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.

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 & Gothelf, 1996; Stancliffe & 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, & Olsson, 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.
Re-conceptualising communicative competence

Practitioners need to have a view of communicative competence that reflects the collaborative and dynamic nature of communicative interaction. Such a view shifts the onus of communicative competence from the individual with a disability to the environment of which they are a part. This approach is contrary to the candidacy model of augmentative and alternative communication (AAC) assessment that saw clinicians waiting for some prerequisite level of cognitive skill before introducing AAC options. The use of candidacy criteria, such as cognitive level or chronological age as the basis for exclusion from services, has been rejected explicitly by the American Speech-Language-Hearing Association (2005) and the National Joint Committee for the Communication Needs of Persons with Severe Disabilities (1992). In its place is the understanding that AAC, under the umbrella of multi-modal communication, reflects a continuum of communication that can range from simple social or turn-taking routines through to more sophisticated use of symbols (Wilkinson & Hennig, 2007, p. 64). Although it took a long time for policy to catch up, intervention became directed at supporting a person’s communication regardless of his/her base level skills. Hence, the communication potential of all individuals, irrespective of their level of intellectual ability, was acknowledged. The clinician’s aim, then, has become to gain a comprehensive understanding of what each person brings to the communication interaction so as to provide supports that enhance that interaction (Iacono & Caithness, 2009). This understanding is determined through assessment of skills rather than deficits in communicative competence, a concept that was originally defined according to standards based on the abilities of people without underlying intellectual impairment that impacted on functional speech (Light, 1989).

Communication competence is a construct best understood within a social interaction context, whereby the communication of each person contributes to the dynamic of the interaction utilising a transactional approach (McLean & Snyder-McLean, 1978). The bidirectional nature of interaction is such that the role and task of a communication partner will shift according to the contribution of the other communicator. Years of mother–child interaction research, for example, has shown that mothers will overcompensate for a child who rarely initiates interaction by being overly directive (Marfo, 1999). This directive style is also evident in caregivers of adults with disability (e.g., McConkey, Purcell, & Morris, 1999). An important component of intervention for people with severe communication impairment is to re-balance that interaction by improving the partner’s ability to recognise and respond to the person’s communicative or potentially communicative behaviour (Bloomberg, West, & Iacono, 2003). This re-balancing is achieved by sharing the focus of intervention between improving the skills of the person with communication impairment and creating a more able communication partner, who is supported to perceive the communicative competence of the person with the disability. This procedure involves learning to recognise and respond to the communicative or potentially communicative signals of a person with severe–profound intellectual disability (Bloomberg et al., 2003). This delicate balance of interpretation and feedback supports the co-construction of meaning, whereby communication partners collaboratively construct an interaction by recognising, interpreting, and responding to communicative attempts and then checking for signals that indicate the appropriateness of the response.

Assessment

According to a re-conceptualised notion of communicative competence within the transactional model of communication, appropriate assessment is crucial in determining intervention targets and strategies that will support a person with severe–profound intellectual disability to participate in a social-communicative interaction (Carnaby, 2007). Iacono and Caithness (2009) described a model of assessment of relevance to people with severe–profound disability across their life stages. The model drew on dynamic, transactional, and participatory processes, also encompassed within the Participation Model that has guided AAC assessment for many years (Beukelman & Mirenda, 2005). The Participation Model provides a holistic approach to developing communication supports, in which assessment and intervention are intricately linked in such an ongoing and iterative process (Beukelman & Mirenda, 2005). Dynamic assessment is an ongoing process of observing communication within unassisted (as often occurs during formal testing) and assisted contexts (as is more typical in intervention). According to transactional approaches, communication is observed and assessed within social interactions in order to determine the reciprocal influence of both communication partners. Participatory processes involve a team of people significant to the person (e.g., family, support people, advocates), as well as the person with disability, working with professionals in the ongoing dynamic assessment.

Using the assessment model proposed by Iacono and Caithness (2009), formal measures such as tests or checklists provide data to supplement observations of the person within real-life contexts and meaningful interactions with regular interaction partners (Bloomberg, West, Johnson, & Iacono, 2009; Dewart & Summers, 1996; Rowland, 2010). For example, one checklist with established reliability (Iacono, West, Bloomberg & Johnson, 2009) is the Triple C – Checklist of Communication Competencies (Bloomberg et al., 2009). The developmental structure of the checklist provides a framework for intervention. Completion of the Triple C by multiple communication partners across environments is necessary to capture the complexity of the nature of interactions for the individual with complex communication needs. A specific assessment tool, such as the Triple C, when considered with other formal and informal strategies for assessment, contributes to an overall understanding of the person’s communicative behaviours, learning and interaction styles, and preferred partners and contexts. The outcome of the entire assessment process is to reach an agreement about how the person communicates. The next step is to use the assessment data to inform strategies that will support the person’s communication in multiple situations.

Informing intervention

The defining elements of a transactional approach to assessment described by Iacono and Caithness (2009) are inherent within current and emerging intervention models for people with severe–profound intellectual disabilities, such as person-centred and supported decision-making approaches.
Person-centred approaches differ from more traditional disability service approaches whereby people’s goals were determined according to what a service could provide (O’Brien, 2007). Instead, a strength-based approach is adopted in which the primary consideration is recognising and valuing the person’s individuality in order to mobilise resources and realise the person’s aspirations. Implementation of person-centred approaches is fundamental to recognising and acknowledging the person and his/her unique circumstances, and precludes a focus on the person’s disability.

Supported decision-making assists people with severe–profound disability in self-determination (Scott, 2007). In adopting this supported decision-making approach, the focus of individual competence, of relevance to skilled-based approaches, changes to that of co-constructed competence, whereby the onus of responsibility for communicative success is shared between the person and his/her communicative partners. A recent example of a supportive process for arriving at decisions about intervention is the supported decision-making framework developed by Watson (2011). Current thinking in relation to supported decision-making for people with severe–profound intellectual disability acknowledges that a person’s ability to communicate and to have his/her preferences realised should not be related to a single measure of cognitive capacity, but rather to a range of factors including the degree of support available to the person (Pepin, Watson, Haglissass, & Larkin, 2010). Beamer and Brookes (2001) highlighted this view in relation to people with severe–profound intellectual disability, stating “where someone lands on a continuum of capacity is not half as important as the amount and type of support they get to build preferences into choices” (p. 4). Watson’s (2011) supported decision-making model is characterised by five phases, each of which is implemented collaboratively: the identification of a decision to be made, listening closely to the individual and to everyone’s opinions, exploring all available options, documenting the barriers and enablers in the process, and, finally, the making of a decision that reflects the person with intellectual disability’s perceived preferences (Watson & Joseph, 2011b).

In any ethical decision about practice, the views of the person with a disability are important. An obvious but often ignored challenge is to ensure that decisions reflect the views of the person with intellectual disability, and not only the views of others involved in the interaction: that is, to ensure message ownership stays with the person being supported. People who feel they know someone with an intellectual disability, well are bound to rely on inferences based on the context and their prior knowledge of the person. An obvious risk is that the meaning assigned to the communication may reflect the hopes, fears and desires of the communication partner, rather than those of the person with a disability (Carter & Iacono, 2002; Grove et al., 1999). Communication partners supporting people with severe–profound intellectual disability must remain ever vigilant to this risk that the person’s “voice” in a decision is usurped or replaced by the hopes or dreams of others. Importantly, researchers have indicated that even the most well-intentioned communication partners may reflect their own views rather than the views of the communication the people they support and that some support strategies are particularly open to this phenomenon (e.g., Mostert, 2010). In the case of Facilitated Communication, for example, communication partners may attribute communication to those who are unable to communicate intentionally without the intervention of a facilitator (see Mostert [2010], for a review of the literature on this phenomenon). Recognising that the process of providing someone to participate in personal decisions is open to exploitation or abuse, any supported decision-making approach taken must as far as possible be a process that is transparent, systematic, and collaborative and that values any independent communication, whether intentional or unintentional, of the person with disability. An approach such as that proposed by Watson (2011) emphasises reliance on a team of supporters rather than a single individual functioning as a proxy decision-maker. Such an approach helps to ensure varied viewpoints are considered in reaching a consensus decision on the person’s own views.

**Determining positive communicative outcomes**

Ensuring that people with severe–profound intellectual disability have communication systems and strategies that meet both their needs and the needs of their communicative partners is an ongoing process. In accordance with the International Classification of Functioning, Disability, and Health model (ICF) (World Health Organization, 2001), providing a means of communication that can be understood and supported by a range of communication partners in different environments for activity and participation in society is a primary goal. Speech pathologists, as professionals specifically trained in multi-modal and interpersonal communication, have a primary role to enact in ensuring this goal is met for people with severe–profound intellectual disability. However, speech pathologists are a scarce resource in the disability sector. As a result, they often take a consultative role with the aim of teaching and guiding others to provide daily support (Johnson, Douglas, Bigby, & Iacono, 2009). Speech pathologists need to provide recommendations that (a) are based on person-centred and dynamic assessment approaches involving various communication partners, and (b) provide strategies to enable a person’s communication partners to interpret communication behaviours, establish consistent and reliable responses and support new modes of communication.

Initially, determining the most useful type(s) of communication supports involves a combination of strategies that include visual aids that document how to recognise and interpret ambiguous communicative signals (e.g., personal communication dictionary, multimedia profile); AAC aids that support expression (e.g., low technology aids) and/or systems that support both expressive and receptive communication (e.g., Key Word Sign) (Johnson et al., 2009). Each of these interventions requires input from the people who regularly interact with the person with severe–profound disability and such input will have been provided during the assessment process. Each strategy requires different levels of support and may not be used by all communication partners. For instance, developing a personal communication dictionary will need input and discussion from familiar communication partners in listing the relevant communication attempts and interpretations (Bloomberg, West & Johnson, 2004). Predominantly, the dictionary will be useful for clarifying the person’s responses when communicating with unfamiliar communication partners. The role of a speech pathologist in supporting the implementation of communication strategies includes (a) ensuring resources and aids are
relevant to the needs and situation of the person so that they can be integrated into meaningful interactions and activities, and (b) providing practical communication support through initial modelling, ongoing advice, and a willingness to evaluate the intervention and re-instantiate dynamic assessment strategies as needed.

**Conclusion**

A human rights framework, such as that outlined in this paper and enshrined in the UNCRPD, promotes the recognition of the diverse communication skills and preferences of people with severe–profound disabilities. A human rights framework for assessment and intervention is inclusive of individuals whose communication may be ambiguous or unintentional, and who may need extensive support to communicate. Providing communication support requires a commitment from all communication partners to be willing to suspend his/her own interests and consider those of the person with disability as distinct from the views of his or her communication partners. Suspicion of one’s own beliefs demands (a) relinquishing assumptions or beliefs about what a person with severe–profound disabilities can achieve, and (b) embracing a process of collaborative observation, interpretation, and development of intervention goals and strategies informed by principles of evidence based practice, the Association’s code of ethics (Speech Pathology Australia, 2010), and ethical decision-making frameworks. Australian speech pathologists working with people with severe–profound disabilities are bound by obligations under the UNCRPD; hence our practice needs to acknowledge the inherent value of all communication, whether intentional or not intentional. In addition, our practice should be highly collaborative and transactional, as exemplified by incorporating models of person-centred practice and supported decision-making. In this way, we may work effectively towards people with severe–profound disabilities gaining access to their communication rights to participate in decisions that affect their lives.

**References**


Hilary Johnson is a speech pathologist and manager at Scope’s Communication Resource Centre. She is also a PhD student and lecturer in augmentative and alternative communication at La Trobe University. Jo Watson is a PhD student at Deakin University and a research fellow at Scope. Teresa Iacono is professor of Rural and Regional Allied Health at La Trobe University. Karen Bloomberg is a speech pathologist at Scope’s Communication Resource Centre and a lecturer in augmentative and alternative communication at La Trobe University. Denise West is a manager and speech pathologist at Scope’s Communication Resource Centre.

Correspondence to:
Hilary Johnson
Scope, Communication Resource Centre
830 Whitehorse Rd, Box Hill 3128, VIC, Australia
phone: +61 (0)3 8643 2001
email: h.johnson@latrobe.edu.au