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COMMENTARY

Participation, equality, and justice in Rwanda for people who experience communication disability: Achieving Sustainable Development Goal 16

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Running head: Communication, equality, and justice in Rwanda (SDG16)

Abstract

The right to communicate, by any means, is key to participation in peaceful and just societies. Participation relies on societal equality which, in turn, depends upon consensus that everyone has the same rights, as well as responsibility to uphold the rights of all. People who experience communication disability are, however, often invisible, misunderstood, stigmatised, and under-enumerated, particularly in resource-limited settings, including humanitarian contexts. A lack of identification and understanding of needs exclude this group from equal societal participation and exposes them to risks, including sexual and gender-based violence (SGBV), which has no place in a peaceful, just, and fair society.

Purpose: In this commentary we explore the importance of the full inclusion and participation of people who experience communication disability, to the fulfilment of Sustainable Development Goal (SDG) 16.

Result: There is a lack of specialist assistance for people who experience communication disability in resource-limited and humanitarian contexts. A broader approach to community and service-provider capacity-building on communication disability demonstrates potential to build stronger institutions and increase societal inclusion and participation, thereby reducing exposure to risks, such as SGBV. Such approaches include increasing public understanding and use of accessible communication strategies, as well as addressing negative attitudes/behaviours and fear.

Conclusion: Speech-language pathologists (SLPs) must be prepared to expand their spheres of influence and develop long-term relationships with stakeholders who can instigate change. This may involve de-emphasising our SLP credentials, instead rebranding ourselves as inclusion specialists, with a focus on communication disability.

Increased inclusion, participation, and protection are achievable for people who experience communication disability if they are understood, counted, and served appropriately. This

requires alignment of communication rights agendas with international development

priorities. As such, this commentary paper focuses on peace, justice, and strong institutions

(SDG16) and simultaneously addresses aspects of good health and wellbeing (SDG 3),

gender equality (SDG 5), reduced inequalities (SDG 10), and partnerships for the goals (SDG

17).

Introduction

The Sustainable Development Goals (SDGs) represent seventeen integrated objectives to achieve Agenda 2030 - an ambitious plan to create an equal world for all, through economic, social, and environmental development (United Nations, 2015). Five pillars underpin the SDGs, including people, aiming to "ensure that all human beings can fulfil their potential in dignity and equality" (United Nations, 2015, p. 3); and peace, aiming for "peaceful, just, and inclusive societies which are free from fear and violence" (United Nations, 2015, p. 4). In pursuit of peaceful and just societies, SDG 16 aims to "promote peaceful and inclusive societies for sustainable development, provide access to justice for all and build effective, accountable and inclusive institutions at all levels" (United Nations, 2018). SDG 16's targets focus on reducing exposure to violence (16.1, 16.2); increasing access to the justice system (16.3); and reducing discrimination (16B).

The role of communication in peaceful and just societies

The right to communicate, by any means, is enshrined in the Universal Declaration of Human Rights, Article 19 (UDHR, United Nations, 1948). This right enables participation at "family, community, national, and global levels" (McLeod, 2018, p. 3) and is therefore key to participation in, as well as the creation and maintenance of, peaceful and just societies. Full participation in society relies on societal equality - a principle expounded in peace, justice, and strong institutions (SDG 16) and the UDHR, which states that "All human beings are born free and equal in dignity and rights. They are endowed with reason and conscience and should act towards one another in a spirit of brotherhood" (Article 1, United Nations, 1948). The fulfilment of this statement depends upon societal consensus that humans share the same rights and have responsibility to uphold the rights of all. Furthermore, it relies on strong institutions to ensure that no-one is excluded from realising their rights - including communication by any means - through law and law enforcement.

Despite this human right, people with communication impairment(s) are known to experience disabling exclusion from social participation (Plan International, 2013). People with communication impairment(s) are often misunderstood, stigmatised, under-identified, and under-enumerated, particularly in low-resource and humanitarian contexts (Smith-Khan et al., 2014). Individuals' personal abilities to understand and be understood combine with inaccessible societies and environments to result in an experience of communication disability.

The impacts of communication disability are wide-ranging, including reduced ability to create strong, protective social networks; limited access to preventative and responsive health and social care; limited education; restricted access to legal services (Marshall and Barrett, 2018); and limited access to the labour market (Law et al., 2009), potentially leading to, and reinforced by, poverty (Hussain et al., 2018).

The human rights agenda connecting the UDHR (United Nations, 1948), the Convention on the Rights of Persons with Disabilities (CRPD, United Nations, 2007) and Agenda 2030 (United Nations, 2015) to peace, justice, and strong institutions (SDG 16), means that people with communication impairment(s), who experience communication disability, must be included and protected as equal members of society, to achieve the SDG 16 targets. The United Nations (2018) states:

> At the core of the 2030 Agenda lies a clear understanding that human rights, peace and security, and development are deeply interlinked and mutually reinforcing. Through its entirety, the importance of enhancing access to justice, ensuring safety and security, and promoting human rights for sustainable development are reflected, while Sustainable Development Goal 16 marks the intersection between sustaining peace and the 2030 Agenda. (United Nations, 2018)

Additionally, the International Communication Project member organisations have collectively acknowledged that inclusion of people with communication impairment(s), who experience communication disability, is critical to the attainment of the SDGs (Hussain et al., 2018).

Aim

In this paper we aim to elucidate the importance of the full inclusion and participation of people who experience communication disability to the attainment of peace, justice, and strong institutions (SDG 16), with additional relevance to good health and wellbeing (SDG 3), gender equality (SDG 5), reduced inequalities (SDG 10), and partnerships for the goals (SDG 17). We develop the points above with examples to show how our collaborations with the United Nations High Commissioner for Refugees (UNHCR) and the United Nations Children's Fund (UNICEF) in Rwanda have contributed to the fulfilment of SDG 16, for people who experience communication disability.

Communication disability, inequality, and injustice: examples from Rwanda

People who experience communication disability are subject to limited identification and understanding of their support needs, that excludes them from equal societal participation and exposes them to protection risks, such as discrimination, violence, abuse, and neglect (Barrett et al., 2021; Women's Refugee Commission, 2014). Moreover, communication disability may be found at the intersection of other risk factors such as refugee status, gender, age, and ethnicity (Izugbara et al., 2018), exacerbating protection risk.

Example 1: Exposure to violence and access to justice

This example addresses SDG 16 (peace, justice, and strong institutions) targets 16.1: Significantly reduce all forms of violence and related death rates everywhere; 16.2: End abuse, exploitation, trafficking, and all forms of violence against and torture of children; and 16.3: Promote the rule of law at the national and international levels and ensure equal access to justice for all. Sexual and gender-based violence (SGBV) is known to increase during humanitarian emergencies (Izugbara et al., 2018). Global evidence suggests that, in these contexts, refugees with communication impairment(s) are at increased risk of exposure to SGBV, as well as disabling exclusion from preventative and responsive services (Marshall & Barrett, 2018; Tanabe et al., 2015; Women's Refugee Commission/International Rescue

Committee, 2013). In Rwanda, as in many resource-limited contexts, speech-language pathologists (SLPs) are limited in number (Wylie et al., 2016) and access to communication accessible services is uncommon. This results in inequality and injustice within communities (Marshall & Barrett, 2018). In 2015, UNHCR Rwanda began collaborating with the authors to investigate the SGBV risks facing refugees who experience communication disability, by interviewing service users and providers (including police and legal services), in camp and urban refugee communities. This led to further projects looking at access to preventative sexual and reproductive health education (SRHE) and solutions-planning to improve communication accessibility across a wide range of refugee communities and services (Marshall et al., 2021). The result has been a comprehensive understanding of the myriad factors affecting access to SGBV prevention and response services for refugees who experience communication disability, as well as an action plan to strengthen equality in service access.

Example 2: Reducing discrimination

This example addresses SDG 16 (peace, justice, and strong institutions) target 16B: Promote and enforce non-discriminatory laws and policies for sustainable development. In Rwanda, as in many places, the intersecting contributors to, and impacts of, communication disability are frequently misunderstood. A root cause analysis of the factors influencing access to services revealed stigma to be a cause of exclusion and discrimination for refugees who experience communication disability (Marshall & Barrett, 2022). Stigmatising attitudes and behaviours limit the scope for societies to be fair and just. Discrimination increases protection risk and reduces access to support. During our work with refugee communities, participants identified that increasing knowledge and understanding of the contributors to, and impacts of, communication disability amongst community members and service

providers is a crucial step in achieving the paradigm shift necessary for attitudinal and behavioural change.

Responding to SDG 16 for people who experience communication disability

Misunderstanding of communication disability, coupled with limited understanding of the support that SLPs can provide, can lead to narrowly defined assumptions about with whom SLPs work; where SLPs work; how SLPs provide support; and SLPs' roles and responsibilities. This is often influenced by a medically focused understanding of communication disability as a 'problem' in the individual that can be 'fixed', rather than as an interaction between a person's functional limitation, other idiosyncratic personal factors, and an exclusionary social and physical environment. Assumptions around the potential for SLP support are consequently often limited to the individual, rather than recognising the possibility to enhance social inclusion and participation.

Having acknowledged these assumptions, we consider that SLPs need to take a broader approach to community and service-provider engagement in issues of communication disability (McAllister et al., 2013). SLPs should challenge prevailing assumptions about their work and involve themselves in the wider disability sphere, where consideration of communication support needs is typically lacking. In so doing, SLPs can support:

1. **Policy makers** to include basic communication support in health, education, protection, and social care plans.

2. **Service planners and providers** to design and deliver communication-accessible services.

3. **Disabled persons' organisations (DPOs)** to build capacity on communication advocacy and support.

4. **Families and communities** to understand causes, nature, and impacts of communication disability, reducing stigma and discrimination

5. **Individuals** to advocate for their participation and access to services.

Through expanding spheres of influence, SLPs can increase access to justice (target 16.3), contribute to reduction in exposure to violence (targets 16.1; 16.2), reduce disability-related discrimination (target 16B) and contribute to increased participation in the creation of peaceful and just societies.

Effecting change: The 'long haul'

As British SLPs, in our collective 48 years of collaborating with colleagues in sub-Saharan Africa, we have developed our approach to engaging with those involved in the planning and delivery of mainstream and specialist disability support services, to advocate for equal inclusion and participation for people who experience communication disability. It has been essential in our work to move beyond the typical SLP sphere of operation and develop a comprehensive understanding of how government, development, and humanitarian sectors operate and identify their priorities (and those of their donors), and for us to advocate for communication accessibility as a cross sectoral issue. Examples include:

1. **Working with global bodies**

   Inputs: Working with United Nations agencies who collaborate and influence government, as well as local and international non-governmental organisations delivering services. This has impact in the country of work and develops scope for global influence (Marshall et al., 2021).

   Outcomes: Through working with the United Nations, we have raised awareness and influenced a range of institutions responsible for policy development, service design and service delivery (United Nations High Commissioner for Refugees, 2021).

2. **Involvement in partner-identified priority issues**

Input: Work responding to inclusion and equality priorities identified by the United Nations on, for example, disability identification and registration, protection, education, and early childhood development.

Outcomes: Implementation of a UNHCR communication disability screening tool for refugee registration (Barrett, 2022); a cadre of staff trained about communication disability (Marshall et al, 2021); strategies to address SGBV (Marshall & Barrett, 2018) and educational exclusion for refugees who experience communication disability (Barrett et al., 2019).

3. **Working with government on policy and operational standards**

Inputs: Responding to government priorities to develop inclusive policies and operating procedures on issues of disability screening, child protection, ECD, inclusive education, and deinstitutionalisation.

Outcomes: Communication included in Rwanda's national policies, training packages, screens, and standards (Chance for Childhood, 2019, 2020; United Nations Children's Fund, Rwanda, 2022).

At every opportunity we have used these broad engagements on disability issues to raise awareness of communication disability and its impacts, networked, developed relationships with new partners, expanded our sphere of influence, and advocated for the inclusion and participation of people who experience communication disability. Persistent, long-term involvement in policy, service development, and community sensitisation can support more inclusive and just societies, supported by a network of strong institutions capable of effecting change.

Conclusion

Increasing visibility and participation is key to achieving inclusion, equality, and justice for people who experience communication disability. We argue that this *must* develop

alongside increased capacity of the institutions responsible for ensuring their safety and protection to ensure communication rights realisation. Working closely with institutions brings opportunities to raise awareness of the protection risks and inequalities faced by people who experience communication-related exclusion and highlights their capabilities and potential to contribute to community cohesion. Only then is it possible to interweave communication rights and support needs into cross-sectoral program development priorities. To do this effectively, it is critical to build long-term relationships with organisations. This may involve 'de-emphasising' our SLP credentials to circumnavigate assumptions about professional roles and responsibilities, instead 'rebranding' ourselves as inclusion specialists, with a particular focus on communication disability. We can do this by aligning communication disability with global agendas, such as Agenda 2030 (United Nations, 2015), the agendas and priorities of key stakeholders, and by collaborating with existing service providers.

Working slowly, and often subtly, to build relationships and influence can lead to longer-term engagements and impacts beyond the initial 'topic of interest'. It is crucial to find innovative ways of working with organisations to influence, effect change, and advocate for communication accessibility and inclusion. Becoming a trusted and available source of support on broader aspects of disability inclusion can increase opportunities for influencing decision-making to include communication accessibility further down the line. Our examples illustrate that broad based support for community and service-provider sensitisation and capacity-building on communication disability shows potential to build stronger institutions and increase societal inclusion and participation, thereby reducing exposure to risks, such as SGBV. The SLP profession can thus contribute to the realisation of communication rights and achievement of the SDGs.

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Declaration of interest

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