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People with communication disabilities speak up for inclusion and participation: How the implementation of the CRPD and SDGs can support this right

The International Communication Project: Raising awareness of communication as a basic human right

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Distinguished delegates of States Parties and Civil Society,

Thank you everyone for joining us this morning - we warmly welcome you.

We believe this is the first COSP Side Event which specifically focusses on communication disability.

Thank you for your interest in this important topic.

And I would like to also thank the Australian Government for their support and co-sponsorship of this side event.

In my presentation on behalf of the International Communication Project (or ICP), I will introduce a broad overview of communication disability and its importance with respect to the Convention on the Rights of Persons with Disabilities and the Sustainable Development Goals, while other presenters will expand on specific aspects, drawing from their perspectives and experiences.

The opportunity to communicate is a basic human right

Communication – is the essence of what makes us human.

Communication enables the right to social participation, inclusion in education and employment, equal justice, civic participation, and to enjoy a quality of life.

It is through communication that we can defend our human rights.

Communication is a fundamental human right – and, just as is the right to air, food or water, it is taken for granted.

And yet for some, there can be barriers to communication which impact on their basic human right to participate and be included fully in society.

Today we will hear from panel members, Ms Meredith Allan and Mr Miles Forma, who for them, communication can be an everyday challenge.

We will also hear how there needs to be more explicit recognition of communication disability within legislation, acts and policies, including specific strategies in how to achieve the Sustainable Development Goals and in implementing the CRPD.

When we refer to people with communication disability, we refer to children and adults with speech, language and communication impairments, which result in difficulties communicating with others, involving understanding others and being able to express their own messages. Communication difficulties may be developmental, arising from birth, or acquired later in life. Communication difficulties can be associated with other conditions, such as hearing loss, cerebral palsy, autism or following stroke, or can be a primary disability in the absence of other conditions, for example a Developmental Language Disorder, Speech Sound Disorders, Childhood Apraxia of Speech, or Stuttering. For some people these difficulties can improve, whilst for others their needs are complex and long term, with significant impact on all aspects of a person's life.

Communication Disability?

There is an absence of specific inclusion and recognition of Communication Disability in international policies

Global prevalence data is limited

We know that overall there is an absence of an understanding and recognition of the impact of communication disability in international conventions and policy, despite the clear positive intentions through specific articles within various declarations and conventions.

The lack of public policy around communication disability is not helped by the fact that there is limited data on the scale and scope of communication disability prevalence.

Communication disability is known to be globally under-recognised and under-reported.

The World Health Organization's *World Report on Disability* estimates that roughly one billion people around the world are living with some form of disability. However, the authors of the report acknowledged that people with communication disability may not be included in this estimate, despite it being noted that they encounter significant difficulties in their daily lives.

Further, while statistical data from Majority World / (or Developing) economies is limited, it is unlikely that the prevalence of communication impairments in these contexts would be lower than those reported in Minority world / or Developed countries.

International Communication Project

A global action platform to raise awareness of the impact of communication disabilities ...

As a brief background, the International Communication Project (ICP), formed by the organizations shown on this slide, and now joined by over 50 organisations and partners world-wide, was established as a global action platform:

- to raise awareness of communication disability around the world, including with international health bodies and policy makers,
- and to advocate for improved services, (including having the ability to access services from speech-language pathologists / therapists and other supports), particularly for those within currently underserved communities and countries.

The ICP is built on the premise that communication is vital to life; yet from a policy and program perspective, is largely ignored as a disability - it is often 'invisible' and 'silent' as a disability.

The aim of the ICP is to ensure that people with communication disorders are empowered to have a 'voice' concerning their human rights and to be included fully in society.

United Nations: UDHR and CRPD

UDHR and CRPD provide a basis for advocacy in relation to the needs and rights of those with communication disability

- **UDHR - Article 19**
“right to freedom of opinion and expression” and to
“seek, receive and impart information and ideas through any media”
- **CRPD - Article 21 highlights the right of:**
“freedom of expression and opinion, and access to information” through all means, including through AAC
 - Article 2 discusses rights and freedoms regarding “communication” and “languages”
 - Article 3 (and others) includes social inclusion and accessibility as common threads, and speaks to the need for communication accessibility

The platforms of both the Universal Declaration of Human Rights and the Convention on the Rights of Persons with Disability (CRPD) provide a blueprint for ensuring people with communication disability can realise their human rights, and is the basis for advocacy in relation to communication disability and working towards communication accessible environments.

Indeed, the rights of people with communication disability are protected under the CRPD.

Specific articles of both UN Instruments provide clear reference to the right to equal and effective communication, specifically article 19 of the Universal Declaration, which sets down the right to freedom of expression and opinion, and Article 21 of the Convention, which again highlights freedom of expression and opinion, - but goes further and recognises the need for access to information including through all forms of communication of a person’s choice and accessible means, including sign language and technology, such as use of Augmentative and Alternative Communication (or AAC).

There are many other pertinent articles that speak to the right to access, justice, education, employment, and habilitation and rehabilitation, with the latter including that services and programs should begin at the earliest possible stage.

Despite this recognition in the Convention (and within certain relevant General Comments), there appears limited global or universal strategies in the implementation of the CRPD, that specifically address the needs of those with communication disability.

So we ask ...

How can people with difficulty in communicating, be assured they can exercise their rights?

And how will the States Parties protect and promote these rights for people with Communication Disability?

Suggestions will be discussed later in this session.

Sustainable Development Goals

I wish to now turn our attention to the UN’s Sustainable Development Goals.

Perhaps nothing more clearly exemplifies why communication deserves greater recognition than the tie between communication disability and the achievement of several of the Sustainable Development Goals.

The ICP through its policy document on the SDGs, has explored this relationship, drawing on the evidence base to discuss the connections and impact, as well as providing clear recommendations. (this document is available on the ICP website and we have copies of this document here today).

Why SDGs matter?

Why do the Sustainable Development Goals matter in the context of communication disability?

Communication disability affects millions of lives across the world, yet its impact is too often ignored.

Individuals with communication disability are often some of the most vulnerable in society, with children and adults with communication disability generally having poorer academic, vocational, social and health outcomes, than those without a communication disability. (ICAN, & RCSLT, 2018)

While we recognise that the SDGs aim to address significant global issues, the International Communication Project contends that any effort to deliver the SDGs should also address communication disability.

Of the 17 goals, a number have relevance to communication disability, as shown on the screen - (including Goals 1, 3, 4, 8, 10, 11, 16)

However, there is particular relevance for the goals concerning - poverty, health and education.

SDG 1. No Poverty

With respect to Goal 1 (No Poverty), researchers have demonstrated a correlation between the levels of communication disability present in communities and socioeconomic status.

There is clear evidence that the prevalence of those with speech, language and communication needs is higher for those in areas of social disadvantage. And in turn, those with a communication disability are far more likely to have long term impacts in terms of economic disadvantage, as well as greater difficulty in accessing services.

FOR EXAMPLE

People with communication impairments were found to be twice as prevalent in areas of social disadvantage across Australia (Reilly, Harper & Goldfield, 2016)

And

In a Canadian longitudinal study spanning 20 years, children with pervasive language problems were more likely to live in economically disadvantaged circumstances, - and at 25 years of age had lower occupational status than their peers

(Beitchman et al., 1996; Johnson et al., 2010)

SDG 3. Good Health and Well-Being

With respect to goal 3, of Good Health and Well-being, achieving this necessitates accessibility and responsiveness of the health system for those with communication disability. People with Communication impairments will often require more frequent interactions with health services, but may have greater difficulty accessing these services. People with communication disability may be more vulnerable during their healthcare encounters, with research reporting negative health outcomes linked to difficulties in communicating within healthcare contexts.

As these examples show ...

A study from the USA demonstrated that children with impairments that would lead to communication disability (such as hearing loss and neurological conditions) had a *two to eight times* increased likelihood of requiring health and medical visits.

A number of studies report on increased health costs for families and additional population healthcare costs involving children with communication impairments.

and

A study in Canada reported that adults with communication impairments had a *three-fold increase* in the risk of experiencing an adverse healthcare event (for example medication errors, and delays in treatment) than those *without* communication impairments.

SDG 4. Quality Education

In terms of Goal 4, of achieving a Quality Education, There is strong evidence that communication disability impacts on educational attainment.

In the Civil Society Forum on Monday, there were clear imperatives expressed around inclusive education – which was stated as critical for children with communication disability.

Given that language is the medium for instruction, classroom participation and assessment of progress in schools - without appropriate and necessary adjustments to support an inclusive communication environment within the education setting and curriculum, those with communication disability are at high risk of educational failure.

AGAIN FOR EXAMPLE

A population study of over 4000 children in Australia found poorer literacy and numeracy outcomes, over time, for children with speech and language difficulties.

A study in Canada, found children identified with language disorders demonstrated poor academic achievement throughout school and extending into higher education.

These problems persist into adulthood, with another study in the USA demonstrating poorer outcomes in educational attainment for young adults with a history of language impairment.

Shortly, we will see a video-ed presentation on how inclusive education is being supported in Rwanda for children with complex communication needs.

A cycle of inequality

People with Communication Disability Experience...

As shown in this slide, a cycle of inequality can be drawn in the context of people with communication disability.

Poverty can contribute to the development of communication disability - but the opposite is also true; communication disability places individuals and their families at greater risk of living in poverty and achieving poorer academic, vocational, social and health outcomes.

Without effective communication, a person is therefore at a significant disadvantage and faces everyday challenges and inequity.

For the SDGs to be truly sustainable, to assist in poverty alleviation, to ensure an individual is able to access health care provision, and to enable that individual to meaningfully engage with, and benefit from education, sustained efforts to address communication disability should be considered as part of all activity to implement the sustainable development goals.

Concluding Remarks

Communication is a basic human right

In concluding, there is clear evidence that communication disability creates significant barriers to the alleviation of poverty, and access to healthcare and education.

As outlined in the ICP Policy document, communication disability is prevalent in all communities, particularly those with low socioeconomic status.

Although presently the majority of evidence is from Developed or Minority World economies, we can project that the presence and effects of communication disability globally is profound, and must be considered in the context of Developing or Majority World countries, who are underserved with respect to addressing speech, language and communication needs. Attention needs to be given to access to early intervention, provision of services from communication specialists, including speech-language therapists and audiologists, and ongoing professional and community supports.

We are aware that there is some great capacity- and service- building initiatives already occurring across Majority World countries, involving awareness raising in the community about the needs of

those with communication disability, the development of formal training programs for speech-language pathologists/therapists, as well as mentoring programs for newly graduating professionals, training programs for rehabilitation and care workers, and provision of services through local or international volunteer programs.

Some of these countries include:

Guyana, Rwanda, Kenya, Zimbabwe, Ghana, Vietnam, Cambodia, Fiji, Indonesia, Bangladesh, Sri Lanka, China, and Papua New Guinea – and no doubt many more.

The ICP, and its members bodies, continue to work collaboratively with people with communication disability, alongside the disability sector and organisations, as well as with international bodies including the UN and the World Health Organisation, and the States Parties, to address the impact and disadvantage associated with communication disability - ensuring that 'no-one is left behind'.

Thank you and I will now hand back to the chair to introduce our next presenter.