

Assessing communication in people with severe–profound disabilities

Co-constructing competence

Hilary Johnson, Jo Watson, Teresa Iacono, Karen Bloomberg, and Denise West

KEYWORDS

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The recent focus on a human rights agenda in Australia has highlighted the vulnerability of people who have little or no speech in gaining access to their communication rights. This paper discusses the complexities of supporting communication for people with severe–profound disabilities within a framework of human rights. People with severe–profound intellectual disabilities are often considered not only unable to speak, but also unable to communicate. This preconception has been refuted and legislation enacted to protect the communication rights of people with severe–profound disabilities. In this paper we present an overview of good communication practices for people with severe–profound intellectual disabilities. Such practice consists of collaborative and transactional assessment and intervention supports, as exemplified in emerging models of supported and person-centred decision-making.

The United Nations' adoption and Australia's ratification of the Convention on the Rights of Persons with Disabilities (UNCRPD; United Nations, 2006) provided clear articulation of the rights of all people, including those with severe–profound intellectual disabilities, to communicate. The right of communication for all has also been recognised internationally, as demonstrated in the United States' Communication Bill of Rights (National Joint Committee for the Communicative Needs of Persons with Severe Disabilities, 1992) and The Montreal Declaration on Intellectual Disabilities (Lecompt & Mercer, 2007). These documents detail people's rights (a) to express themselves and be understood in all environments regardless of their cognitive and communication skills, (b) to receive interventions to improve their communication, and (c) for their communication to be treated with respect and dignity. These rights are also reflected in the ethical principles enshrined in professional codes of ethics and codes of practice by which Australian speech pathologists (Speech Pathology Australia, 2010) and other health care professionals practice (e.g., OT Australia, 2001).

In this article we discuss the issues and complexities of supporting communication for people with severe–profound disabilities within a human rights framework. The pertinent issues for speech pathologists include evaluating notions of communicative competence that incorporate models of good practice for assessment and intervention, person-centred approaches, and supported decision-making.

Human rights

Despite the appeal and vision of universal human rights, it is apparent that not everyone's rights, especially those with the most severe disabilities, are being realised (Brown & Goheff, 1996; Stancille & Abery, 1997; Watson & Joseph, 2011a; Wehmeyer, 1998). Such views impact on the most disempowered in our community: people who are seldom heard, rarely named, infrequently counted, and largely ignored (Watson & Joseph, 2011a). Their disempowerment in part may be attributable to having multiple disabilities and complex health needs, and being unable to communicate formally with symbols (Grove, Bunning, Porter, & Otsson, 1999). Some of these people may have communication skills that are considered to be unintentional. That is, they lack awareness that their behaviour (including their communication) has an impact on others in their environment.

One reason for excluding people with severe–profound disabilities, and even denying their personhood, relates to the lack of acceptance and understanding of their unique needs and strengths, particularly in relation to communication. Clegg (2010), in stating that “we need to have a different way of respecting the inherent humanity of people with ID [intellectual disability]: not just different versions of ourselves because they are themselves” (p. 15), encouraged society to embrace diversity. Communication assessment processes for people with severe–profound intellectual disabilities should begin with an acknowledgement that their communication is complex and whether intentional or not, should be respected and valued. Such acknowledgement means that practitioners need to be skilled in recognising the individualised communicative signals of people with severe–profound intellectual disability, to ensure that assessment and intervention strategies have been chosen in recognition of these (often person-specific) signals. In addition, practitioners need to be able to support others to recognise the person's communicative signals so that the communicative rights of people with severe–profound intellectual disabilities are upheld.



Hilary Johnson
(top), Jo Watson
(centre) and
Teresa Iacono

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