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Communication disability in low and middle-income countries: a call to action

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INTRODUCTION

Communication is essential to interaction and participation in life. The right to communicate is enshrined in the Universal Declaration of Human Rights[1] and impacts achievement of all United Nations Sustainable Development Goals, enabling connectedness, expression of needs and participation in education, employment and society. Living with communication disability can impact education, work, play and well-being.

Despite the high prevalence of communication disability, it is frequently overlooked in global disability service developments, policy initiatives and research. The needs of people with communication disability (PWCD) remain unheard. To achieve equity in health and disability services, communication disability needs foregrounding, particularly in low and middle-income countries (LMICs), where formal supports for PWCD are limited or non-existent and stigma is widespread.[2] It is time to put the needs of PWCD on the agenda.

COMMUNICATION DISABILITY: INVISIBLE, YET COMMON

Communication encompasses speaking, understanding, written, signed and non-verbal modalities. Communication disability is experienced when an individual communicates differently from the majority of people in their community, affecting their participation. Communication disability may result from a primary communication impairment, for example, developmental language disorder, voice disorder, stammering or can be linked to congenital, developmental, acquired and degenerative health conditions, for example, hearing loss, cerebral palsy, autism spectrum disorder, stroke, Parkinson's disease. How an individual experiences communication disability depends on environmental and personal factors, such as the

SUMMARY BOX

⇒ Communication disability is a common but under-reported and often neglected part of health, rehabilitation and disability services, despite communication being a human right.
⇒ Communication disability has far-reaching impacts throughout life.
⇒ Innovation is required in contexts where services for people with communication disability are limited—particularly low and middle-income countries.
⇒ Local and national governments, funders/commissioners, communication disability experts, universities, non-government organisations, communities, health, social care, rehabilitation services and education sectors all have a role to play in putting communication disability on the global disability/(re)habilitation agenda.

skills of communication partners, availability of therapy and other supports, attitudes and the individual's resilience as well as the nature of the impairment.[3]

Communication disability is often invisible and unnoticed by governments, professionals and the public.[4] It is under-reported in the estimated 16% of the world's population (including almost 240 million children)[5] who experience disability. The World Report on Disability acknowledged that 'People with … communication difficulties, and other impairments may not be included in estimates [of disability], despite encountering difficulties in daily life' (World Health Organization, p22).[6] PWCD may be registered only with their most visible impairment, or as having 'multiple disabilities', with the communication disability unspecified and/or not receiving intervention. Population-level screening tools for disability often include limited detail on communication. For example, the Washington Group/UNICEF Child Functioning Module includes only two broad questions focused on speech intelligibility, that may fail to detect the full range of communication disabilities.[7]

In high-income countries (HICs) communication disability has a high prevalence, although data are incomplete.[8] For example, a review by Raghavan et al,[8] of data about paediatric speech and language disorders, revealed the lack of robust population-level data on its incidence and prevalence. Communication disability among school-aged children accounts for more than three times the combined prevalence of children with physical/medical disability, intellectual disability and hearing impairment.[9] Stransky et al[9] report that 9.9% of adults have speech, language and voice disabilities in the USA, and the US Department of Education[10] reported that 16.4% of children with disabilities aged 6–21 years received services for primary speech or language impairments.

In LMICs, the prevalence of communication disability is poorly understood, and estimates may be conservative. Up to 11.3% of children in LMICs are reported to have some form of neurodevelopmental disability[11] and up to 25% of children across 63 LMICs are suspected of having developmental delay,[12] with communication impairment common in both conditions. Stigma in LMICs may result in people hiding those with communication disabilities, influencing household survey data (Owusu, personal communication, October 2021). Communication disability is often poorly understood and mistakenly attributed, for example, to inability to speak a particular language, alcoholic intoxication, psychosis, a curse or supernatural forces.[13]

Communication disability can be associated with a wide range of adverse outcomes. These include the following:

a. Poorer educational achievements including challenges in achievement in both literacy and mathematics.[14]

b. Issues with employment and economic success, with people with developmental language disorder more likely to be employed in unskilled occupations, earning lower incomes.[15]

c. Social exclusion, negative attitudes and behaviours, bullying and poorer mental health,[16] with problem behaviours occurring more commonly in children with language disorders.[17]

d. Poorer health and increased healthcare costs, with PWCD experiencing both high rates of healthcare utilisation and ongoing unmet healthcare need.[9]

e. Increased risk of exposure to abuse/violence, compounded by issues preventing and reporting abuse/violence.[18]

f. Increased likelihood of involvement in the justice system, with high rates of language disorder evident among young offenders.[19]

Several of these outcomes have direct and/or indirect economic impacts on PWCD. Furthermore, the impacts of communication disability extend beyond the individual with communication disability, to their family and carers. For example, families may report pervasive fear about their child's safety (eg, risk of abuse); social relationships (eg, making and maintaining friends) and life chances, including attaining financial independence.[20]

Outcome studies are predominantly from HICs, where there is typically access to assessment, therapy services and educational support. There is little information on trajectories and outcomes for PWCD in LMICs, despite likely high prevalence.

COMMUNICATION DISABILITY WORKFORCE RECOMMENDATIONS FOR LMICS

The 2030 Agenda for Sustainable Development[21] outlined an ambitious plan, underpinned by a vision focused on societies that are 'equitable, tolerant, open and socially inclusive', meeting the needs of the most vulnerable (Hopkins et al, p5).[19] Progress in meeting the needs of PWCD continues to be inadequate. Recognition of communication disability and strategic developments to address the needs of PWCD are urgently needed, to develop appropriate and accessible services for all.

An appropriate communication (re)habilitation workforce needs to align with economic, population, cultural and practical needs in LMICs, especially because workforce development is time and resource intensive.[22] Examples of contextually responsive approaches to service development for PWCD in LMICs are proposed in the Equitable, Population-based, Innovations for Communication (EPIC) Framework,[23] and the Afrocentric Communication Disability Rehabilitation Framework.[22] EPIC adopts a decolonising critical lens to consider how services for people with communication and swallowing needs can be offered in ways that are more equitable, address the needs within the whole population and harness innovation. Synergistically, the Afrocentric Communication Disability Rehabilitation Framework also highlights the need to leverage change to build capacity in the community to meet population needs and promote equity in ways that are culturally and contextually responsive. Synergies across these models highlight the importance of meeting population needs in innovative ways, focusing on equity and harnessing local expertise to build culturally and contextually appropriate services.

Support for PWCD, particularly in resource-constrained contexts, should acknowledge four key considerations:

1. The need for *a multitiered communication disability workforce* to provide system-wide support. In HICs, services to support PWCD rely heavily on specialised services, provided by speech and language therapists/pathologists (SLTs), audiologists and other communication 'experts', historically providing individually focussed models of rehabilitation. Efforts to improve services for PWCD in LMICs frequently attempt to replicate HIC approaches, or example, training SLTs and providing individual services. Yet in many LMICs, communication professionals are rare, resulting in reliance on community members, or a community-based rehabilitation (CBR) workforce underprepared to work with PWCD.[6] In 2023, WHO resolved to strengthen rehabilitation in health systems.[24] A timely opportunity exists to move towards a more multitiered

workforce. The SLT workforce is extremely limited in LMICs, therefore strategic role redesign is required, ensuring SLTs are embedded in the public sector for improved equity or within community-level services, to improve accessibility. (Re)focussing the SLT role towards population-health and capacity-building may reach more PWCD.[19] Role redesign for specialised professions, such as SLTs, may enable them to work alongside other existing services/supports, to expand access to services. For example, CBR has improved rehabilitation and social inclusion for people with disabilities in LMICs, although attention to communication disability has been limited. Role redesign would enable SLTs and other communication specialists to collaborate cross-sectorally to provide CBR workers with support and training about communication. Mid-tier workers, educated to use a narrower range of skills and knowledge than SLTs, could also provide some communication services within a community health model, supported, mentored and supervised by SLTs or other communication specialists.[19] Global growth in telehealth services may offer potential to increase access to communication disability support, although the complex nature of communication may make it challenging to provide culturally responsive services online without local facilitation and translation. Furthermore, issues of digital poverty may further highlight inequity of access for telehealth services.

National policymakers have a key role in developing a workforce and designing roles/strategies that impact PWCD at a population level, rather than reinforcing high income models of service delivery. Using CBR and mid-tier workers to scale-up communication disability rehabilitation and promote social inclusion requires changes in how SLTs are educated, employed, deployed and evaluated.

2. Interventions addressing communication disability require *medium to long-term input*, focusing on the development/restoration of individuals' speech, language or voice, and/or more effective communication, use of assistive products and improving communication environments (including communication partner skills). The Global Cooperation on Assistive Technology initiative (https://www.who.int/initiatives/global-cooperation-on-assistive-technology-%28gate%29) aims to enhance the availability of assistive technology, using a range of generalised to specialised services and supports. While such resources can support some communication needs, successful implementation often requires ongoing support. For example, if a PWCD is given a communication board or book (containing, pictures, letters words and/or phrases to support communication), content needs to be tailored to the individual, and the PWCD and their communication partners need to be taught how to use this new system of communication effectively. Monitoring for use is vital, with the book/ board requiring regular updating as the PWCD's needs change, particularly important for children.

3. *Information about communication disability* that is evidence-based, contextually appropriate, accessible and widely available, is required to facilitate self-help, help-seeking and promotion of accessible communication environments.[19] Community stigma remains a barrier to improving participation and inclusion for PWCD in LMICs.[2] Organisations of people with disabilities (OPDs), influential community members and community organisations, can all support communities to enhance participation, inclusion and the realisation of communication rights.[19]

4. Recognition that *communication (disability) and culture are intertwined* is essential. Many communication rehabilitation resources are language-specific and context-specific, originating from HICs. Cultural interpretations of communication disability vary[13] and interventions for PWCD should draw on local knowledges of speech and language development, explanatory models of language, language socialisation, child-rearing and health beliefs.[19]

SUMMARY

Communication disability is often invisible and has long-lasting and wide-ranging impacts. The needs of PWCD are under-recognised, particularly in LMICs. Urgent action is needed to address the need for services and support for people impacted by communication disability. Putting communication on the global disability agenda and integrating it explicitly into policy is an important step. Decisions should be informed by robust discussion about effective ways to address communication rights. Multipronged approaches include leveraging capacity of CBR and mid-tier workers, role redesign for specialists (such as SLTs and audiologists) and enhancing community capacity to support PWCD. Full participation for PWCD will only be achieved when communication is truly recognised as a human right, and support is seen as essential to supporting participation and well-being. Local and national governments, funders, PWCD, communication disability experts, universities, Non-Governmental Organisations (NGOs), OPDs, communities, health, social care and education sectors are asked to heed this call to action, to work collaboratively to develop innovative and local, contextually appropriate solutions to support everyone to have the right to communicate.

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Author note The reflexivity statement for this paper is linked as an online supplemental file 1.

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