SLT: "You don't need to fill it" [a cup]

Another instance of this occurred in the discussions between an insider and an outsider trainer. Here, an outsider answered another insiders' question about foreign bodies and dysphagia.

Outsider SLT: "Yes yes lots of fish bones chicken bones [this is commonly seen in] seaside towns do you have lots of them?"
Insider SLT: "Yes yes of course" (seemed puzzled/annoyed)
Outsider SLT: "yes this is common in seaside towns"
Insider SLT: "Yes because you have the bones… will get stuck"

Organising theme 2: Cultural confusion

This organising theme described how the cultural differences within the group of insiders and outsider caused confusion at times.

BT1. Cultural differences

This basic theme described the cultural differences between insiders and outsiders. Often this took the form of different uses of humour. Misunderstandings often arose when outsiders appeared to light-heartedly correct insiders or make jokes about insiders' abilities to focus on tasks.

Outsider SLT "Let's see what you're trying to say and not doing a very good job at it!" (pushing and teasing insider for clarification).

Insiders often did not ask explicit questions to outsiders (except when questions were solicited by outsiders or when following other insiders' lead). An example of cultural differences in question-asking occurred during classroom-based training occurred when an insider pointed to one of the outsider trainers. A second outsider trainer noticed this and asked if the insider wanted to talk the outsider being pointed at. The insider then asked the first outsider a question. Sometimes insiders explicitly referred to cultural or identity differences between insiders and outsiders. In this example, for a practical training exercise, insiders jokingly demonstrated their desire to work with an outsider.

> Insider SLT: "I want the foreign touch!"

Insiders sometimes commented on the cultural appropriateness of their work. Here an insider commented that they felt an informal communication screen they had developed with outsider support would be too challenging for their client caseload because of the cultural differences.

> Insider SLT : This is too hard for my children they will fail I wanna assess Down syndrome but not Down syndrome in the modern world"

Two insiders discussed how they would amend or adapt resources developed with outsiders for their own practice to make it more suitable.

> Insider SLT: "We can make our own [version of the assessment] in clinic and it can be a bit different"

BT2. Language confusion

This basic theme illustrates outsiders' confusion regarding insiders' language and meaning. Insiders and outsiders often experienced a breakdown in communication. Often outsiders did not understand what was being asked or commented on by insiders. Where this happened, outsiders tried to spend time understanding by asking further questions to clarify meaning. However, sometimes outsiders were still unable to understand. Sometimes outsiders' prompts for clarification appeared to be interpreted by some insiders as outsiders understanding them. In the example below, several insiders wanted to

discuss "concept papers," and an outsider asked for clarification of what a concept paper was. After a discussion between insiders and outsiders in which outsiders had tried to find out what group members meant by the term concept paper, an outsider asked a forced alternative question to focus definitions.

> Insider SLT: "Oh so my worries about it…"
> Outsider SLT: "So the question is is it the same or different?"

Once, an outsider tried to move on from a subject they appeared not to understand by commenting:

> Outsider SLT: "A research project for you there!

Organising theme 3: Negotiating needs

This organising theme describes the professional needs of insiders, and how this was negotiated between insiders and outsiders.

BT1. Clinical fear

This basic theme describes insiders' clinical fear. Clinical fear refers to a specific worry regarding working with certain conditions or client groups. Over the training sessions, it emerged that many of the insiders were frightened by working with some client groups, such as people with dysphagia. Here insiders discussed receiving referrals for clients they felt ill-equipped to work with. However insiders felt trapped between refusing a referral (either directly to PWD or to the referrer), as previous refusals had resulted in the insider being reported to their employer.

> Insider SLT: "I was scared… not scared I was not confident I can't do… it all it builds"

> Insider SLT: "Is there a dysphagia for paediatrics focus to this? it scares me to death"

BT2. Need for career advice

This theme describes insiders requesting advice for further education. Over the training period, insiders raised the topic of how to complete research for further education, which was not a planned component of the training. Although some insiders wanted to learn more to be able to complete research and add to the knowledge base, many wanted to know about further education, such as specific research degree programmes (Master's and PhD), and wanted more knowledge about research in general to help with their personal or professional goals.

> *Insider SLT: "I would love [learn more about research] to prepare myself before I do my Master's then the other is to be equipped with knowledge so I can add to the theory"*

4.4.4.2 Global theme 2. Support

The second global theme "Support" used outsider data to describe how outsiders aimed to support insiders despite challenges. It consists of three organising themes.

Table 4.20 Outsider participant observation basic, organising and global themes

Basic themes	Organising themes	Global themes
1. Culturally appropriate examples	1. Minimising cultural confusion	2. Support
2. Explanation of style		
1. Encouragement	2. Supportive behaviours	
2. Promoting positive learning experience		
3. Ensuring understanding		
1. Power dynamic	3. Outsiders as leaders	
2. Agenda		

Organising theme 1. Minimising cultural confusion

This organising theme explores how outsiders aimed to be clear to insiders in terms of language, meaning and intention. It describes how, although outsiders may have used culturally appropriate examples, confusion was still experienced between both groups.

<u>BT1. Culturally appropriate examples</u>

This basic theme describes how outsiders tried to use culturally appropriate examples in their training. Although a previous excerpt indicated one insider's frustration (see 4.4.4.1 basic theme for "power"), this generally appeared to be either appreciated or respected by the insider group members. Within the training sessions, outsiders would ask for local equivalents. Outsider trainers would ask attendees for appropriate local-language examples, check the pronunciation and usage of the local word, then use these examples in their training.

Outsiders and insiders often discussed the need for culturally appropriate resources, and to think about what would be appropriate for insiders to use for their own practice. When discussing resources, outsiders (trainees and attendees) encouraged insiders to think practically about what would be appropriate and feasible.

> *Outsider SLT: "plan around the fact you don't have fancy resources, know your limitations"*

The below example shows an insider and outsider attendee planning appropriate resources for a paediatric communication screen. Attendees were planning on using resources familiar to their clients. Here an outsider appeared to prompt an insider to think about what would be most suitable for their assessment.

> *Insider SLT: "what sort banana are we talking about? Wooden or real?"*
> *Outsider SLT: "What with make the most sense?"*
> *Insider SLT: "It says here material should be cheap and easy to find"*
> *Outsider SLT: "Have you seen a wooden banana?"*
> *Insider SLT: "Yes of course but I don't know how cheap it is"*

Outsiders prompted insiders to be culturally or clinically appropriate for their clients in practical sessions where they perceived this not to be happening. One example of this occurring was when working directly with clients.

(Insider SLT working with a child who had a very short attention span.)
Insider SLT managed to do some of the assessment she was trialling, then the child stopped attending.
Insider SLT sang a religious song with child which appeared to soothe him.
Afterwards outsider SLT talking about singing religious songs may be considered inappropriate and also not useful (e.g. a nursery rhyme may have been more useful)

BT2. Explanation of style

This basic theme explores how outsiders explained differences of teaching style to insiders to justify their method and to aid insiders' understanding within this context. For this example, an outsider trainer had asked the group a deliberately ambiguous question. Here, insiders informed the outsider that they were confused by this.

Insider SLT: "this - your question confuses you"
Outsider SLT1: "it's designed to confuse you! I'm reeling you in!" (mimics reeling in) (group look puzzled)
Outsider SLT2 : "(UGN1), they have a thing called 'devil's advocate'" (group now seemed to understand the purpose of task)

Here, another outsider explained the outsider trainer's teaching style, and acted as a bridge between the two cultures. Later the outsider trainer explicitly use the term "devil's advocate" to explain what they were doing in debating with an insider:

Outsider SLT: "I'm going to argue I'm being devils advocate" (explanation of why disagreeing)

Organising theme 2. Supportive behaviours

This organising theme explores how outsiders tried to create a supportive environment for learning.

BT1. Encouragement

This basic theme describes how outsiders aimed to encourage insiders to participate and share their experiences. This took the form of praising and complimenting the insiders' work. Another way outsiders encouraged insiders was by sharing their own experiences. Here, insiders discussed how they still had clinical fear. The outsider trainer tried to relate their experiences to the team and have a frank discussion about practice.

Outsider SLT: "it can be scary"

Outsider SLT: "I still get fear"

The sharing of their experiences appeared to allow insiders to feel more comfortable and less anxious. Outsiders then moved to reassure insiders on their rights as clinicians (e.g., to refuse clients they felt inexperienced to work with) and further discuss clinical fear to reduce it.

Outsider SLT: "What <u>do</u> you do if you have a patient that is unresponsive?"

BT2. Promoting positive learning experience

This basic theme is about how outsiders tried to create a positive learning experience for all group members. Outsiders often provided opportunities to ask questions in a supportive environment, rather than insiders having to ask for clarification. However, when insiders did not respond, the outsider then asked insiders directly.

Outsider SLT: "[terminology] who doesn't know this term? [insider], do you know what I mean?"

BT3. Ensuring understanding

This theme explores how outsiders tried to ensure insiders' understanding of the training topics, terminology and cultural misunderstandings.

Outsider SLT: "Extrapolate do you know this word?"

> *Outsider SLT: "The word bolus is a general term"*

Checking was often followed by explanation. Here the researcher interpreted outsiders as appearing to be checking the insiders' knowledge and experience levels to reflect on whether they themselves were training at the right "level." However, outsiders were often concerned with insiders' knowledge levels. The following example concerned the need for definitions for a language screen attendees were developing.

> *Outsider SLT: "There's a comment here that people would find definitions for the paraphasias, circumlocutions, preseveration useful"*
> *Outsider researcher: "Would you find it useful?"*
> *Insider SLT: "yes because [SLTs] might not know [these terms]"*

Organising theme 3. Outsiders as leaders

This organising theme explores how — although outsider trainers held relative authority positions in the training sessions — they allowed for some flexibility in agendas so insiders' concerns could be voiced.

BT1. Power dynamic

This theme describes the power dynamic between outsiders and the group. As trainers, the outsiders were in a position of power. Within the group of attendees there was a mix of power amongst insiders and outsiders. Outsider attendees may have had more power than many of the insider attendees (due to being an outsider, the status of roles, or their experience levels). Some insider attendees may have had more power than other insiders based on their role, occupation or experience level. This example shows an outsider trainer prompting and pushing the trainees where insiders appeared to lack the confidence to make clinical decisions.

> *Outsider SLT "I just asked you, I want you to say how you will assess this, explaining how you are going to do this… [and] plan of how you are going to do this"*

The outsider role within this training dynamic varied. Outsiders roles included teaching, counselling, and signposting to available resources or support networks.

> *Outsider SLT: "epistemology (writes on board) it is a pattern of understanding"*

> *Outsider SLT "What are you worried about?"*

> *Outsider SLT: "There is a lots of tutorials [online] at how to do a database search"*

Trainers predominately took teaching roles. Here outsiders adopted different styles of a teaching role dependent on the situation, such as authoritative, facilitator, or demonstrator.

> *Outsider SLT: "right can everyone leave their phones and computers and cameras alone unless it is really really urgent"*

> *Outsider SLT: "So imagine if you needed information - what would you need to know"*

BT2. Agenda

This theme describes how although training topics were selected by insiders, outsiders linked this to their own agendas. Agendas included strategic topics such as the political importance of services for PWCD, rights of SLTs, and research. Outsiders suggested that it was important to show the demand for services for PWCD in order for services to be commissioned and for policy to reflect the needs of PWCDs. One way this could be demonstrated was by undertaking research.

> *Outsider SLT: "It is only when there is policy can speech therapy be action"*

4.4.4.3 Summary

The thematic analysis of participant observation produced two global themes: "Togetherness" and "Support." This shows how positivity, inclusivity and encouragement from both insiders and outsiders brought each other together to reduce potential challenges. Three main findings from the themes of "Togetherness" and "Support" were produced. Firstly, the majority of insiders, at some times, showed signs of not fully participating in the training. Outsiders would ask insiders for their engagement and to aim to have good time-keeping for the week to benefit from training.

Secondly, the differences in culture between insiders and outsiders are hard to escape. Cultural differences between insiders and outsiders caused confusion to both, with at times each confused by the others' actions. During the observations, outsiders seemed to aim to facilitate cultural understanding by asking if particular actions or objects would be appropriate in their setting, and checking insiders' understanding by asking terms. Insiders tried to increase outsiders' understanding by giving more description or information where they appeared to perceive an outsider's confusion.

Thirdly, the fundamental roles of outsiders observed were ones of relative power. Outsiders were either in direct authority roles (such as trainers) or had more experience or qualification working with PWCD. Despite this, outsiders sought to share power by asking insiders to contribute their learning needs, with outsiders effectively working to support them. Outsiders can share their agendas, perspectives and approaches of how to strengthen and expand services while ultimately allowing insiders to make the choices of whether this is relevant for how they see the services that they work in.

4.5 Discussion

Following the presentation of the phase one results, this section discusses the data and synthesises the different data sets to respond to each of the four research objectives. For each objective, findings are discussed and related to the literature. Limitations are discussed at the end of the section.

Each research objective was addressed by a number of data sets. Table 4.21 shows each research method and the type of data produced by each method of data collection.

Table 4.21 Relating research objectives to data collection

Research objective	Data used
1) To explore and describe the process and history of the development of services for PWCD in Uganda.	• Document analysis • Outsider interview • Insider interview
2) To describe and explain insiders' perceptions and experiences of the contributions of outsiders and outsider support, to the development of services for PWCD in Uganda.	• Insider interviews
3) To describe and explain outsiders' perceptions and experiences of their contribution to the development of services for PWCD in Uganda.	• Outsider interviews
4) To analyse and interpret insider/outsider collaboration and working practices.	• Participant observation

4.5.1 The process and history of services for PWCD in Uganda

The process and history of services for PWCD in Uganda was addressed by the first research objective: to explore and describe the process and history of development of services for PWCD in Uganda. This objective was met by data from the document analysis and the two sets of interview data to produce five findings. The document analysis revealed three findings, one from each category:

> 1. From C1: Although there are improved and increased services for PWCD in Uganda, PWCD still face challenges in their everyday lives.
>
> 2. From C2: SLT roles for insiders have developed over time with similarities and differences to outsider roles.
>
> 3. From C3: Services for PWCD have been developed in multiple ways by insiders and outsiders.

One finding was produced from both the insider and outsider thematic networks relevant to this research objective.

> 4. From insider GT3: Services have developed over time, with greater planning and coordination in recent years with the aim of sustainability.
>
> 5. From outsider GT2 and GT4: Services have developed, however there are a number of challenges that prevent or threaten development.

Documenting the historical medical administration in Uganda, Beck (1970) rejected the idea of history repeating itself, claiming that early healthcare challenges were unique to the specific context of their time. Surprisingly, from this perspective, there are still notable similarities between early medical outsiders and current outsiders involved in Ugandan SLT services — including a lack of research or evidence base, low numbers of trained personnel, and anxieties about service sustainability (Beck, 1970). These similarities suggest that changes (either in outsider approaches or in Ugandan context) have not been sufficient to avoid historical comparison.

Complementary findings from document analysis and interviews confirms that the main outsider NGO responsible for the SLT in Uganda began working in 1986. Interestingly, there is some indication of Ugandan SLT existing earlier, as one outsider noted the national hospital (built in 1962 (White, 2000)) had a room labelled "speech and language therapy." While it is possible that the hospital — built as a "gift" from Britain but paid for by Uganda (Naggaga, 2017) — was initially intended to provide SLT, a lack of additional evidence may suggest the room-labelling reflected outsiders' health concerns and was never implemented by Ugandan insiders.

The SLT degree programme was viewed in documents and interviews as a means to sustainably develop services for PWCD. There were, however, discrepancies regarding the timeline of the SLT programme. Documents cited a start date of 2008; interviews from insiders and outsiders described a start date of 2007. This discrepancy extended to the first graduating cohort of SLTs, which was cited as either 2011 or 2012. Documents and interviews revealed an eight-year development period from course-conception to the first cohort of students, which some outsiders perceived as too long and considered to be an effect of the Majority World context. Insiders and outsiders perceived bureaucracy as a challenge in developing and implementing the programme.

There was varying agreement regarding the outsider NGO's involvement in developing the SLT course. Though all insiders and outsiders agreed the NGO's involvement ended earlier than planned, they disagreed over why this happened — suggesting a lack of communication or transparency. Another

outsider-led SLT training course ended due to financial reasons after only one cohort of 18 students graduated in Zambia (Beneke, 2016). Partnerships may eventually come to an end, but planning and dealing with transitions is essential. Nganwa et al. (2013) described how links between services for people with disabilities typically broke down after projects ended. Pfeiffer et al. (2008) argued that NGOs should adopt a code of conduct to minimise challenges and service collapse. This was published prior to the withdrawal in Uganda, and apparently not taken into account. The SLT programme continues to run, however both insiders and outsiders had concerns about the readiness for insiders to lead the programme. Many respondents expressed concerns about the quality of the education provided. Some drew parallels to an occupational therapy degree programme which followed a similar trajectory in terms of outsiders starting a course then leaving and reducing their involvement.

Insiders and outsiders described challenges in registering SLT as a profession with the appropriate Ugandan government Ministry. There was disagreement about whether this had been achieved. Regardless, only a small number of the Ugandan graduates were working full-time as SLTs. Many worked part-time or in their prior job posts, incorporating SLT where possible. Some left Uganda to work abroad (returning to their home countries if sponsored). Rizvi (2006) recommended guaranteeing job posts to reduce "brain drain." Doing so in Uganda could minimise numbers of SLT leaving, as well as offering security and safety to SLTs already practising in Uganda under the title of their old posts. An active SLT association was believed to be one way of allowing SLTs to coordinate with the relevant stakeholders to register SLT as a profession and secure job posts.

Concurrent with service development at the university and national hospital, many insiders and outsiders were involved in other aspects of services for PWCD. This included buying-in or recruiting volunteer outsider SLTs to develop small therapeutic services, to work in schools, or to work privately with insiders' children. In spite of these approaches, document analysis and interviews still showed the majority of PWCD had not benefitted from SLT. This may be because of a lack of personnel; a lack of access to services; or because SLT is

not the most appropriate, or urgent need for PWCD in Uganda. From the insider interviews and document analysis, PWCD and parents of PWCD did want SLT services, but they also wanted practical rights such as schooling, job opportunities, independence, reduced stigma, and the opportunity to contribute to the Ugandan economy. This is supported by findings in Minority World countries from Wickenden (2011), who found that PWCD were more concerned with issues of independence and society, compared to specific intervention from SLT. For the future, insiders and outsiders wanted increased services and improved training opportunities for SLT, as well as inclusion of PWCD within society. Insiders and outsiders believed the service existed to meet the needs of PWCD. As service users, the needs of PWCD should be the primary concern — with SLTs facilitating discussion or campaigning for other services and rights.

4.5.2 Insiders' perception of outsiders' contributions to services for PWCD

Insiders' perceptions of outsiders' contributions to services for PWCD were addressed by the second research objective: to describe and explain insiders' perceptions and experiences of the contributions of outsiders and outsider support, to the development of services for PWCD in Uganda.

The insider data produced three global themes in total. Two are relevant to the second research objective: "Mother child relationship" and "Shared values." The insider interview data focused heavily on relationships generally: the dynamics of the relationship between insiders and outsiders, how good relationships could be formed, the importance of shared values. Four key findings from the insider thematic analysis are presented for discussion.

>   1. From OT4: Insiders viewed outsiders' contributions as being largely related to the specific roles of outsiders, however variables such as their age, skills and experience were also important.
>   2. From OT6: Insiders viewed outsiders as having a higher status than insiders, regardless of their skills or experience levels.
>   3. From OT5: Insiders viewed outsiders' contribution as not always culturally appropriate, however insiders are selective about what they pick and choose from outsiders' offerings.

4. From GT1 and GT3: Insiders view outsider support as unstable and transient.

There were a matrix of factors informing how insiders considered the successfulness of outsiders. Firstly, insiders viewed outsiders' contributions to be related to their specific working roles. Roles such as lecturer or trainer were considered to be the most needed and most appropriate for sustainability. Where there was a need for clinically practicing SLTs, insiders felt that these needed to work with insiders. Some insiders felt non-visiting or short-term outsiders could be useful, but their roles needed clear definition to be advantageous to Ugandan services for PWCD. Observers and voluntourists were perceived to make little or no contribution — potentially causing more challenges than benefits. Hickey et al. (2012:42) made a distinction between 'vacation-minded' and 'volunteer-minded' tourists, and called for a balance between outsiders' desire for holiday experiences and altruism. Outsider organisations should have an obligation to check perspective outsiders motivations for working in Majority World countries (Hickey et al., 2012).

Relatedly, insiders viewed longer-term outsider commitments as more successful. Where possible, insiders also preferred outsider qualities of age, experience and preparedness. These preferences reflect Laleman et al.'s (2007) findings regarding insider preferences of outsider doctors working in sub-Saharan Africa, in which participants doubted the effectiveness of young, inexperienced outsiders. Following the withdrawal of the main NGO providing outsider support in Uganda, insider SLTs or students lost much of the planned CPD and outside clinical expertise. As such, newly-qualified outsider SLTs may not be able to provide what insiders need.

Regardless of outsider skills and experience levels, insiders viewed outsiders as having a higher status than their Ugandan counterparts. Even following the qualification of Ugandan SLTs, insiders remained at a lower status — an imbalance experienced by both insiders and outsiders, and evidenced in their relative collaborative roles (with outsiders giving clinical advice and insiders providing cultural guidance). This may reflect an internalised colonial mentality in Ugandan culture which views Africans as inferior (Aghili, 2013) and means

outsiders are still afforded higher status and power (Pedersen, 2012), a vestige of colonialism with enough historical inertia to make change challenging (Steyn, 2001). Across East Africa, Lough and Carter-Black (2015) found that Kenyans considered white volunteers to have superior knowledge, resources, experience and trustworthiness while Miller et al. (2011) explored Kenyan patient's attitudes around the ethnicity of doctors — finding that (whilst half of participants expressed no preference) half preferred a doctor of a similar ethnicity for conditions that were considered less severe, and an Asian or European doctor for conditions considered more severe. For SLT in Uganda, this may mean that either CDs are considered severe conditions, or that outsider SLTs are superior.

Moncrieffe (2009:91) described Ugandan's feelings of inferiority as stemming from negative and unpleasant interactions with 'people like them' and positive interactions with 'people not like them.' Considering PWCD, this attitude may have become further ingrained given the stigma regarding disability in Uganda, and the perceived support from outsider SLTs. Though contemporary insiders attempted to "prove" their equality in clinical settings by demonstrating equal knowledge and expertise, some described witnessing PWCD and their families choosing outsider SLTs over themselves. Whilst all insiders felt Ugandan SLTs were more appropriate for Uganda, one insider described SLT in Uganda as a 'white idea.' As Ugandan SLTs begin to outnumber outsiders in the profession, it will be interesting to see if these perceptions remain.

Cultural differences were often difficult for both groups to navigate. Insiders described their cultural avoidance of conflict and confrontation, often resulting in misunderstanding and resentment when communicating with outsiders. When outsiders' contributions were culturally inappropriate, insiders would not challenge outsiders but, instead, would "pick" specific outsider ideas and adapt them for a Ugandan context. This cultural difference was particularly challenging for insiders when outsider training or theory was inflexible. Insiders discussed challenges of being taught about SLT technology that was not available to them, or approaches to therapy that were culturally inappropriate (such as parents using toys or male SLTs doing specific therapy activities such as singing nursery rhymes). Hickey et al. (2012) described this inflexibility as devaluing SLTs skills and forcing insider SLTs to make culturally inappropriate

recommendations to their clients. During one interview, an insider asked the researcher for advice as to how, as a male, he could provide SLT to children. He objected to sitting on the floor and singing to a child as men in his culture do not do that. This challenge is noteworthy as there is a significantly higher ratio of males:females on the Ugandan SLT course compared to many Minority World countries, with some Ugandan cohorts being exclusively male. As an alternative approach, Hickey et al. (2012) suggested that parents could interact with their children around shared chores or locally-used toys. As a new profession in Uganda, SLT needs to carve out its own professional identity using appropriate recommendations based on evidence.

Insiders' perceived outsider support as being unstable and transient. Insiders were typically aware that support was time-limited and finite. When support ended, there were typically long periods with no support, waiting for the next outsider or outsider package of support to arrive. Even where support was planned and coordinated, insiders were aware of the likelihood of it ending prematurely. This happened at an individual level when outsiders left their roles in Uganda for personal reasons (which Brown (2008) noted ended one in every five overseas assignments) and at an organisational level, when an NGO changed direction and withdrew ahead of the planned timescale. The results may suggest an expectation of untrustworthiness and unreliability based on patterns of outsider support ending. Pierre et al. (2013) described a number of pressures that outsiders may experience, and stated that sending-organisations need to provide adequate medical and psychosocial support, particularly in low-resource settings. Changes at an individual level may be hard to plan for. However, they may be mediated by organisations relying less on small numbers of individuals (often one), keeping the momentum of support going, and recruiting the preferred types of outsider. At an organisational level, Pfeiffer et al. (2008) called for NGOs to adopt new codes of conduct when working within health systems in order to avoid sudden and unplanned changes.

Given the importance of relationships to insiders, improving trust is a fundamental aspect of developing successful partnerships in the Majority World (Costello and Zumla, 2000). However this is challenging when Mukasa (1999) found that frequent change and high turnover of expatriate staff caused a lack

of cohesion among NGO activities and expansion — an effect exemplified in the data from this study. A high turnover and lack of consistency in Uganda caused unnecessary changes to the workloads of staff, and replication of services. One insider commented that replication of outsider support kept insiders stuck at the same level, referring to this constantly-stunted development as a "vicious cycle." Nganwa et al. (2013) stressed the importance of a country's government taking responsibility for the training and highlighted the difficulties of an NGO being responsible for the training of Tanzanian CBR — which were again reflected in the current data. Where a project is unable to commit for long-term support, it is likely that support will not be sustainable and NGOs should be transparent about what they can offer. Insider acceptance of unstable or unsustainable support may relate to the concept of receiving such "gifts" (Mauss, 1954), where a rejection of an outsider's offering would be seen as rude and demeaning. Within this exchange, insiders must appear grateful for whatever is offered, regardless of whether it is wanted or effective.

4.5.3 Outsiders' perception of outsiders' contributions to services for PWCD

Outsiders' perceptions of outsiders' contributions to services for PWCD was met by the third research objective: to describe and explain outsiders' perceptions and experiences of their contribution to the development of services for PWCD in Uganda. The outsider interview data was analysed to produce four global themes. Three were relevant for the third research objective, these were: "Relationships;" "Reconciling Ugandan independence and outsiders' expertise;" and "Development approach." Four key findings from this analysis will be discussed:

1. From OT4: Outsiders were conscious of working under the legacy of colonialism in Uganda.
2. From GT1: Outsiders viewed relationships with insiders and outsiders to have different focuses.
3. From GT3: Outsiders felt that the development approach used was directly related to the quality and sustainability of their contribution.
4. From OT4: Outsiders viewed the ability to make a practical difference as important.

Outsiders described their awareness of Uganda's colonial history, describing discomfort with their privileged status in Uganda. The privilege afforded to white outsiders in Majority World countries (Aghili 2013) is inherent even in the terminology describing their outside status. The term "expatriate" typically refers to white 'priviledged migrants' (Fechter and Walsh, 2010:1198) while the term "immigrant" typically refers to African, Asian or Arab people working abroad (Koutonin, 2015). Outsiders were aware of many privileges and opportunities this "expatriate" status afforded, such as being able to navigate political structures with greater ease than their insider counterparts. Outsiders were also able to suggest therapy techniques that would be seen as culturally strange within Uganda (as their knowledge was more respected and the novelty of their status allowed them cultural leeway). Insider and outsider collaborative roles were divided. Outsiders viewed themselves as providing clinical expertise, and insiders as providing cultural expertise. Although outsiders felt insiders were the most appropriate people to work with PWCD in Uganda, they still doubted insiders' ability to undertake "lead" roles such as lecturing. This may be a realistic view of the readiness of the insider group. It may also reflect a conscious or unconscious level of paternalism.

Outsiders related differently to insiders and other outsiders. Outsiders viewed relationships with other outsiders as supportive friendships: providing opportunities to talk about personal and occupational challenges and frustrations. Black (1989; cited in Copeland and Norell 2002) described how such friendships offered support from environmental stressors, particularly during adjustment to a new cultural context. Though some outsiders reported similar friendships with insiders, they tended to view their connection to insiders as working relationships. Much of the available literature was written by outsiders, who typically described outsider-insider relationships as providing guidance and information rather than deep friendships. Some outsiders may consider themselves 'cosmopolitans' and aim to integrate and socialise with insider colleagues (Bochove and Engbersen 2015:305). As a result of language and cultural differences, these relationships may be hard to develop with insiders. Because of this, many outsiders remain in what Bochove and Engbersen (2015:295) describe as an 'expat bubble.'

Outsiders believed that the model of development used in supporting services for PWCD directly affected the quality and sustainability of their contribution. Outsiders attempted to customise approaches to services for PWCD rather than replicating services from Minority World countries. This reflected Robinson et al.'s. (2003) work, describing how a stakeholders' workshop sought to avoid the replication of services in Uganda, while Wickenden et al. (2003) described the importance of this approach in the development of a Sri Lankan SLT training programme. A customised or unique approach was felt to blend the evidence base of SLT with the Ugandan cultural context. Failure to do so, outsiders believed, would result in failure and outsiders often critiqued other outsiders who they felt did not adapt their approaches to reflect the Ugandan context. Although there is limited research describing cultural adaptions in health training programmes, Hickey et al. (2012) noted that attempts to ignore language and culture differences when exporting SLT practices internationally could be seen a neocolonialist practice.

Outsiders valued the ability to make a practical difference. Most outsiders felt the best ways of "making a difference" involved contributing directly (in a training, lecturing, or clinical role) though some outsiders saw a limited need for indirect roles such as fundraising. The majority of outsiders also felt those who contributed on a smaller scale (such as outsider observers) had a negative effect and sought to discourage such contributors. Such short-term contributions may be related to how Uganda is seen as a recipient of international aid. Whilst some aid may be given as a "gift," (Eyben, 2006) this has the consequence of restating and reinforcing the power divide between the giver and receiver.

4.5.4 Comparison of insiders' and outsiders' perceptions of outsiders' contributions to services for PWCD

Comparison between insider and outsider global themes revealed two insider global themes and one outsider global theme covering elements of relationships. Both insiders and outsiders valued the importance of relationships. Insiders valued relationships as core value, while outsiders also discussed the topic alongside development approaches — indicating that

Ugandan insiders saw relationships as fundamental to collaboration, with outsiders more concerned about practical aspects of service-development. This may reflect findings from Bradshaw and Goldbart (2013) who found care staff learnt from observing more experienced staff. This may suggest insiders have more to gain from such interactions with clinically-experienced outsiders. Furthermore, due to being in another country, outsiders are always "at work" during their time in Uganda. As such, they may have been drawn to favour personal friendships with other outsiders as a means to find comfort and relaxation in the familiarity of their own culture (Kennedy, 2004) and as a chance to discuss strategic issues away from the presence of insiders.

Comparison of the insider theme of "mother-child relationship" and the outsider themes of "relationships" and "reconciling Ugandan control and outsider expertise," reveals key differences in how insiders and outsiders understood relationships. Insiders focused on the mother-child analogy — generally expressed positively — in which outsiders were seen as supportive "mothers" and insiders as receptive "children." The literature suggested differences in how East African and British cultures view the concept of "family." In Uganda, the family has an extended structure which operates as a social unit for production (Muhwezi, 2007) and as a safety net against challenges (Seeley et al., 1993). In Britain, people have generally de-emphasised family networks in favour of supportive friendship groups (Koffman et al., 2012). Additionally, outsiders were particularly uncomfortable with the "mother" analogy as it was recalled the paternalism of colonial times. Outsiders also felt their support would be rejected (or become unnecessary) when insiders no longer needed their support.

Table 4.22 Comparison of insider and outsider global themes

Insiders	Outsiders
Mother child relationship	Reconciling Ugandan control and outsiders expertise
	Relationships
Shared values	Development approach

Outsiders varied when assessing the success and impact of their contributions. Some felt that they could have done more, or contributed more effectively.

These criticisms often related to larger concerns about the sustainability of services. Many outsiders felt the withdrawal of NGO support hampered their contributions. While some measured their success by concrete markers (e.g., the number of graduating Ugandan SLTs), many expressed sadness that a planned transition period had not happened, and described feeling that the newly qualified SLTs would struggle without the NGO's promised mentorship and support. Outsiders were also unsure as to whether their contributions were successful based on differences in culture. They typically described Ugandan culture as hard to read and identified a Ugandan unwillingness to say "no" to others (which insiders explained as not wanting to embarrassing outsiders or themselves). Although cultural barriers left outsiders uncertain of their effectiveness, insiders descriptions of "skill picking" suggest that outsiders' contributions were at least partially useful.

On their part, insiders credited outsiders with "bringing" SLT to Uganda but perceived a need for continued outsider support until they had sufficiently developed in experience. Although outsider involvement in Uganda has reduced, the majority of the insiders expected continued support and welcomed continued outsider involvement on the degree programme.

Both insiders and outsiders described preferred qualities of outsiders (see Table 4.23). This comprised specific personality traits such as patience and flexibility. The importance of these traits is supported by Tucker (2015) who found both traits allowed for adaption to cultural attitudes, new ways of working, and seeking input from others.

Despite consensus of preferences amongst those interviewed, interviewees and documents indicated that outsiders may not always work according to the ways desired by both insiders and some outsiders. This was most commonly seen in the time lengths of outsider visits: long-term commitments were desired by insiders but not always received. Insiders also described having little say or influence in the type of outsiders received, and often had to compromise.

Table 4.23 Ideal outsider factors

Outsider qualities	Length of visit	Familiarity	Roles
Patience	Long-term	Repeat visits to Uganda	Support
Flexibility	Short-term if there are frequent visits		Training / mentoring
Skills			

A need was identified to establish a point at which insiders would cease to be cultural informants and instead be regarded as clinicians in their own right, able to work at a peer-to-peer level with outsiders. There is a question of how new models of intervention and practice may develop in Uganda and other Majority World countries and be used to inform practice in these Majority World countries, which, according to Nixon et al. (2015), rarely happens. Furthermore, when the majority of research and practice recommendations come from Minority World countries, clinicians may find it more useful to apply Minority World principles despite potential cultural barriers. Both insiders and outsiders made this compromise, perhaps feeling a duty to share what was seen as the best available clinical approaches (Nixon et al., 2015).

Many of the outsiders in phase one discussed their motivations for working abroad in the context of religion — either as part of their own spirituality or in terms of working for a religious organisation. Uganda is a country with a high level of religiosity, with one insider remarking: "in Africa, ain't nobody here who isn't spiritual." Despite a possible match in shared values between insiders and religious outsiders, motivations based on doctrinal duty or philanthropy (as opposed to models based of rights and dignity) may reflect a problematic approach (Nixon et al., 2015) similar to that of the early missionaries described in 2.4.2.

4.5.5 Insider and outsider collaboration

The fourth research objective was to analyse and interpret insider/outsider collaboration and working practices. This explored insider and outsider collaboration and was achieved through the use of participant observation. The three key findings from the thematic network analysis will be discussed.

1. From OT1: Insider participation is fundamental to effective collaboration.
2. From OT2 and OT4: Cultural differences exist between insiders and outsiders but can be reduced.
3. From OT3 and OT5: Flexibility with needs and agendas promotes mutual supportive working.

Participant observation analysis revealed the majority of insiders showed signs of not participating fully during the training sessions. Although technology offers potential benefits when learning — assisting in note taking and providing further reading (Roberts and Rees, 2014) — insiders did not appear to be learning in such a fashion, a problem shared in many institutions (Behol and Dad, 2013). Insider could have been using phones or iPads for matters unknown to outsiders. Insider lateness may likewise relate to public transport challenges in Uganda, cultural attitudes to timekeeping, and financial challenges. Bodnar et al. (2015) reflected on barriers to participation in Uganda, revealing performance-affecting financial hardships even when compensation was provided by projects. Burleson and Chipidza (2017) described general challenges of absenteeism and moonlighting in Ugandan culture, and Ahmed et al. (2017), revealed flexible attitudes to timekeeping.

Cultural confusion sometimes resulted in impasses, which could sometimes be resolved by discussing misunderstandings. Outsiders appeared to check and facilitate both theirs and insiders' cultural understanding — asking if particular ways of working or resources would be appropriate in Uganda, and explicitly checking that definitions were understood. At times, insiders appeared to try to increase outsiders' understanding by explaining cultural context. Drawing on the idea of skill picking (described in section 4.5.2), it may be that insiders only paid attention when information was deemed relevant or important to an East African context — perhaps explaining insiders' varying participation. The accessibility of resources discussed in training may also be seen as a barrier, a challenge also addressed by Bodnar et al. (2015). Insiders disagreed as to whether they should be taught about resources not presently available in Uganda. Some insiders may have considered such teaching irrelevant in their practice.

When some insiders appeared concerned that an informal screening assessment they were developing as part of a group was not useful to their practice, some were overheard commenting: "we can make our own clinic and it can be a bit different." That the insiders did not raise this concern with outsiders may relate to the perceived power discrepancy between insiders and outsiders. Mizzi (2017) highlights the importance of outsiders decolonising learning spaces by considering equity and the need for taking multiple perspectives. Outsiders could share their agendas and perspectives and approaches while ultimately allowing insiders to decide what is relevant to their context. In Uganda, insiders often acted in supportive roles, however this was often difficult because of personality clashes. Respect, effective communication of roles, and conflict resolution would all aid in promoting equal collaboration between insiders and outsiders.

4.5.6 Limitations

This section discusses the specific challenges unique to phase one, focusing on the three main methods of data collection. A discussion of the general limitations of the study can be found in section 7.4.

Several potentially appropriate documents could not be sourced. The main outsider NGO involved in supporting the SLT course had annual review documents available on their website, but a number were missing — corresponding to the years decisions were made to end support in Uganda. As these inaccessible documents may have provided key information about the plans and reason behind the withdrawal, the NGO was contacted to ask if copies could be provided, however they replied that they were unable to do so. Application through the Freedom of Information Act (2000) was not possible as NGOs are not included in the Act (Bond, 2015). Altheide et al. (2008) described how the availability of documents is often indicative of power imbalances between organisations and individuals. NGOs are powerful organisations, and way to mitigate against power is to explore contradictory evidence (Altheide et al., 2008). This was attempted through the integration of document analysis and interview data, revealing conflicting accounts as to how NGO support ended prematurely.

Another limitation of document analysis was that search terms were restricted to English. Insider-written documents made up at least 16 of the 74 analysed documents. Provision for documents in other languages may have increased the number of insider-authored documents, allowing for greater inclusion of insider-raised issues. Whilst the search of these documents may have produced interesting results, it was beyond the scope of a PhD to source foreign-language documents and have them translated to English to assess for relevancy to the research objective.

Documents by non-English speaking outsiders were also excluded. During interviews, it became apparent that outsiders from countries that did not have English as a first language were also involved in supporting services for PWCD. As described in section 1.3, for the purpose of this research, outsiders were defined as a "non-native individual or institution operating in a particular country," in this case, Uganda. Within this definition, non-English-speaking outsiders were excluded, though a number of documents were included from authors from continental Europe which were published in English. This limitation reflects wider debates of language exclusion within research.

During the interview process, two participants requested to be interviewed together. During this joint interview, questions were asked about cultural differences. The participants were from two different Ugandan ethnic backgrounds, and explicitly demonstrated some of the cultural differences and variability within different ethnic groups in Uganda. Each discussed practices that were taboo or rule-bound within their culture. This showed some of the challenges in labelling Ugandan culture as homogenous, demonstrating how outsiders may cause offence by working in a way that is not culturally suitable to their clients. As suggested by McLafferty (2004), conducting more interviews as either joint interviews or focus groups may have allowed participants to reflect together on the questions and yielded further interesting data on cultural differences. This may be important as Uganda has a variety of ethnic groups and there may be further cultural challenges amongst insiders of differing ethnic backgrounds.

The participant observation period was relatively short, consisting of 10 days over two visits, approximately a year apart. Researchers typically suggest that participant observation is conducted over a longer period of time, requiring further immersion within a community (Kawulich, 2005). However, this data collection was always intended to be comparably smaller than the document analysis and interviews, and to be supplementary and enhance these data sets. Participant observation was focused on the mentoring project, where attendees met for a total of 10 days. Although the time spent conducting participant observations was relatively short, this offered some of the few accessible opportunities to observe collaboration between insiders and outsiders working in services for PWCD.

4.6 Summary

This chapter has outlined the full study of phase one. It has provided a country background of Uganda, described the specific methods used, reported the results and discussed the results in relation to the research objectives and literature. There were sixteen findings from the ethnographic case study of phase one. The next chapter draws on the results of phase one for the development of phase two of the study.

5   Phase two: pilot study

5.1   Introduction

The previous chapter outlined phase one of the research. Phase two of the research explored insider perceptions of outsiders' contributions to the development of services for PWCD in a wider, global context. In this chapter, section **5.2** presents the objective of phase two; section **5.3** details the specific methods used; section **5.4** presents the results by country; Section **5.5** presents the discussion of phase two results; and section **5.6** concludes the chapter with a summary.

5.2   Research objective

Following the findings from phase one, it was decided to explore perceptions of outsider contributions in other Majority World countries, using a pilot study to begin to investigate whether the situation was similar in other countries, and to ascertain if case study surveys were a useful and appropriate means of exploring this phenomena. It was decided to further explore this phenomena across countries that varied by Human Development Index (HDI), so as to examine development of services for PWCD, and outsiders' contributions to these services across the different settings in relation to the development theories outlined in 2.3. As an overview of the 2012 HDI ranks and relative levels, countries were ranked and categorised as very high (with Norway ranking the highest (1)), high, medium and low (with The Central African Republic ranking the lowest (186)) (Malik, 2013). Whereas phase one considered both insider and outsider perspectives, phase two of the research solely explored insider perceptions. As phase one revealed that many outsiders work in multiple countries, there would be a risk of reduplication — and only small amounts of additional data — if outsider perspectives were explored in this phase. By focusing on insiders across different settings, phase two aimed to show if and how insiders across different country contexts differ in their perception of outsiders' contributions.

The research objective for phase two was: To interpret and explain perceptions of outsider contributions in five Majority World countries.

5.3   Method

A survey was identified as the most appropriate instrument of data collection for the phase two pilot study. Although pilot studies are often used for survey research, they are less associated with case study research (Flyvberg, 2006). Other methods of data collection (such as interviews) were considered, but rejected due to a lack of feasibility with conducting international research in multiple Majority World countries (because of the financial cost and time constraints of a PhD study). Use of a survey was also consistent with the ethnographic case study approach (the overall approach taken across this research). The questions posed in the survey were specifically designed to obtain a mixture of data that could be analysed: both qualitative and quantitative. Schensul and LeCompte (2013) justify the inclusion of quantitative methods in ethnographic research — provided the questions are based on concepts and constructs identified in the previous qualitative phase of data collection. As such, quantitative questions in phase two drew on concepts identified in the qualitative research of phase one. Phase two was therefore designed as a pilot study, to see if case study survey research was a useful way of researching the fifth research objective.

5.3.1 Country selection criteria

The phase two survey was designed to be completed by participants in countries which fulfilled the criteria of (1) being former British colonies, (2) having a high, medium or low HDI and (3) being under-served by SLT services. Former British colonies were selected to minimise language problems and explore countries with comparable colonial histories to that of Uganda and of each other. This was based on the findings from phase one which revealed colonialism to have shaped, and continue to influence and inform insiders' and outsiders' perspectives of outsiders' working. In order to select appropriate countries for this phase, the 53 countries that were members of the Commonwealth in 2014 were used to produce a matrix (see appendix 9). As described in 1.2.4, there is no single agreed definition to provide a classification

of a country's development status. However, this study used HDI to classify countries as either Majority or Minority World (Alam, 2008). Therefore, countries that had low, medium or high HDI, were included. Countries which ranked as having a 'very high' HDI score (49 in 2013 (UNDP and Malik, 2014)) were excluded.

For the remaining Commonwealth countries, consideration was given to the presence and type of insider / outsider collaboration and the availability of insider contacts in each country. To do this, Google searches were completed for all countries to assess whether there was an SLT training programme; if there were insider SLTs; and documented outsider SLT working. The resulting matrix listed all commonwealth countries categorised as having a high, medium or low HDI, with an SLT training programme, insider SLTs and outsider involvement. 10 countries met the inclusion criteria. Uganda was excluded from this as it had already been subject to research in phase one. India, Nigeria, South Africa and Malaysia were not selected as — although there is documented outsider working in each country — these were judged to have less potential for producing insiders who had had direct experience of working with outsiders. Five countries that fulfilled the inclusion criteria — Kenya, Sri Lanka, Jamaica, Trinidad and Tobago, and Bangladesh — were initially selected to span the range of low - high HDI scores. At the data collection stage, no response was received from Bangladesh despite extending the survey response period. Malaysia was then selected on a pragmatic basis based on the professional network of one of the supervisors and the readily available open register of SLT professionals.

Table 5.1 summarises the HDI of all countries included in phase two. Although more recent HDI scores have been published (UN, 2017), at the time of research the 2013 figures were the most recent scores available and were therefore used when selecting countries. A brief summary of each selected country is provided to give context: focusing on colonial history; services for PWCD; and history of insider / outsider collaboration.

Table 5.1 Human development index score from 2012 for the five countries'
sampled

	Kenya	Jamaica	Sri Lanka	Trinidad and Tobago	Malaysia
HDI rank (2013)	147	96	73	64	62
HDI category	Low	High	High	High	High

The Republic of Kenya

Kenya is an East African country, sharing boarders with Tanzania, Uganda,
South Sudan, Ethiopia and Somalia. As such it is the closest comparator with
Uganda. It has an estimated population of 46,790,758 (CIA, 2017). In 2013,
Kenya ranked 147th on the HDI placing it in the "low" category of human
development (United Nations Development Programme and Malik, 2014).
Kenya gained independence in 1963 following a bloody uprising against British
colonial rule (Parry, 2016).

According to the country's 2009 census, Kenya had a disabled population of
over 1.3 million (Kenya National Bureau of Statistics, 2013). Since the census
acknowledged speech and language difficulties as disabilities, this figure
included many of the country's PWCD. Further to this, the UK Department for
International Development (2003) stated that over half a million Kenyan children
had communication problems.

Rehabilitation for hearing impairment started after 1958 when an SLT resident
in Kenya was asked to establish a clinic for PWCD (Mbaluka, 2012). In 2014
there were 16 SLTs known to be working in Kenya, of whom six were East
African, three were short-term volunteers, and seven were immigrant SLTs
(Reichel et al., 2014). At present, there is an association of Kenyan speech and
language therapists (ASLTK) with regular conferences. As well as outsider SLTs
working in Kenya directly with PWCDs, outsiders have also been involved in
CPD training (Marshall, 1997). Furthermore, two new Master's level SLT
programmes have been developed in conjunction with outsider partners (Staley,
2013). Both programmes have outsider involvement, one of which is modelled
on an outsider programme that ran in Zambia that incorporates online learning

into the training (Staley, 2013). At present, awareness and cost are among the main barriers to PWCD accessing SLT in Kenya (Genga, 2011; Gill, 2009).

Jamaica

Jamaica is an island country in the Caribbean Sea. It fell under Spanish rule following the arrival of Columbus in 1494, before coming under British rule in 1655. Jamaica gained its independence from Britain in 1962. In 2016, its population was 2,730,894 (Statistical Institute Jamaica, 2017). In 2013, Jamaica ranked 96th on the HDI, placing it in the "high" category of human development (United Nations Development Programme and Malik, 2014). The 2011 Jamaican census recorded data on people over the age of 5 with reported communication difficulties (revealing 76,878 with some sort of communication difficulties (Statistical Institute Jamaica, 2017)). Unusually, more females than males were reported to have difficulties.

Public SLT posts are available at four hospitals in Jamaica, though Wray and Skeete (2006, cited in Adedeji-Watson, 2010) stated that these had each been vacant for up to a decade. In 2011, there were five SLTs: four practicing privately and one practicing both publicly and privately (Sowden, 2011). With SLTs practicing privately and concentrated in the capital, Kingston, there are both financial and geographical barriers to PWCD accessing SLT in Jamaica. This lack of access is exacerbated by a lack of awareness from both the public and other health professionals (Sowden, 2011; Adedeji-Watson, 2010). Outsider involvement in Jamaica has taken the form of research (University of Cincinnati, 2012), training (Jamaica Information Service, 2007), and clinical SLT work.

The Republic of Sri Lanka

Sri Lanka is an island country in South Asia. It shares maritime borders with India and the Maldives. It gained independence from Britain in 1948 but held dominion status until 1972. In 2016 it had an estimated population of 22.235 million (CIA, 2016). In 2013, Sri Lanka ranked 73rd on the HDI, where it is placed in the "high" category of human development (UNDP and Malik, 2014).

The Sri Lankan Cleft Lip and Palate Project began in the early 1980s with an MDT outsider team providing surgical intervention, therapy and training (Wirt et

al.,1990; Lamabadusuriya and Mars, 2008). Following a well-established link, insiders and outsiders planned how health personnel could be trained to meet the needs of PWCD, which resulted in the first SLT course being developed in Sri Lanka (Wickenden et al., 2001). This course was custom-developed, and included specific country-appropriate modules (Wickenden et al., 2001). This training course began as a diploma-level qualification in 1998, with the first Sri Lankan SLTs qualifying in 2000 (Wickenden et al., 2003), and in 2008 converted from a diploma to a degree programme (Walpita and Ginige, 2014). Wijekoon (2008) states how there was only one practising SLT in Sri Lanka before 1998, with numbers in 2014 having increased to around 65 (Walpita and Ginige, 2014) working mainly in hospitals and educational settings (Gomesz, 2010).

The Republic of Trinidad and Tobago

Trinidad and Tobago comprises two islands in the Caribbean Sea. It shares maritime borders with Barbados, Grenada, Guyana and Venezuela. Previously regarded as separate nations (and ruled variously by the French, Spanish and Dutch empires), Trinidad and Tobago were united under British rule in 1797 and gained independence from the British Empire in 1962.

In 2013, Trinidad and Tobago ranked 64th on the Human Development Index, placing it in the "high" category of human development (UNDP and Malik, 2014). The 2011 Trinidad and Tobagan census reported a population of over 1.3 million, with 52,243 PWD (Central Statistical Office, 2017). This 2011 census recorded severe communication disabilities affecting 'speaking or understanding (lots of difficulty or cannot do at all),' which indicated that 5778 people had this sort of CD (Central Statistical Office, 2017:online).

The first in-country SLTs were Trinidad and Tobagan nationals who trained abroad (most commonly in the USA or UK) and returned to practise at home. One post was created in the Port of Spain general hospital in the 1970s, while numbers of practitioners have remained in the low single digits until the 2000s, whereupon they rose to approximately 14 SLTs working in Trinidad and 4 in Tobago (Lindsay, 2016). These 18 practising SLTs have developed a niche within the health system, with some working publicly but the majority in private practice. They have worked alongside outsider volunteers (often sponsored by

the local government), and have recently launched an in-country Master's degree programme in 2013, with the first cohort graduating in 2016 (Lindsay, 2016). Although this course was a national initiative, there has been some involvement from outsiders (Molrine and Drayton, 2013). There is a Trinidadian and Tobagan organisation of Speech-Language Pathologists and Audiologists which formed in 2009 (SLAATT, 2015).

<u>Malaysia</u>

Malaysia is a peninsular country in Southeastern Asia. It was a British colony from 1867 to 1957, when it gained independence. In 2016 its population was recorded at just under 31 million (CIA, 2017). In 2013, Malaysia ranked 62nd on the Human Development Index, placing it in the "high" development category (UNDP and Malik, 2014).

SLT services were first introduced by outsiders (mainly from the UK, USA and Australia) in the 1960s, after which the first Malaysian SLTs began overseas training before returning to practise in Malaysia (Van Dort, 2005). The first recorded instance of a Malaysian SLT working in the public sector was in 1974 (Santiago and Stansfield, 1998). Between 1985 and 1990, the potential for an in-country university programme for SLT was suggested, resulting in one university sending an ENT registrar to the UK to study SLT in order to set up the SLT programme on their return (Ahmad et al., 2013). In 1994, an undergraduate degree programme was established, with the first cohort graduating in 1999 (Van Dort, 2005). The Malaysian Association of Speech-Language and Hearing (MASH) was officially registered in 1995 (Cheng, 2010). There are now two undergraduate university programmes for SLT. Of the locally trained graduates, approximately half work in general or university hospitals nationally, with the other half working in the private sector, or for NGOs, or in neighbouring countries (Van Dort et al., 2013). As of 2017, 103 SLTs were registered in Malaysia (MASH, 2017). Challenges within the profession include a shortage of culturally and linguistically appropriate assessment resources (Phoon and Maclagan, 2009).

5.3.2 Survey instrument

An initial survey was designed to be piloted to check for clarity before distribution. The piloting process will described in 5.3.3. The survey was informed by the emerging results of phase one. Not all the phase one data analyses had been completed at the time of designing the survey. Therefore, where analyses were still underway, themes were used to inform the survey, and where findings had been produced these were used. This resulted in eight main topic areas (described below) which related to specific themes and findings from phase one.

1. Outsider commonalities

This topic aimed to describe and explore insiders' perceptions of "typical" outsiders. This topic built on data collected in insider and outsider interviews from phase one (in which both groups of participants discussed common features of a "typical" outsider) and developed from a key phase one finding: "insiders viewed outsiders' contributions as being largely related to the specific roles of outsiders, however variables such as their age, skills and experience were also important" (see 4.5.2).

2. Outsider roles

This topic was selected to identify the roles outsiders had undertaken whilst working in-country. This emerged from the phase one finding: "Insiders viewed outsiders contributions as being largely related to the specific roles of outsiders, however variables such as their age, skills and experience were also important" (see 4.5.2).

3. Collaboration

This topic was selected to identify whether insiders' perceived outsiders to be aiming to collaborate; and, if so, what they perceived outsiders' methods of collaboration to be. This topic emerged from the category of "SLT roles" and insider global theme of "Mother - child relationship" (4.4.1.2 and 4.4.2.1).

4. Rationale for collaboration

This topic was selected to explore why insiders believed outsiders worked in a specific way. This topic explored views about motivations and aims of outsiders

which emerged from the insider global themes of "Mother - child relationship" and "Shared Values" (4.4.2.1 and 4.4.2.2), and outsider global themes of "Relationships" and "Reconciling Ugandan independence and outsiders' expertise" (4.4.3.1 and 4.4.3.2).

<u>5. Judgement on present outsider contributions and effectiveness</u>

This topic was selected to explore insiders' judgements on outsider contributions and effectiveness. Specifically, items in the survey were designed to look at the ability of outsiders to be effective both culturally and sustainably. Phase one revealed cultural differences between outsiders and insiders affect their effectiveness, and approaches lacking sustainability would not be effective long-term. The concept of cultural differences having the potential to cause misunderstandings came from a key finding from the participant observation discussion: "Cultural differences exist between insiders and outsiders but can be reduced" (see 4.5.5). Effectiveness related to the stability of outsider contributions, something both insiders and outsiders in phase one described as important. This related to the phase one findings of "Insiders view outsider support as unstable and transient" and "Outsiders felt that the development approach used was directly related to the quality and sustainability of their contribution" (see 4.5.2 and 4.5.3 respectively).

<u>6. Ideal outsider qualities and contributions</u>

This topic was selected to identify participants' views on preferred outsider qualities. Survey items focused on views about outsiders' qualities, skills and experience. This was identified for exploration following the similar ideas about an "ideal outsider" from both insiders and outsiders from phase one (see 4.5.4).

<u>7. Views on outsider perspectives</u>

This topic was selected to explore insiders' views of outsiders' perspectives. Survey items focused on what insiders perceived to be outsiders' perceptions of the country, of services for PWCD and whether these perceptions change over the course of an insider-outsider relationship. This was identified for further development from the finding of "Services have developed, however there are a number of challenges that prevent or threaten development" (see 4.5.1).

8. Insider/outsider equality

This topic was selected to explore equality, status and treatment of insiders and outsiders. Survey items were designed to explore and identify differences in the ways that insiders and outsiders related to each other during collaboration related to perceptions of power balances. This topic area developed from findings of "Insiders viewed outsiders as having a higher status than insiders, regardless of their skills or experience levels" (see 4.5.2) and "Outsiders were aware of their working within the context of the colonial history of Uganda" (4.5.3).

Demographics

The final section of the survey asked insiders to report some key demographic information. As politics and terminology varies across countries, the decision was made for all questions (except an item about participants' age) to be open to allow for self-declaration. This would allow for participants to describe (or choose not to describe) themselves as they saw themselves, whilst remaining sensitive to the impacts of identity politics.

5.3.3 Pilot survey

The resulting survey was 11 pages long (see appendix 10). The first two pages comprised a covering letter and information about the research. The next section asked participants to complete three tick-box questions to confirm their eligibility for inclusion. Inclusion criteria required participants to (1) work in supporting PWCD or training others to work with PWCD, (2) to have worked or interacted with outsiders as part of their working with PWCD; and (3) to be able to complete the survey in English. Pages 4-10 featured the survey items. Items included both open and closed questions. Closed items used both multiple choice, forced choice and Likert scale questions. Open question items asked participants to comment freely on a topic, as well as allowing participants to add further detail on their closed responses if desired. The final section asked participants to add their demographic details.

Four people were identified from both the researcher's and supervisory teams' personal contacts to be invited to complete the pilot survey. Two were recently graduated SLTs from the Ugandan SLT course, one was an SLT from West Africa and finally, one physiotherapist from West Africa. The range of pilot participants was selected to represent the range of specialists who worked with PWCD as well as other health professionals who may also work with PWCD in absence of SLTs. Personal communication with SLTs in Uganda had shown that both physiotherapists and occupational therapists had taken on some of the roles or duties more commonly associated with the work of SLTs in Minority World countries.

The pilot survey participants had been asked by email to gauge their interest in taking part. The pilot survey was then sent to each of the four by email. The survey and participant information were included both in the body of the email (so participants could reply to the email by filling in their responses directly: a useful option in cases of low bandwidth) and as a Microsoft Word attachment (that could be downloaded, completed, saved, then returned). Pilot participants were asked to complete the survey and provide comments on the design. Response rate from the pilot survey was n=3.

Amendments and final survey

The respondents made comments in addition to completing the pilot survey and as a result a number of minor amendments were made. These were either typographical or design/layout amendments. One pilot participant sought clarification on the definitions for the terms "insider" and "outsider." Amendments were therefore made to clarify terminology in the survey introduction. In terms of layout, follow-up questions were listed as part of a question to prompt completion of both parts of a question. The final survey instrument was 10 pages long, featuring 18 main questions with 81 items. Surveys were personalised to each country — so, for example, surveys distributed to Kenya referred to Kenya throughout the document (see appendix 11 for a sample survey).

5.3.4 Participants

The participants for phase two comprised insiders only as noted in 5.2. Having identified the topics and initial questions for the survey, consideration was made to who the potential participants should be and who the survey should include in order to most fully represent the people involved in services for PWCD.

Inclusion criteria

Participants were insiders working to support or provide services for PWCD. Insiders were defined as native (or locally trained) individuals operating in each country. This excluded outsiders, who were defined as foreign, non-native health professionals working in the selected countries. To ensure surveys were completed by insiders only, the surveys were sent with accompanying information in which participants were asked to tick to confirm that they met the eligibility criteria (described in 5.3.3).

Sampling

Non-probability methods of sampling were used. Purposive sampling allowed for the strategic identification and recruitment of participants who met the inclusion criteria and could provide information relevant to the research objective, based on their experiences (Bryman, 2012). Snowball sampling allowed for contact with a relatively small and hard-to-contact sample of the population (Bryman, 2012).

The sample of insider participants for phase two was similar to the sample of insiders in phase one in that it included a range of professionals who worked with PWCD. Although the sample size was too small to achieve thematic saturation, it nonetheless represented a large proportion of the population serving PWCD in each Majority World country surveyed.

Recruitment

Participants were recruited by direct contact with potential participants and with gatekeepers. Potential participants were contacted directly where contact details were available publicly in a professional capacity, for example, on open registers of professionals and clinic websites. Potential gatekeepers were identified across all country settings. These were individuals working at specific

organisations which were identified as providing services for PWCD. These included SLT and OT private practices, NGO organisations, institutions that trained SLTs, associations of SLTs, and special schools. A separate participant letter was sent with each survey and email.

<u>Ethical considerations</u>

Ethical approval was granted by Manchester Metropolitan University for the whole research study. For phase two, specific considerations were made. Email reminders were sent a maximum of two times following the initial email contact, unless participants specifically asked for additional reminders. Data were collected via a password-protected email address, and stored on a password-protected computer. Returned surveys were assigned a number and country reference (for example, K1 to refer to a Kenyan participant). No names were stored with surveys, to further respect confidentiality.

5.3.5 Data collection procedure

Following identification of gatekeepers and potential participants, the survey instrument was distributed by email. A separate participant letter was sent with each survey and email. This letter offered a brief introduction to the researcher, the research, eligibility criteria and brief instructions detailing how to complete the accompanying survey (see appendix 12 for the participant letter). Surveys were emailed from 12th November 2015 and replies accepted until 28 February 2016. Surveys were initially sent to five of the six countries: Bangladesh, Kenya, Sri Lanka, Jamaica and Trinidad and Tobago — with Malaysia later included (see section 5.3.1).

5.3.6 Data analysis

As there were both quantitative and qualitative components of the survey, the data analyses were designed to reflect this complexity. Analysis of the quantitative data (both demographic and survey question data) used descriptive statistical analysis using IBM SPSS statistics (version 21). Once all surveys had been returned, an SPSS spreadsheet was created and all the closed-question data were coded (including for "no response") and inputted manually.

Analysis of the qualitative data used Thematic Network Analysis (TNA) (Attride-Stirling, 2001) for the interpretation of open-ended questions and comments (see 4.3.2 for an explanation for TNA). Similar to the justification of TNA for 4.3.2 and 4.3.3, TNA here offered a transparent approach for data analysis, which in turn enhanced replicability of the research. Use of TNA for analysis of data for phase two also allowed a more direct exploration and comparison with the findings produced from phase one (see chapter 6.2). Returned surveys were exported from Pages documents (version 5.2) into NVivo (version 10.2.2).

Survey responses were read and re-read to allow for the familiarisation of the text. Analysis followed the same six steps of TNA outlined in 4.3.2, and again a coding framework was devised based on recurrent topics, words and phrases following familiarisation of the text. The framework was then applied to the text using open coding. Data from all countries were used to create the thematic network.

5.4 Results

The results section will firstly present the demographic detail of participants. It will then provide an overview of the thematic network produced from participants' open responses. Finally, the quantitative results will be presented and use specific relevant themes from the network analysis for interpretation.

Results were explored and interpreted by both individual country and compared. As purposive sampling methods were used (including snowball sampling and using gatekeepers) it is not possible to state how many people were invited to take part in the research. However, the number of potential participants and gatekeepers who were directly contacted by the researcher can be reported. Response rates for this were calculated for each country. Table 5.2 shows the primary response rates of participants contacted directly.

5.4.1 Participant demographic data

Participants from the five included countries varied in terms of their occupation, qualifications and age. As numbers of respondents and the number of people working with PWCD in some countries is small, some demographic details of

the Jamaican and the Trinidad and Tobagan participants have been collated to maintain anonymity.

Table 5.2 Response rate for all countries

	Kenya	**Bangladesh**	**Sri Lanka**	**Trinidad and Tobago**	**Jamaica**	**Malaysia**	**Total**
Directly contacted participants	11	12	7	11	5	76	122
Responses	4	0	2	1	1	9	17
Total	36.4%	0%	28.6%	9.1%	20%	11.8%	13.9%

Gender

Table 5.3 shows the gender of participants by country. The response rate for participants self-reporting their gender was 13 out of 17. The thirteen that responded identified as female. Even allowing for the consideration of the four participants who did not disclose their gender, this shows a trend for SLT as a profession that is predominately female.

Table 5.3 Gender of participants

	Kenya	**Sri Lanka**	**Jamaica**	**Trinidad and Tobago**	**Malaysia**
Female	3	2	1	1	6
Male	-	-	-	-	-
No response	1	-	-	-	2

Nationality

Participants were asked: "What is your nationality?" Response rate for this item was 14 out of 17.

Table 5.4 Nationality of participants

	Kenya	**Sri Lanka**	**Jamaica**	**Trinidad and Tobago**	**Malaysia**
Nationality	Kenyan - 2	Sri Lankan - 2	Jamaican - 1	Trinidad and Tobago - 1	Malaysian - 6
No response	2	-	-	-	3

Age

Participants were asked: "What is your age?" and to self-report this from a choice of age bands. Response rate for this item was 15 out of 17. Participants ranged in their ages. The most frequently occurring age of participants was 25-29.

Table 5.5 Age of participants

	Kenya	Sri Lanka	Jamaica and Trinidad and Tobago	Malaysia	Total
20-24		1			1
25-29		1		3	4
30-34			1	1	2
35-39	1			1	2
40-44	1			1	2
45-49	2				2
50-54					-
55-59			1	1	2
60+					-
No response				2	2

Occupation

Participants were asked to self-report their occupation with the item: "What is your professional occupation?" Response rate for this item was 16 out of 17. Twelve participants described themselves as SLTs, two as SLT students, one as an SLT assistant and one as an OT. This information will not be summarised by country so as to maintain participant anonymity.

Involvement in supporting PWCD

Participants were asked: "How are you involved in supporting people with communication disabilities?" Response rate for this item was 12 out of 17. Three of the four Kenyan participants responded to this, all three working in a clinical setting: one worked with both children and adults, one worked with just children, and one did not state the clinical group they worked with. The final Kenyan participant responded "fully involved" to this question and so was not

interpreted. Both Sri Lankan participants gave their role as students. Both the Jamaican and Trinidad and Tobagan participants did not respond. Of the nine Malaysian participants, two described their role as training SLTs; three gave their role as clinical but did not state the clinical group they worked with; one participant described their role as clinical working only with children, and another as clinical working with both children and adults; two did not disclose this information.

Educational level

Participants were asked to: "Please detail your professional qualifications." Response rate for this item was 15 out of 17. Of the 15 that that responded, the most commonly reported highest qualification was Bachelor's degree (by five participants), followed by Master's degree (by four participants). Two participants were students working towards a Bachelor's degree. A further two were educated to PhD. One participant was educated to diploma level, and one participant had online training. This information will not be summarised by country so as to maintain participant confidentiality.

Training abroad

Participants were asked: "Have you ever received training abroad? If so, please give details of which qualifications and where." Response rate for this item was 14 out of 17. Seven participants across all five countries indicated that they had, to a range of levels. Seven indicated they had not. Of the four Kenyan participants, two had received training abroad. These were both SLTs. Of the Sri Lankan participants, neither had received training abroad. Of the Jamaican and Trinidad and Tobagan participants, one had received training abroad to a Master's level, the other did not respond. Of the Malaysian participants, two did not disclose this information, three had not trained abroad, and four had trained abroad.

5.4.2 Thematic Network

Open responses from all data were compiled, coded and organised into basic, organising and global themes. Data came specifically from ten open response questions (see appendix 10), as well as where participants had provided additional comments for any of the other survey questions.

In total, 44 codes were identified for the coding framework, which were then applied to open survey responses. These codes were then grouped for similarities in topics to result in six basic themes. Basic themes were organised into three organising themes, and one global theme which reflect the responses of all participants. The global theme is outlined in this section, and used to help interpret descriptive data from the survey.

5.4.2.1 Global theme 1. Outsiders' inherent status allows them to set terms of collaboration

This global theme described how insiders perceived outsiders to have inherent power based on history. This included the power all outsiders had as a legacy of colonialism, as well as the power SLTs have as being seen as the people to have first developed SLT before "bringing" the profession to other countries. This power allowed outsiders to set the terms of their contribution, although outsiders may not have been aware of this explicitly. There are three organising themes in this global theme, each comprises two basic themes which will be described below.

Table 5.6 Outsiders' inherent status allows them to set terms of collaboration

Basic theme	Organising theme	Global theme
Outsiders need to collaborate because of cultural differences	Power imbalances	Outsiders inherent status allows them to set terms of contribution
Outsiders' skills and knowledge regarded as superior		
Received and desired outsiders	Preferred elements of outsider support	
Best practice to aspire to, and worst practice to avoid		
Outsiders' assumptions are typically negative but can change	Outsider rationales for involvement	
Outsiders' different motivations affect contributions		

Organising theme 1. Power imbalances

This organising theme described an imbalance of power between insiders and outsiders. Though outsiders have been important in the history of services for PWCD in Majority World countries, they have not been solely responsible for

developing these services and, as such, outsiders do not form the entire narrative. As professionally equivalent counterparts, insiders commented on the cultural appropriateness of outsider working. They felt outsiders often experienced cultural differences while working. When outsiders were aware of these differences, outsiders would link with insiders to minimise the differences and use insiders' expertise.

> M4: "As this is not their home country, it is simply more parsimonious to link up with insiders and work from there. A bundle of sticks is better than one."

Some outsiders were unaware of cultural differences and would work without guidance from insiders, or prefer to practice in ways appropriate to their setting in a Minority World country. Whether through a lack of awareness or active choice, this resulted in inappropriate services provision.

> M4: "Mistakes in clinical judgement especially, if one is rigid and can't see beyond the Western World."

BT1. Outsiders need to collaborate because of cultural differences

The first basic theme described how collaboration is used by outsiders. Outsiders were working in a new culture in Majority World countries, and as such there were cultural differences between outsiders and insiders. These cultural differences could result in challenges.

> M8: "[outsider nationality] has often affected working relationships. Outsiders from [nearby countries] are much easier to work with because there appears to be a shared culture and a more equal relationship. Outsiders from the UK and Australia know a lot about and are sensitive to cultural differences. Outsiders from the USA tend to be more forthright and more certain that their point of view is the right one"

Therefore, insiders felt that one of the main reasons that outsiders collaborated was to reduce their cultural differences. However, insiders commented that not all outsiders were aware that the differences in culture could result in their

clinical skills being inappropriate or having a limited effect. This occurred when outsiders were inflexible in their practice, and used the same approaches that they had used in their 'inside' country.

> SL2: *"Over-estimating their techniques in a different culture and a language environment"*

BT 2. Outsiders' skills and knowledge regarded as superior

The second basic theme described how outsiders are perceived as being, or having superior skills and experience due to their outsider status. This appeared to be related to the view of outsiders "bringing" SLT to a country. This perceived superiority could be seen in how outsiders' practice and how outsiders were treated by insiders and PWCD.

> M5: *"They are seen to have more knowledge and therefore more respected."*

Insiders commented that many outsiders assumed their way of practice was the correct way of practising. Where this occurred, insiders felt that the treatment offered by inflexible outsiders was inappropriate to clients' needs.

Where insiders commented on the power balance in their relationship with outsiders, the majority of insiders noted that it was often unequal, with PWCD often preferring to receive intervention from outsiders.

> J1: *"This really depends on the target group… some parents/caregivers may tend to accept the outsiders' suggestions over insiders'"*

However, even amongst experienced SLTs in countries where SLT is relatively more established (such as Malaysia), insiders often described how outsiders were frequently automatically seen as more skilled. Language used by insiders was often suggestive of outsiders being superior, or being regarded paternalistically.

> *M1: "because they give the best service and we learn new things each time meet them"*

Organising theme 2. Preferred elements of outsider support

This organising theme described insiders' preferences and views of the challenges of outsider support. Preferences often included qualities about the outsiders (such as their personality and personal characteristics) and perceptions of the best way of outsiders contributing to services.

BT3. Received and desired outsiders

This basic theme described outsider qualities that insiders encountered, qualities they desired and qualities they found undesirable. There was often a discrepancy between the outsider qualities desired and the outsider qualities encountered. Qualities included the skills, experience, personality of the outsider, as well as the time length of their contribution.

Received outsiders were noted as being almost exclusively female. For other demographical information there was some variation, for example, outsiders' age and experience level. This also varied by country. Malaysian insiders noted that the outsiders they worked with were generally older (at least in their 30s) and very experienced. Kenyan insiders noted that received outsiders often included very-recently graduated SLTs who were very young. There was a significant range in the length of time outsiders stayed in country for, ranging from weeks to many years.

> *K3: "Difficult to answer as there is a lot of variation! Age usually between 20 – 50 years. Experience varies from new grads to PhD holders. Length of stay between 3 weeks to 10 years!"*

Insiders' desired outsiders included those with specific skills sets, or experience to work with specific client groups. Personality characteristics such as flexibility, personableness and professionalism were desired and most suited for collaboration. There was a clear preference for longer-term outsiders, although shorter-term outsider roles were appropriate where they were appropriately linked to specific services (for example, if part of a wider project, or if less

cultural adaption was required as part of their role). Despite preferences, insiders would settle for other or less desirable outsiders or ways of working as the demand services for PWCD was so great. Where short-term working was less wanted (or actively unwanted), this was often related to a lack of continuity between any repeat visits.

J1: "sporadic intensive short-term visits with little to no emphasis on training insiders that makes it somewhat difficult to reap benefits from these outsiders"

Insiders across all countries noted that a lack of flexibility (or an inability to adapt), and a lack of cultural awareness were the least desired character traits in outsiders. One Kenyan insider described unwanted qualities from outsiders as:

K2: "Child abuse traits, cultural bias against the black person, overbearing free sexual orientation"

This was interpreted to mean that racism and abusive behaviours were unwelcome. "Overbearing free sexual orientation" was interpreted to mean homosexuality, which in Kenya is often perceived negatively and criminalised. "Child abuse traits" in this context was interpreted to mean any abusive or neglectful behaviours or actions perpetrated by an outsider.

BT4. Best practice to aspire to and worst practice to avoid

This basic theme described how although there are inevitable challenges of outsider working, insiders ultimately perceive better and worse ways of outsider involvement. Insiders consider best practice to be practice that is responsive and flexible to the local needs, such as taking cultural differences into account, working with the local community and the resources available and ensuring the sustainability of their work.

Conversely, worst practice was felt to be that which ignored or did not adapt to the local environment, local culture and local services. It also included working

in a way that was not sustainable (such as not ensuring work could be continued or completed by insiders after outsiders had left).

> *SL2: "Liaising with related professionals intensively until the work done if they are unable to stay for long inside."*

> *K1: "Once they have started something, train the locals and do constant follow up until you are sure we can now stand on our own"*

Discussion between both insiders and outsiders can help to surface what may be taken for granted or assumed, and allow both to work more transparently.

> *M5: "It helps to discuss ways to overcome problems"*

These challenges can then be understood by each party, allowing each to have an understanding of their desired contribution.

Organising theme 3. Outsider rationales for involvement

The third organising theme described insiders' perception of outsiders' rationales for working to support services for PWCD in their country. Rationales were guided by outsiders' impressions of services in the country and the country itself, and their motivations for working in the country. Reasons were often linked, for example, outsiders may perceive services in a country to be limited, and be motivated to "give something back."

> *SL2: "Sri Lanka is a country which has minor resources which is true… [it] needs more support. [Outsiders] bring big plans, but after they leave they don't care about [continuing support]"*

BT5. Outsiders' assumptions are typically negative but can change

Insiders believed that, generally, outsiders had negative assumptions of both their country and services for PWCD in their country. Assumptions often influenced outsiders in deciding to work in Majority World countries. Insiders felt

that outsiders perceived their countries to be suffering hardships of poverty, disease, war, or to be unstable or dangerous. Insiders felt that outsiders considered nationals of the country they were working in to be friendly, but often perceived the education level of insiders (both the general public and SLTs) to be significantly lesser than their own. Insiders felt that whilst assumptions were grounded in some truths, assumptions often exaggerated negative aspects.

> *K2: "That it's a place full of pestilences, hunger and war"*

> *M4: "Some are surprised how much more clinical skill Malaysian SLPs have"*

In terms of services, all insiders who commented described that they felt outsiders perceived services for PWCD in their country to be under-resourced, in terms of personnel and assessment and therapy materials.

> *T&T1: "Public services inadequate"*

One Malaysian insider noted that where outsiders' perceptions were inaccurate, this was often linked into a lack of personal outsider research or preparation, or no prior experience in working in another country. Despite negative perceptions, insiders felt some outsiders' perceptions changed to more closely align with insiders' and therefore enabled outsiders to work in a more positive and suitable way.

> *M5: "Despite the lack of resources, the outsiders find that with a little creativity and initiative a comprehensive training programme can be developed with those with communications difficulties"*

Insiders felt outsiders' perceptions of Majority World countries and services for PWCD in Majority World countries informed their justification for working abroad. Insiders felt that outsiders considered themselves to need to help increase (or if they were not aware of existing services, start) services for PWCD. Therefore, perceptions informed outsider motivations. Motivations will be discussed in detail in the next basic theme.

BT6. Outsiders' different motivations affect contributions

This basic theme described how insiders perceived outsiders' motivations affecting their contributions. Insiders felt that outsiders generally had good intentions in wanting to help support services for PWCD in their country. Insiders perceived outsiders to be sacrificing by working abroad, by incurring costs or working unpaid. Some insiders also perceived some outsiders to see a financial opportunity in working somewhere where services for PWCD were limited.

Most insiders felt that outsiders' motivations were similar to their own and were positive and realistic. However, some insiders described how outsiders often had grandiose plans to start with which were either not fully implemented, or were not continued after the outsider left. Another insider described how they felt that some outsider organisations (such as universities and NGOs) were motivated by their own gains, which in turn affected their contribution to services for PWCD.

> *J1: "Unfortunately, some institutions are motivated by overall programme ratings for [their] colleges or universities. As such, they may have the wrong motive and only provide a destitute state of services for individuals with communication difficulties."*

Where there were differences in motivations, insiders felt that these should be discussed openly with outsiders in order to help both parties work towards the same goals.

5.4.2.2 Summary

This section presented and summarised the global theme produced from analysis of the survey data: "Outsiders inherent status allows them to set terms of contribution." This is used to interpret the descriptive data outlined by topic in the following sections (sections 5.4.3 to section 5.4.11), and discussed in section 5.5.

5.4.3 Outsider commonalities

The survey had three questions focusing on outsider demographics. This section describes the nationalities of outsiders that insiders have worked with, and some perceived outsider demographics. Exploration of the global theme shows BT3: "Received and desired outsiders" to be relevant for discussion here. This basic theme described insiders' overview of outsiders they had worked with; and their preferences for outsider qualities they felt were valuable and a disinclination for outsider qualities that were not valued or perceived as negative.

Survey question number	Question	Response
5	Thinking just about outsiders that you have worked with, what countries did they come from?	Open response

The first question for this topic area was question five. Response rate for this item was 88.2%, with one Malaysian and one Kenyan participant not completing this item. Respondents reported having worked with outsiders from 19 different countries. Table 5.7 shows the outsider country of origin ordered by the HDI (UN and Malik, 2014). Countries ranked 1-51 are considered to have "very high" human development.

Table 5.7 Outsiders' countries of origin

Outsider country of origin (ordered from high to low HDI)	Number of responses
Australia (2)	10
Netherlands (4)	3
USA (=5)	12
Germany (6)	5
New Zealand (7)	3
Canada (=8)	4
Singapore (=9)	5
Denmark (=10)	1
UK (14)	10
Hong Kong (=15)	1

Outsider country of origin (ordered from high to low HDI)	Number of responses
Korea (=15)	1
Japan (17)	2
Turkey (69)	1
Iran (75)	1
Thailand (89)	1
China (=91)	1
Philippines (117)	3
India (135)	6
Uganda (164)	1

This showed a number of patterns relating to HDI, geographic location and colonial links. Firstly, the majority of outsiders encountered came from countries with very high development. The most common country of origin of outsiders was the USA (reported by 12 respondents), Australia and the UK (both by 10 respondents). Some outsiders were reported as coming from countries with low HDI, with the next most common country of origin being India (6 respondents). Other than India and the Philippines, outsiders coming from countries that were below the rank of "very high" were typically encountered by only one participant. Secondly, where outsiders came from Majority World countries, these were typically nearby countries (e.g., Kenyan insiders noted an outsider from Uganda). Thirdly, seven of the 12 countries ranking as "very high" (and the most common countries of origin for outsiders) had English as a main or official language. This was reflective of British imperial history, as many English-speaking countries are former British colonies. This may further make it easier for outsiders from these countries to work in the five countries surveyed.

Survey question number	Question	Response
6	Which of these statements best describes your thoughts on the nationalities of outsiders who support services for people with communication disabilities in [country]	Multiple choice (single answer)

The second question for this topic area was question six. Response rate for this item was 100%. Overall participants were more likely to identify outsider

nationality having no influence on working relationships (11 participants),
compared to it having an influence on their working relationship (6 participants).
A comparison of the responses by country for item 6.a 'the nationality of
outsiders has never affected our working relationship' revealed that more
Kenyans (3:1) and Malaysians (5:4) thought this. Both Jamaica and Trinidad
and Tobago participants indicated that the nationality of outsiders had never
affected their working relationships, however the low numbers from these two
countries may have influenced the majority overall. The two Sri Lankan
participants were divided over the effects of nationality and working
relationships.
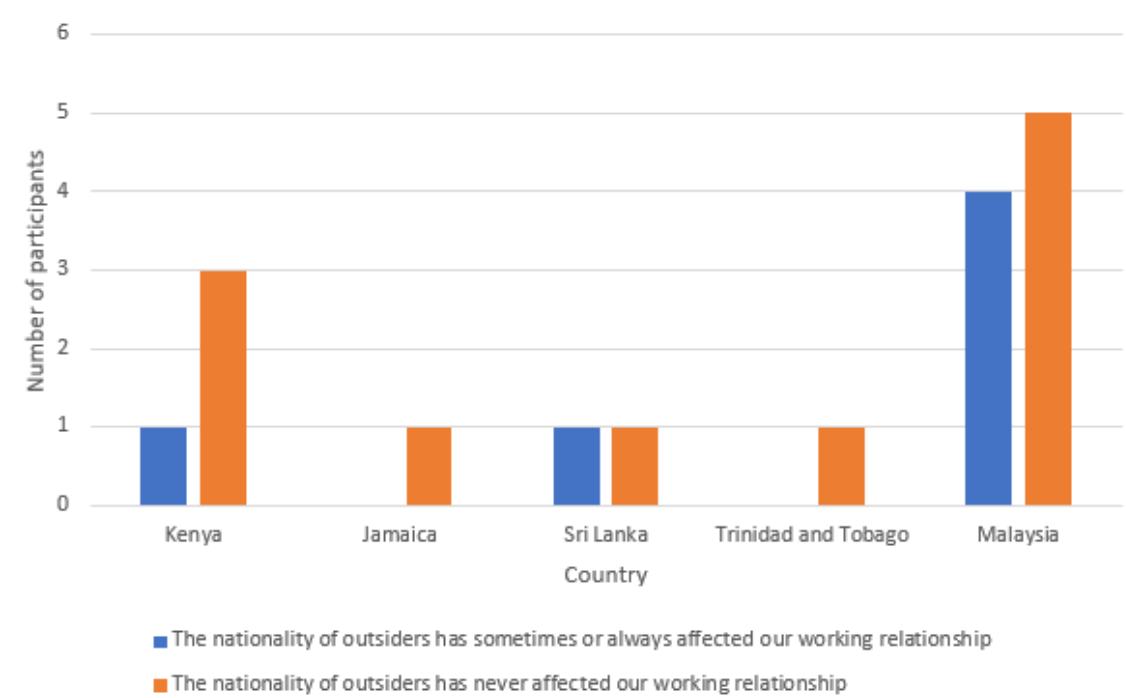
*Figure 5.1 Showing insiders' perception of the effects of outsider nationality by
country*

Survey question number	Question	Response
7	From your experience, described a "typical" outsider who works to support services for people with communication disabilities. For example, their age, experience level, length of stay, etc.	Open response

The third and final question for this topic area was question 7. Response rate
for this item was 58%, with both of the Sri Lankan participants, the one Trinidad
and Tobago participant, one Kenyan and three Malaysian participants not

completing this item. As such, descriptions for typical outsiders came from only Kenya, Jamaica and Malaysia.

BT3 "received and desired outsiders" highlighted the typical received outsiders, and was described in 5.4.2.1.

<u>Key differences and similarities by country for descriptions of outsiders</u>
For question 5, countries with the greatest number of respondents (Malaysia, Kenya and Sri Lanka) indicated the greatest range in country of origins for outsiders. Both Caribbean countries indicated outsiders from the fewest countries — the Jamaican insider noted outsiders from USA only, and Trinidad and Tobago insider from the UK, USA and Canada. These two countries may have had the smallest range due to having no apparent official link with outsiders through a training programme, or based on low respondent numbers.

For question 6, although the majority of insiders noted that the nationality of outsiders had never affected their working relationship (11), where there was more than one respondent per country, some insiders noted that nationality had had a difference. This was seen most prominently for Malaysian participants and for the two Sri Lankan participants. The Kenyan participant who felt the nationality of outsiders had sometimes or always affected their working relationship added further detail to share that an amount of contextualisation is needed for any outsider to become familiar with the "processes and systems, culture, language." It may be that countries with the most respondents were more likely to have experienced more outsiders, in turn from a greater range of countries and thusly be more likely to experience more cultural differences from outsiders.

For question 7, insiders noted a range amongst typical outsiders. Three of the four Kenyans responded to this item, and whilst they noted that there was variation amongst outsiders, they were more likely to have experienced young, student or newly qualified SLTs who typically stay short-term. However one noted that some more experienced SLTs "have stayed for over 30 years and that way we gained a lot." Both the Jamaican participant and the Malaysian participants were more likely to describe outsiders as older, highly experienced,

with a lot of knowledge to share. Whilst outsiders in Malaysia worked both short or long-term, the Jamaican participant noted that outsiders typically worked short-term, typically spending one week in country, working across several sites. In both countries, outsiders who work short-term are typically tied to specific projects. Some of the outsiders that stayed long-term in Malaysia were permanent residents.

5.4.4 Outsider roles

Insiders were asked to indicate which roles outsiders had worked in to support services for PWCD. This was asked by one question, which asked participants to note which roles they had experienced outsiders working in from a list of 12 roles. There were two basic themes of particular importance to this topic, BT2. "Outsiders' skills and knowledge regarded as superior" and BT3. "Received and desired outsiders."

Survey question number	Question	Response
1	From your working experience, which of the following roles have outsiders filled in [country] to support services for people with communication disabilities?	Multiple choice (multiple answer)

Question one was the only question for this topic area. Response rate was 100%. Table 5.8 shows the roles undertaken by outsiders by country of respondents. The most commonly reported roles undertaken by outsiders were providing direct services to PWCD (14), followed by the training of either parents or carers, or local health professionals (both 13). Interestingly, the training of parents or carers was not selected by either of the Sri Lankan participants. The outsider role reported least frequently was the funding of scholarships for professionals to train to support PWCD, (N=1, Sri Lanka). Insiders often felt that it was important for outsiders not to take on certain roles, such as the provision of funding or lobbying or advocacy. Where insiders wanted outsiders to be involved in direct therapy, it was important for their approach to be appropriate to the culture and not be considered "controversial." Insiders were consistent in their view that outsiders' work should be sustainable.

> K1: *"the outsiders want to assist and that is good, but the problem is that those outsiders never do any follow up of what they have started"*

Table 5.8 Frequency of insiders' responses by country for roles undertaken by outsiders

Role	Kenya		Sri Lanka		Jamaica		Trinidad and Tobago		Malaysia		Total responses for each role	
	No. of respondents	%	No. of respondents	%	No. of respondents	%	No. of respondents	%	No. of respondents	%	No. of respondents	%
Campaigning for more services for PWCD	4	12.5	0	-	0	-	1	14.3	5	55.6	**10**	**52.6**
Campaigning for the rights of PWCD	3	9.4	0	-	0	-	0	-	4	44.5	**7**	**36.8**
Providing direct services to PWCD	4	12.5	0	-	1	20	1	14.3	8	88.9	**14**	**73.7**
Training of parents or carers of PWCD	4	12.5	0	-	1	20	1	14.3	7	77.8	**13**	**68.4**
Training teachers about CDs	4	12.5	1	11.1	1	20	1	14.3	5	55.6	**12**	**63.1**
Training local health professionals about CD	3	9.4	2	22.2	0	-	1	14.3	7	77.8	**13**	**68.4**
Raising awareness about CD	4	12.5	1	22.2	1	20	1	14.3	5	55.6	**12**	**63.1**
Research into CD	2	6.3	1	11.1	0	-	0	-	5	55.6	**8**	**42.1**
Fundraising for PWCD	2	6.3	1	11.1	0	-	0	-	3	33.4	**6**	**31.6**
Funding scholarships for professionals to train to support PWCD	0	0	1	11.1	0		0		0	-	**1**	**5.3**
Resources for PWCD	2	6.3	1	11.1	1	20	1	14.3	7	77.8	**12**	**63.1**

Key differences and similarities by country for descriptions of outsiders

Table 5.8 shows the percentage of respondents to allow for a comparison by country despite variable participant numbers. Interestingly, despite the outsider role of "providing direct services to PWCD" being experienced by the majority of insiders, this was not a role noted in Sri Lanka, possibly because the respondents were students and therefore had less experience. This was also the case for the joint second most commonly experienced outsider role of "training parents or carers of PWCD." The other joint second most commonly experienced outsider role of "training local health professionals about CD" was experienced by all except the Jamaican participant. Participants from all countries except Jamaica and Trinidad and Tobago had all experienced outsiders researching CD.

The outsider role of "funding scholarships for professionals to train to support PWCD" had been experienced by the fewest participants, one each from Malaysia and Sri Lanka. The outsider role of "fundraising for PWCD" was the second least commonly experienced role and was seen in Kenya and Sri Lanka (by half of respondents) and in Malaysia (experienced by one-third of respondents). This role was not experienced by either respondent in the Caribbean countries.

5.4.5 Collaboration

This section of the survey asked three questions about how insiders and outsiders had worked together. Exploration of the global theme indicated two relevant themes for discussion: BT1, "Outsiders need to collaborate because of cultural differences," and BT2, "Outsiders' skills and knowledge regarded as superior" which are discussed within this section.

Survey question number	Question	Response
2	If insiders and outsider have worked together to support services for people with communication disabilities, how is this initiated?	Multiple choice (multiple answer)

The first question for this topic area was question two. Response rate was 100%. Participants were asked to choose one of the six options provided. However, some participants chose more than one option. Therefore responses

are presented instead of cases. Table 5.9 summarises the 36 responses from participants. Of the responses, the most commonly reported mode of initiation of working together was by an insider organisation (36.1% of all responses). The least common mode of initiation was by a single outsider initiating the work (2.8% of responses).

Table 5.9 Showing who insiders perceive to initiate collaboration

How working together is initiated	Number of responses	Percent of responses
Single insider	7	19.4
Insider organisation	13	36.1
Single outsider	1	2.8
Outsider organisation	9	25.0
Not known	3	8.3
Other	3	8.3
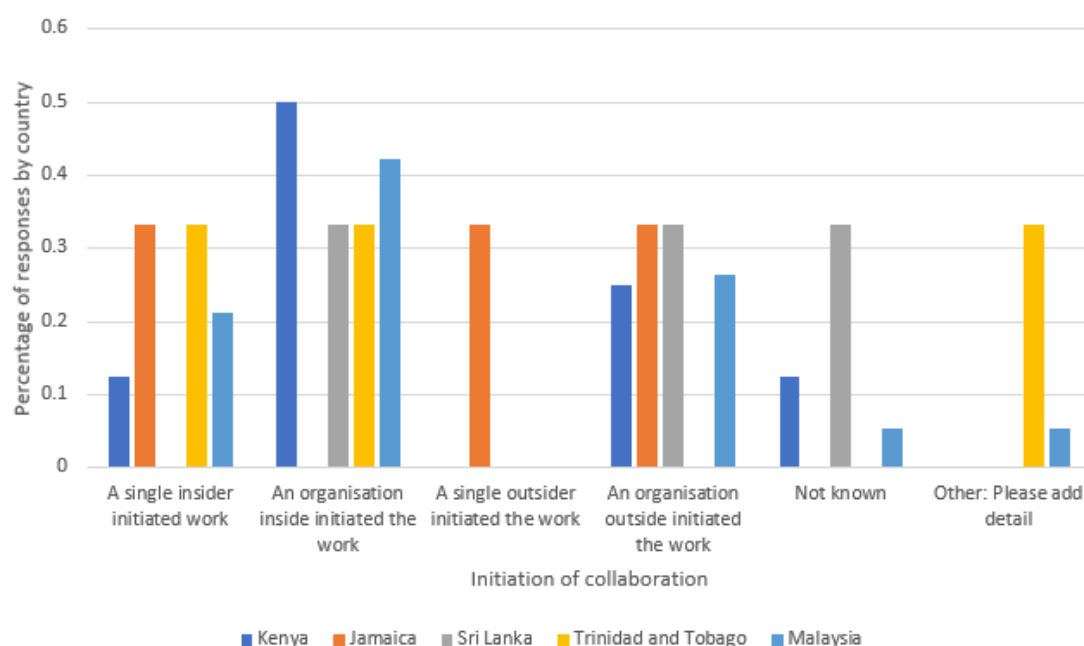
Figure 5.2 Showing the breakdown by country of insider-outsider collaborative initiation

Insider initiation of collaboration by both individuals and organisations was more commonly reported than outsider initiation by individuals and organisations (55.5% of responses compared to 27.8% of responses). Organisation initiation by both insider- and outsider-based organisations was more commonly reported

by participants than individual initiation by both insider- and outsider-based organisations (61.1% of responses compared to 22.2% of responses). Figure 5.2 shows the responses of the initiation of collaboration by country.

Survey question number	Question	Response
3	Which of these best describes the most common way that insiders and outsiders work to support services for people with communication disabilities?	Multiple choice (single answer)

The second question for this topic area was question three. Response rate for this item was 100%. Participants were asked to choose one option from the four options provided, however some participants chose more that one option. This resulted in 24 responses from the 17 participants, shown in Table 5.10. Equal collaboration was most common response (reported by 47.1% of participants). Outsider-led and insider-led collaboration were reported by equal numbers of participants (each 41.2%).

Table 5.10 Insiders and outsiders work to support services for PWCD

Most common way that insiders and outsiders work to support services for PWCD	Number of responses	Percentage of participants
Insider-led	7	41.2%
Outsider-led	7	41.2%
Equal	8	47.1%
Other	2	11.8%

Figure 5.3 shows the responses by country. Kenya and Malaysia reported the lowest occurrence percentage of outsider-led collaboration (25% and 33% respectively). Kenya reported equal collaboration as the most common way of working (reported by 75% of participants). Malaysian participants reported insider-led collaboration as the most common way of working (reported by 41.7% participants).

The other "options" were selected by the Jamaican participant and one Sri Lankan participant. The Jamaican participant noted that this involved an outsider working with the Jamaican counterpart to culturally guide their clinical

recommendations. The Sri Lankan noted that insiders would initiate work and request specific outsiders to assist them.

Both the Trinidadian and Jamaican participant indicated that equal collaboration was the most uncommon way of working, instead indicating that both insider-led and outsider-led (or, for the Jamaican participant, "another way of working") were the most common ways of working.
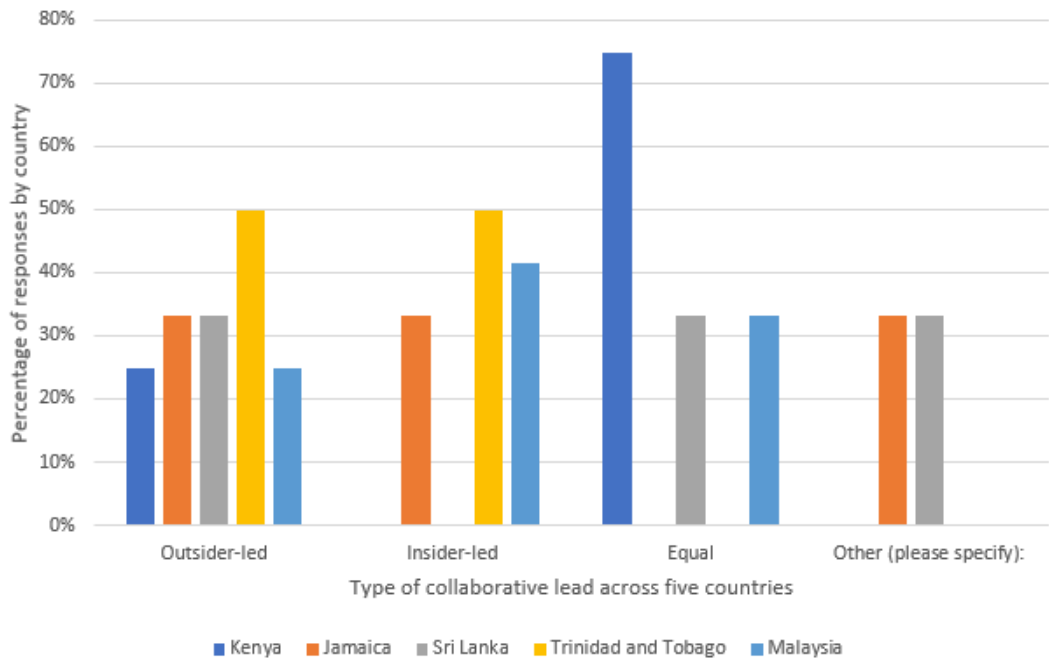
Figure 5.3 Showing the breakdown by country of collaborative lead

Survey question number	Question	Response
4	Which of these statements best describes the aims of outsiders who support services for people with communication disabilities in [country]?	Multiple choice (single answer)

The third and final question for this topic area was question four. Response rate was 100%. Table 5.11 shows that, across the five countries, fifteen participants felt that outsiders aimed to work with insiders, compared with two participants who believed that the majority of outsiders aimed to work independently of insiders. One participant (from Malaysia) ticked both options.

Table 5.11 Working together or independently responses by country

	Kenya	Sri Lanka	Jamaica	Trinidad and Tobago	Malaysia	Total
Number of respondents in each country	4	2	1	1	1	17
The majority of outsiders aim to work with insiders	4	1	1	1	8	15
The majority of outsiders aim to work independently of insiders	0	1	0	0	2	3

Exploration of the thematic analysis gave additional insight into the topic of collaboration. Despite similar numbers for insider/outsider/equal working, the way outsiders work together sometimes brought its own challenges. Insiders found it particularly challenging when outsiders were "domineering" or had the "assumption of their knowledge being correct." Aside from the intentions of the outsider whether or not to work with insiders, one interpretation is that there may be cultural aspects to working collaboratively.

Insiders from Malaysia noted a cultural/hierarchal divide in culture which influenced how different members of society talked to each other. They noted that their communication style is non-confrontational, and insiders may accept outsiders' ideas without discussion. True collaboration was therefore challenging if these culturally divergent ways of communicating were not negotiated, especially where outsiders were unaware of these cultural differences.

Ultimately, the best way of collaborating was when there were shared goals or ways of working.

> *K3: "When your vision and purpose are aligned, it makes it a lot easier to collaborate"*

A popular reason that insiders felt outsiders aimed to work together with insiders was so the outsiders could reduce the cultural differences between themselves

and their clients. Where insiders felt outsiders did not work with insiders, they did not add detail to explain why they thought this was.

<u>Key differences and similarities by country for collaboration</u>
For question 2, responses from all countries revealed the most commonly reported mode of initiation of working together was by an insider organisation. Both initiation by insider and outsider organisation were more commonly reported than initiation by insider or outsider individuals. Only the Jamaican participant noted that working together had been initiated by a single outsider.

For question 3, equally-led collaboration was the most common way of working. Both insider-led and outsider-led working were the joint second most common way of working. Interestingly, in Kenya, one participant felt that outsider-led collaboration was most common, and no participants felt that insider-led collaboration was the most common way of working together. In Sri Lanka, one participant felt that outsider-led collaboration was the most common way of working, the other participant felt that an equal collaboration was more common. Both Caribbean participants noted collaboration was usually either insider-led or outsider-led. The Jamaican participant however also described another option which was the outsider providing suggestions while consulting an insider to consider cultural differences (see section 5.4.2.1). Interestingly, in Malaysia, insider-led collaboration was noted by the most participants, followed by equal collaboration, then finally outsider-led collaboration.

For question 4, responses indicated that the majority of insiders felt that outsiders aimed to work with insiders (15 of the 17). One Malaysian participant indicated that both working with or independently of insiders were equally likely for outsiders. However working with insiders was indicated by all Kenyan and both Caribbean insiders. One Sri Lankan and two Malaysians indicated that outsiders worked independently of insiders. Interestingly, the Sri Lankan participant who felt that the majority of outsiders aimed to work independently of insiders also indicated that collaboration between insiders and outsiders was more likely outsider-led.

5.4.6 Rationale for collaboration

The survey had three questions focusing on rationales for collaboration. Data from the two open response questions were analysed in the thematic network analysis. The most relevant theme for this topic is BT6. "Outsiders' different motivations affect contributions," which will be discussed in relation to this topic.

Survey question number	Question	Response
8	In your experience, what do you think motivates outsiders to work in developing services for people with communication disabilities in [country]?	Multiple choice (multiple answer)

The first question for this topic area was question 8. The response rate for this question was 100%. The most commonly perceived motivation of outsiders was to work in their country by observing services for PWCD in another context (82.4% of all respondents). There were two second-most-commonly perceived motivations which were indicated by 70.6% of respondents, which were personal experience and career experience.

The opportunity to make money was listed by the fewest participants (11.8%). Five participants gave additional responses, including the opportunity to improve existing services, family or links with organisations and providing donations.

Table 5.12 Showing insiders beliefs about the most common motivating factors for outsiders to work in their country

Motivation	Kenya	Sri Lanka	Jamaica	Trinidad and Tobago	Malaysia	Total responses
To observe services for people with communication disabilities in another context	4	2	1	1	6	14
Charitable / altruistic motivation	2	1	1	1	4	9
Religious motivation	-	-	1	-	3	4
Personal experience	3	1	1	-	7	12
Career experience	4	-	-	1	7	12
Opportunity to make money	-	-	-	-	2	2
Tourism	1	1	-	-	4	6
Other: Please add detail	-	1	1	-	3	5

Survey question number	Question	Response
9.a	In your experience, do you think outsiders' motivations for working with people with communication disabilities in [country] are similar to your own motivations?	Open response

The second question for this topic area was question 9.a. Response rate for this item was 94.1%, with one Malaysian participant not responding. Insiders largely felt that outsiders' motivations for working to support services for PWCD in their country were similar to their own. They felt that this motivation offered a fundamental basis for collaboration, and that similar goals (as explored in 5.4.4) formed the best basis for collaboration. Only the Jamaican participant detailed the effects of negative motivations: by working for their own personal gain, outsiders had not made a meaningful contribution or improved services in this reported instance. Despite this, the majority of insiders felt outsiders' motivations were positive, and in many cases, saw outsiders as "sacrificing" in some way:

> *M6: "I feel like they have a greater motivation and enthusiasm which brings positive energy to the people who work together with them."*

The sixth basic theme, "Outsiders' different motivations affect contributions" can be explored to further understand outsiders motivations to work both in a particular country, and to support services for PWCD in that country. Though insiders' perceptions of outsiders' motivations to work in their country varied, two main reasons were noted. Insiders felt that outsider may have been specifically commissioned, or that familial ties drove the motivation to work in that country.

Survey question number	Question	Response
9.b	What effect, if any, does this have on working together?	Open response

The third and final question for this topic area was question 9.b. Response rate for this item was 100%. Shared motivations were believed to facilitate a shared understanding, which in turn would foster more successful working.

> M1: "With a similar motivation and some similar goals, it will drive a positive force in working together."

Participants from all countries noted how such shared goals benefitted them both personally (e.g., in being able to have a stronger bond with the outsiders) and professionally (in allowing for the best use of limited resources).

Key differences and similarities by country for rationale for collaboration

For question 8, the most common motivation insiders believed outsiders to have was to observe services for PWCD in another context. This was indicated by all participants across all countries.

The opportunity to make money was the least frequently identified motivation. The two participants who believed this to be a motivating factor were both from Malaysia, where this may be a greater possibility compared to the other countries. Religious motivation was also an infrequently identified motivation, reported only by participants from Jamaica and Malaysia. Tourism was cited as a motivation by participants from Kenya, Sri Lanka and Malaysia, but not the two Caribbean countries. The Jamaican participant and one of the Sri Lankan participants each listed other motivations. The Jamaican noted an additional reason as outsider institutions being motivated to improve their institutional ratings; The Sri Lankan noted "financially based" motivations (despite neither of the two Sri Lankan participants citing the motivation of opportunity to make money).

For question 9.a, two participants (Sri Lankan and Malaysian) noted outsiders to have different motivations to their own. In this case, they thought that outsiders' motivations were better than insiders'.

SL2: "Outsiders have a better motivation than insiders as they are expending more money for everything… They are volunteers."

One other insider (from Malaysia) was unsure of whether motivations were similar, and noted that this could vary from person to person. All other participants felt that outsider motivations were the same as their own.

For question 9.b, only the Jamaican participant explicitly noted motivations that could have negative affects. One Malaysian participant noted that whilst motivations could be different among everyone, providing outsiders practised in accordance with the local ethical ways of working that motivations would not result in negative practice.

5.4.7   Judgement on present outsider contributions and effectiveness

The survey had three questions asking insiders to judge present outsider contributions and outsider effectiveness. This included one open and two closed questions. Data from the open question was used for the TNA, and the resulting most relevant themes are discussed here in reference to this topic area.

Survey question number	Question	Response
12	What are the most common cultural misunderstandings between outsiders and insiders who work together to support services for people with communication disabilities?	Open response

The first question in this topic section was item 12, which revealed cultural misunderstandings between insiders and outsiders. Exploration of the global theme revealed three particularly relevant basic themes related to this topic. These were BT1. "Outsiders need to collaborate because of cultural differences"; BT3. "Received and desired outsiders"; and BT4. "Best practice to aspire to, and worst practice to avoid."

Some of the most common cultural misunderstandings were due to language or accent differences. Aside from potentially causing misunderstanding, insiders noted that some outsiders were not flexible in either their linguistic knowledge or resources that they brought, and that this meant their therapeutic approaches

were not culturally appropriate. Other cultural aspects that caused challenges included attitudes to time-keeping, completing procedures, and client relationships.

> *T&T1: "They find it difficult to understand the culture and the speed at which things move. It is frustrating for the insiders working in these conditions"*

> *K3: "The importance of forming relationships with your clients / patients. For example, you will often be invited / expected to share a meal with the family."*

There was a challenge when outsiders were unaware, ignorant or inflexible to cultural differences. These factors were consistently cited by all participants as examples of the worst outsider practices. Conversely, best practice involved making and using locally developed approaches, and working with insider counterparts to ensure sustainability

> *J1: "Implementation of a programme that can be continued by insiders."*

> *K2: "Development of practice models that are engineered locally"*

Despite cultural differences existing between insiders and outsiders, BT1 revealed that outsiders needed insiders in order to help them navigate cultural differences. This indicated that often insiders felt themselves working as cultural guides to help outsiders' practice.

Survey question number	Question	Response
16	From your own experience, please rate the following types of outsider contributions in terms of their value for developing services for people with communication disabilities.	Likert scale

The second question for this topic area was question 16. This asked participants to rate eleven different types of outsider contributions in terms of their value on developing services for PWCD. Response rates for this question

varied, with one participant only completing one question. Table 5.13 displays the roles and their value rankings for all insiders.

Roles to do with training and direct clinical services were ranked as being of greatest value by the most participants. "Training of parents or carers of PWCD" and "Training of local health professionals" were rated most commonly as having significant value (each by 76.5% participants). This was followed by "Supporting PWCD with direct intervention" (70.6% participants) and "Training teachers" (64.7% participants). Only one role was noted to be of no value. This was "Providing funding for individual intervention." The roles that were least commonly experienced were "Providing funding for individual intervention" (not experienced by 52.9%) and "Providing funding for scholarships to support people with communication disabilities" (not experienced by 47.1%).

Table 5.13 Showing insiders' ratings for the value of different outsider roles

Outsider role	No value	Little value	Some value	Significant value	Have not experienced	No response	Total
Campaigning for increased communication services	-	-	29.4%	47.1%	17.6%	5.9%	100%
Campaigning for rights of people with communication disability	-	5.9%	11.8%	35.3%	41.2%	5.9%	100%
Supporting people with communication disabilities with direct intervention	-	5.9%	17.6%	70.6%	5.9%	-	100%
Training of parents or carers of people with communication disability	-	-	11.8%	76.5%	11.8%	-	100%
Training of teachers	-	-	17.6%	64.7%	11.8%	5.9%	100%
Training of local health professionals	-	-	5.9%	76.5%	11.8%	5.9%	100%
Raising awareness of communication disabilities	-	11.8%	29.4%	41.2%	11.8%	5.9%	100%
Research into communication disabilities in [country]	-	5.9%	23.5%	41.2%	23.5%	5.9%	100%
Providing funding for individual intervention	5.9%	11.8%	17.6%	5.9%	52.9%	5.9%	100%
Providing funding for scholarships to support people with communication disabilities	-	5.9%	11.8%	29.4%	47.1%	5.9%	100%
Resources/funding for resources for people with communication disabilities	-	5.9%	23.5%	29.4%	35.3%	5.9%	100%

Survey question number	Question	Response
18	From your own experience of working with outsiders to develop services for people with communication disabilities in [country], please evaluate the following statements.	Likert scale

The final question for this topic area was question 18. This asked participants to evaluate 12 statements focused on the effectiveness of outsider contributions. Response rates for items varied, with several participants not completing certain items. Table 5.14 summarises the responses from all participants.

Table 5.14 Insiders' evaluations of aspects of outsider contributions

Statement	Strongly disagree	Disagree	Neither agree or disagree	Agree	Strongly agree	No response	Total
Working together with outsiders has generally been successful	-	-	-	47.1%	47.1%	5.9%	100%
There are clinical challenges in working with outsiders	-	23.5%	17.6%	47.1%	5.9%	5.9%	100%
There are cultural barriers in working with outsiders	5.9%	17.6%	11.8%	47.1%	17.6%	-	100%
Outsiders have effectively contributed to the development of services for people with communication disabilities	-	-	11.8%	47.1%	35.3%	5.9%	100%
Outsiders' contributions have been appropriate to the needs of [country]	-	17.6%	5.9%	52.9%	23.5%	-	100%
Outsiders' contribution has made a lasting difference	-	-	29.4%	41.2%	29.4%	-	100%
Outsiders' contributions have led to fewer opportunities for local health professionals	29.4%	47.1%	17.6%	5.9%	-	-	100%
Outsiders are needed in [country] to support services for people with communication disabilities	-	-	11.8%	64.7%	17.6%	5.9%	100%
Outsiders are wanted in [country] to support services for people with communication disabilities	-	-	23.5%	47.1%	23.5%	5.9%	100%
Short-term (3 months or less) work is most suitable in [country]	5.9%	11.8%	47.1%	17.6%	5.9%	11.8%	100%
Medium-term (between 3 months and a year) work is most suitable in [country]	-	11.8%	17.6%	23.5%	11.8%	35.3%	100%
Long-term (more than a year) work is most suitable in [country]	5.9%	-	35.3%	29.4%	23.5%	5.9%	100%

94.1% of insiders either agreed or strongly agreed that working with together with outsiders has generally been successful. However, the majority of participants felt there had been both clinical challenges and cultural barriers when working with outsiders. The majority of participants felt that outsiders had effectively contributed to the development of services for PWCD, and that their contributions had been appropriate. Overall, the majority of participants either agreed or strongly agreed that outsiders contributions had made a lasting difference (70.6%).

In terms of the need for support, most participants felt that having outsider support had not led to fewer opportunities for insiders. The majority of participants felt that outsiders were wanted and needed to support services for PWCD, however it was interesting to note discrepancies. More participants either agreed or strongly agreed that outsiders were needed (82.3%), than wanted (70.6%). It is unclear whether this reflects the personal attitudes of the respondents, or their perceptions of other insiders in their country.

The next subsection of the item asked participants whether short-term, medium-term, or long-term work was suitable for outsiders. Short-term work was described as being three months or less. Medium-term work was described as being between three months and one year. Long-term work was described as being more than one year. For short-term work, the majority of participants (47.1%) neither agreed or disagreed that this was the best way of working. A large proportion of participants (35.3%) did not respond to the question concerning medium-term work as the most suitable. Long-term work was the most preferred time length of outsider work, with the majority of participants believing it to be the most suitable.

Key differences and similarities by country for judgement on present outsider contributions and effectiveness

Item 16 asked participants to rate different outsider roles for effectiveness. Three roles related to campaigning or awareness raising; three roles involved training others; three roles involved funding; one role related to direct clinical services; and one role related to researching CD. The Trinidad and Tobago participant rated all but one role as having significant value ("research into

communication disabilities"), which will be the only role discussed below for this participant.

Campaigning

Of all the campaigning roles, Kenyans found campaigning for increased services for PWCD to be of significant value (75%).

Training

In terms of training, all Kenyans found training parents or carers of PWCD to be of significant value, with both training of teachers and health professionals found to have significant value by 75% of Kenyans. Both Sri Lankans felt the training of teachers, and of local health professionals by outsiders to be of significant value. Of the three training roles, Malaysian participants rated the training of parents or carers of PWCD to have the most value (88.9% finding it to be of some or significant value).

Funding

The roles of outsiders providing funding for individual intervention for PWCD and outsiders providing funding for scholarships to support PWCD had each not been experienced by 75% of Kenyan participants. However, the two Sri Lankan participants both found this to be of significant value. The providing of resources/funding for resources for people with communication disabilities was rated as having significant value, and the funding of individual intervention, and providing funding for scholarships to support people with communication disabilities were all of some value to the Jamaican participant. In Malaysia, the majority of participants (55.6%) had not experienced outsiders providing either resources or funding for PWCD, or funding for individual intervention for PWCD.

Direct clinical services

All Kenyan participants found outsiders supporting PWCD with direct intervention to be of significant value. This contrasted with the two Sri Lankan participants: one of whom felt that this would have no value, and one of whom had no experience of this approach. A possible explanation for this is that as the Sri Lankan participants were both students, they had less experience of working clinically with outsiders.

Research

Both Sri Lankan participants agreed that outsiders completing research into communication disabilities to be of significant value, as did the Jamaican participant. This contrasts with the Kenyan participants who respectively felt outsiders producing research into communication disabilities was of some value (50%), or little value (25%). Malaysian participants indicated that outsiders producing research into communication disabilities was valued with 44.4% believing it to be of significant value, and 11.1% believing it to be of some value.

The Trinidadian participant found all outsider roles to be of significant value, *except* for the role of researching communication disabilities — which the participant found to be of some value.

For item 18, participants were asked to rate how they agreed with statements about the effectiveness of outsider contributions. Three of the Kenyan participants each rated there being clinical challenges and cultural challenges when working with outsiders. The Trinidad and Tobago participant agreed that there were clinical and cultural challenges when working with outsiders, as did the majority of Malaysian participants. One Sri Lankan thought there were cultural or clinical challenges when working with outsiders. Whilst the Jamaican participant neither agreed nor disagreed that there had been clinical challenges when working with outsiders, they agreed that there were cultural barriers when working with outsiders.

Caribbean participants neither agreed or disagreed that outsiders' contributions had made a lasting difference. For contributions, the two Sri Lankan participants varied in their responses. There was disagreement over whether outsiders had effectively contributed to service development, and whether their contribution had made a lasting difference. Three Kenyan participants felt that outsiders had effectively contributed to the development of services, with the remaining one neither agreeing or disagreeing. The Kenyan participants gave mixed responses for their ratings about outsiders contributions being appropriate — with two participants disagreeing and two strongly agreeing.

The majority of Kenyans (three out of four) strongly disagreed that outsider involvement had led to fewer opportunities for Kenyan health professionals. The two Sri Lankan participants were divided on this issue: one agreeing and one strongly disagreeing. Despite this, both Sri Lankans agreed that outsiders were wanted and needed to support services for PWCD.

For the time-length of contributions, there were increased numbers of non-responses from participants. However, there were some clear differences between countries in this regard.

The Trinidad and Tobago participant agreed that short-term work was most appropriate, and neither agreed or disagreed that long-term work was most appropriate.

The two Sri Lankan participants indicated that medium-term work was the most appropriate way of working, with both agreeing with this item. This was similar to the Malaysian participants' responses, where there was the most agreement that medium-term work with most suitable, with a number of participants neither agreeing or disagreeing that either short-term or long-term work was most suitable.

This contrasts with the Jamaican participant who neither agreed or disagreed that short-term or medium-term options were most suitable, but agreed that long-term contributions were most suitable. All Kenyan participants either agreed or strongly agreed long-term was the most appropriate way of working.

5.4.8 Ideal outsider qualities and contributions

This section of the survey focused on what insiders considered to be ideal outsider qualities and their preference in the type of outsiders they received. This topic was explored by three questions in the survey. This included both open and closed questions. Data from the open questions were used for the thematic analysis, and the most relevant themes from the resulting global theme will be discussed in relation to this topic area.

Survey question number	Question	Response
14	To what extent do you agree with the statement "outsider contributions need to be sustainable in order effectively to support services for people with communication disabilities?"	Multiple choice (single answer)

The first question for this topic area was question 14. This was a Likert scale question asking respondents to rate their agreement to the above statement. This had a response rate of 100%.

Table 5.15 shows participants' rating of the need for sustainability from outsiders by each country. This shows that overall, the largest majority of participants either agreed (eight) or strongly agreed (seven) that outsider contributions needed to be sustainable in order to affect the support services for PWCD. One participant neither disagreed or agreed. The final participant strongly disagreed with this statement.

Table 5.15 Participants' rating of the need for sustainability from outsiders, by country

	Kenya		Sri Lanka		Jamaica		Trinidad and Tobago		Malaysia		Total	
	No.	%	No.	%	No.	%	No.	%	No.	%	No.	%
Strongly disagree	1	25	-	-	-	-	-	-	-	-	1	5.9
Disagree	-	-	-	-	-	-	-	-	-	-	-	-
Neither disagree of agree	-	-	-	-	-	-	-	-	1	11.1	1	5.9
Agree	1	25	-	-	1	100	1	100	5	55.6	8	47.1
Strongly agree	2	50	2	100	-	-	-	-	3	33.3	7	41.2

Survey question number	Question	Response
15	What do you think are the best ways to ensure sustainable working practices from outsiders when working to support services for people with communication disabilities?	Open response

The second question for this topic area was question 15. Response rate for this was 64.7%. Sustainability was linked to BT4, "Best practice to aspire to, and worst practice to avoid," where it related to outsiders' involvement being focused on the needs of the service in country. A key element of the best practice of sustainability was the appropriate training and the end of outsider support only once insiders could complete work independently.

The Trinidad and Tobago participant and 5 Malaysians did not respond to this item. Insiders from the four countries that responded felt that the best ways of ensuring sustainability from outsiders' contributions was for outsiders to have adequate information of what was needed; for their contributions to be linked in with existing services and communities, and to make sure training or programmes had been implemented adequately, and checked to ensure insiders could maintain services independently.

> *M8: "As far as possible, all projects initiated by outsiders should be in the form of an action research wherein outsiders spend time with insiders within an organisation to build up relationships and to commonly identify project goals."*

> *J1: "Implementation of a programme that can be continued by insiders."*

> *K1: "Once they have started something, train the locals and do constant follow up until you are sure we can now stand on our own"*

Survey question number	Question	Response
17	In your opinion, what qualities, skills and experiences would be most and least wanted from outsiders who support services for people with communication disabilities?	Open response

The third and final question for this topic area was question 17. This was designed to elicit responses which could be grouped together to form specific ideal outsider specifications. Responses for this question were analysed using TNA to produce the global theme. Exploration of this revealed two particularly

relevant basic themes related to this question, BT3 "Received and desired outsiders" and BT4 "Best practice to aspire to, and worst practice to avoid."

Question 17 was made of two elements: most wanted and least wanted outsider qualities. The first part of the question had a response rate of 100%. In terms of what was wanted, some noted specific roles, such as delivering direct intervention with PWCD, training roles, and providing CPD, and a similar number of insiders noted specific personal qualities rather than roles or ways of working. Where clinical roles were desired, insiders often wanted outsiders to work in specific areas, such as dysphagia and voice disorders (e.g., Jamaica). In Malaysia and Sri Lanka, outsiders were also wanted to provide CPD. Insiders consistently valued sustainable approaches. Insiders described how it was important that whatever role outsiders were working in, they ensured the sustainability by providing adequate support, working closely with insider counterparts and only left once insiders were able to work without outsider support.

The second part of the question asked participants which outsider qualities were specifically not desired, Response rate for this was 70.5%, and was not completed by two Malaysian and the one Trinidad and Tobago participant. Responses included personality traits such as self-centredness, inflexibility, being manipulative and domineering. Outsiders lacking in skills and experience, or those that overestimated their skills were also unwanted. The three roles unwanted from outsiders included: writing journal articles about limited services, lobbying and funding.

Ideal roles involved equal collaboration, often as part of a wider, multi-disciplinary team which would benefit insiders in other related professions.

Key difference for ideal outsider qualities and contributions
Data from question 14 showed the majority of participants either agreed or strongly agreed that outsiders contributions needed to be sustainable, although one participant from Kenya strongly disagreed with this. One of the nine participants from Malaysia neither agreed or disagreed with this.

Data from question 15 showed some differences by country about how outsiders can ensure sustainability. Both Jamaican and Kenyan participants indicated that training of SLTs and AHPs was important. This was not mentioned by the Sri Lankan participants (who preferred outsider internships or liaison with professionals) and was only noted by one Malaysian in the event of an outsider having specialist skills only. However, the countries that responded all indicated that it was crucial that whatever was done by insiders was monitored until insiders were able to complete working independently.

Question 17 showed differences amongst insiders from the five countries for the wanted outsider qualities, skills and experiences. Resources were wanted by participants from Sri Lanka, Jamaica and Trinidad and Tobago. Personality traits were mainly noted by Malaysian and Kenyan participants. Specifically, creativity was mentioned by Malaysian participants only. The ability to work together was noted by only Malaysian and Sri Lankan participants, and the need for experience was noted in all but the Caribbean countries. Responses about what was not wanted came from Kenya, Sri Lanka, Jamaica, and Malaysia. Responses described personality traits, skills and experience and roles. Interestingly, the majority of descriptions of personality traits and skills were reported by Malaysians. Specific roles were noted only by the Jamaican and Kenyan participants.

5.4.9 Views on outsider perspectives

This section of the survey focused on what insiders believed outsiders' perceptions regarding their country and services for PWCD were. This section explored this topic with four open response questions. Data for these for questions were analysed using thematic network analysis to produce a global theme. The most relevant theme from this is discussed in relation to each question in this topic section.

Survey question number	Question	Response
10.a	From your experience of working with outsiders to support services for people with communication disabilities, what do you think are outsiders' typical initial perceptions of [country]?	Open response

The first question for this topic area was question 10.a. Response rate for this item was 82.3%. Respondents from all countries felt that outsiders had negative perceptions of their country. Respondents felt that outsiders judged their country in terms of what it was lacking, such as public services and resources. Only two respondents noted outsiders to have positive perceptions (both Kenyans).

BT5. "Outsiders' assumptions are typically negative but can change" was particularly relevant to this topic. Insiders felt that outsiders' perceptions of their country were typically negative, or inaccurate exaggerations of negative qualities of Majority World countries. Insiders felt that outsiders perceived their countries to be unsafe, unsanitary or unstable. Only two participants felt outsiders had positive first impressions, however this was balanced with negative beliefs:

> K3: "Beautiful country with friendly and helpful people. There may be a perception that it unsafe due to recent terrorist attacks."

Survey question number	Question	Response
10.b	Do their perceptions tend to change during the course of working together?	Open response

The second question for this topic area was question 10.b. Response rate for this item was 76.4%. Of these, four participants indicated that outsiders' perceptions change, three participants that they did not. Four participants thought that perceptions could change, and two were unsure whether perceptions changed.

Where insiders perceived outsiders to have strong negative perceptions of their country (such as being dangerous), the majority of insiders felt that these often changed to become either more realistic or positive.

> J1: "Usually they tend to change as they become immersed into the cultural and understand the dynamics of the Jamaican people."

Insiders also felt that outsiders' perceptions changed if they had previously assumed a country to be mainly monocultural once experiencing a country as multicultural. Where insiders felt outsiders perceived a country to have limited public services, insiders felt outsiders' perceptions were less likely to change.

Survey question number	Question	Response
11.a	From your experience, what do you think are outsiders' perceptions of services for people with communication disabilities in [country]?	Open response

The third question for this topic area was question 11.a. Response rate for this item was 82.3%. There were two common types of response for what insiders perceived to be outsiders' perceptions. Firstly, there was a need for support (four participants). Secondly, services for PWCD were limited (ten participants). At times, insiders felt that outsiders had no awareness of existing (despite limited) services for PWCD in their country.

BT5. "Outsiders' assumptions are typically negative but can change" was particularly relevant to this topic. This showed that insiders perceive outsiders to focus on what a country is lacking in. In terms of specifically working to support services for PWCD in their country, insiders felt outsiders often perceived services to be non-existent, very limited, or inaccessible to the majority:

> *J1: "A nation of deprived, under-serviced, and sparsely educated individuals in need of support. This perception is somewhat guided by our (parents, caregivers) response to outsiders. The history of our country surrounds a very strong colonial past where we depend heavily on the input of outsiders than that of our own."*

> *T&T1: "Public services inadequate."*

> *K2: "That they don't exist totally as there no reports, publications etc."*

Survey question number	Question	Response
11.b	Do their perceptions tend to change during the course of working together?	Open response

Item 11.b asked participants whether they felt outsiders' perceptions about services for PWCD changed over the course of working together. Response rate for this item was 82.3%. The majority of these participants (six) indicated that they felt outsider perceptions sometimes changed. Often participants noted that outsiders adapted but did not note if their perceptions changed. Five participants thought that outsider perceptions did not change, and three felt they did.

The most relevant theme was BT5, "Outsiders' assumptions are typically negative but can change." This indicated that insiders' beliefs as to whether or not outsiders' perceptions changed to be linked to what their perceptions before were. Where perceptions related to limited services, although some outsiders' perceptions may not change, other outsiders will work to create increased services which appears to change their perception. After outsiders had spent time in-country working in services for PWCD, some insiders felt that outsiders' perceptions about the services changed.

> M4: "Yes, Change is inevitable."

5.4.10 Insider/outsider equality

This section of the survey explored the theme of equality between insiders and outsiders. This was explored in the survey by one multiple choice question. There was one particularly relevant basic theme for this topic, BT2, "Outsiders' skills and knowledge regarded as superior."

Survey question number	Question	Response
13	In your experience, which of these statements best describes the treatment of outsiders who support services for people with communication disabilities in [country]?	Multiple choice (single answer)

Response rate for this item was 100%. Although this multiple choice question was intended to be answered with a single answer, one participant selected both options and provided comments which were interpreted. The majority of participants across the countries indicated that insiders and outsiders were treated differently, with 14 of the 17 responses indicating a difference in treatment. Three participants indicated that insiders and outsiders were treated equally, and one participant ticked both options. Table 5.16 summarises all insiders' responses for this item.

The basic theme "Outsiders' skills and knowledge regarded as superior" helps to interpret this result further. A finding of this theme was that outsiders may be more respected than insiders, which may also influence client preferential treatment.

> J1: "Some parents/caregivers may tend to accept the outsiders' suggestions over insiders'."

Insiders had mixed feelings about whether they were treated equally by outsiders. One insider felt outsiders may cast judgement about insiders' approach to developing services for PWCD.

> J1: "Between professionals, I believe there is a clear respect and appreciation for each person's skill set."

> M8: "Sometimes they do recognise the fact that people are trying their best and perhaps professionals in other countries would act in the same way if there such a demand for services. Although, I would add that many of us locals could and should improve services."

Table 5.16 Comparisons of perspectives of insider and outsider equality across countries

	Kenyan participants	Sri Lankan participants	Jamaican participants	Trinidad and Tobago participants	Malaysian participants	Total
Outsiders and insiders are treated equally	1	-	1	-	2	4
Outsiders and insiders are treated differently	3	2	1	1	7	14

<u>Key difference for ideal outsider views on insider/outsider equality</u>

Data from item 13 showed the majority of participants felt that insiders and outsiders were treated differently, however there was some variation amongst the countries. Sri Lanka and Trinidad and Tobago were the only countries from which no participants believed insiders and outsiders were treated equally. The Jamaican participant ticked both options to indicate that they felt insiders and outsiders were treated both equally and differently. They expanded on this in the comments explaining this varies amongst different insiders, and that whilst professionals were more likely to treat insiders and outsiders the same, they described that insider clients (parents or carers) as more likely to treat outsiders in a preferential way. They considered this difference to be reflective of Jamaican culture.

5.4.11 Summary

The phase two pilot study survey was completed by 17 respondents across five countries with differing HDI. Quantitative data were described and textual data from the surveys were used to produce one global theme which was described and related to each topic area, and used to further interpret quantitative data. The next section will discuss the results of phase two.

5.5   Discussion

Following the presentation of the phase two pilot study results in the previous section, this section discusses the results in relation to the research objective. Table 5.17 explains how this objective was achieved. The section will include a brief discussion of the participant demographics across the five countries,

before focusing on the research objective and limitations of this phase of research.

Table 5.17 Research objective

Research objective	Data used	Results produced
To interpret and explain perceptions of outsider contributions in five Majority World countries.	• Insider surveys	• Descriptive statistics • Thematic network analysis

5.5.1 Participant demographics

This section of the survey collected demographic and background detail about the participants. Across all demographic questions, a maximum of 17 participants completed most items. Demographic items were placed at the end of the survey in order to encourage rich data earlier in the survey, however this approach may have caused some participants not to complete this information. Furthermore, questions about participants' demographics may have been considered sensitive.

Thirteen of the seventeen participants reported their gender. All thirteen that responded reported their gender as female. It may be the case that those who did not disclose their gender were male respondents choosing to protect their anonymity (in a field in which male SLT professionals are rare and therefore potentially easier to identify from gender data). Regardless, a higher proportion of females:males in the profession of SLT would be consistent with a predominantly female international profession (Boyd and Hewlett, 2001). Culturally, a profession dominated by one gender has implications. Jochmann (2006) noted the limitations of a service where, in one case, SLT stopped due to a Muslim client refusing to take advice from a white, non-Muslim female practitioner.

Regarding nationality and ethnicity, respectively 15 and 10 participants provided this information. Participants from Malaysia reported this information least. In Malaysia, the word "Bumiputera" is used to denote people indigenous to Malaysia. In the 1970s, policies were implemented by government to favour the Bumiputera population (Gomez and Saravanamuttu, 2013). Non-disclosure

here may thus relate to sensitivities relating to ethnicity and nationality. Similarly, the non disclosure from one Kenyan participant may relate to recent ethnic tensions (Fick, 2017). As outlined in 1.2.5, the terminology of "insider" and "outsider" were planned to capture the phenomena of nationals and non-nationals working in a country. However, it may be that this information was too sensitive to be captured by this terminology. It is likely that there is no perfect terminology to represent this phenomenon, and that in different settings it has more complex connotations. Representativeness is more typically associated with quantitative research than qualitative research (Malterud, 2001). This was a predominantly qualitative study using Lincoln and Guba's (1985) alternative criteria. Although this phase had a quantitative component, the overall sampling aim was to sample purposively and not to maximise representativity (Mujere, 2016).

5.5.2 Insider perceptions of outsiders' contributions to services for PWCD

The phase two pilot study survey responses to open questions were analysed to create a thematic network, and descriptive statistics were used to summarise and describe the quantitative data. These were both interpreted and resulted in two main findings that explain insiders' views.

> 1. From OT1: There is an imbalance of power and roles between insiders and outsiders.
> 2. From OT2 and OT3: There is mismatch between insiders' and outsiders' wants and needs.

Both of these findings focus on splits between insiders and outsiders, both in terms of power and roles, and in terms of wants and needs. Each finding is discussed in turn, and a suggestion to reduce these differences is proposed below.

The first finding shows an imbalance of power and roles between insiders and outsiders. In four of the five countries surveyed (all except Trinidad and Tobago), outsiders were probably the first people delivering SLT. However, there are now insider SLTs in these countries and in many instances, the number of

insider SLTs exceeds the number of outsiders. Despite this, even in Malaysia where the SLT training course has been running the longest and has been producing insider SLTs since 1999 (Van Dort, 2005), insider SLTs still appear to have greater respect for outsiders' skills than their own. This could be reflective of the early service development (it may take a long time to fully gain independence from external support), or perhaps outsiders are generally perceived as having superior skills. Literature is limited in describing the preferential treatment of outsider SLTs. However, in the wider literature, Lan (2011:1680) noted that white, English speaking expatriates working in Taiwan were often preferred to locals, with some foreign participants referring to this as 'positive racism.' Often insiders described how they (or other insiders) perceived outsiders to be more respected or more skilful in SLT than themselves. The current data suggests outsiders were often perceived as clinical experts and the insiders as cultural guides or experts in direct roles, when working together. As well as revealing the perception of outsiders being more skilled than themselves, some language appeared to show some insiders to be aware of this perception, but to be cynical of it.

There was a suggestion of an element of choice that outsiders have. In terms of how outsiders work with insiders, insiders felt that this was often based on what outsiders wanted. Insiders gave a range of reasons why outsiders may work in their country, and such choices may well vary from person to person. The language used by insiders further reflected this, with comments such as "outsiders want to share" showing a degree of advantage, privilege and power that insiders perceive outsiders possessing (Tiessen and Heron, 2012). Although not described explicitly by insiders, it may be there is a tenuous balance between what outsiders "want" to give and what insiders "need" or "want" to receive. Just as how people with privilege may not like reminders of their position (Greenaway et al., 2017), it may be that insiders do not always describe this explicitly as it serves to remind them of injustice. This choice is ultimately outsider power, as they control their contribution.

Different outsiders' nationalities may also reveal further power differences. Outsiders mainly came from Minority World countries, rather than other Majority World countries. The finding that outsiders are perceived as having more power

than insiders is at odds with research looking at power amongst immigrants/ expatriates in the US. Martinez et al., 2011, for example, found that people of a minority ethnicity in an organisation were at a disadvantage. However in a Majority World context, insider descriptions may be an implicit recognition of western privilege. Western privilege is the specific privilege that people from the western world (or Minority World countries) may be seen to have (Maher and Lafferty, 2014). There may be similarities between other privileges, such as white privilege and economic privilege (Maher and Lafferty, 2014). Outsiders from Minority World countries have a particular privilege compared to outsiders from Majority World countries, which allow Minority World outsiders to have more power compared to their insider counterparts. Outsiders from Majority World countries may not work in other Majority World countries due to having less power or ability to move than outsiders from Minority World countries. In Majority World countries, services for PWCD were limited, with fewer personnel compared to Minority World countries. This may be because SLTs from Majority World countries either choose to remain in their own country rather than move to another, or, if they do move, work in Minority World countries. It may also be challenging for SLTs from Majority World countries to work as outsiders in Minority World countries. Several English speaking Minority World countries (e.g., the UK, Ireland, USA, Canada, Australia and New Zealand) are part of a Mutual Recognition of Credentials Agreement. Whilst SLTs from countries outside of this Mutual Agreement may be still able to gain professional SLT membership in other countries, it may be more challenging for them to work abroad. It may be that outsiders benefit from their privilege and power to the extent that their ability to work in another Majority World country is not questioned or challenged. This may in turn mean that outsiders from the Minority World assume working in the Majority World means licence to work in whatever way they choose.

The literature on highly skilled migration mainly focuses on "brain drain," the movement from low to high income countries (Pang et al., 2002; Mullan, 2005). However, looking at highly skilled migration from the Minority to Majority world, Van Dalen and Henkens (2007) note that outsiders from Minority World countries are characterised as being young, well educated, with a high income, and possibly with friends or family abroad. As insiders reported on the

demographic factors of outsiders, these results are their perceptions. Although the research cannot fully comment on all of Van Dalen and Henkens' (2007) outsider demographical findings, insiders felt that outsiders were typically young. Furthermore, the majority of insiders reported that outsiders typically came from Minority World countries. Here, outsiders have had the joint advantage of possessing a degree and entering a profession in a country which boasts an active and established professional body.

Here, first world privilege would not only extend to the ability of SLTs from such countries to move and work freely, but may also mean such SLTs appear more respected or prestigious to non-member countries, especially where SLT services are new. This may create a dichotomy between the different types of outsiders. Although the majority of respondents felt outsider nationality had no effect on working relationships, those that did noted differences in how outsiders from different nationalities worked together.

Whereas outsiders from geographically closer, more culturally similar countries, were more valued for their shared culture and equal relationships, it may be that outsiders from Minority World countries are solely valued for their skills and experience. Amongst Minority World countries, some outsiders may have comparatively more cultural differences. A number of respondents perceived outsiders from European countries and Australia to be more culturally sensitive than outsiders from the US, which may be explained by a lack of cultural competence or cultural intelligence, perhaps due to limited exposure to other cultures (Crowne, 2008). McCarthy (2018) noted that the number of US citizens holding passports has been as low as 15%, which may have affected their exposure to other cultures. This finding may be challenging when the majority (80% of insiders) noted working with US outsiders.

Despite a perceived privilege, outsiders faced potential hardships in contributing to services for PWCD in Majority World countries. Some insiders felt outsiders made sacrifices by working to support their services: both financially (e.g., in loss of earnings, or paying to volunteer), and in terms of career (Handy and Mook, 2011). This suggests that, whilst being in the relatively privileged position of being able to contribute to services for PWCD in a Majority World country,

such involvement comes at expense to outsiders. It may be that where insiders perceive outsiders to be lacking commitment (e.g., because of ending a commitment early or not completing planned subsequent follow up support), the outsiders are facing such financial challenges and instead lack the means rather than the will to commit.

The second finding from the phase two showed a mismatch between insiders and outsiders in what each wanted for themselves or services, and their needs. Insiders noted inherent challenges associated with outsider working, however stated that some outsiders resulted in fewer challenges than others. As such, there was a preference for certain "types" of outsiders. Insiders often noted that outsiders did not meet their desires.

Length of contract was a key factor in insiders' preferences. There was variation across country participants over the preferred time length for outsiders' contributions. The Malaysian preference for shorter-term involvement may relate to the country's relatively more established SLT course, with insiders and outsiders requiring less time to adapt due to experience and established infrastructure. The Trinidad and Tobago participant preferred short-term (3 months or less) contributions. Though the reasons for these preferences were not expanded on, Shin et al. (2007) described the need for US professionals to adjust their behaviour to fit the local values of visited cultures, and it may be that some cultures are more similar and therefore require less adaption. Geographically or culturally similar countries may find initial collaboration to be a smoother process and it may be that some of the countries become used to a particular outsider culture. For example, although the Trinidad and Tobago participant did not detail whether they were educated in-country, they are likely to have trained abroad and thus may have already required the cross-cultural knowledge to facilitate collaborations.

In terms of the roles insiders want outsiders to undertake, training roles (of parents or carers of PWCD; local health professionals and teachers) and supporting PWCD with direct intervention were considered to be of the most value. These were generally the most commonly reported outsider roles. Interestingly, the main differences indicated that outsider roles of providing

resources for PWCD, and raising awareness of CDs were noted by a greater proportion of respondents than felt them to be of significant value. This may either suggest that these roles are generally considered less important; that insiders felt outsiders were not best placed to work in these roles; or that there is an over-saturation of this type of support.

Another key factor that influenced insiders' preferences were outsiders' qualities. This included outsiders' personalities and specific experience or skillsets. Participants from Malaysia, Sri Lanka and Trinidad and Tobago wanted CPD. This may be reflective of having comparatively higher numbers of SLTs compared to Kenya and Jamaica. Only the Jamaican participant detailed the specific clinical skills that were wanted from outsiders. The Kenyan participants were more likely to describe specific personality traits about the outsiders they most wanted, where open-mindedness, flexibility and reliability were most wanted. Two also did describe the experience level wanted. Some of the Malaysians also indicated desired personality traits which were similar. This may have been the result of higher participant numbers for these countries, which gave a greater variety of opinions. Alternatively, it could be that both in Kenya and Malaysia that specific clinical work or approaches were less needed (perhaps, because of the longer SLT history in Malaysia), or just that the fundamentals of relationships were more important to collaborate rather than the specific skills being used. Huang et al. (2005) found that traits such as extroversion, agreeableness and openness were well suited to expatriate's successful settling in Taiwanese workplaces, however, specific personality traits may be more appropriate in specific cultural contexts.

Phase two insiders felt that outsiders lacked awareness of what services for PWCD already existed in their country. This lack of awareness could result in the replication and inefficiency of services. Approaches for services for PWCD should not only be responsive to a Majority World country's needs (McAllister et al., 2013), but insiders should be responsible for the planning and development of services in their country. Such insider-led service development would help prevent the replication of services and training curriculum from Minority World to Majority World country, which has been an important consideration for

developing new services for PWCD in some countries (Robinson et al., 2003; Wickenden et al., 2003).

Hickey et al. (2012) noted the benefit of pre-departure training. Outsider preparation could increase an outsider's awareness of services already in country to avoid the pitfalls mentioned above. As the majority of respondents reported that collaboration was generally initiated by organisations rather than individuals, organisation-run training could be one way that this lack of outsider awareness could be reduced or resolved. Motivations may be a factor that influences outsiders' preparations before working in a host country. Outsiders' inadequate preparation or lack of realistic awareness of services for PWCD may in turn influence how they choose to contribute. Hickey et al. (2012) noted that motivations are important to address, as outsider-focused motivations may result in inappropriate or unsustainable services. However, the motivations of outsider organisations or institutions are equally important to be aware of and address. Although only one respondent described explicitly negative outsider motivations, high numbers of respondents perceived that outsiders were motivated by wanting a personal or career experience for themselves.

As the need for sustainability was rated highly by all except one participant (Malaysia) this is clearly a desirable way that insiders want services, and outsiders involved in them, to develop. However respondents described how they perceived outsiders to leave or projects to end either early, or before they felt their contribution to be sustainable. The need for sustainability in services for PWCD is supported by the literature (Barrett and Marshall, 2013; Hickey et al., 2012). Generally, longer-term work is most suitable for service development work. However whatever time-length outsiders are able to commit to, they need to ensure projects are completed or passed over to insiders in order to maintain sustainability. Outsiders should aim to avoid the "rushing off" from a project that insiders often described. As there were differences between preferred contribution time lengths, outsiders should consult with insiders to discuss the preferred support.

As outsider SLTs may require time, training and support to be able to suggest culturally appropriate support (Hickey et al., 2012), it may be that Trinidad and

Tobago has less cultural differences between insiders and the outsiders that work there (from the US, Canada and the UK). This may mean there is some shared culture and therefore requires less time to adjust culturally.

Other cultural differences, such as language is another way outsider SLTs may find challenges in how they can support services for PWCD. Despite all countries having an English speaking population, Table 5.18 shows that the total proportions vary significantly. In Kenya and Sri Lanka, for example, English speaking outsiders may find it particularly challenging to provide direct intervention. Despite this, all Kenyan participants felt direct intervention was of significant value. Conversely, the Jamaican participant felt direct intervention was only of some value. Language, however is not the only type of cultural difference (Moran et al., 2014). Both Caribbean participants agreed that there were still cultural differences (such as attitudes to time-keeping, the way the health systems work, and concepts of play) when working with outsiders.

Table 5.18 English speakers from five countries (adapted from Crystal (2012)

	Population (2001)	Number of English speakers for first and second languages		Total population of English speakers	Total percentage of population
Kenya	30,766,00	-	2,700,000	2,700,000	8.8
Sri Lanka	19,400,000	10,000	1,900,000	1,910,000	9.8
Jamaica	2,665,000	2,600,000	50,000	2,650,000	99.4
Trinidad and Tobago	1,170,000	1,145,000	800	1,145,800	97.9
Malaysia	22,230,000	380,000	7,000,000	7,380,000	33.2

The two findings from this phase of research concern differences between insiders and outsiders in terms of roles and power, and wants and needs. Similar to how shared responsibility and planning is important in health research partnerships (Emanuel et al., 2004), discussion between insiders and outsiders may help to make preferences and expectations explicit, and reduce challenges. This could occur both before, during and after collaboration.

5.5.3 Limitations

Some of the limitations of the pilot study relate to the general limitations of survey research — especially the potential for low response rates, missing data (Bryman, 2012). Phase two was planned as a pilot study covering five of the ten countries eligible for inclusion using the country selection matrix to produce a manageable amount of data. However, response rates were low (in one case, to the extent that there were no responses from Bangladesh). Low response rates can raise concerns of representativeness (Bryman, 2012). However, the calculated response rates from direct contact of 15.5% for all countries is considered acceptable in the context of marketing research (Hikmet and Chen, 2003). Sheehan (2001) describes how the response rate for email surveys has declined since their first use in academic research. Although the survey could have been administered by post, it was thought that this would have likely yielded poorer results due to a number of the countries having an inconsistent postal system.

When population and response numbers are low, it is difficult to generalise the responses received. This makes it particularly challenging in the case of both Jamaica and Trinidad and Tobago as there was only one respondent in each country. Although both Jamaica and Trinidad and Tobago are estimated to have the smallest population of SLTs, it is unwise to generalise the views of individuals to the wider country populations, even with small population numbers. Therefore, interpretation of findings from these countries should be considered with this in mind.

Similarly, the aim of exploring the research objective in relation to HDI rank was challenging due to the lack of responses from Bangladesh. After consulting the devised matrix, Malaysia, a high HDI country, was included. This selection was made based on time pressures described in 5.3.1. This meant that only one "Low" ranking HDI country was included (Kenya). Countries with a lower HDI may have been less likely to reply due to general country context difficulties (such as poor communications infrastructure) coupled with fewer SLTs. The literature has shown that response rates are lower amongst people with low-incomes (Korinek et al., 2006).

Whilst services for PWCD include SLTs, there are other services that may offer specific support for PWCD. Other services for PWD were also contacted, such as audiology services, ENT services, specialist schools and nurseries, charities and NGOs. These appeared to have yielded no or low results, as there was only one respondent who was not in the profession of SLT or in training to join it. This may suggest that other professions either have less contact with PWCD or outsiders, or that these services also have low personnel numbers, similar to SLT. This may be indicative of limited services for PWCD generally in these countries. Furthermore, although the study included participants who were SLT students, only SLT students completed the survey for Sri Lanka. Students will have less experience of working with outsiders, and it may be that any work with outsiders is a part of their training. This is likely to have implications for transferability.

Finally, although measures were taken to reduce the language differences between participants and the researcher, through both the selection of countries and the piloting of the survey, interpretation of some responses on the survey was challenging. Although English is an official language in these countries, it may not have been a first language for some respondents or respondents may have spoken a different dialect of English. On one occasion, a participant wrote that they did not understand a question and so did not answer it. Some language used by participants was ambiguous and hard to interpret, for example when asked what type of help was least wanted, a participant responded "the acts." This meant that some text segments were not analysed for the TNA.

5.6   Summary

This chapter has described the methods used for the phase two pilot study, the results and discussion. The main findings produced from descriptive data analysis and TNA were: There is an imbalance of power and roles between insiders and outsiders, and there is a mismatch between insiders' wants and needs, and those of outsiders. The next chapter will discuss the results of both phase one and phase two together, as a synthesis.

6   Discussion

6.1   Introduction

This chapter draws together the findings of both phases of the study, discussing the degree to which these relate to previous literature and how the various models of development may be applied to the findings. Section 6.2 begins with a brief overview of the findings. It provides a synthesis of the two phases by grouping findings by topic similarity to arrive at key statements. Key statements take the form of summaries, implications and recommendations. Section 6.3 explores the key statements in relation to the development theories outlined in chapter 2. Section 6.4 concludes and summarises the chapter.

6.2   Findings from phase one and phase two

The overarching aim of the study was: to investigate the processes and perceptions of collaboration between insiders and outsiders in developing services for PWCD in Majority World countries, with a particular emphasis on the contribution and roles of 'outsiders.' This was achieved through five research objectives. Objectives were divided across the two phases of research. Four objectives related to phase one, and one related to the phase two pilot study. There were 18 findings: 16 from phase one and two from phase two (described in detail in chapters 4 and 5). Table 6.1 summarises the findings by research objective and phase of research.

This study used an exploratory sequential design. This meant that the two phases of research were collected independently of each other, with the first phase informing the second phase. As data sets from each phase were analysed separately, the two sets of findings are now drawn together for discussion (Ivankova et al., 2006).

This somewhat unconventional structural approach for a thesis discussion was deemed the most useful approach to synthesise all data sets from the two phases. Although there is limited explicit procedural outline of how to integrate

Research phase	Research objective	Findings
Phase one	1.1) To explore and describe the process and history of the development of services for PWCD in Uganda.	1. Although there are improved and increased services for PWCD in Uganda, PWCD still face challenges in their everyday lives. 2. SLT roles for insiders have developed over time and have similarities and differences to outsiders. 3. Services for PWCD have been developed in multiple ways by insiders and outsiders. 4. Services provided by insiders have developed over time, with greater planning and coordination in recent years with the aim of sustainability. 5. Services provided by outsiders have developed, however there are a number of challenges that prevent or threaten development.
	1.2) To describe and explain insiders' perceptions and experiences of the contributions of outsiders and outsider support, to the development of services for PWCD in Uganda.	6. Insiders viewed outsiders' contributions as being largely related to the specific roles of outsiders, however variables such as their age, skills and experience were also important. 7. Insiders viewed outsiders as having a higher status than insiders, regardless of their skills or experience levels. 8. Insiders viewed outsiders' contributions as not always culturally appropriate, however insiders are selective about what they pick and choose from outsiders' offerings. 9. Insiders view outsider support as unstable and transient.
	1.3) To describe and explain outsiders' perceptions and experiences of their contribution to the development of services for PWCD in Uganda.	10. Outsiders were conscious of working under the legacy of colonialism in Uganda. 11. Outsiders viewed relationships with insiders and outsiders to have different focuses. 12. Outsiders felt that the development approach used was directly related to the quality and sustainability of their contribution. 13. Outsiders viewed the ability to make a practical difference as important.
	1.4) To analyse and interpret insider/outsider collaboration and working practices.	14. Insider participation is fundamental to effective collaboration. 15. Cultural differences exist between insiders and outsiders but can be reduced. 16. Flexibility with needs and agendas promotes mutual supportive working.
Phase two	2.1) To interpret and explain perceptions of outsider contributions in five Majority World countries.	17. There is an imbalance of power and roles between insiders and outsiders. 18. There is mismatch between insiders' and outsiders' wants and needs.

separate phases of research in mixed method studies, this study used a 'weaving approach' as outlined by Fetters et al. (2013:2142). The combination of elements from both of these approaches allowed for the comparison of different findings from different data sets. For this synthesis, all 18 findings were brought together and grouped by subject into topics, allowing findings to be discussed for similarities and differences (Sandelowski et al. 2006). This in turn enabled overall key statements to be produced for each topic.

A review of the findings revealed five topic areas. These were: **Power** (findings 7, 10, 16 and 17); **Culture** (findings 8 and 15); **Roles** (findings 2, 6, 11 and 17); **Exchange** (findings 13, 14 and 18); and **Development approaches** (findings 1, 3, 4, 5, 9, 12 and 16). It is important to note that findings relating to multiple topics were grouped by the most pertinent issue to form each topic group. Resultantly, some key topics were related. For example: roles may have influenced or been influenced by power, and power may in turn have influenced how exchange occurred. Grouped findings are discussed in turn by their topic areas in reference to the other findings and literature. For each of the five topic areas, at least one key statement was generated. Key statements formed summaries, implications and recommendations of the findings.

6.2.1 Power

Four findings related to power in some way. The findings came from both phases of research. The findings were:

- 7: Insiders viewed outsiders as having a higher status than insiders, regardless of their skills or experience levels.
- 10: Outsiders were conscious of working under the legacy of colonialism in Uganda.
- 16: Flexibility with needs and agendas promotes mutual supportive working.
- 17: There is an imbalance of power and roles between insiders and outsiders.

These findings revealed a perceived power discrepancy between insiders and outsiders. Finding 16, however, went further: showing that a more equal and mutually beneficial way of working could be effected when outsiders relinquished some of their assumed or given power.

Outsiders were felt to have more power than insiders, and typically benefited from higher status by virtue of their "outsiderness." This may suggest that nationality influenced power more than other markers of status (such as experience or professional skills) as, even when outsiders were considered less experienced by insiders, they received greater respect.

Ugandan insiders perceived outsiders as having a higher status than insiders. The majority of insiders from the five countries in phase two felt that insiders and outsiders were treated differently by other insiders, such as PWCD and professionals. Outsiders from phase one felt that they were treated differently — typically preferentially — compared to insiders, and were uncomfortable about this. Both insiders and outsiders often suggested that this difference was rooted in British colonialism. Although some insiders from both phases mentioned colonialism, they generally talked about the current power dynamic with outsiders. This may suggest differences between insiders and outsiders — in that insiders were more concerned with the practical challenges or reality of current outsider power, while outsiders found the power dynamics problematic. This suggests that, for both groups, the legacy of colonialism raised similar-but-different challenges in how it was perceived to shape current outsider involvement. This difference may have related to specific feelings and situations regarding imperial- and colonised-countries' roles. Whilst colonialism negatively impacted all countries researched, each country has a different colonial history. Coovadia et al. (2009) noted that countries' specific historical features could affect modern day health outcomes. Newton et al. (2017:23) argued that ignorance of a country's colonial history — 'Historical Negation' — shifted the perceived causes of challenges from a societal to an individual-level.

Section 2.2 outlined four main models of colonialism. It may be that countries with features of settlement colonies (such as Kenya) experienced greater inequality and power divides than former direct colonies. Additionally, some countries, such as Malaysia and Sri Lanka, experienced relatively more precolonial development (Lange et al., 2006). Regardless of type, all models of colonialism resulted in significant inequality. Findings relating to power from the two insider data sets show a consistency in how insiders feel their outsider counterparts are still afforded a higher status.

Bobowik et al. (2018) showed that although negative portrayals of colonialism were prevalent within former coloniser countries, older attitudes of colonial benevolence still existed. Anxiety or uncomfortableness were often experienced by outsiders, which is similar to findings of Bobowik et al. (2018) who summarised that guilt and shame were commonly felt by people of former

colonising countries. Outsiders were typically uncomfortable about having a higher perceived status and advantage in Uganda: describing a reluctance to work in ways reminiscent of colonialism while simultaneously feeling unsure about how else to approach their roles.

One key way this anxiety manifested for outsiders was the dilemma of wanting insider SLTs to be responsible for their own training and profession while simultaneously feeling insiders were not ready for this responsibility. (In phase one, this feeling may have been exacerbated by the premature withdrawal of NGO support.) This dilemma may, in fact, have represented a legitimate concern shared by insiders who consistently discussed the need to ensure a sustainable transfer of power and responsibility. Insiders and outsiders noted that support contracts from NGOs or other Minority World organisations often ended prematurely or without consideration of insiders' readiness and abilities to continue.

Whereas outsiders largely understood colonialism in negative terms, Licata et al., (2018) suggested that, for people living in an environment clearly shaped by colonialism, the term held more complex connotations. These connotations potentially included viewing elements of colonialism in a positive, paternalistic way (Bobowik et al., 2018). This was revealed in two distinct ways though the language of insider groups. Firstly, insiders tended to perceive outsiders as having *brought* or *given* SLT to their countries almost as a gift. Secondly, insiders tended to perceive outsiders as senior. Insiders from phase one viewed the insider/outsider relationship through the metaphor of a mother-child relationship (insiders as children, outsiders as mothers) while insiders from phase two indicated that they regarded outsiders as more professionally advanced or superior. Whilst this perception may, in some contexts, have reflected outsiders' recent involvements in the initial development of SLT services (outsiders' volunteering may have been seen as caring, and those working as educators or trainers seen as experts), such views were also prevalent amongst insiders in countries with an older and more established SLT profession. It would be interesting to know if this feeling of inferiority was felt by the first SLTs trained in Minority World countries, or if this was linked explicitly to a postcolonial relationship. How long outsider SLTs will be regarded as superior

— or whether insiders will eventually regard themselves as "mothers," or equals — remains to be seen.

Despite insiders' perception of a power imbalance in the status accorded to outsiders, the observed outsiders in training positions did attempt to rebalance the power dynamic. This was done through flexibility with the training agenda and insiders' needs, by including insiders in the setting of learning priorities, and by altering or adapting the learning schedule to fit these needs and priorities. This way of working may be especially important in a training position, where trainers automatically have a higher assumed amount of power (Brookfield, 2017). The need for outsiders to work in an equitable manner which takes on multiple perspectives was also highlighted by Mizzi (2017), who explored how an outsider faculty could best work whilst teaching overseas. Despite this adaptivity being observed by the researcher in the current study, insiders across all countries noted that some outsiders worked in ways that were not equal with insiders. This will be discussed in more detail in 6.2.2.

Even with such adaptive approaches, the fundamental question of when — if ever — outsiders will be treated as professionals with equal knowledge and experience to outsiders, remains unanswered. Specifically: when will insiders cease to be seen as cultural informants and instead be seen as clinicians/peers (something that relates strongly to section 6.2.2: Roles). As the SLT profession develops globally, and more insider-led clinical research is produced (as in Malaysia and Sri Lanka), insiders may become more respected at an international level. Although, to date, models of intervention and practice developed in Majority World countries are rarely reported to inform Minority World practice (Nixon et al., 2015).

One unexpected aspect of the findings was the perceived difference in how outsiders' nationality affected perceived power. Both insiders and outsiders had mixed opinions as to whether outsiders' nationality affected working relationships. However, where participants did perceive differences in the effects of nationality, they noted that some US outsiders behaved in a culturally imperialistic way. There are several possible explanations for this finding. Firstly, there may have been broad cultural differences between outsider groups

(explained in more detail in 6.2.4), including specific behaviour amongst US citizens that is perceived by insiders as cultural imperialism. Perhaps — as citizens of a former British colony which gained relatively few colonial possessions late in the imperial era — US citizens outsiders are less aware of their country's role in colonialism, and therefore less sensitive to the perceived power they have. Secondly, as this research focused on former British colonies, there may be differences (based on historic links and associations) in how insiders perceive British outsiders and non-British outsiders. This effect is unlikely to account for the negative perception of US outsiders however, as similar opinions were not voiced when discussing Australian, Canadian, Dutch, or Indian outsiders. Finally, as the researcher herself was a British outsider, insiders may have felt less able (through social etiquette) to express negative views about British outsiders and thus may have directed their criticisms elsewhere.

All outsiders interviewed in phase one were British, which may have influenced their discomfort with their association to colonialism and informed their specific ways of working (as observed). As outsiders were not included in phase two, it is not clear whether British outsiders in other settings experience the same discomfort based on a differing colonial history, or if non-British outsiders feel the same way.

Key statement:
1. <u>Power between insiders and outsiders is unbalanced. However, with awareness, outsiders can address this and provide more positive sustainable services for PWCD.</u>

The topic of "power" closely influences the topics of 'roles' and 'exchange' discussed in the next two sections.

6.2.2 Roles
Four findings from three different research objectives concerned roles. These came from both phases of research. All four findings focused on the differences in roles between insiders and outsiders. The findings from the insider-focused data explicitly showed differences in roles. However, findings from the outsider

data showed that outsiders considered these differences in roles to be linked to differences in relationships. This may suggest that the perceived differences in roles from insiders' perspectives directly related to power, whereas for outsiders the differences were perceived as an indirect consequence of their power.

The four findings were:

- 2: SLT roles for insiders have developed over time with similarities and differences to outsider roles.
- 6: Insiders viewed outsiders' contributions as being largely related to the specific roles of outsiders, however variables such as their age, skills and experience were also important.
- 11. Outsiders viewed relationships with insiders and outsiders to have different focuses.
- 17: There is an imbalance of power and roles between insiders and outsiders.

The first and last findings show how — in spite of a shared profession — insiders felt there were differences between roles.

Insiders from both research phases often commented on how most outsiders were typically professionally senior to themselves. This was often related to outsiders coming from countries where SLT was more established and working in senior roles such as lecturers, trainers, or clinical leads. Some outsider roles were considered more useful as contributions and therefore preferred by insiders: such roles typically involved the passing on of knowledge, such as lecturing or training. However, outsiders did not always work in these preferred roles. Both phases of research showed that both groups saw insiders as providing cultural guidance to outsiders, and outsiders as providing clinical expertise to insiders. Furthermore, Lough et al. (2018) found that international health volunteers typically had a lack of understanding of their roles, which resulted in local staff perceiving international health volunteers to be unwilling to support existing public health systems. As this study showed, insider and outsider roles often developed or evolved informally. This suggests a need to have improved clarity of both insiders' and outsiders' roles.

The way in which insiders and outsiders interacted may have caused different roles to develop. Role development may have been further influenced by the different relationships outsiders had with insiders and outsiders. Outsiders regarded their relationships with other outsiders as being based in friendship, serving to provide personal support. Whilst some outsiders also regarded their relationships with insiders as friendships, outsiders more typically viewed these as working relationships existing to provide strategic support for the development of services for PWCD. It may be that relationships between insiders and outsiders required more time to develop based on differences in culture and language, in which case outsiders working for a limited time may have found it more challenging to form relationships with insiders. This may have served to further differences between insiders and outsiders, and influence the strategic "use" of insiders as cultural informants. Despite this study's findings of differing relationships, Ahmed et al. (2015) suggested that relationships formed between insiders and outsiders as part of a medical partnership in Sudan may help to create future collaborations.

Whilst such an arrangement of roles may have made sense during initial collaborations, this was concerning and problematic when insiders were equivalently qualified, or more qualified, than their outsider counterparts. Some outsiders with relatively limited experience (e.g., students or newly qualified practitioners) may have been expected to have greater competence than they in fact did, leading to the potential for inappropriate roles being assigned to them. This needs to be considered, especially as Hickey et al. (2012) found that such outsiders may be taking resources from insiders, reducing insiders' ability to work and continuing to devalue insiders' roles.

Key statements:
2. Insiders preferred outsiders to work in roles involving knowledge sharing.

3. Insiders are used as cultural informants, outsiders are used as experts.

6.2.3 Exchange

Four findings related to the idea of "exchange." These findings considered what insiders and outsiders were each perceived as "giving" and "receiving," and

explored the idea of reciprocation. The findings came from both phases of research, using data from all but the first research objective. These were:

- 8: Insiders viewed outsiders' contribution as not always culturally appropriate, however insiders are selective about what they pick and choose from outsiders' offerings.
- 13: Outsiders viewed the ability to make a practical difference as important.
- 14: Insider participation is fundamental to effective collaboration.
- 18: There is mismatch between insiders' and outsiders' wants and needs.

The topic of "exchange" concerned how the contributions of outsiders and insiders intersected and impacted each other and services. This topic was not found in any of the findings from the first research objective, perhaps because the document analysis revealed low numbers of insider-produced or collaboratively-produced documents. The writing of documents may have been one area in which exchange or collaboration was uncommon. Only four of the analysed documents were written collaboratively. It may have been that insiders and outsiders each produced documents according to their roles or context (e.g., insiders solely writing national policy documents based on knowing the context in Uganda; outsiders solely writing journal articles based on their professional experience) and — as the profession was relatively new in Uganda — full exchange of ideas through documents had not yet "crossed over."

The outsiders from phase one expressed a need to be able to make a practical difference. This suggested a need to have something to offer insiders, and a need for this offering to be wanted. This was contrasted with descriptions of other outsiders whom they perceived either not to be making a practical difference, or to be making only a small difference. This was caused by outsiders having limited or inappropriate skill sets. These outsiders were typically perceived quite negatively and seen to be taking up more resources than they had been offering. This reflected recommendations from Hickey et al. (2012), who warned about outsider voluntourists using more resources than they contributed. It suggests a need to make the "give and take" relationship between insiders and outsiders an equal exchange in which insiders' preferences regarding outsiders' necessary qualities and ways of working could be prioritised. Through this, the longer-term, more-experienced outsiders

desired in all researched countries (except Trinidad and Tobago) could be prioritised over short-term, less-experienced outsiders. This may be particularly important as Vodopivec and Jaffe (2011) showed how some sending organisations advertised for volunteers with no qualifications, a practice which may serve to offer nothing to local SLTs and PWCD while simultaneously undermining how some PWCD or carers and parents of PWCD view insider SLTs (see 6.2.1). It may prove challenging for insider SLTs to set their own terms (or even equal terms of exchange) both because of the power dynamic and because some sending organisations receive payment from outsiders.

As the insiders from phase one viewed outsiders' contributions as not always being culturally appropriate, they adopted a strategy of selecting what they felt was useful from outsiders' "offerings." Elements of this finding relating to "exchange" will be discussed here, and elements relating to "culture" will be discussed in 6.2.4. Outsiders were often unaware that, when their contributions were seen as inappropriate, insiders would often silently adapt suggestions to make them more appropriate. As insiders did not discuss these cultural changes with outsiders, relationships did not appear reciprocal as outsiders appeared to be "givers" of advice and Ugandans "receivers."

Reciprocity did exist in other ways. Generally, in both phases of research, outsiders were felt to "give" SLT, but also "take" the opportunity or experience of working in a Majority World country. This reflects findings from Shields et al. (2016:323) who described the exchange between visiting occupational therapists and physiotherapists and local community members as 'giving and taking of learning.' It may be that insiders and outsiders have different motivations or expectations of collaboration which affect reciprocity. Elnawawy et al. (2014) found that local health workers wanted skills, knowledge, support and coaching, whilst international medical volunteers wanted travel, experience of working in a new setting and to have a positive impact.

An imbalance between the wants and needs of insiders and outsiders was found across both research phases. Though insiders' preferences for outsider- and support-type varied between countries, there was an overall discrepancy between these preferences and what outsiders were actually perceived to

deliver. Balandin et al. (2007) described clear communication between partners as a crucial tool in equal exchanges, but clear communication was not reported in any of the phase two countries. As for phase one, Ugandan insiders' did not actively request what they wanted from outsiders, although some insiders reported giving feedback when specially asked by outsiders. This may have been cultural (discussed later, similar to "skill-picking"), or perhaps related to the power imbalance previously discussed. Alternatively, it may have related to the fact that Uganda is the recipient of a large amount of aid and has many services and programmes planned by overseas charities.

The issue of who initiates requests for service development was raised by Marshall (2003), who suggested that outsiders should critically assess whether a request for involvement is appropriate. Whilst it may be important for both insiders and outsiders to reflect on the planned development, it may also be challenging for stakeholders in Majority World countries to request services. Stakeholders may be unaware of different types of services, and may either take whatever is suggested or aim to replicate other countries' services or ways of practice.

Observation of both insiders and outsiders in phase one showed how participation was fundamental to effective exchange. Participation was often not possible due to insider absences during training, or not fully engaging in training sessions. Though non-participation may have been explicable culturally or situationally (Hausken and Ncube, 2016) it was a major barrier to exchange.

Key statement:
4. Insiders should set the terms of what they want, outsiders should ask what they can give.

6.2.4 Culture
Two findings from phase one concerned culture explicitly. They were:
- 8: Insiders viewed outsiders' contribution to be not always culturally appropriate. However insiders are selective about what they pick and choose from outsiders' offerings.

- 15: Cultural differences exist between insiders and outsiders but can be reduced.

Whilst culture was described as important in the second phase of research, this was typically in relation to other topics, and so linked into other findings.

Insiders from all countries noted the cultural differences between outsiders and themselves. Insiders from phase one described taking the essence of the ideas that outsiders were bringing, and reworking them to fit their context without informing outsiders of the cultural differences necessitating such adaptation. This was described as "skill-picking." Despite phase two insiders noting that outsiders were often culturally inappropriate, skill-picking was only noted in Uganda, and may have related specifically to the types of data collection used to gain information, or reflected a unique element of Ugandan culture. Although diverse, Ugandan culture has been broadly described as conformist and non-confrontational (including, for example, a polite avoidance of direct requests (Meierkord, 2016)). Building from the ideas of power (mentioned in 6.2.2), these cultural features may have been exacerbated when dealing with outsiders who were perceived to possess a higher status.

During observation of the training sessions in phase one, it became apparent that cultural differences between insiders and outsiders could be actively reduced during collaboration. For this to happen, outsiders needed firstly to have an awareness and sensitivity of the cultural differences, and secondly to be culturally competent in using this knowledge appropriately (Brach and Fraserirector, 2000). Cultural competence is a process that requires awareness, knowledge, skill, encounters and desire (Campinha-Bacote, 2002). Whilst one cannot become fully culturally competent — as there is no end point to this objective — cultural humility is an important element of competence as it is the willingness to understand another culture (Tervalon and Murray-Garcia, 1998). Barrett (2016) reflected on her own experience of working as an SLT in East Africa and described a need for individuals in the profession to champion cultural humility, however, this study found that insiders across all countries noted that some outsiders were not culturally competent, and also lacked the foundations of being competent (such as awareness and sensitivity). Here,

cultural humility should also be a key value of training institutions and outsider sending organisations (Barrett, 2016).

Participants (both insiders and outsiders) from both phase one and phase two were aware of cultural differences and believed effective collaboration could serve to reduce challenges. Insiders further stated that outsiders *needed* insiders to collaborate with in order to reduce cultural differences and increase the cultural appropriateness of their work with PWCD. This meant that insiders were often required to be cultural guides, rather than professional peers — an effect seen across all countries, regardless of the age of the insider SLT profession in the country. Interestingly, insiders felt that some outsiders did not seek to collaborate, resulting in less culturally appropriate services. Whilst a small number of researchers have discussed the effects of culturally inappropriate outsider intervention (Hickey et al., 2012; Wickenden et al., 2003; Robinson et al., 2003) this consideration does not appear to have influenced all outsiders' contributions.

The literature on cultural diversity within SLT focuses on meeting the needs of indigenous or minority communities in Minority World countries (Downing and Kowal, 2011) or majority communities in Majority World countries (Pillay and Kathard 2015). A lack of diversity in the UK SLT profession (Marshall, 2000) may affect outsiders' cross-cultural awareness and adaptability as, even domestically, British SLTs struggle to meet the needs of culturally diverse populations. In the former British settler colonies of Australia, Canada and South Africa, SLTs face challenges in adequately serving indigenous and linguistically-diverse communities (Ball and Bernhardt, 2008; Pascoe and Norman, 2011; Pearce and Williams, 2013; Inglebret et al., 2008). Furthermore, Hammer et al. (2004) found, in a study of SLTs in the US, that many SLTs felt anxious or unprepared to work with clients from other cultures in the US. Despite curriculum changes designed to increase US educated SLTs' cultural competence, over a decade later, Kimble (2013) found that US SLTs felt uncomfortable or ill-equipped to provide services to clients who spoke English as an additional language. Although outsiders in phase one stressed the importance of cultural adaption, insiders still reported having to modify outsiders' recommendations to fit the Ugandan context. Perhaps even

conscientious outsiders are unable to close the gap of cultural differences completely.

Increasing the diversity of the profession and increasing the cultural competence of SLTs may result in more culturally appropriate practice. Carr et al. (2001) revealed that Tanzanians order of preference when working with other professionals was (1) other Tanzanians, (2) outsiders from Minority World countries, and finally (3) outsiders from other East African countries last. This contrasts with findings from this study, as insiders from both phases of research described outsiders from close or neighbouring countries as better suited for collaboration due to shared culture and context. This may suggest that there are differing preferences concerning the preferred nationality of outsiders, perhaps because of the way culture affects the work of an SLT. Although culturally-similar outsiders were considered the most appropriate collaborators by the participants in this study, the vast majority of outsiders came from geographically far, and more culturally dissimilar contexts. While partnerships between Majority World countries were considered particularly valuable — these do not make up the majority of collaborations.

Both phases of research showed that the outsiders perceived as most successful were those that showed flexibility when encountering cultural differences. Inflexibility was seen as ethnocentric, detrimental and ineffective. Ethnocentrism — the assumption that a person's own culture is more important than another — has been shown to negatively affect culturally competent practice (Pickering, 2003). Shaffer et al. (2006) described how cultural flexibility and ethnocentrism, positively and negatively affected levels of expatriate effectiveness of overseas assignments. Ethnocentrism was reported across both phases of this study, indicating a substantial challenge across collaborative services for PWCD. Relating this to power imbalances, insiders may have felt less able to discuss this with outsiders. Cultural awareness training may serve to reduce and manage ethnocentricity amongst outsiders, and Shaffer et al. (2006) found that outsiders' ability to adjust their way of working in an unfamiliar environment affected their contribution to services. This suggests that training for outsiders also needs to focus on recognising and avoiding ethnocentric practice and increasing flexibility. Furthermore, whilst models of cultural

competence such as the Purnell model (Purnell, 2002) and The Process of Cultural Competence (Campinha-Bacote, 2002) have suggested that awareness is a foundation on which competency is based, it has been noted that an increase in knowledge about different cultures does not necessarily result in improved competence (Betancourt et al., 2003).

Key statement:

<u>5. Cultural differences exist, however the best outsiders are culturally competent and flexible. Insiders may not actively inform outsiders of the most appropriate ways of working, but are more likely to share this information, if asked.</u>

6.2.5 Development approaches

Six findings related to the topic of development approaches. All came from phase one. These findings were:

- 1: Although there are improved and increased services for PWCD in Uganda, PWCD still face challenges in their everyday lives.
- 3: Services for PWCD have been developed in multiple ways by insiders and outsiders.
- 4: Services have developed over time, with greater planning and coordination in recent years with the aim of sustainability.
- 5: Services have developed, however there are a number of challenges that prevent or threaten development.
- 9: Insiders view outsider support as unstable and transient.
- 12: Outsiders felt that the development approach used was directly related to the quality and sustainability of their contribution.

Services for PWCD in Uganda have developed in a myriad of ways: a mixture of individual and organisational support, using both direct and indirect approaches, delivered by insiders and outsiders — sometimes collaborating, sometimes not. Insiders included PWCD and parents/carers motivated by personal or familial connections to CD. Such grassroots development reflects the history of self-help groups in Minority World countries, where services were started by or for parents of PWCD (AFASIC, no date).

Regardless of the approach used, low numbers of personnel and the time commitments of outsiders created challenges. This meant that services were often driven by one or a few highly motivated and committed key stakeholders, which meant the services' overall longevity depended on these individuals remaining in these positions. This dependence on a small number of outsider personnel was one of the reasons Ugandan insiders perceived outsider support as unstable and transient. Outsiders were often committed for specific amounts of time, often leaving gaps in which outsider roles were unfilled. Insiders were disappointed by early withdrawals, but not surprised. Some outsiders were also frustrated with this. The differences in insider and outsider reaction may be due to an expectation of what NGOs represent to each. There is a high number of foreign NGOs in Uganda which may encourage reliance on aid (Dicklitch, 1998), often without a plan for long-term sustainability. Outsider frustration may be related to their time invested in an organisation and a sense of losing sustainability, however, it is worth noting that even with supportive legislation and intentions for change, that change is slow (Goldbart and Sen, 2013).

The study showed that the ending of partnerships in development often occurred prematurely (Akukwe, 1998), or during a project when knowledge building about successful projects was at its highest (Ahmed et al., 2017). As these disruptions affected developing services, there was a need for clear planning (and for this to be agreed by both insiders and outsiders beforehand), and for project changes to be minimised. There was also a need for flexibility to amend approaches where necessary (Acharya et al., 2017). This is supported by Ahmed et al. (2015), who found clear, organised planning was an important part of the success of a medical partnership in Sudan, whilst still allowing for flexibility in the event of unforeseen challenges.

Outsiders explicitly discussed how the specific development approaches used by individuals or organisations were directly related to the perceived success or failure of developing services for PWCD. Outsiders believed indirect training approaches were more successful. This finding may relate to the fact that interviewed outsiders were more likely to have had involvement with the strategic planning or delivery of the Ugandan SLT education programme (itself an indirect approach).

Despite this, all groups of participants described particular preferences for outsider involvement. This included detail of short, medium or long-term involvement; and the level of experience that an outsider SLT had. Whilst sustainability was an important focus for insiders and outsiders, views on the best way of achieving this varied. This may mean that insiders and outsiders needed to have awareness and an agreement of the best way of working towards this goal. Zachariah et al. (2009) found that the high staff turnover within NGOs hindered the sustainability of partnerships, meaning NGOs may not have been best placed to conduct sustainable research. A lack of research into sustainability in this field consequently means there are limited ways of knowing when a project or services are sustainable. As the literature on partnerships between Minority and Majority World countries has typically been written by Majority World researchers, it is difficult to know how often collaboration meets the needs of the Majority World, particularly the need for sustainability.

Key statements:

6. There are many different approaches to service development, however insiders and outsiders should collaborate to find the most appropriate and realistic approach that will lead to sustainability. Although unnecessary changes to approaches should be avoided as much as possible, both insiders and outsiders need to be flexible and amend approaches, if necessary.

7. Services for PWCD in Uganda started with outsider involvement. They have improved over time but are not equitable and not yet sustainable.

6.3   Development theories

This section uses the development theories outlined in 2.3 to explain and add further insight into the seven key statements.

6.3.1 Modernisation Theory

Based on the work of Rostow (1991), Modernisation Theory posits a linear model of development applicable across all countries and contexts, categorised

into five main stages of development. This theory was summarised in 2.3.1. Using Rostow's (1991) Modernisation Theory criteria, the researcher classified each of the six countries researched by their present economic conditions.

Uganda - stage 1 *Traditional Society*
Kenya - between stage 2 *Preconditions for Take-Off* and stage 3 *Take-Off.*
Sri Lanka - stage 3 *Take-Off*
Jamaica - stage 3 *Take-Off*
Trinidad and Tobago - between stage 3 *Take-Off* and stage 4 *Drive to Maturity*
Malaysia - between stage 3 *Take-Off* and stage 4 *Drive to Maturity*

This variation appears to indicate that SLT is being developed in countries at different economic stages. However, this development is often due to outsider involvement and financial assistance rather than in-country initiation. Therefore, Modernisation Theory may not be able to explain how SLT will develop in these countries as they are not following the development pattern of "developed" economies. As countries are not following this pattern, there are gaps in services. These gaps are often filled by outsiders in order to develop the service.

Of the seven key statements, two related to development approaches, summarised below:
- 6. That there are different ways that services can develop, and
- 7. That services for PWCD had started in Uganda but were not yet sustainable or accessible.

Neither of these findings can be explained by Modernisation Theory. The idea of there being different ways of approaching service development challenges the singular, linear vision of Modernisation Theory (which is further contradicted by the presence of services for PWCD in a stage 1 country). However, the fact that services in this stage 1 country are not yet sustainable may provide some support for the theory.

The development of services for PWCD at early levels of economic development may explain some of the challenges in these countries.

Specifically, services for PWCD have and are being developed without wider health infrastructure or more general infrastructure such as roads and transport. This has resulted in geographical and economically inaccessible services, something noted in countries across both phases of research. Services for PWCD remain unequal in their access because of the barriers of infrastructure despite services for PWCD being described as a human rights issue by much of the literature (Kathard and Pillay, 2013). This suggests that there needs to be more development of infrastructure to increase access. PWCD and their parents or carers identified a need for increased special education schools and jobs for PWCD. This suggests there are additional ways that services for PWCD can develop to best meet their needs, which may also avoid some of the challenges associated with outsider SLT practice.

Of course, seeing the endpoint of SLT service development as a simple replication of Minority World services requires an ethnocentric perspective — a criticism often applied to Modernisation Theory, as it reinforces practices of colonialism (Rovers et al., 2016). This challenge was further echoed within SLT by some Minority World outsiders, such as Wylie et al. (2016), who questioned if SLTs would always be the most relevant people to support PWCD. Despite this, insiders from both phases of research wanted more outsider SLT assistance.

6.3.2 Dependency Theory

Dependency Theory argues that the postcolonial relationship between Minority World- and Majority World-countries prevents the development of Majority World countries and continues the economic exploitation that began in the colonial era (James, 1997). This theory was summarised in 2.3.2.

Two of the key statements related to Dependency Theory.
- 1. Power between insiders and outsiders is unbalanced. However, with awareness, outsiders can address this and provide more positive sustainable services for PWCD.
- 3. Insiders are used as cultural informants, outsiders are used as experts.

A strength of this theory is its acknowledgement of the power relationship between the Majority and Minority world — power being a key topic of this study. Though Kirigia et al. (2006:89) note that, in healthcare, Dependency Theory often focuses on challenges of brain drain, or the 'poaching' of specialists from the Majority World — the data, findings and key statements of this study, do not support this. None of the six countries explored by this study, reported "brain drain" as a challenge. The literature review instead showed this brain drain problem was actively considered in the planning of the initial training course in Sri Lanka. This Sri Lankan course was initially and purposefully created as a diploma course — rather than an internationally transferable degree programme — to prevent the "brain drain" of SLTs (itself perhaps a potential example of engineered dependency and power imbalance). Likewise, while the data collection in phase one revealed that some Ugandans had left to practise in other countries, these were all in sub-Saharan Africa, not the Minority World. Conversely, the literature review showed that — in the Caribbean and Kenya — SLTs had trained abroad in Minority World countries and returned to practise in the Majority World: an inversion of the "brain drain" phenomena.

The power imbalance between insiders and outsiders referenced in key statement 1 may reveal further nuance from a Dependency Theorist's perspective. Rather than "poaching" insider SLTs, key statements 1 and 3 may indicate outsiders are exploiting Majority World settings by training SLTs who will never be their equal. The use of insider SLTs as cultural guides — rather than equal partners — may have eroded local PWCD confidence in insiders and the restrictions placed on insider professionals (even when intended to stop the negative effects of a brain drain) and thus may have exacerbated the power imbalance between insiders and outsiders. In the terminology of Dependency Theory, this could be perceived as a deliberate underdevelopment of services. Furthermore, a lack of insider-focused research (or even collaborative research) has allowed outsiders to define the narrative of services for PWCD in these countries, and may have minimised the insiders' ability to develop services based on research. The fact that CDs have not been prioritised in international literature, such as the WHO's recommendations, has also fostered underdevelopment in Majority World countries.

6.3.3 World Systems Theory

World Systems Theory states that countries belong in three hierarchically organised zones of economic activity. Zone one (the core) comprises countries with vast amounts of accumulated capital; Zone two (the semiperiphery) comprises countries with smaller amounts of accumulated capital; Zone three (the periphery) countries are those with low levels of wealth and underdeveloped infrastructure (Peet and Hartwick, 2015). This theory was summarised in 2.3.3.

Two key statements below can be related to World Systems Theory.
- 2. Insiders preferred outsiders to work in roles involving knowledge sharing.
- 4. Insiders should set the terms of what they want, outsiders should ask what they can give.

The key statements represent ideals which did not always happen. The study revealed that some outsiders were perceived to have worked in ways that benefitted themselves more than insiders. This could be seen, through a world systems perspective, as outsiders from zone one exploiting zones two and three. This was further reflected in the literature, with collaborative work typically focusing on outsider gains (F.A. Jones et al., 2013) perhaps reaching its extreme with the othering of reciprocal learning by researchers such as Busse et al. (2014:2), who referred to the learning of outsiders in Majority World countries as 'reverse innovation', rather than simply innovation. Similarly, points relating to power discrepancies and underdevelopment by a lack of research — discussed under Dependency Theory — are also relevant here due to the similarities in each theory's view of economic exploitation between countries.

World Systems Theory also may provide some explanation for why partnership collaboration between Majority World countries appears uncommon, despite a preference amongst insiders for outsiders from similar contexts. Due to the higher economic status of Zone one countries, it may be that, for zone two and zone three countries, potential partnerships with zone one countries are considered such attractive and beneficial opportunities, that they are prioritised over other potential collaborative partners. In spite of this, individual insiders

expressed preferences for outsiders from neighbouring or culturally-similar countries — perhaps because the semi-periphery and periphery have more in common than with countries in the "core," which actively exploits them. Mawdsley (2012:256) described the concept of 'south-south' foreign aid and development co-operation (co-operation between countries in the same economic zones) which would reject the economic exploitation World Systems Theorists see as inherent in inter-zone interactions — potentially providing a more equal, reciprocal relationship not mired in the history of exploitation.

6.3.4 Postdevelopment Theory

Postdevelopment Theory argues that the idea of development is racist and neo-imperialist. Attempts made by the Minority World to "develop" Majority World countries are viewed as smokescreens to distract from damage being done in the latter (Thomas, 2000:3, cited in Ziai, 2007). This theory was summarised in 2.3.4.

Three of the seven key statements (summarised below) are related to Postdevelopment Theory.

- 5. Cultural differences exist, however the best outsiders are culturally competent and flexible.
- 3. Insiders are used as cultural informants, outsiders are used as experts.
- 7. Services for PWCD in Uganda started with outsider involvement. They have improved over time but are not equitable and not yet sustainable.

That services in Uganda have improved over time, but are not equitable and not yet sustainable, may be explained using Postdevelopment Theory. The first two of these key statements suggest that offering culturally inappropriate outsiders or services is a superficial or insignificant gesture from outsiders. This is perhaps best evidenced in some of the codes and categories from the document analysis (see examples in 4.4.1.2). Although insiders from both phases of study had clear preferences regarding factors such as the experience level and flexibility of outsiders, insiders from most countries described that these preferences were not consistently met.

This failure to achieve equitable and sustainable services may further suggest the development of services for PWCD on such a small-scale offered only a piecemeal approach to a large need. It could be argued that the support from international NGOs serves primarily to raise their own profile and that of the Minority World countries they operate from, as they are seen as improving the lives of PWCD whether or not this improvement actually materialises. Promoting success stories while not addressing challenges (such as cultural barriers), or not sharing information from projects (whether perceived as "failures" or "successes" or abandoned early) leaves little information to learn from. It may be that, similar to the avoidance of publishing negative results in research (Fanelli, 2012), outsiders do not report the challenges of developing services for fear of loss of funding. However, the findings from this study (indicating consistent challenges across all countries) suggest that there is a need for transparency in collaborative development work.

Just as foreign aid receives criticism from some for reducing the ability or necessity of domestic governments to make improvements (Bräutigam and Knack, 2004), it may be that outsider involvement in providing SLTs or training courses reduced a country's perceived need and responsibility to develop appropriate services for PWCD. Nganwa et al. (2013) stressed the need for a country's government taking responsibility for the training of CBR workers to support PWCD and highlighted the pitfalls of an NGO being responsible for training. When governments were not responsible for services, and NGOs suddenly leave (as happened in Uganda), services were threatened. The withdrawal of SLTs from NGOs was seen in this study and was similarly reported in Tanzania by Nganwa et al. (2013). Furthermore, reliance on outsider NGOs may have increased the likelihood of repetitive creation of, or tension between, similar services operating unconnected services in the same country (Pfeiffer et al., 2008). Following the withdrawal of one NGO's support, another outsider may perceive an absence of support or services and may so set about creating similar initial services, rather than building on existing developments. This may occur despite the fact SLTs may not even be the most appropriate service for meeting PWCDs needs in all settings (Wylie et al., 2016).

In keeping with the broader criticisms of Postdevelopment Theory, this theory fails to acknowledge the fact that insiders from Majority World countries may be the ones requesting outsider involvement. It also considers all outsider input as harmful and having questionable motives, regardless of any sustainability it provides.

6.3.5 A summary on development theories

Whilst development theories may be limited, or inappropriate in their explanation according to some critics, there may be fundamental points from each theory that accurately relate to the development of services. It is the view of the researcher that no single development theory can account for the current services for PWCD in Majority World countries. Instead, different key statements may better illustrate different development theories. Modernisation Theory best offers explanations for the challenges in service development, seen in key statements 6 and 7. Dependency Theory best offers explanations for challenges in power and roles, seen in key statements 1 and 3. World Systems Theory may offer some insight into key statements 2 and 4. Key statements 3, 5 and 7 may relate generally to Postdevelopment theories.

6.3.6 Outsider context

The researchers' role as an SLT may have influenced elements of the research. In terms of the overall approach, her professional role may have made her an advocate for the profession, or influenced the content or style of what participants discussed. Regarding the data collection and analysis, there may have been a greater focus on SLT rather than services for PWCD as a whole. However, there was limited documentation of non-SLT services for PWCD in the six countries, and even less documentation of the involvement of outsiders in these services. The researcher aimed to make this evident by stating the proportion of insider, outsider or collaborative documents. Although all participants interviewed in phase one were connected to SLT in some way, the researcher also included non-SLT outsiders for their perspectives. For the analysis, the researcher's perspectives and experiences as an SLT may have influenced the interpretation and abstraction of the data. However, it is not the view of the researcher that Majority World countries necessarily "need" SLT; or

that SLT is the best way of meeting the needs of PWCD (Wylie et al., 2016); or, indeed, that outsiders are best placed to support this (Laleman et al. 2007).

6.4   Summary

This chapter synthesised the findings from phases one and two to arrive at seven key statements, and discussed the relevance and usefulness of four development theories in explaining the development of services for PWCD in six Majority World countries. The next chapter will conclude the thesis.

7   Conclusion

7.1   Introduction

This chapter presents the conclusion. This section reiterates the aims and objectives of this study. Section 7.2 provides a summary of the study. Section 7.3 presents the key statements from the six countries. Section 7.4 discusses the implications for practice. Section 7.5 discusses limitations. Section 7.6 identifies areas for future research. Finally section 7.7 concludes the thesis.

The aims and objectives of the study were:

Aim

To investigate the processes and perceptions of collaboration between insiders and outsiders in developing services for PWCD in Majority World countries, with a particular emphasis on the contribution and roles of "outsiders."

Objectives

1.To explore and describe the process and history of the development of services for PWCD in Uganda.

2. To describe and explain insiders' perceptions and experiences of the contributions of outsiders and outsider support, to the development of services for PWCD in Uganda.

3.To describe and explain outsiders' perceptions and experiences of their contribution to the development of services for PWCD in Uganda.

4. To analyse and interpret insider/outsider collaboration and working practices.

5. To describe and explain perceptions of outsider contributions in five Majority World countries.

7.2   Summary of the study

The study had two phases. Phase one comprised a single-country case study in Uganda, and phase two comprised a pilot study using case study survey research in five Majority World countries. 18 key findings from the two phases were synthesised into seven key statements that related to the research objectives. Although four of the five objectives were designed to investigate the

phenomena of outsider involvement in the development of services for PWCD in Uganda, three of these objectives produced similar findings across the five Majority World countries in phase two.

7.3   Key statements resulting from the study

The **key statements** across all six countries were:

1. Power between insiders and outsiders is unbalanced. However, with awareness, outsiders can address this and provide more positive sustainable services for PWCD.
2. Insiders preferred outsiders to work in roles involving knowledge sharing.
3. Insiders are used as cultural informants, outsiders are used as experts.
4. Insiders should set the terms of what they want, outsiders should ask what they can give.
5. Cultural differences exist, however the best outsiders are culturally competent and flexible. Insiders may not actively inform outsiders of the most appropriate ways of working, but are more likely to share this information, if asked.
6. There are many different approaches to service development, however insiders and outsiders should collaborate to find the most appropriate and realistic approach that will lead to sustainability. Although unnecessary changes to approaches should be avoided as much as possible, both insiders and outsiders need to be flexible and amend approaches, if necessary.

One key statement was specific to Uganda:

7. Services for PWCD in Uganda started with outsider involvement. They have improved over time but are not equitable and not yet sustainable.

While the Ugandan case study reflected the starting point for the study, the commonality across Majority World countries surveyed (regardless of their level of development and differing geographical locations) suggests that there are

several implications for practice when SLTs from the Minority World engage with Majority World countries.

7.4 Implications for practice

This study contributes new knowledge to a topic that is under-researched, both generally (in terms of service development in Majority World countries) and specifically (in terms of development of services for PWCD in Majority World countries). A number of the resulting recommendations may be used to inform future collaborations and development practice. Recommendations for successful collaboration between insiders and outsiders, both at an individual and organisational level, are outlined below for each of the five phases of outsider support: initiation, preparation, implementation and end-of-support.

Initiation

Marshall (2003) stated that outsiders should critically assess whether a request for involvement is appropriate. Building on this, the study showed that *both* insider and outsider partners in a prospective collaboration should consider if they are the right people to collaborate with — for example, do they have the desired experience, skills, knowledge, time and commitment? Answering this question may depend on who initiates the discussion to support services for PWCD in a given country, but should be guided by key statement 4. Insiders should aim to recruit outsiders who match the specific requirements of a setting/ project (as there was variation regarding insiders' preferences for outsider types and skillsets). Outsiders should research the existing services for PWCD in the Majority World country they wish to work in, and ask if their support is wanted and how they can best help. Key statement 1 showed that power differences exist between insiders and outsiders, but outsiders can minimise these differences. If services are found to be lacking, and keeping in mind the imbalanced power outsiders often have in former colonial countries, outsiders should further reflect and consider how they can best contribute.

As evidenced by key statement 5, cultural differences between insiders and outsiders are likely. Open discussion should take place at this stage to increase knowledge and communication and reduce differences. Outsiders should undertake training or sensitisation in the host country's culture, particularly if

they have not worked abroad before. Outsiders should be aware of the history foreigners have had in the host country, and consider how this could affect their treatment and relationships with stakeholders. Such knowledge may assist an outsider in avoiding ethnocentric practice.

Preparation

At this stage, insider and outsider partners should collaborate by planning a service for PWCD. A small number of studies describe the development of collaborative support for such services (Robinson et al., 2003; Wickenden et al., 2001) and acknowledge the need to build on existing health and education infrastructure. The findings of this study support these recommendations, and further suggests that this should include consideration of general infrastructure (such as transport, communications, etc.) which may either be needed (if lacking) or connected to (if in existence). Outsider support needs to be practical within the needs of each setting. As evidenced by key statements 2 and 4, insiders and outsiders need to discuss the best way of outsiders contributing to services for PWCD and, where possible, outsiders' contributions should be directly related to specific insider-identified needs. This is important when addressing power discrepancies between insiders and outsiders (as seen in key statement 1). There should be clear planning about the roles and responsibilities of each party. Where services for PWCD are new and there are few or no insider professionals, key statement 3 (using insiders as cultural informants and outsiders as experts) may be acceptable initially. However, where there are existing insider SLTs, this should be avoided. As key statement 7 shows, when services are not yet sustainable, there should be agreement on planned timescales and an agreed measure of sustainability. Finally, the outsider exit strategy needs to be planned, with an agreed timescale.

Implementation

At this stage, insiders and outsiders should be clear about their roles and contributions. Throughout the collaboration, there should be clear communication between partners to address sustainability. Guided by key statement 6, there should be flexibility and discussion throughout the whole collaborative period to respond to unanticipated challenges. As with the development stage, outsider support should be guided by the wants and needs

of insiders where possible — with agreement between both parties regarding the level to which these can be accommodated — and reviewed regularly.

<u>End of outsider support</u>

Key statement 6 reveals many different existing models of development aimed at creating sustainability. Sustainability can be ensured by having clearly-defined support goals, plans, timescales and a measurable way of marking progress. Literature on collaboration for services for PWCD suggests that sustainability is a priority within some collaborations (Robinson et al., 2003; Ahmad et al., 2013), however much of the literature is unclear as to how sustainability can be defined and measured (Johnson and Hitchens, 2011; Domsch, 2012). Insiders and outsiders in this study described sustainability as the ideal of insiders independently providing the same level and quality of services as were currently provided with outsider support.

The literature on collaboration for services for PWCD commonly comprises reports from the beginning or middle stages of collaboration (such as Robinson et al., 2003), but very little at the end. If collaboration is a key part of a project, outcomes should be shared regardless of each project's "success" or "failure"— allowing others to learn. This is important, as key statement 7 shows that services in Uganda are not yet considered sustainable, despite having no further outsider support.

There is a need for outsiders (both individuals and organisations) to follow existing guidance relating to cultural competence, and to have clear communication with insiders to ensure this is best achieved.

7.5 Limitations

Limitations of the study can be broadly split into those relating to the research methodology chosen, those relating to the overall design, and those relating to the scope of the research aim. Specific limitations relating to each method of data collection and interpretation have been discussed in chapters 4.5.6 and 5.5.

As described in 3.2.3, the study used an exploratory sequential case study design, incorporating both ethnographic case study and case study survey research approaches. A limitation of this research design is that some have regarded it as an initial step before specific causal research can be completed to generate hypotheses (Streb, 2012). Furthermore, the flexibility of this research design has often been considered a weakness (Streb, 2012). However, an exploratory sequential case study design was deemed appropriate because of the lack of previous available research. It also allowed for flexibility between the two research phases and reduced the challenges of gathering in-depth data on a global scale.

Ethnographic case study approaches have specific challenges, with three key limitations outlined by Fusch et al. (2017). Firstly, becoming embedded within the studied culture can be a limitation when conducting ethnographic case studies over short time periods. In this study, not only was the researcher an outsider SLT, but also someone with no prior experience of working abroad — the researcher was an "outsider" to the phenomenon of being an outsider. Insiders or outsiders working in-country may be better placed to conduct this kind of research. A non-experienced outsider may find it beneficial to have an extended in-country data collection phase, where resources allow. However, despite the in-country data collection period being relatively short, there were some signs that the researcher was at least partly embedded, such as being asked by insiders for SLT advice.

A second limitation is that of small participant numbers. Qualitative research aims to answer questions of "what" and "how," often aiming to explore, classify and develop, rather than aiming to test hypotheses. Data are often related to individual human perspectives, experiences or behaviours. Although the researcher interviewed and observed a small number of people in Uganda in 2015 and 2016, Fusch at al. (2017) noted that it is not sample sizes (small or large) that indicate data saturation, rather it is the proportion of participants within a target population that informs data saturation. From this perspective, a large proportion of the *population* of insider and outsider SLTs were included in this study, who were purposively sampled to gather rich data. One challenge within this was not being able to interview or observe SLTs who taught on the

SLT Bachelor's degree programme, as consent was not obtained. However, it was possible to interview and observe non-SLT teaching staff. As the proportion of parents or carers of PWCD was low, however, it would be beneficial for future research to include a larger number of these participants in order to have a better representation of this group — particularly as they make up the majority of stakeholders in each country.

A final limitation of the ethnographic case study approach is transferability. The concept of transferability was suggested by Lincoln and Guba (1985) as a qualitative equivalent of the quantitative term generalisability. Transferability considers whether a study has universal applications. As qualitative studies are unique, and their data may not directly transfer to another study, Fusch at al. (2017) described the need for good data collection and analysis procedures to minimise concerns about transferability. Fusch at al. (2017) further suggested sharing interpretations with participants as a way of assisting transferability. Future researchers could include this more explicitly as part of the analysis and results phase, with all participants. Whilst this was not completed formally, later collaborative work between the researcher and Ugandan SLTs (Sowden and Musasizi, 2017; Sowden et al., 2016) corroborated interpretations from phase one.

The limitations of the phase two pilot study related mainly to issues of no response and item non-response (Chmiliar, 2010). For one country, there were no respondents. Instead another country was selected. For the final five countries surveyed, there was a low response rate (which was estimated at 15.5% for all countries), although this is considered acceptable in the context of marketing research (Hikmet and Chen, 2003). The returned surveys featured item non-response which can result in data bias, however results were evaluated to consider item non-response (Chmiliar, 2010). Researchers could consider additional measures by which to enhance the response rate, such as using a survey-hosting website and publicising the survey through professional organisations, in addition to emailing participants directly (Sheehan, 2001). However, as a pilot study, the phase two case study survey was designed as a small-scale study for future research. As a pilot study, it is hoped that the challenges of low response rate could be resolved for a future, larger study.

One of the main limitations of qualitative (or predominately-qualitative) research is researcher bias. Although some qualitative researchers use bracketing as a way to minimise researcher bias, tensions exist around the use of bracketing (Tufford and Newman, 2012). Bracketing requires a researcher to suspend their cultural beliefs and influences. Instead, a reflexive diary was used to help identify, engage with, confront and challenge the researcher's own cultural beliefs and influences (Crotty, 1998).

Bias was mitigated in two further ways. Firstly, as part of the supervision process, the researcher discussed and examined the themes of the research to allow for further interpretation and debate. Secondly, negative case analysis was used: a conscious search for outlying or contrary themes within the data (Lincoln and Guba, 1985). This was completed by examining contradictory perceptions, and further search and use of identified contradictory perceptions.

Although this study aimed to research services for PWCD, it centred particularly on SLT. As the provision for SLT in the researched countries is low, it is likely that the majority of PWCD either do not have their needs met by SLT, or instead have their needs met by other services. Although efforts were made to include non-SLTs (other professionals and parents and carers of PWCD), the majority of participants were SLTs. Therefore, for future research, researchers could place increased focus on existing services for PWCD, identify the relevant staff, such as those identified by Wylie et al. (2017), and seek to include them in the research. The study introduced new terminology of "insiders" and "outsiders." This terminology was selected to capture the phenomenon of foreigners working in Majority World countries with nationals. Whilst alternative terminology was considered, competing terms were ultimately rejected as they were felt to either be unfamiliar complex language (such as "autochthonous") or to have negative connotations. "Insider" and "outsider" were therefore selected as the least emotionally-loaded terms, and clear enough to be readily understood by people across different country settings. With the introduction of new terminology during data collection, there was the potential for confusion. To minimise this, during interviews, phase one participants were introduced to the

terminology with verbal explanations, and phase two participants were introduced through written explanations in large, bold-print font.

This study focused on insiders and outsiders, and asked for both to share their perceptions of outsider contributions. The researcher was a British, mixed race, female SLT in her late twenties at the time of data collection. As such, she was an outsider. It may be that the researcher's position affected insiders' responses, and resulted in insiders expressing relatively positive sentiments towards the involved outsiders. This may have been more pronounced for the data collection in the first phase of research, where insiders were in close proximity to the researcher.

Although use of survey for phase two may have reduced some of the effects of the researcher being an outsider (despite full disclosure of this), the survey yielded less in-depth data from all participants and a direct comparison between both insider data sets was challenging. As it was not possible to produce detailed findings for each country in phase two, insider data from all phase two countries was interpreted as a whole to produce findings for comparison with findings from phase one. Again, measures to increase the response rate for future case study surveys would help greatly. Phase one explored both insiders' and outsiders' perceptions, whereas phase two focused solely on insiders' perceptions. This focus was chosen to, firstly, minimise repetition of data from outsiders who may have worked in multiple country contexts, and, secondly, to give insiders' perceptions greater prominence in the research as the wider literature is typically outsider-focused (Shields et al., 2016). Resultantly, insiders were either the focus of, or included in, four of the five research objectives. However, despite the inclusion in the first and fourth research objective, documents authored by insiders made up only a small proportion of the documents used during the document analysis stage of research.

Some of the limitations of the study relate to the research settings. Firstly, there were few Majority World countries that possessed both an SLT course and outsider support. The researcher decided that for manageability, five countries would be selected for research in phase two. The matrix used in phase two identified ten potential countries for inclusion (nine excluding Uganda). In view

of the low numbers of respondents in phase two, it would have been interesting to gather more data from the remaining four countries. Unfortunately, due to time constraints, this was not possible. In addition to taking measures to increase the response rate, future research could build on the phase two pilot study to continue to collect data from the remaining countries identified, and potentially to all Majority World countries on the matrix.

Another challenge of this study was that the researcher did not speak languages other than English, thus limiting the Majority World countries that could be included. Although the countries selected all had English as an official language, there were some challenges in the understanding and interpretation of a small amount of data from both phases of research (both in the transcription of recorded interviews from Uganda and in the written responses of the survey). It would be interesting to explore and include non-English speaking participants and documents within future research, in order to gain a fuller picture of stakeholder views.

7.6   Areas for future research

This study explored insider and outsider perceptions of outsider contributions to sustainable services for PWCD in Majority World countries. The topics of service development for PWCD in Majority World countries and perceptions of outsider involvement in the Majority World both lack research. The findings of the study contribute to a small knowledge-base in these areas.

Throughout the research process, a number of related questions and topic areas were identified as important but beyond the scope of the research aim.

Firstly, it was not feasible to repeat the phase one ethnographic methodology for phase two. Therefore, a pilot study of half the countries in the country selection matrix was undertaken. It would be interesting to extend the pilot case study survey (whilst making the necessary improvements to increase participant response rates) in the additional countries, as the pilot study findings broadly reflected those of phase one, but were arguably, less resource-intensive to carry out.

Secondly, it would be interesting to investigate how countries with limited services for PWCD could best plan and organise appropriate and sustainable services, without simply replicating culturally- and structurally-inappropriate services of the Minority World. One approach to researching this would be to initially focus on what services a country or countries already possess, and then explore how services are being coordinated and planned at a strategic level, by collecting data from key stakeholders. It may be that insiders would be better placed to undertake this research, so as to avoid the potential for outsider judgement or pressure to change.

Thirdly, as many insiders in the former British colonies studied felt the nationality of outsiders often influenced their way of working, it would be interesting to explore this on a broader scale. Do different former colonial powers providing services for PWCD in former colonies represent the new "'scramble for Africa,'" as Gorman (2008:83) suggests? Whilst a potentially complex research project, this could be explored by studying and comparing SLT development in Anglophone, Francophone and Lusophone countries and exploring who the outsiders are, and what the perceptions and motivations of their work is. It may be that the phase two survey could be adapted for use in such a context.

Fourthly, it would be interesting to follow up insiders' feelings that outsiders from neighbouring Majority World countries were the most appropriate collaborators in supporting services for PWCD. Anecdotal evidence suggests this type of collaboration happens on a relatively smaller scale within SLT services in Majority World countries. Action research may be an appropriate way of studying the current modes of support in a setting, before planning and taking action by involving partners or collaborators from neighbouring countries, then collecting and analysing the findings, reflecting upon these to share with in-country stakeholders and stakeholders in other Majority World countries.

Fifthly, as services in some Minority World countries are also considered under-served and may draw on outsider SLT input, it would be interesting to explore whether there were similar challenges and imbalances in the insider / outsider relationship when working without the spectre of a colonial history. This would

be perhaps best explored using a case study approach to provide a historical and social context of a country in addition to an analysis of present collaborative practices.

Finally, as the interviewed parents and carers of PWCD all prioritised other services for their children — including appropriate schooling and employment — over SLT, it would be informative to research how these needs can be met and to ask if and how SLT should assist in delivering such services. Action research with key stakeholders may be a useful approach to gather initial information of the priorities of needs, and present challenges in addressing these needs.

7.7   Conclusion

This study investigated the processes and perceptions of the collaboration between insiders and outsiders in developing services for PWCD in Majority World countries, with a particular emphasis on the contribution and roles of outsiders. This study has added to the knowledge base by revealing that both insiders and outsiders perceived challenges between the two groups in terms of uneven power and roles, and insiders further perceived challenges in outsiders' cultural appropriateness. This study has shown the need for insiders to be able to set the terms of what is wanted and needed, and for outsiders to try to meet this need. This study has demonstrated that there are many perceived ways of collaborating to develop sustainable services, but that there should be clear plans to work towards when developing such services (with flexibility to amend approaches where needed). Finally, this study has shown how — after several decades of outsider support and an SLT training programme for insiders — services for PWCD are still not sustainable in Uganda: demonstrating the lengthy gestation period of developing services and highlighting the requirement for greater coordinated collaboration. These findings will provide valuable guidance to improve outsider contributions at each stage of collaboration. In addition, the study has shown how both ethnographic case studies and survey case studies are useful and appropriate for the data collection of perceptions of outsider contributions to sustainable services for people with communication disabilities in Majority World countries.

The seven key statements showed insider preferences for outsider contributions, which were in part guided by experience of outsider practice they considered challenging. This study re-framed the narrative by redressing the balance of under-representation of insiders' perspectives on services for PWCD, which will aid future, more equal collaborations.

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Appendices

Appendix 1 - Ethical approvals
Manchester Metropolitan University ethical approval

MANCHESTER METROPOLITAN UNIVERSITY
FACULTY OF HEALTH, PSYCHOLOGY AND SOCIAL CARE

M E M O R A N D U M

FACULTY ACADEMIC ETHICS COMMITTEE

To: Ryann Sowden

From: Prof Carol Haigh

Date: 25/02/2014

Subject: Ethics Application 1210

Title: An investigation of the contribution of outsiders into development of sustainable services for People with Communication Disabilities in Majority World countries

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

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COLLEGE OF HEALTH SCIENCES
SCHOOL OF PUBLIC HEALTH
HIGHER DEGREES, RESEARCH AND ETHICS COMMITTEE

14th July, 2014

Ryann Sowden
Post-Graduate Research Student
Manchester Metropolitan University
Faculty of Health, Psychology and Social Change

Re: Approval of Proposal titled: An investigation into the perceptions of 'outsider' contributions to sustainable services for people with communication disabilities in majority world countries

This is to inform you that, the Higher Degrees, Research and Ethics Committee (HDREC) has granted approval to the above referenced study. The HDREC reviewed your proposal during the 118th meeting on 01st April, 2014 and made some suggestions and comments which you have adequately incorporated:

	Document Name	Version Date
1	Research Protocol	May, 2014
2	ALL Informed Consent Documents	May, 2014
3	Data collection tools	May, 2014

Note that the initial approval date for your proposal by HDREC is 14th/07/2014, and therefore approval expires at every annual anniversary of this approval date. The current approval is therefore valid until: 13th/07/2015

Continued approval is conditional upon your compliance with the following requirements:

1) No other consent form(s), questionnaire and/or advertisement documents should be used. The consent form(s) must be signed by each subject prior to initiation of any protocol procedures. In addition, each subject must be given a copy of the signed consent form.

Valid Thru:
1 3 JUL 2015

Uganda National Council for Science and Technology

Dear   Ms. Sowden,

RE: AN INVESTIGATION OF THE CONTRIBUTION OF OUTSIDERS INTO THE DEVELOPMENT OF SUSTAINABLE SERVICES FOR PEOPLE WITH COMMUNICATION DISABILITY IN MAJORITY WORLD COUNTRIES

This is to notify you that the Uganda National Council for Science and Technology (UNCST) approved the above protocol on **23 January 2015.**

The approval is subject to the following condition:
  1. Payment of the research administration and clearance fee of 300 US Dollar.
Payment is made to Standard Chartered Bank Speke Road Branch; the account title is UNCST and the account number is 8705611811400. If however you wish to pay in Uganda shillings, the account number is 0105610632101. If you intend to wire the research fees, the swift code is SCBLUGKA. Note that bank charges will entirely be the researcher's responsibility.

  2. Obtaining of clearance to the study districts from the Research Secretariat, Office of the President;
The process of obtaining clearance from the Research Secretariat, Office of the President is handled by UNCST on behalf of the researcher. Once approval has been secured, you will be notified.

Yours sincerely,

Executive Secretary
UGANDA NATIONAL COUNCIL FOR SCIENCE AND TECHNOLOGY

Appendix 2 - Reflexive diary excerpts

Diary March 2014

It was interesting to consider what CPD training events meant to people. These not only provides training, but also act as a social event for people who are not only separated by large geographical distances, but busy timescales. This is not even 'just' the normal social element that may be provided by training, but a specific bonding experience for people linked by their unique experience, e.g. by being members of a profession that has small numbers, but also having a bond through people who are considered 'pioneers' (as the first Ugandan SLT). I wonder what this means where people both describe themselves as pioneers and guinea pigs - do these idea hold concurrently, and does meeting fellow pioneers reducing feelings of being guinea pigs?

Diary April 2015

Today was spent with a Ugandan SLT. towards the end of the day, we started talking about roles and resources. During this conversation, the SLT asked if I was aware of any resources for parents and children discussing puberty. These resources were needed for parents of both typically developing children and children with disabilities, who would ask the SLT to help advise them in this area. What really struck me about this conversation was not so much the specific ways in which the SLTs role and clientele was different to that of the UK, but that there was a real need for this information to support PWCD and their parents and carers in perhaps more general ways. This supported some of the interviews with parents: revealing that their chief priorities were things like access to school, jobs and a general reduction of stigma.

It may be that resources in Uganda are not even necessarily lacking but are hard to access so we talked about who might have resources that could be used. We talked about developing specific resources and how this could be done, as there were cultural differences in how puberty was understood.

Appendix 3 - Phase one country background

Phase one country background
The Republic of Uganda's most recent Human Development Index (HDI) ranking is 0.456, positioning the country at 161 out of 187 countries and territories: low in the UN's human development category (United Nations Development Programme [UNDP], 2013).

Country geography
Uganda is a land-locked East African country, covering land of 241,038 square kilometres (Central Intelligence Agency (CIA) Factbook, 2017). Uganda shares borders with South Sudan, Kenya, Rwanda, Tanzania and the Democratic Republic of the Congo. The equator runs through the south of the country, and as such has an equatorial climate. Uganda has a relatively high altitude, averaging approximately 1100 metres above sea level. The southern region of Uganda includes the capital and most populated city, Kampala, as well as a large section of Lake Victoria.

A brief history of Uganda
In pre-colonial times, the area covered by present-day-Uganda comprised separate autonomous ethnic groups, from the monarchical Bantu-speaking cultures of Lake Victoria to the disparate chiefdoms and non-centralised societies of the East and North (Amnesty International, 1989).

Prior to British annexation, the area of East Africa now covered by the state of Uganda comprised several distinct East African tribal territories, each of which had their own, traditional systems of social organisation and unwritten law. The most populous of these ethnic groups was the Bugandan people, resident in southern Uganda (Reid, 2014). This changed in 1884, when the area was annexed by the British Empire and controlled by the East Africa Company. The country's name, Uganda, derives from a British mis-pronunciation of the Bugandan tribal group — who came to be favoured by the British after helping the colonisers subdue and conquer northern tribes, the origin of a North / South hostility which persists through Uganda's post-colonial history (Reid, 2014).

In 1894, after ten years of supervision by the British East Africa Company, Uganda was officially established by the British Empire as a British Protectorate. British Protectorates were colonial territories which fell under British jurisdiction without being considered full subjects of the reigning British monarch (Weis, 1979)**.** Unlike many other colonial territories, neighbouring Kenya for example, Uganda's status as a British Protectorate afforded the territory an economically limited, degree of self-governance, during which many Indian citizens of the British Empire were brought to Uganda to work in colonial government and administration. Uganda's economy at this time was dominated by the growth and export of cotton. (Reid, 2017).

Uganda gained independence from Britain in 1962 under the leadership of Prime Minister (later President) Milton Obote: a non-Bugandan politician and a member of the Northern-based Lango population. In 1967 under Obote, Uganda declared itself a constitutional republic. Obote's politics were heavily influenced by the post-colonial African Socialist philosophy which was then

flourishing in neighbouring Tanzania under President Julius Nyerere (Friedland and Rosberg, 1964). His wide-ranging reforms included enforced nationalisation of banking and commercial sectors and the dissolution of Uganda's traditional kingdoms. Under this banner of socialism, Obote's reforms had the joint effect of alienating the anti-socialist Western powers and acting as a cover for brutal anti-unionist and anti-Asian domestic policy (Mutibwa, 1992), all contributing to a state of internal instability.

In early 1971, General Idi Amin (then head of the Ugandan Army) deposed Obote in a military coup d'etat. Amin gathered support from many Ugandans, eager to see Obote's regime toppled. Initially friendly to international (particularly Western) interests, Amin sought to undo the socialist policies of Obote's government and at first appeared to shun the leadership role entirely, declaring himself a 'soldier, not a politician' Fairhall (1971:9). Within a year of the coup, however, Amin had declared himself President of Uganda and launched a campaign of violence and suppression against political opponents and rival ethnic groups, particularly the Lango people, from whom Amin's rival Milton Obote had descended (Fairhall, 1971). Under Amin, it is estimated that more than 300,000 Ugandans were murdered for ethnic or political reasons. His regime oversaw the expulsion from Uganda of over 60,000 Asians and the collapse of Ugandan infrastructure (Otiso, 2006). In 1979, another two presidents briefly came to power: Yusufu Lule and his successor Godfrey Binaisa (Otiso, 2006).

In April 1979, Amin was forced to flee Kampala by Tanzanian forces (backed by exiled opponents of Amin) and, by early 1980, former president Milton Obote once again took the reins of power in the country, only to oversee more bloody civil war and once again perpetrate political violence against the population including torture, murder and detention without trial (leading Amnesty International to claim that the state-sanctioned killings and violence begin by Amin only increased under Obote's second period of leadership (Amnesty International, 1989). Obote was once again overthrown in 1985 and, after a short period of struggle, succeeded by another rebel turned leader, Yoweri Museveni.

Following several decades of civil war and military coups d'etat - Uganda has, since 1986, experienced a period of relative stability (CIA, 2014) under incumbent president Yoweri Museveni. Through his participation in the IMF's Economic Recovery Programme, Uganda has secured approximately $700 million per annum in international aid and investment since 1991 (CIA, 2014).

People and population
The 2014 Ugandan census reported a population of 34.6 million (Uganda Bureau of Statistics, 2016). In addition, there is a large refugee population from South Sudan, the Democratic Republic of the Congo, Burundi, Somalia and Rwanda, which in 2017 totalled more than 1 million people (UN High Commissioner for Refugees, 2017).

The majority of the population in Uganda are Ugandan nationals, comprising 98.5% of the population (Uganda Bureau of Statistics, 2016). The people of Uganda identify themselves as originating from 19 main ethnic groups (Otiso, 2006). The largest ethnic groups in Uganda are Baganda (16.5%); Banyankore

(9.6%); Basoga (8.8%) Bakiga (71.%); Iteso (7.0%); Langi (6.3%); Bagisu (4.9%); Acholi (4.4%); Lugbara (3.3%), with 32.1% of the population belonging to other ethnic groups (Uganda Bureau of Statistics, 2016).

Uganda has two official languages, English and Kiswahili. Mukama (2009) described 63 languages / dialects which fall under three language families - Bantu, Sudanic and Nilotic. Uganda is a multi-lingual society, where Ugandans will typically use many languages to varying proficiency (Mpuga, 2003). In 1995, Uganda recognised Ugandan sign language as an official means of communication used by 25,000 people. To this day, however, its use is mainly confined to urban areas (Lutalo-Kiingi, 2014).

The majority of Ugandans identify as religious, with only 0.2% of the population identifying as non-religious. Most Ugandans identify as having a Christian faith, with the majority of Ugandans being Catholics (39.3%) and Anglicans (32%). The Muslim community totals 13.7% of Ugandan population (Uganda Bureau of Statistics, 2016).

Economy
Although rich in natural resources (minerals and oil) Uganda's main economy is agriculture, which employs 80% of the working population (CIA, 2014). 69% of the population depend on subsistence farming as their main source of livelihood (Ugandan Bureau of Statistics, 2016). Despite this, only 10% of the land is considered to have a high production (Otiso, 2006). 0.5% of the Ugandan population have professional occupations (Ugandan Bureau of Statistics, 2016).

Although markers have indicated that poverty levels in Uganda have decreased since 2002 (Daniels and Minot, 2015), there is a high poverty rate, with a household income of $US 1 per day for 34% of the population (CIA, 2014). Child labour continues to exist in Uganda despite significant recent legislation to limit its practice (Bureau of International Labor Affairs, 2016). Child labour is most prevalent in agriculture, Uganda's biggest industry. It is estimated that over 30% of Ugandan children aged 5-14 are currently engaged in some form of child labour (Bureau of International Labor Affairs, 2016).

Politics
Uganda's highest political office is President. Under Yoweri Museveni, presidential elections were introduced in Uganda in 1996. Museveni has since won five elections. The most recent (in 2016) was heavily contested (Murray et al., 2016). Museveni retained his position amid violent protests, accusations of voting abnormalities and the arrests of political opponents (Kron, 2016): events which led many Ugandans and international observers to question the integrity of the result (Gibb, 2016; Abrahamsen and Bareebe, 2016). Amnesty International's 2017 International Report identifies current human rights violations in Uganda including restriction of political freedom, state harassment of journalists and human rights activists, unlawful killings by security forces, and the suppression of LGBT rights events (Amnesty International, 2017).

Under the influence of American Evangelical Christianity (Gettleman, 2010), Uganda's government passed an Anti Homosexuality Act (2014:6) providing strict sentencing guidelines for those found guilty of 'attempts to commit the offence of homosexuality.' Aside from the immediate human rights violation

(Ugandan Minister for Ethics and Integrity, James Nsaba Buturo, was quoted as saying, 'homosexuals can forget about human rights' (Gettleman 2010:no page number)), the 2014 act also has negative impacts on people seeking healthcare (Beyrer, 2014): a potential disaster in a country where 15% of the male homosexual population is HIV positive (UNAIDS, 2014). Further human rights issues in Uganda have been flagged by the Human Rights watchdog organisation Freedom House, who draw attention to Uganda's one-party leadership and limited civil liberty (Freedom House, 2015). While the Museveni administration has traditionally promoted a free press and free elections, recent years have seen crackdowns on internet use and anti-government radio stations as well as the arrests of significant political opponents (Democracy Web, 2016).

4.2.6   Infrastructure

According to the World Bank, Uganda spends 11% of its GDP on infrastructure development: $1 billion per year (Ranganathan and Foster, 2012). While Uganda currently has relatively well-developed sanitation, power generation and water infrastructure, other aspects of infrastructure (including transport infrastructure and road maintenance) are still underfunded and under-developed (Ranganathan and Foster, 2012). The rural / urban divide in Ugandan infrastructure is particularly stark. A lack of rural transport infrastructure means that the rural poor (particularly agricultural workers) are often required to walk miles every day across gravel tracks, in order to trade and earn a living (World Bank, 1995). In terms of access to technology, the majority of Ugandans (55%) access news and information by radio, with only 7.3% accessing news and information through the internet (Ugandan Bureau of Statistics, 2016).

Education

Prior to the establishment of Uganda, traditional education existed (Kristensen et al., 2003). Formal education was introduced in Uganda by Christian missionaries in the 1880s (Ssewamala et al., 2014). These early missionary projects had no formalised curriculum, using teaching to further their missionary aims (Ojijo, 2014). Formal schools were established in the early 20th century, and the curriculum expanded to focus on English and the study of literature alongside Christianity (Ojijo, 2014). The Catholic missionaries who ran these schools exclusively targeted the children of Ugandan chiefs, hoping that alumni would graduate to achieve key positions in society and carry the Christian message with them (Ojijo, 2014). Under the British Colonial Phelps-Stockes Commission in 1924, education was expanded to a wider section of the population but also diverted away from literary and academic standard of European education to instead focus on teaching vocational and community skills based on a colonial perception of African living: a shift that many colonial historians have interpreted as racist and subordinating (Uchendu, 1979, cited in Ojijo, 2014). Following independence, in 1962, the Obote administration moved to universalise education in Uganda, with a particular focus on improving educational access for girls and rural children (Ojijo, 2014). Unfortunately, the previously mentioned turbulent political climate that followed independence meant many of these plans were not fully implemented until 1997.

In 1997, Uganda adopted a policy of universal primary education (UPE), aiming for all Ugandan children to complete seven years of primary school education

(Ssewamala et al., 2014). Initially UPE was open to four children per family (Penny et al., 2008). However this was later expanded to all children. Although UPE remains free to parents and carers (primarily covered by government grants), parents are responsible for the cost of additional expenses such as school resources, uniforms and school meals.

A number of challenges have emerged from UPE. The dramatic increase in children attending schools means that Uganda now has some of the highest student-teacher ratios globally (Deininger, 2003). Both poverty and poor infrastructure contribute to the number of children not completing education, especially in rural areas: poor families often require children to work for money, and poor infrastructure often prevents travel to schools (Ssewamala et al., 2014). As of 2016, 13% of children of primary school age were reportedly not attending school, and 22% of secondary school aged children had left education early (Ugandan Bureau of Statistics, 2016). Girls are more likely to have never attended school, or to have left school early (Ugandan Bureau of Statistics, 2016). Sexual inequality is exacerbated by the unavailability of sanitary products (meaning menstruating girls often miss large amounts of school (Montgomery et al., 2016)) although, in spite of this, educational enrolment for girls did increase significantly at the end of the 20th century (Deininger, 2003; Nishimura et al., 2008).

Despite the increased provision with UPE, it is estimated that 68% of children do not complete primary level education (Mwesigwa, 2015). The 2014 Ugandan census revealed a literacy rate of 72.2% of the population over the age of 10, with significant differences between urban and rural areas (Ugandan Bureau of Statistics, 2016).

Although the government is responsible for leading the provision in education, especially at primary level, individuals and groups both from the private sector and NGOs join the government in providing additional education in Uganda (Ministry of Education and Sports, 2001). Universal secondary education (USE) was introduced in Uganda in 2007 (Ugandan Bureau of Statistics, 2016).

Formal special education in Uganda was also developed from a colonial British model with the first formal special schools established by charities or missionaries from the 1950s onwards (Kristensen et al., 2003). Although Uganda aims to provide inclusive education, some students with special needs receive education in a special school (Kristensen et al., 2006). However, Uganda's special schools do not meet the minimum educational standards of the Ugandan Education Standards Agency (Kristensen et al., 2006). The majority of special schools are boarding schools, where long distances from students' communities often reduces the contact with children's families (Kristensen et al., 2006). Furthermore, many children with disabilities do not attend school at all (Kristensen et al., 2006), for example: only 2% of Deaf children attend school (Miles et al., 2011).

At the tertiary level, universities in Uganda experience a number of challenges. Following the increased number of students completing education (following from the successes of UPE and, more recently, USE), universities have had to rapidly expand over a period of a single decade (Otiso, 2006). Otiso (2006:8) notes challenges including 'poor student supervision, inadequate funding for

classrooms, dorms, sewerage and other infrastructure, equipment and libraries.'

Health

Uganda has a high infant mortality rate of 56/1000 (CIA, 2018), a maternal mortality ratio of 343/100,000 (African Health Observatory and WHO, 2016) and life expectancy at birth was 54.4 for males and 57.3 for females (CIA, 2018).

Causes of death include HIV/AIDS (17.4%), lower respiratory infection (9.6%), malaria (5.6%), diarrhoeal diseases (5.3%), stroke (3.9%), preterm birth complications (3.5%), birth asphyxia and trauma (3.2%), road injury (2.9%), ischaemic heart disease (2.4%) meningitis (2.2%) (WHO, 2015). In terms of the MDGs, since 2000 Uganda had reductions in the maternal mortality rate (360 per 100,000 live births), the deaths from HIV/AIDS (169 per 100,000), deaths from malaria (54.7 per 100,000), and since 1990 a reduction in the under 5 mortality rate (66 per 1000 live births) (WHO, 2015). Despite this progress, only two health MGDs were achieved: reductions in the under five mortality rate and tuberculosis mortality rate (African Health Observatory and WHO, 2016). Uganda has a very high rate of death and traumatic injury from road accidents: 27.4 per 100,000 population (WHO, 2015). 70% of Ugandan road injuries affect pedestrians and motorcycle users (WHO, 2015)). As such, traumatic head injuries (and associated problems) are prevalent in the Ugandan health system, presenting regularly in SLT clinics. Malaria and AIDS-related deaths are also prevalent in Uganda: both appearing in the three most common causes of death in the country (WHO, 2015). Preventable diarrhoea diseases also cause over 18% of yearly deaths (WHO, 2015).

As mentioned in 2.4.2, the emergence of western style medicine and health care in Uganda occurred through foreign medical missionaries, and for services for the Imperial British East Africa Company (Beck,1970). During the First World War, Ugandans were recruited into the African Native Medical Corps, to perform manual labour and basic first aid (Baronov, 2010). East Africans began being trained as medical attendants Mulago Hospital and Makerere Technical College in 1925 (Beck, 1970). The first medical course evolved around this time, into a seven year course similar to those in Great Britain (Williams et al., 1952). Midwifery and nursing were taught in Mengo Hospital in 1917 and 1928 respectively (Mengo Hospital, 2017) with the professions being regulated by the Ugandan Nurses and Midwives Council from 1922 (Ministry of Health, 2016).

As with the education, the health sector in Uganda suffered during the politically turbulent 1970s and 1980s. Under Obote and Amin, the health system was severely underfunded. Staff faced low salaries and delays in payment; medical centres faced shortages of resources including medicine and equipment (Zaramba, 2006).

Under Museveni's rule, the Ugandan government used two main approaches to improve healthcare. Firstly, user fees were introduced in the 1980s, in spite of concerns about how this would affect vulnerable groups' access to services (Tashobya et al., 2006). Secondly, foreign aid money was heavily invested into the health sector: a move which also led to health policy being influenced by the aims and agendas of the donors of the aid (Tashobya et al., 2006). Healthcare markers continued to improved during Museveni's second administration

(1996-2002), however financial support that was largely provided from foreign aid and donors significantly reduced due to concerns about the health sector becoming a 'bottomless pit' (Zaramba, 2006:5) whose fragmented and duplicated structure often wasted resources. In response to this, Museveni's government aimed to coordinate the health system for donors while also abolishing user fees in the state sector in 2001. Following this re-structuring, healthcare in Uganda has been divided between the state and private sectors.

Uganda operates a multi-tier system for healthcare access: starting with locally based Village Health Teams, equipped to provide medical advice and dispense certain medicines to a population of 1000; through to sub-county level Health Centres, led by medical officer and containing a dozen or so medical staff, trained to provide outpatient support and maternity services to a population of 20,000; through to full hospitals; and finally reaching The Mulago National Referral Hospital in Kampala (Kavuma, 2009). The idea behind this system is that relatively simple health issues can be treated locally, while more complex cases can be passed up through the system's tiers to reach the appropriate level of care. In practice, however, this system often breaks down through localised corruption, geographical obstacles and lack of resources (Kavuma, 2009).

Despite the abolition of state sector patient user fees in 2001, the financial impact of healthcare on Uganda's poorest has not fallen, but rather increased, partly due to an increase in use, contributing to a reduction of availability of medicines (Xu et al., 2006).

Additionally, since the abolition of hospital fees, many doctors working in the public sector have turned to private healthcare to supplement their relatively small state income (Kavuma, 2009), sometimes illegally charging state patients for services in state hospitals (Nassaska, 2015). This, alongside a large demand for healthcare and a long waiting list at Mulago, has led to an estimated 50% of health services in Uganda being delivered privately (Nassaska, 2015).

Uganda's recent human rights record (see section 4.2.5) has further complicated the country's access to international healthcare aid. Although Beyrer (2014) advocates for NGOs to not withhold or reduce aid in response to their records on human rights, many institutions (including the US government) announced a withdraw of healthcare funding in 2014 (Butagira, 2014).

Disability
Uganda is considered to have relatively progressive laws concerning disability compared to other countries in sub-Saharan Africa (Yeo and Moore, 2003). Internationally, Uganda has signed legislation advocating for the rights for people with disability (PWD) such as the 2008 United Nations Convention on the Rights of Persons with Disabilities (Abimanyi-Ochom and Mannan, 2014; Hartley et al., 2005).

Estimates on the incidence of disability in Uganda vary. The 2014 census indicated that 13.6% of the Ugandan population over the age of 5 has a disability (Ugandan Bureau of Statistics, 2016), whereas the Ugandan Bureau of statistics and ICF International (2012) suggested that 19% of the Ugandan

population have a disability. Using the population recorded by the Ugandan 2014 census of 34.6 million, this would indicate that 4,705,600 Ugandans have a disability, whereas the figure of 19% would suggest 6,574,000 Ugandans have a disability. Following the breakdown of many health services in Uganda, Wilson (1994) reports there was an increase in disability, particularly cognitive disabilities, because of failing immunisation programmes and a reduction in safe birthing practices.

The National Union of Disabled Persons of Uganda (NUDIPU) formed in 1987 in response to the lack of involvement and representation of PWDs in the planning and execution of programmes designed to benefit them. Previously, programmes were typically performed through charitable ventures and separated PWDs from their communities (NUDIPU, year unknown). NUDIPU brought together PWDs and sought to challenge this top-down model of working, which resulted in over 47,000 PWD obtaining employment within the Ugandan government (Yeo and Moore, 2003).

Communication disability in Uganda
Communication disability in Uganda is not widely recognised. There is limited public and political awareness (Jones et al., 2013; Hartley, 1998). Attitudes to PWCD in Uganda vary but they are often stigmatised. Jones et al. (2013) discussed with two PWCDs their experiences of having acquired communication disability (CD). Here they reported being laughed at because of their disability, being perceived as having a mentally problem or being perceived as having the flu (Jones et al., 2013).

As briefly discussed in chapter 2, there is limited data regarding the prevalence of CD in Majority World countries (Wylie et al., 2013). There are general estimates for the incidence of CD in Uganda. Hartley and Wirz (2002) suggest that between 38% and 49% of all disabled people in Majority World countries may have CD. Using the previously mentioned estimated prevalence of disability of 4,705,600 as a lower estimate and 6,574,000 as an upper estimate, this would suggest that between 2,498,120 and 3,221,260 people in Uganda may have either a communication and/or swallowing disability.

Services for PWCD
There are limited services for PWCD within the Ugandan healthcare system (Barrett, 2010). Awareness and understanding of CD is also limited (Jones et al., 2013). In the absence of services and support, PWCD may be restrained within the family home, or sent away to family in rural areas (Baptist Missionary Society, 2015). Little has been written about PWCD and their carers' use of traditional medicine services, however Hartley et al. (2005) reported people with disabilities, including CDs, changed health worker or traditional healer when their disabilities failed to improve. Services for PWCD include SLT, as well as alternative or complementary services. This includes other health services such as occupational therapy, and special education schools. In Uganda, there is a high prevalence of CDs caused by diseases such as cerebral malaria; infections such as measles, meningitis and HIV/AIDS; and trauma from road traffic accidents, assaults and war (Jochmann, 2006; Alcock and Alibhai, 2013).

Starting in 1986, the main SLT service in Uganda was delivered by the UK NGO Volunteer Services Overseas (VSO) who supplied expatriate SLTs (typically one

at a time on a rotational basis) to Uganda's capital, Kampala (Barrett and Marshall, 2013). The first SLTs were based in Kyambogo, with later SLTs typically based at Mulago hospital, the National Referral Hospital in Uganda. This arrangement was typical of Majority World countries' services at the time which tended to rely on imported Minority World countries' therapists. Barrett (2010:2) reported that many Ugandan stakeholders felt this mode of delivery made SLT services 'inaccessible to the vast majority of the Ugandan population.' Robinson and Tumweheire (2002, cited by Barrett, 2010:6) calculated that 90% of the PWCD seen by the [NGO] SLTs lived within 15 km of Mulago Hospital in Kampala. Due to this rural / urban division, over 98% of Ugandans with disabilities are geographically isolated from potential SLT assistance (Hartley and Wirz, 2002).

An alternative model to encourage sustainability was suggested in the early 2000s. To engage with local stakeholders, a two-day workshop took part to address topics such as the needs of PWCD; who would be the appropriate professionals to work with PWCD; and how best professionals could be trained to work with PWCD (Robinson et al., 2003). Here, stakeholders discussed the training of SLTs and CBR workers to work at different levels to improve access for PWCD; whether an SLT course should have international accreditation; what educational level professionals should be trained to (e.g. Diploma, Bachelor's or Master's) (Robinson et al., 2003). Following the stakeholder workshop, the Ugandan government pledged to employ the trained professionals to work with PWCD (Robinson et al., 2003).

An SLT Bachelor's degree course was eventually established at Makerere University, the oldest Medical School in East Africa (Kiguli-Malwadde et al., 2006), with training provided by both Ugandan lecturers in other disciplines and outsider SLTs. Documents cite the first intake of students in 2008, and their graduation in 2012 (Barrett and Marshall, 2013). The Ugandan SLT course also received students from East Africa, with several students from neighbouring Rwanda, Kenya and Tanzania. In 2010 another stakeholder workshop explored how services for PWCD could be structured within the health and education sector, resulting in recommendations for government (Barrett and Marshall 2013). In 2011, a mentoring project began (lead by the researcher's Director of Studies), offering support to the development of sustainable services for PWCD. This mainly worked by supporting the Ugandan trained SLTs by providing CPD opportunities (Rochus et al., 2014).

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Appendix 4 - Phase one participant information sheets

<u>**Participant Information Sheet : Interview**</u>
An investigation into the perceptions of 'outsider' contributions to sustainable services for people with communication disabilities, in Majority World countries.

You have been invited to take part in a PhD student research project. Before you decide to take part, it is important for you to understand why the research is being done and what it will involve. Please take time to read the following information carefully. Talk to others about the research project if you wish, or contact the researcher at:

ryann.sowden@stu.mmu.ac.uk
Or:
Miss Ryann Sowden
Speech and Language Therapy Clinic
Elizabeth Gaskell Campus
Hathersage Road
Manchester
M13 0JA
England

The purpose of the study is to collect both native and foreign people's views on the contributions of foreigners to the development of services for people with communication disabilities in Uganda.

This part will give you more detailed information about the conduct of the research project. Ask the researcher if there is anything that is not clear or if you would like more information. Take time to decide if you wish to take part.

1. What is the purpose of the research project?
The purpose of the research project is to investigate how foreigners have contributed to the development of sustainable services for people with communication disability in Uganda in order to inform best practice and support future services.

2. Why have I been chosen?
You have been selected to take part in the research as you are a speech and language therapist (SLT), a student SLT, healthcare or teaching professional, Ministry of Health or NGO worker. This research will look at how foreigners are seen to support services for people with communication disabilities.

3. Do I have to take part?
No. Taking part in the research is completely voluntary. It is up to you to decide whether or not to take part. If you do, you will be given this information sheet to keep and be asked to sign a consent form. You are still free to withdraw at any time without giving a reason.

4. What will happen to me if I take part?
If you decide to take part in the research:
• The researcher will contact you to arrange a time for you to be interviewed.
• The interview will last a maximum of one hour. This will take place in a public place
• The interview will consist of questions primarily drawing on your experiences in Uganda of:
  • foreigners involved in helping people with communication disability
  • how foreigners' contributions have helped service developments
  • how you think can foreigners best help in the future
• Interviews will be recorded and typed onto a secure computer. The original recordings will then be destroyed. The transcript on the computer will not contain any identifying details e.g. name, address etc.
• Notes may be taken during the interview, however, these will be destroyed after the interview.
• All information will be kept in confidence.
• If you would like to see a copy of the interview transcript, please ask the researcher for a copy.

5. What are the possible advantages/disadvantages of taking part?

If you decide to take part you may be helping the development of services for people with communication disabilities in Uganda and other countries. The only disadvantage is giving up your time.

6. What happens when the research study stops?
Once the interviews have been completed they will be transcribed. Direct quotations may be used in the research. The research will be submitted to Manchester Metropolitan University. I hope to publish the research once this has been submitted and passed. Participants will receive a summary of the report.

7. Will my taking part in the study be kept confidential?
All data will be stored anonymously on a secure password-access computer. Only my supervisor and I will have access to this. You will not be identified in the research by name unless you request this. Once the study has been completed, and passed, all data on the computer will be
destroyed. Procedures for handling, processing, storage and destruction of their data are compliant with the Data Protection Act 1998.

For more information, please contact the researcher or supervisor of the research:

Researcher's details:
Miss Ryann Sowden
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ryann.sowden@stu.mmu.ac.uk

Supervisor's details:
Dr. Julie Marshall
Research Institute of Health and Social Change (RIHSC) /
Department of Health Professions
MMU, Elizabeth Gaskell Campus
Hathersage Road
Manchester
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England
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An investigation into the perceptions of 'outsider' contributions to sustainable services for people with communication disabilities, in Majority World countries.

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3. Do I have to take part?
No. Taking part in the research is completely voluntary. It is up to you to decide whether or not to take part. If you do, you will be given this information sheet to keep and be asked to sign a consent form. You are still free to withdraw at any time without giving a reason.

4. What will happen to me if I take part?
If you decide to take part in the research:
• The researcher will collect notes from conversations between you and other consenting participants.
• This may be done during joint consultations with patients or at meetings or training events.
• Notes will be typed up at the end of the day and stored on a secure computer. Original notes will be destroyed once typed and stored.

5. What are the possible advantages/disadvantages of taking part?
If you decide to take part you may be helping the development of services for people with communication disabilities in Uganda and other countries. The only disadvantage is giving up your time.

6. What happens when the research study stops?
Once the interviews have been completed they will be transcribed. Direct quotations may be used in the research. The research will be submitted to Manchester Metropolitan University. I hope to publish the research once this has been submitted and passed. Participants will receive a summary of the report.

7. Will my taking part in the study be kept confidential?
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Information Sheet

Title of Project: An investigation into perceptions of outsider contribution to sustainable services for people with communication disabilities in Majority World countries.

Researcher: Ryann Sowden

Can you help with some research?

It is about **communication problems.**

Communication problems mean it can be hard to:

- Talk
- Read
- Listen
- Write

Research can help find out:
• How **Ugandans and Muzungu** can work together to **help people with communication** problems.
•   This may help other people with communication problems

- I would like talk to you about:
- **Can Muzungu help** people with communication problems?
- This will take about 30-40 minutes

- I will tape record our talk

- I will keep the recording in a safe place. I will not let anyone else listen to it

- I will use your words but not say who you are

- It will be at your hospital

If you have any questions:

> ## You do not have to do the research.
>
> - **It is your choice.**
>
> - **You can change your mind.**
>
> - Saying "no" will **not** change or stop you getting help for communication problems.

Ask me now

Ask me later : ryann.sowden@stu.mmu.ac.uk

Ask my boss : j.e.marshall@mmu.ac.uk

Researcher's details:
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Communication problems mean it can be hard to:

• Talk

• Read

• Listen

• Write

• This may help other people with communication problems

I would like to watch you and your SLT working together to find out:

• **Can Muzungu help** people with communication problems?

• This will take about 30-40 minutes

I will write notes about our conversation

• I will keep the notes in a safe place. I will not let anyone else see them

• I will use your words but not say who you are

- It will be at your hospital

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Appendix 5 - Phase one interview topic guide

Miss Ryann Sowden

An investigation into the perceptions of 'outsider' contributions to sustainable services for people with communication disabilities, in Majority World countries.

PHASE ONE

Phase One interview topic guide: 'Outsiders'

Purpose of this interview:
The purpose of the interview is to investigate the perceptions of 'outsider' contributions to sustainable services for people with communication disabilities (PWCD) in Majority World countries. The interviewer aims to collect important data on the past-, present- and potential future-development of services for people with communication disabilities in Uganda. It is hoped this data will contribute to the development of East African services in three ways. Firstly: it is hoped the data will increase the evidence base for services for people with communication disabilities in East Africa. Secondly: by examining positive working examples of outsider/insider collaboration, it is hoped the data will promote sustainable development of future services in Uganda. Finally: by examining the history of outsider/insider collaboration in Uganda, it is hoped the data may provide useful information for the development of services for people with communication disabilities in other under-served countries.

Interview facts:
• The interview should last approximately 60 minutes.
• The interview will be recorded on dictaphone. (Some notes may be taken.)
• The interviewer will begin by focusing on demographic details (e.g. area of work) and then move on to
specific details about how you see the relationship of 'outsiders' and 'insiders' in Uganda.

Background details
• What is your education / training background?
• What is/was your area of work and how long have you been involved in this work?
• Have you worked in any countries other than Uganda?

Interview topic guide
Part a.
• Could you tell me what you know about how services have developed for PWCD in Uganda.
• Before the first Ugandan SLTs qualified what services were there for Ugandan PWCD?
• How do you see existing services for PWCD changing in the future?
Part b.
• Tell me how you started working in services for PWCD in Uganda?
• What were your reasons for working in services for PWCD in Uganda?
• In what way have you supported services for PWCD?

- Tell me about your role and how long you have been in post in Uganda.
- What was your best or biggest contribution?
- What are the challenges and successes of working as an outsider?
- Is there anything you would do differently if you were to do things again?
- What do you think are the most important aspects of collaboration between outsiders and insiders?
- What do you perceive to be the key skills needed for outsiders to have to collaborate with insiders?
- How do you see Ugandans and outsiders working to help PWCD in the future?

Miss Ryann Sowden

An investigation into the perceptions of 'outsider' contributions to sustainable services for people with communication disabilities, in Majority World countries.

PHASE ONE

Phase One interview topic guide: 'Insiders'

Purpose of this interview:
The purpose of the interview is to investigate the perceptions of 'outsider' contributions to sustainable services for people with communication disabilities in Majority World countries. The interviewer aims to collect important data on the past-, present- and potential future-development of services for people with communication disabilities in Uganda.

It is hoped the data will contribute to the development of East African services for PWCD in three ways. Firstly, it is hoped the data will increase the evidence base for services for people with communication disabilities in East Africa. Secondly: by examining positive working examples of outsider/insider collaboration, the data will promote sustainable development of future services in Uganda. Finally, by examining the history of outsider/insider collaboration in Uganda, it is hoped the resulting data may provide useful information for the development of services for people with communication disabilities in other under-served countries.

Interview facts:
The interview should last approximately 60 minutes.
The interview will be recorded on dictaphone. (Some notes may be taken.)
The interviewer will begin by focusing on demographic details (e.g. your area of work) and then move on to
talking about specific details about how you see the relationship of 'outsiders' and 'insiders' in Uganda.

Background details
• What is your education / training background?
• What is your area of work and how long have you been involved in this work?
• What does your current role involve?
• Have you ever worked outside Uganda?
Interview topic guide
Due to the broad range of 'insider' roles in Uganda, topics will be selected from the following guide by
relevance to each individual participant.

Interview topic guide
Part a.
• Could you tell me what you know about how services have developed for PWCD in Uganda.
• Before the first Ugandan SLTs qualified what services were there for Ugandan PWCD?
• What is the current situation of services for PWCD?

• How do you see existing services for PWCD changing in the future?

Part b.
• Tell me about how you started working with developing services for PWCD?
• Please tell me about your reasons for working for services for PWCD?
• Tell me about when you have encountered 'outsiders' in your current / previous roles in services for
PWCD.
• What were your best or biggest contributions?
• What have been some of the challenges and successes of collaborative work between insiders and
outsiders?
• What do you think are the most important aspects of collaboration between outsiders and insiders?
• What do you perceive to be the key skills needed for outsiders to have to collaborate with insiders?
• Is there anything you would do differently in the future?
• Do you think outsiders should play a role in the future to support services for PWCD?

Appendix 6 - Phase one consent forms

Consent Form: Interviews

Title of project: An investigation into the perceptions of 'outsider' contributions to sustainable services for people with communication disabilities, in Majority World countries.

Name of researcher: Miss Ryann Sowden

Please initial each box

1. I confirm that I have read and understand the information sheet dated _____ for the above study.

2. I have had the opportunity to consider the information, ask questions and I have had all my questions answered satisfactorily.

3. I understand that my participation is voluntary and that I am free to withdraw at any time without giving any reason.

4. I agree for direct quotations from my interview to be used in the research report. All identifying information will be removed and a pseudonym (false name) will be used.

5. I agree for my interview to be recorded, typed verbatim and stored until completion of completion of the PhD: at which time the information will be destroyed.

6. I agree to take part in the above study.

_____   _____   _____

Name of Participant   Date   Signature

_____   _____   _____

Name of Person taking consent   Date   Signature

Consent Form : participant-observation

Consent for adult participants : Interview

Title of project: An investigation of the contribution of Muzungu into development of services for Ugandans with communication disabilities

Researcher: Ryann Sowden

Please tick (√) to agree:

1. I have read the information sheet (   )

2. I have understood the information sheet (   )

3. I have been able to ask questions about the research (   )

4. The researcher has answered my questions about this research (   )

5. I understand it is my choice to take part in this research (   )

6. I understand I can change my mind and stop at any time (   )

7. If I stop taking part in the research it will not affect me receiving speech and language therapy (   )

8. I agree for our talk to be recorded   (   )

9. I understand my name will not be used in the report (   )

10. I agree for my words to be used in the report (   )

11. I agree to take part in this research (   )

Name ....
Signature/ thumb print

Signature ....

Date ....

Consent for adult participants : Observations

Title of project: An investigation of the contribution of Muzungu into development of services for Ugandans with communication disabilities

Researcher: Ryann Sowden

Please tick (√) to agree:

1. I have read the information sheet (   )

2. I have understood the information sheet (   )

3. I have been able to ask questions about the research (   )

4. The researcher has answered my questions about this research (   )

5. I understand it is my choice to take part in this research (   )

6. I understand I can change my mind and stop at any time (   )

7. If I stop taking part in the research it will not affect me receiving speech and language therapy (   )

8. I agree for our talk to be written down   (   )

9. I understand my name will not be used in the report (   )

10. I agree for my words to be used in the report (   )

11. I agree to take part in this research (   )

Name ....
Signature/ thumb print

Signature ....

Date ....

Appendix 7 - Phase one observation layout

Participants	Observational Notes	Initial interpretations

Document number	Document title	Document type	Insi der	Ou tsi der	Coll abor ative	?
1	The Fourth East African Conference on Communication Disability: Strengthening Partnerships to Promote Services	**Conference report**			Y	
2	Embedding Speech and Language Therapy Services in Uganda's Health and Education Systems				Y	
3	Makerere University: ANNOUNCEMENT FOR 2015/2016 UNDERGRADUATE PRIVATE ADMISSIONS	**University policy documents**	Y			
4	MAKERERE UNIVERSITY : ACADEMIC REGISTRAR'S DEPARTMENT PRIVATE ADMISSIONS, 2014/2015 CUT OFF POINTS 2014/2015		Y			
5	Makerere University: EMPLOYMENT OPPORTUNITIES (EXTERNAL ADVERTISEMENT) ACADEMIC & ADMINISTRTIVE STAFF.		Y			
6	Higher Education Students' Fianancing Board: CALL FOR LOAN APPLICATIONS		Y			
7	MAKERERE UNIVERSITY ACADEMIC REGISTRAR'S DEPARTMENT ADMISSIONS, 2014/2015 ACADEMIC YEAR		Y			
8	MAKERERE UNIVERSITY ACADEMIC REGISTRAR'S DEPARTMENT ADMISSIONS, 2013/2014 ACADEMIC YEAR		Y			
9	MINISTRY OF HEALTH: THE ALLIED HEALTH PROFESSIONALS COUNCIL NOMINATION OF COUNCIL CHAIRPERSON, COUNCIL AND ADVISORY BOARD MEMBERS.		Y			
10	MAKERERE UNIVERSITY: ADMISSION REQUIREMENTS, 2015/2016 ACADEMIC YEAR		Y			
11	Newsletter of the National Black Association for Speech-Language and Hearing: Report of The Fifth East African Conference on Communication Disability Mombasa, Kenya – September 2-5, 2013	**Newsletter**		Y		
12	Looking to the future with Uganda's first Speech and Language Therapists	Newsletter		Y		
13	The state of ACCESS TO EDUCATION BY WOMEN & GIRLS WITH DISABILITIES THE CASE OF UGANDA	**National policy document**	Y			
14	Improving disability services in developing countries	**Project report**		Y		
15	Research-informed development of appropriate services for people with disabilities in Majority world countries (underserved countries)			Y		
16	Out of Africa: The Spreading Self-Help Movement		Y			
17	Services for people with communication disabilities in Uganda			Y		

Document number	Document title	Document type	Insider	Outsider	Collaborative	?
18	Mulago Speech Therapy Project, Kampala, Uganda			Y		
19	Study Speech and Language Therapy at Makerere University	**University recruitment leaflet**			Y	
20	Corsu Career Jobs	**Volunteer adverts**				?
21	Spring of Hope Uganda Volunteer Opportunities					?
22	Spring of Hope Uganda Why Children with Disabilities?					?
23	Help at our special needs children's center near Kampala, Uganda					?
24	Help stuttering students in Uganda towards self confidence and self reliance					?
25	Speech and language therapists and audiologists Volunteer opportunities overseas for speech and language therapists (SLT)					?
26	Speech and Language Therapist NGO Jobs - CoRSU					?
27	Speech and language therapist volunteer jobs l VSO Ireland			Y		
28	speech and language therapist Voluntary opportunity in Uganda			Y		
29	Speech and language therapist					?
30	Spring of Hope Uganda SoHUG: Volunteer					?
31	Spring of Hope Uganda SoHUG: Real Stories					?
32	VSO ANNUAL REPORT AND FINANCIAL STATEMENTS FOR THE YEAR ENDED 31 MARCH 2011	**NGO documents**		Y		
33	VSO Annual Country Review Report – Uganda Financial Year 2011 – 2012			Y		
34	VSO Uganda Strategy 2012–15			Y		
35	VSO Uganda's success in speech and language therapy			Y		
36	VSO Uganda Annual Report 1st April 2012 - 31st March 2013			Y		
37	VSO Uganda Annual Report 1st April 2013 - 31st March 2014			Y		
38	Empowered autistic children Uganda	Webpages	Y			
39	How can Uganda address the stammering problem?		Y			
40	Kyaninga Child Development Centre			Y		
41	Uganda - East Africa - Africa - Your country - Prospective International students - The University of Sheffield		Y			

Document number	Document title	Document type	Insi der	Ou tsi der	Coll abor ative	?
42	Private Speech & Language Therapy Services (PSLTS)		Y			
43	Uganda: Muk Speech Therapy Course Cash-Strapped		Y			
44	Speech Language Therapy in East Africa: Developments in the Region			Y		
45	BMS Helping the silent speak: speech therapy in Uganda			Y		
46	Speech Therapy work in Uganda			Y		
47	Graduate sets up autism school in Uganda					
48	our journey from michigan to uganda: Empowering & Equipping	Blog		Y		
49	our journey from michigan to uganda: Our Story			Y		
50	Speech Therapy at Ewafe			Y		
51	Uganda SLT conference Placement Reflection – Uganda			Y		
52	Communication rehabilitation in sub-Saharan Africa / A workforce profile of speech and language therapists	**Journal articles**		Y		
53	Delayed primary palatal closure in resource-poor countries: Speech results in Ugandan older children and young adults with cleft (lip and) palate			Y		
54	Developmentof a'communication disability model'and its implication on service delivery in low-income countries			Y		
55	Impact of Early Synchronous Lip and Palatal Repair on Speech			Y		
56	Implementation of the World Report on Disability: Developing human resource capacity to meet the needs of people with communication disability in Uganda			Y		

Document number	Document title	Document type	Insi der	Ou tsi der	Coll abor ative	?
57	Involving people with communication disability in research in Uganda: A response to the World Report on Disability			Y		
58	Normative Nasalance Data in Ugandan English-Speaking Children			Y		
59	Preliminary Planning for Training Speech and Language Therapists in Uganda			Y		
60	Short-term effect of short, intensive speech therapy on articulation and resonance in Ugandan patients with cleft (lip and) palate			Y		
61	Speech characteristics in a Ugandan child with a rare paramedian craniofacial cleft: A case report			Y		
62	The impact of palatal repair before and after 6 months of age on speech characteristics			Y		
63	Give me someone who has been here before'	**Bulletin Articles**			Y	
64	Assistants in Uganda				Y	
65	East Africa will rise to meet its communication challenges			Y		
66	East African conference continues to grow			Y		
67	**Helping the world to speak**					
68	**It's time to take a deeper look**					
69	Looking to the future with Uganda's first SLTs			Y		
70	Makerere University students play their part in ICP2014			Y		
71	Nairobi conference unites regional SLTs			Y		
72	**Therapy in Tanzania**					
73	**Unity is strengths in East Africa**					
74	Voluntary Services			Y		

Appendix 8 - Documents for document analysis

Appendix 9 - Phase two country matrix

Commonwealth country	HDI rank 2013	HDI 2013 (low, medium, high or very high)	L, M, H IC 2014	SLT situation as of 2015			
				Training course	SLTs?	Insider SLTs	Outsider involvement?
Antigua and Barbuda	61	High	H	Y (UWI)	Y		
Australia	2	Very high	H	Y	Y	Y	Y
The Bahamas	51	High	H	Y	Y		
Bangladesh	**142**	**Low**	**LM**	**Y**	**Y**	**Y**	**Y**
Barbados	59	High	H	Y (UWI)	Y		
Belize	84	High	UM	Y (UWI)	N	N	Y
Botswana	109	Medium	UM	N	Y		Y
Brunei Darussalam	30	Very high	H	N	Y		
Cameroon	152	Low	LM				Y
Canada	8	Very high	H	Y	Y	Y	Y
Cyprus	32	Very high	H	Y	Y		
Dominica	93	High	UM	Y (UWI)			
Fiji	88	High	UM		Y		Y
Ghana	138	Low	LM		Y	Y	Y
Grenada	79	High	UM	Y (UWI)			Y
Guyana	121	Medium	LM	Y (UWI)		N	Y
India	**135**	**Medium**	**LM**	**Y**	**Y**	**Y**	**Y**
Jamaica	**96**	**High**	**UM**	**Y (UWI)**	**Y**	**Y**	**Y**
Kenya	**147**	**Low**	**LM**	**Y**	**Y**	**Y**	**Y**
Kiribati	133	Medium	LM				
Lesotho	162	Low	LM			N	N
Malawi	174	Low	L	N		N	Y
Malaysia	**62**	**High**	**UM**	**Y**	**Y**	**Y**	**Y**

Commonwealth country	HDI rank 2013	HDI 2013 (low, medium, high or very high)	L, M, H IC 2014	SLT situation as of 2015			
				Training course	SLTs?	Insider SLTs	Outsider involvement?
Maldives	103	Medium	UM		Y	Y	
Malta	39	Very high	H	Y	Y	Y	Y
Mauritius	63	High	UM		Y		
Mozambique	178	Low	L	?			Y
Namibia	127	Medium	UM		Y		
Nauru	-	-	-				
New Zealand	7	Very high	H	Y	Y	Y	Y
Nigeria	**152**	**Low**	**LM**	**Y**	**Y**	**Y**	**Y**
Pakistan	146	Low	LM	Y	Y	Y	
Papua New Guinea	157	Low	LM		Y		Y
Rwanda	151	Low	L	N	Y	Y	Y
Seychelles	71	High	H		Y		
Samoa	106	Medium	LM				Y
Sierra Leone	183	Low	L				
Singapore	9	Very high	H	Y	Y	Y	Y
Solomon Islands	157	Low	LM				
South Africa	**118**	**Medium**	**UM**	**Y**	**Y**	**Y**	**Y**
Sri Lanka	**73**	**High**	**LM**	**Y**	**Y**	**Y**	**Y**
St Kitts and Nevis	73	High	H	Y (UWI)			Y
St Lucia	97	High	UM	Y (UWI)			Y
St Vincent and The Grenadines	91	High	UM	Y (UWI)	Y		
Swaziland	148	Low	LM		Y		Y
Tanzania	159	Low	L		Y	Y	Y
Tonga	100	High	UM				

Commonwealth country	HDI rank 2013	HDI 2013 (low, medium, high or very high)	L, M, HIC 2014	SLT situation as of 2015			
				Training course	SLTs?	Insider SLTs	Outsider involvement?
Trinidad and Tobago	**64**	**High**	**H**	**Y (UWI)**	**Y**	**Y**	**Y**
Tuvalu	-	-	UM				
Uganda	**164**	**Low**	**L**	**Y**	**Y**	**Y**	**Y**
United Kingdom	14		H	Y		Y	Y
Vanuatu	131	Medium	LM				Y
Zambia	141	Medium	LM	Y			Y

Appendix 10 - Phase two pilot survey

An investigation into the perceptions of 'outsider' contributions to sustainable services for people with communication disabilities, in Majority World / developing countries

This survey has been developed from research into the perceptions of outsiders' contributions to sustainable services for people with communication disabilities, in Uganda.

"Insiders" are defined as native (or locally trained) individuals or institutions operating in Ghana

"Outsiders" are defined as foreign, non-native health professionals working to develop / establish services in under-served countries.

"People with communication disabilities" are defined as children and adults who have difficulty with aspects of speech, language or swallowing.

1. You have been selected to take part in the research as you are a speech and language therapist (SLT), a student SLT, another healthcare or teaching professional, or an NGO worker. This research will look at how outsiders are seen to support services for people with communication disabilities.

2. This survey aims to discover:
• your experiences and perceptions of the contributions of outsiders to services for people with communication disabilities in Ghana.
• the impact you feel outsiders have had on services for people with communication disabilities.
• your thoughts on what makes a successful collaboration with outsiders, in relation to these services.
• any specific challenges you have encountered when working with outsiders.

3. The survey should take 20 - 25 minutes to complete. Please feel free to add as much detail as you like. Your insights and experiences will be highly valued. The data collected will be confidential and anonymous and will be published as part of my PhD research.

I have received ethical approval from Manchester Metropolitan University for this research.

1. What are the possible advantages/disadvantages of taking part?
If you decide to take part you may be helping the development of services for people with communication disabilities internationally. The only disadvantage is giving up your time.

2. How will the data be used?
Completed surveys will be analysed and findings reported anonymously in my PhD thesis to Manchester Metropolitan University. Direct quotations may be used in the write up. I hope to publish the research once this has been submitted and passed. Participants will receive a summary of the report.

3. Will my taking part in the study be kept confidential?
All data will be stored anonymously on a secure password-protected computer. Only my supervisors and I will have access to this. You will not be identified in the research by name. Any quotations used will be anonymised to prevent identification of participants.

Procedures for handling, processing, storage and destruction of their data are compliant with the Data Protection Act 1998.

Thank you for your time.

Ryann Sowden,

If you have any questions, please contact me or my Director of Studies for more information:

Ryann Sowden, post-graduate research student at Manchester Metropolitan University
ryann.sowden@mmu.ac.uk

Director of Studies: Dr Julie Marshall, Manchester Metropolitan University
j.e.marshall@mmu.ac.uk

Please complete this section to see if you meet the criteria for the study.

Please mark X to all that apply. To take part in this research, you must meet <u>all</u> of the following criteria:	425 of 450
All of part of my work is to support people with communication disabilities OR to train others to do so	
I have worked/interacted with outsiders as part of my work with people with communication disabilities	
I am confident in my ability to read and respond to survey questions in English	

Please complete this survey with reference to your experience with outsiders in Ghana.Your experience may range from working with just one outsider to working with many outsiders. Please use any examples from your own experience that you feel are relevant.

1: From your working experience, which of the following roles have outsiders filled in Ghana to support services for people with communication disabilities?	**(Please mark X to all that apply)**
Campaigning for more services for people with communication disabilities	
Campaigning for the rights of people with communication disabilities	
Providing direct services to people with communication disabilities	
Training of parents or carers of people with communication disabilities	
Training teachers about communication disabilities	
Training local health professionals about communication disabilities	
Raising awareness about communication disabilities	
Research into communication disabilities	
Fundraising for people with communication disabilities	
Funding scholarships for professionals to train to support people with communication disabilities	
Resources for people with communication disabilities	
Other: Please add detail	

2: If insiders and outsider have worked together to support services for people with communication disabilities, how is this initiated?	**(Please mark X to all that apply)**
A single insider initiated work	
An organisation inside Ghana initiated the work	
A single outsider initiated the work	
An organisation outside Ghana initiated the work	
Not known	

2: If insiders and outsider have worked together to support services for people with communication disabilities, how is this initiated?	*(Please mark X to all that apply)*
Other: Please add detail	

3: Which of these best describes the most common way that insiders and outsiders work to support services for people with communication disabilities?	*(Please mark X to the answer that best applies)*
Outsider-led	
Insider-led	
Equal	
Other (please specify):	

4: Which of these statements best describes the aims of outsiders who support services for people with communication disabilities in Ghana?	*Please say why you think this is*
The majority of outsiders aim to work *with* insiders in Ghana?	
The majority of outsiders aim to work *independently of* insiders in Ghana?	

5: Thinking just about outsiders that you have worked with with, what countries did they come from?

6: Which of these statements best describes your thoughts on the nationalities of outsiders who support services for people with communication disabilities in Ghana?	*Please say why you think this is*
The nationality of outsiders has sometimes or always affected our working relationship	
The nationality of outsiders has never affected our working relationship	

7: From your experience, describe a "typical" outsider who works to support services for people with communication disabilities. For example, their age, experience level, length of stay etc.:

8: In your experience, what do you think motivates outsiders to work in developing services for people with communication disabilities in Ghana?	*(Please mark X to all that apply)*
To observe services for people with communication disabilities in another context	
Charitable / altruistic motivation	
Religious motivation	
Personal experience	
Career experience	
Opportunity to make money	
Tourism	
Other: Please add detail	

9: In your experience, do you think outsiders' motivations for working with people with communication disabilities in Ghana are similar to your own motivations?

— What effect, if any, does this have on working together?

10: From your experience of working with outsiders to support services for people with communication disabilities, what do you think are outsiders' typical initial perceptions of Ghana?

— Do their perceptions tend to change during the course of working together?

11: From your experience, what do you think are outsiders' perceptions of services for people with communication disabilities in Ghana?

— Do their perceptions tend to change during the course of working together?

12: What are the most common cultural misunderstandings between outsiders and insiders who work together to support services for people with communication disabilities?

13: In your experience, which of these statements best describes the treatment of outsiders who support services for people with communication disabilities in Ghana?	*Please say why you think this is*
Outsiders and insiders are treated equally in Ghana?	
Outsiders and insiders are treated differently in Ghana?	

14: To what extent do you agree with the statement *"outsider contributions need to be sustainable in order effectively to support services for people with communication disabilities?"* *(Please mark X to the answer that best applies)*				
Strongly disagree	Disagree	Neither agree or disagree	Agree	Strongly agree

15. What do you think are the best ways to ensure sustainable working practices from outsiders when working to support services for people with communication disabilities?

16. From your own experience, please rate the following types of outsider contributions in terms of their value on developing services for people with communication disabilities.

(Please mark X in the relevant box for each option)

	No value	Little value	Some value	Significant value	Have not experienced
Campaigning for increased communication services					
Campaigning for rights of people with communication disability					
Supporting people with communication disabilities with direct intervention					
Training of parents or carers of people with communication disability					
Training of teachers					
Training of local health professionals					
Raising awareness of communication disabilities					
Research into communication disabilities in Ghana					
Providing funding for individual intervention					
Providing funding for scholarships to support people with communication disabilities					
Resources/funding for resources for people with communication disabilities					

17: In your opinion, what qualities, skills and experiences would be most and least wanted from outsiders who support services for people with communication disabilities?

Most wanted	Least wanted

17: In your opinion, what qualities, skills and experiences would be most and least wanted from outsiders who support services for people with communication disabilities?	

18. From your own experience of working with outsiders to develop services for people with communication disabilities in Ghana, please evaluate the following statements.

Please mark X in the relevant box to show your response to each statement and add any comments you may have.

	Strongly disagree	Disagree	Neither agree or disagree	Agree	Strongly agree	*Please add comments*
Working together with outsiders has generally been successful						
There are clinical challenges in working with outsiders						
There are cultural barriers in working with outsiders						
Outsiders have effectively contributed to the development of services for people with communication disabilities						
Outsiders' contributions have been appropriate to the needs of Ghana						
Outsiders' contribution has made a lasting difference						

18. From your own experience of working with outsiders to develop services for people with communication disabilities in Ghana, please evaluate the following statements.

Please mark X in the relevant box to show your response to each statement and add any comments you may have.

Outsiders' contributions have led to fewer opportunities for local health professionals						
Outsiders are needed in Ghana to support services for people with communication disabilities						
Outsiders are wanted in Ghana to support services for people with communication disabilities						
Short-term (3 months or less) work is most suitable in Ghana						
Medium-term (between 3 months and a year) work is most suitable in Ghana						
Long-term (more than a year) work is most suitable in Ghana						

Any Further Comments:
If you have any further comments on the role of outsiders in Ghana in supporting services for people with communication disabilities, please add them here.

Demographic Questions:

The following questions look at basic demographic information and your experience with outsiders.

Q: What is your gender:

(Please leave blank if you do not wish to disclose)

Q: What is your nationality:

(Please leave blank if you do not wish to disclose)

Q: What is your age:

20-24	25-29	30-34	35-39	40-44	45-49	50-54	55-59	60-64	65-69	70+

(Please leave blank if you do not wish to disclose)

Q: What is your ethnicity:

(Please leave blank if you do not wish to disclose)

Q: What is your professional occupation?

Q: How are you involved in supporting people with communication disabilities?

Q: Please detail your professional qualifications

Q: Have you ever received training abroad? If so, please give details:

Thank you very much for participating in this research.

Appendix 11 - Phase two final survey

<u>**An investigation into the perceptions of 'outsider' contributions to sustainable services for people with communication disabilities, in Majority World / developing countries**</u>

This survey has been developed from research into the perceptions of outsiders' contributions to sustainable services for people with communication disabilities, in Uganda.

__"Insiders"__ are defined as native (or locally trained) individuals or institutions operating in Kenya

__"Outsiders"__ are defined as foreign, non-native health professionals working to develop / establish services in under-served countries.

__"People with communication disabilities"__ are defined as children and adults who have difficulty with aspects of speech, language or swallowing.

1. You have been selected to take part in the research as you are a speech and language therapist (SLT), a student SLT, another healthcare or teaching professional, or an NGO worker. This research will look at how outsiders are seen to support services for people with communication disabilities.

2. This survey aims to discover:
· your experiences and perceptions of the contributions of outsiders to services for people with communication disabilities in Kenya.
· the impact you feel outsiders have had on services for people with communication disabilities.
· your thoughts on what makes a successful collaboration with outsiders, in relation to these services.
· any specific challenges you have encountered when working with outsiders.

3. The survey should take 20 - 25 minutes to complete. Please feel free to add as much detail as you like. Your insights and experiences will be highly valued. The data collected will be confidential and anonymous and will be published as part of my PhD research.

I have received ethical approval from Manchester Metropolitan University for this research.

1. What are the possible advantages/disadvantages of taking part?

If you decide to take part you may be helping the development of services for people with communication disabilities internationally. The only disadvantage is giving up your time.

2. How will the data be used?

Completed surveys will be analysed and findings reported anonymously in my PhD thesis to Manchester Metropolitan University. Direct quotations may be used in the write up. I hope to publish the research once this has been submitted and passed. Participants will receive a summary of the report.

3. Will my taking part in the study be kept confidential?

All data will be stored anonymously on a secure password-protected computer. Only my supervisors and I will have access to this. You will not be identified in the research by name. Any quotations used will be anonymised to prevent identification of participants.

Procedures for handling, processing, storage and destruction of their data are compliant with the Data Protection Act 1998.

Thank you for your time.

Ryann Sowden,

If you have any questions, please contact me or my Director of Studies for more information:

Ryann Sowden, post-graduate research student at Manchester Metropolitan University
ryann.sowden@mmu.ac.uk

Director of Studies: Dr Julie Marshall, Manchester Metropolitan University
j.e.marshall@mmu.ac.uk

Please complete this section to see if you meet the criteria for the study.

Please mark X to all that apply. To take part in this research, you must meet <u>all</u> of the following criteria:	436 of 450
All of part of my work is to support people with communication disabilities OR to train others to do so	
I have worked/interacted with outsiders as part of my work with people with communication disabilities	
I am confident in my ability to read and respond to survey questions in English	

Please complete this survey with reference to your experience with outsiders in Kenya. Your experience may range from working with just one outsider to working with many outsiders. Please use any examples from your own experience that you feel are relevant.

1. From your working experience, which of the following roles have outsiders filled in Kenya to support services for people with communication disabilities?	*(Please mark X to all that apply)*
Campaigning for more services for people with communication disabilities	
Campaigning for the rights of people with communication disabilities	
Providing direct services to people with communication disabilities	
Training of parents or carers of people with communication disabilities	
Training teachers about communication disabilities	
Training local health professionals about communication disabilities	
Raising awareness about communication disabilities	
Research into communication disabilities	
Fundraising for people with communication disabilities	
Funding scholarships for professionals to train to support people with communication disabilities	
Resources for people with communication disabilities	
Other: Please add detail	

2. If insiders and outsider have worked together to support services for people with communication disabilities, how is this initiated?	*(Please mark X to all that apply)*
A single insider initiated work	
An organisation inside Kenya initiated the work	
A single outsider initiated the work	
An organisation outside Kenya initiated the work	
Not known	
Other: Please add detail	

3. Which of these best describes the most common way that insiders and outsiders work to support services for people with communication disabilities?	(Please mark X to the answer that best applies)
Outsider-led	
Insider-led	
Equal	
Other (please specify):	

4. Which of these statements best describes the aims of outsiders who support services for people with communication disabilities in Kenya?	Please say why you think this is
The majority of outsiders aim to work *with* insiders in Kenya?	
The majority of outsiders aim to work *independently of* insiders in Kenya?	

5. Thinking just about outsiders that you have worked with, what countries did they come from?

6. Which of these statements best describes your thoughts on the nationalities of outsiders who support services for people with communication disabilities in Kenya?	Please say why you think this is
The nationality of outsiders has sometimes or always affected our working relationship	
The nationality of outsiders has never affected our working relationship	

7. From your experience, describe a "typical" outsider who works to support services for people with communication disabilities. For example, their age, experience level, length of stay etc.:

8. In your experience, what do you think motivates outsiders to work in developing services for people with communication disabilities in Kenya?	**(Please mark X to all that apply)**
To observe services for people with communication disabilities in another context	
Charitable / altruistic motivation	
Religious motivation	
Personal experience	
Career experience	
Opportunity to make money	
Tourism	
Other: Please add detail	

9.a. In your experience, do you think outsiders' motivations for working with people with communication disabilities in Kenya are similar to your own motivations?

9.b. What effect, if any, does this have on working together?

10.a. From your experience of working with outsiders to support services for people with communication disabilities, what do you think are outsiders' typical initial perceptions of Kenya?

10.b. Do their perceptions tend to change during the course of working together?

11.a. From your experience, what do you think are outsiders' perceptions of services for people with communication disabilities in Kenya?

11.b. Do their perceptions tend to change during the course of working together?

12. What are the most common cultural misunderstandings between outsiders and insiders who work together to support services for people with communication disabilities?

13. In your experience, which of these statements best describes the treatment of outsiders who support services for people with communication disabilities in Kenya?	*Please say why you think this is*
Outsiders and insiders are treated equally in Kenya?	
Outsiders and insiders are treated differently in Kenya?	

14. To what extent do you agree with the statement *"outsider contributions need to be sustainable in order effectively to support services for people with communication disabilities?"*

(Please mark X to the answer that best applies)

Strongly disagree	Disagree	Neither agree or disagree	Agree	Strongly agree

15. What do you think are the best ways to ensure sustainable working practices from outsiders when working to support services for people with communication disabilities?

16. From your own experience, please rate the following types of outsider contributions in terms of their value on developing services for people with communication disabilities.

(Please mark X in the relevant box for each option)

	No value	Little value	Some value	Significant value	Have not experienced
Campaigning for increased communication services					
Campaigning for rights of people with communication disability					
Supporting people with communication disabilities with direct intervention					
Training of parents or carers of people with communication disability					

16. From your own experience, please rate the following types of outsider contributions in terms of their value on developing services for people with communication disabilities.

(Please mark X in the relevant box for each option)

Training of teachers					
Training of local health professionals					
Raising awareness of communication disabilities					
Research into communication disabilities in Kenya					
Providing funding for individual intervention					
Providing funding for scholarships to support people with communication disabilities					
Resources/funding for resources for people with communication disabilities					

17. In your opinion, what qualities, skills and experiences would be most and least wanted from outsiders who support services for people with communication disabilities?

Most wanted	Least wanted

18. From your own experience of working with outsiders to develop services for people with communication disabilities in Kenya, please evaluate the following statements.

Please mark X in the relevant box to show your response to each statement and add any comments you may have.

	Strongly disagree	Disagree	Neither agree or disagree	Agree	Strongly agree	*Please add comments*

18. From your own experience of working with outsiders to develop services for people with communication disabilities in Kenya, please evaluate the following statements.

Please mark X in the relevant box to show your response to each statement and add any comments you may have.

Working together with outsiders has generally been successful						
There are clinical challenges in working with outsiders						
There are cultural barriers in working with outsiders						
Outsiders have effectively contributed to the development of services for people with communication disabilities						
Outsiders' contributions have been appropriate to the needs of Kenya						
Outsiders' contribution has made a lasting difference						
Outsiders' contributions have led to fewer opportunities for local health professionals						
Outsiders are needed in Kenya to support services for people with communication disabilities						
Outsiders are wanted in Kenya to support services for people with communication disabilities						

18. From your own experience of working with outsiders to develop services for people with communication disabilities in Kenya, please evaluate the following statements.

Please mark X in the relevant box to show your response to each statement and add any comments you may have.

Short-term (3 months or less) work is most suitable in Kenya						
Medium-term (between 3 months and a year) work is most suitable in Kenya						
Long-term (more than a year) work is most suitable in Kenya						

Any Further Comments:

If you have any further comments on the role of outsiders in Kenya in supporting services for people with communication disabilities, please add them here.

Demographic Questions:

The following questions look at basic demographic information and your experience with outsiders.

Q: What is your gender:
(Please leave blank if you do not wish to disclose)

Q: What is your nationality:
(Please leave blank if you do not wish to disclose)

Q: What is your age:

20-24	25-29	30-34	35-39	40-44	45-49	50-54	55-59	60-64	65-69	70+

(Please leave blank if you do not wish to disclose)

Q: What is your ethnicity:
(Please leave blank if you do not wish to disclose)

Q: What is your professional occupation?

Q: How are you involved in supporting people with communication disabilities?

Q: Please detail your professional qualifications

Q: Have you ever received training abroad? If so, please give details of which qualifications and where:

Thank you very much for participating in this research.

Appendix 12 - Phase two letters

Dear Sir or Madam,

My name is Ryann Sowden. I am a speech and language therapist from Manchester, England. I am currently studying for a PhD at Manchester Metropolitan University and Dr Julie Marshall is my Director of Studies.

I am researching collaboration between professionals across the world, specifically the ways in which local and foreign professionals work together to provide training for professionals and services for people with communication disabilities in low income, middle income and under-served countries.

Having completed an in-depth study, examining local and foreign collaboration in Uganda, I am now looking to expand my research by exploring local and foreign collaborations in several other countries. I would very much like to include Kenya.

Would be willing to take part in this study?

This research will take the form of a short survey that is attached to this email. The survey explores your experiences and opinions regarding foreign speech and language therapy professionals in Kenya.

If you are interested, please firstly check that you are eligible. This means:

• All of part of your work is to support people with communication disabilities, or to train others to do so

• You have worked/interacted with outsiders as part of your work with people with communication disabilities

Please then complete the survey by downloading the attached Word document, filling in your answers, saving the completed document and then sending it back to me as an attachment.

Finally, if you know anyone else who might be willing to complete this survey, please would you forward this email to them.

I hope this research will identify views regarding the successes, challenges and opportunities involved in collaborating internationally. I hope my findings will benefit the development of services for people with communication disabilities globally.

I would be grateful if you would reply Thursday 31st December.

Thank you for your time. If you have any queries please don't hesitate to get in touch with me or my supervisor by email (provided below).

Yours sincerely

Miss Ryann Sowden

PhD student at Manchester Metropolitan University
ryann.sowden@stu.mmu.ac.uk
Director of Studies: Julie Marshall j.e.marshall@mmu.ac.uk

Dear

My name is Ryann Sowden. I am a speech and language therapist
from Manchester, England. I am currently studying for a PhD at Manchester
Metropolitan University and Dr. Julie Marshall is my Director of Studies .

I am researching collaboration between professionals across the world,
specifically the ways in which local and foreign professionals work together to
provide training for professional and services for people with communication
disabilities in low / middle - income and under-served countries.

Having completed an in-depth study, examining local and foreign collaboration
in Uganda, I am now looking to expand my research by exploring local and
foreign collaborations in several other countries. I would very much like to
include Kenya.This research will take the form of a short questionnaire, which
can be completed electronically. This questionnaire will explore participants'
experiences and opinions about working with foreign SLT professionals in
Kenya.

Given your local expertise, I would like to ask if you would be prepared to
forward my questionnaire (by email) to people in Kenya who may be eligible to
complete my questionnaire.

Potential participants should fulfil **all** of the following criteria:

- Be native to Kenya.
- Work mostly or partly to support people with communication
disabilities and/or train others to do so
- Have interacted with foreigners as part of their work

If you would be able to do this (or if you would like further information about my
study), please could you reply to this email and I will send you the questionnaire
and a covering email for you to forward to anyone who you think might be
eligible.

I hope my findings will benefit services for people with communication
disabilities globally.

Thank you for your interest

Yours sincerely,

Miss Ryann Sowden

PhD student at Manchester Metropolitan
University ryann.sowden@stu.mmu.ac.uk

Director of Studies: Julie Marshall j.e.marshall@mmu.ac.uk

Appendix 13 - Researcher reflection

Reflection
I outlined my interest in the research area and motivation to complete research in 1.2.5. In this section I will reflect on my research journey, and how my personal experiences may have shaped this.

I first became interested in the field of services for PWCD in Majority World countries whilst completing my final year project as a student SLT exploring attitudes towards communication disabilities in Jamaica. After qualifying from MMU as an SLT, I worked as a coordinator for a befriending charity, where my role was to recruit, train and match volunteer befrienders with children with disabilities. Here I became interested in volunteer roles, motivations, and their challenges and successes. After this, I worked as a newly qualified SLT in one of the most deprived towns in the UK.

When the opportunity to apply for a studentship at MMU researching services for PWCD in LMICs came up, it felt like an excellent opportunity to draw together my professional interests by researching the process and perceptions of the development of services for PWCD in LMICs, with a particular emphasis on the contribution and roles of 'outsiders.' The study consisted of two phases, with the first phase planned to be set in Uganda based on my Director of Studies professional links through a SLT mentoring project. Phase two was left open but planned to be set in between 3-5 other Majority World settings. Initially I found academic writing challenging, particularly understanding and writing about the philosophical aspects of methodology, however I managed to successfully complete my transfer report and transition from MPhil to PhD.

Gaining ethical approval had some challenges. I gained ethical approval from Manchester Metropolitan University without difficulty, and wanted to gain ethical approval from the University in Uganda that was associated with the speech and language therapy degree. This process had its challenges for me, as someone unused to the ethical approval procedure in Uganda. I was fortunate to have support from an SLT on the ground who was able to assist me with the process. This support helped me to gain institutional ethical approval, although it was a stressful and at times confusing experience, after which I learnt that further ethical approval at a national research level was required. Again, this process was challenging but I was supported by the same SLT in Uganda, as well as a University administrator. Their kind and supportive help meant that despite taking over 18 months to complete, was ultimately successful. This process highlighted some of the challenges of completing research in other countries, where procedures are unfamiliar and as an outsider, it is at times hard to be confident of progress or an end point.

I enjoyed the data collection period, particularly conducting interviews. These interviews not only provided the explicit data, but events and specific interactions within interviews further allowed me to reflect particularly on power and cultural differences. Some interviews in particular made me reflect both on my status as a foreigner (where I variably appeared to be seen as colleague, expert or naive), but also being a woman and an SLT. This happened particularly when, on one occasion one participant did not like the terms insider and outsider, as they felt as though this highlighted differences and was

contentious. Here, I used this opportunity to have a further discussion about my motivations as a researcher, and to discuss alternatives for the terms.

From prior experience of interview transcription I was aware of the time needed to complete this stage. As interview data were collected over two visits spaced a year apart, I was able to complete these at a steady pace and to begin analysis following the first visit to Uganda, and felt I did this well. I selected thematic network analysis (TNA) as the most appropriate method of data analysis for interview, participant observation and some of the survey data. This was selected as TNA offers a transparent approach with clear steps for the analysis of data, which would in turn enhance replicability of the research. Despite this, I initially struggled with the coding of interview data, which was analysed first. At the first stage of TNA I over-coded some of the insider interview transcripts by not using the same names of codes. Whilst this error proved costly in time, this process did assist me in greater familiarisation with the data, and ultimately helped my completing the analysis of this data set, and allowing me to become more familiar with the process for the other data sets.

Towards the end of the phase one analysis, I began to decide the selection criteria for the phase two countries. I decided that five countries would allow for a range of responses from participants, and would vary by their HDI rank. Following the successful pilot of the survey instrument, this was amended and distributed amongst stakeholders in five Majority World countries. The data collection period was initially planned to last three weeks, which was extended for another four weeks. However because there was still no response from Bangladesh, I decided to extend the data collection time period and try to recruit participants from another country. Were I to complete this again, I would have invited all countries that met the selection criteria, or a medium or low ranking HDI country in the place of Bangladesh. This would have allowed for data from the full range of low-, middle- and high-income countries. However, because of the time constraints, I selected Malaysia as a setting based on the professional network of one of my supervisors and the readily available open register of SLT professionals.

One area I became especially interested in was development. Specifically, whether there were particular courses or patterns to development. Whilst reading widely, I became interested in development theories. I wondered if these could inform the overall development of services for PWCD, and contextualise outsiders' involvement. Although no single development theory was selected to best explain the all findings, they each were able to provide explanations over development and outsiders' involvement. Whilst much of the literature focuses solely on the lack of financial resources of Majority World countries on service development, I believe that a fundamental and much overlooked aspect of why service development has challenges is because of a lack of infrastructure.

Over the four and a half years, personal difficulties made me decide it was important to change my work-life balance. As a result, I suspended my studies for a period and then transferred from full time to part time study. Despite these challenges, I feel that this change helped me in having more time to reflect on the findings and implications of the study. I have learnt about the need for

planning and coordination for both small and large scale collaboration projects, and the need for there to be balance and equalisation between insiders and outsiders in terms of their power, roles, their wants and needs, and the need for outsiders to be culturally appropriate and flexible.

The study resulted in main findings in the form of key statements. Many of these key statements are comments on the existing dynamics of collaborating and potential solutions for how challenges within these dynamics can be reduced. I hope that these key statements are considered and used to guide current and future collaborative work between insiders and outsiders in developing services for PWCD in Majority World countries.

I plan and using my research skills as a way of collaborating and developing services for PWCD. My long-term professional goal is to work as a speech and language therapist in Jamaica for at least part of the year, where I hope to see services develop.