

For people with communication disability, complaining about their treatment isn't so simple

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Credit: AI-generated image (disclaimer)

With the release of the disability royal commission's <u>final report</u>, the <u>harrowing treatment</u> of people with disabilities in Australia has been starkly displayed.



Just prior to the report's release, media reports about abuse and neglect prompted National Disability Insurance Scheme (NDIS) commissioner Tracy Mackey to <u>say</u> anyone on the scheme who is concerned about the care they're receiving and doesn't have someone to advocate for them should get in touch with the scheme's quality and <u>safety commission</u>.

But this fails to acknowledge the systemic barriers people with <u>communication</u> disability face. For many, picking up the phone or completing an online form without support is not possible.

Communication is a human right

As part of the <u>United Nations' Declaration of Human Rights</u>, everyone has the "right to freedom of opinion and expression."

Acknowledging this, the disability royal commission made specific recommendations around <u>enabling autonomy and access</u> through "communication access." Acknowledging that failure to do so can lead to <u>poor health</u>, education, employment and justice outcomes, with increased risk of harm during emergencies and natural disasters.

Communication access is necessary for everyone in society, but especially for the <u>1.2 million Australians</u> who live with a communication disability.

But what does 'communication access' mean?

Communication is enormously diverse. We use spoken, written and sign language, gesture, pictorial and digital forms, facial expression, vocalization, and physical expression to convey meaning. Through these, we can communicate our needs, thoughts and concerns.



Critically, the success of any communicative attempt requires the communication form to be acknowledged, valued and supported. Our <u>environment</u> has a profound impact on how successful communication is—irrespective of a person's abilities or impairments.

Over the last 40 years we have witnessed a significant shift in attitudes towards people with disability in Australia. There is now <u>legal</u> entitlement for "people with disability to exercise choice and control."

An independent review of the <u>NDIS</u> is due to report by the end of October 2023 with pressure on costs and growth to ensure sustainability. But enabling people to communicate and exercise choice demands we design and resource accessible communication environments.

What's it like to live with a communication disability?

Every day, people experience barriers to receiving and sharing information. These barriers can affect how they engage in meaningful interactions and how safe they feel. Inadequate communication accommodations can lead to difficulties accessing health care, using public transport, even ordering a coffee.

The disability royal commission <u>exposed</u> failures that have caused immense harm. The agency of people living with communication disability has <u>not been respected</u>, with devastating consequences.

Communication barriers exist within the context of high rates of <u>abuse</u>, <u>violence</u> and <u>deprivation of basic needs</u>, including food, shelter, or assistive aids. These rates are almost double those reported for people living without disability.

What is communication access?



<u>Communication access</u> occurs when everyone can meaningfully access information and get their message across. The commission <u>called it</u> "a critical safeguard against violence, abuse, neglect and exploitation."

Yet common approaches to communication accessibility—including those used by government bodies such as the National Disability Insurance Agency (which administers the NDIS)—have limited value.

The commonly applied <u>Easy Read</u> format—which combines text with layout and imagery to explain information—for example, lacks <u>standardized design principles</u>. It is only useful for supporting <u>specific groups</u>.

<u>Universal design</u> principles go someway in <u>supporting agency</u> for people with communication disability. These principles aim to recognize, value and accommodate a broad range of users of specific products or environments. But tailored attention to <u>individual communicative</u> requirements is essential too.

What should happen next?

There have been <u>calls</u> to enhance communication access for many years. While the commission's recommendations are an important step, the real challenge lies ahead.

The government taskforce charged with acting on the commission's recommendations should begin by <u>acknowledging the expertise</u> of people with communicative disability.

<u>Co-design</u> is a core tenet of the NDIS; however, people with communication disabilities are <u>frequently excluded</u> from sharing their perspectives. So governments need to look for ways to make co-design <u>communicatively accessible</u>. This must include engaging with multiple



modes of communication, including <u>visual aids</u>, <u>key words</u>, <u>augmentative communication</u>, and <u>physical forms of expression</u>. People with communication disability must play a central role in all <u>stages of the policy design process</u>: as informants, design partners and users.

NDIS funding models must cover making a person's support and service network an accessible communication environment. People with communication disability <u>tell us</u> that time, sustained engagement and relationship building are essential. While strategies are person-specific, <u>practical considerations</u> include ensuring access to assistive equipment and devices, providing choices, checking own understanding, and paying attention to non-verbal communication.

The costs of doing so are offset by the <u>economic value</u> of better health and well-being, employment, education, health, leisure and access to justice.

As the disability royal commission showed, poor oversight has resulted in significant harm, with inadequate <u>safety and incident reporting</u> measures that have translated to increased risk for people experiencing barriers to communicating their concerns.

At a minimum, communication access standards should ensure disability providers have base-level skills to recognize and support <u>diverse forms</u> of <u>communication</u>. Feedback and complaint mechanisms must also <u>go beyond</u> traditional formats of written and verbal communication.

As a community we must learn, not just from the stories and experiences shared with and by the disability royal commission, but also from how people with disability were <u>supported to provide them</u>. Through acknowledgement of the diversity of communication and by providing communication supports, we now have the opportunity to build inclusive environments.



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