

ARTICLE

The Ethics of Inclusion in AAC Research of Participants with Complex Communication Needs

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If qualitative researchers in lifelong disability are to produce authentic findings on the experiences, perceptions and expectations of people with disabilities, research methods must include people with disabilities as participants. People with complex communication needs (CCN) are often excluded from participating in generic research, disability research and augmentative and alternative communication (AAC) research because of negative assumptions by researchers, Human Research Ethics Committees [HRECs] and collaborating disability organisations about their cognitive capability and ability to consent to participation. Such attitudes disadvantage people with CCN, perpetuate their social exclusion and are a breach of human rights under the United Nations Convention on the Rights of Persons with Disabilities (United Nations, 2006). However, there are indications of improvements in ethical approaches to inclusive research that enable people with CCN to execute their right to be involved in research and have their voices heard.

Keywords: Research ethics; lifelong disabilities; complex communication needs; AAC; inclusive research

Those responsible for the ethical review of research, and indeed some researchers, may underestimate the abilities of people with complex communication needs (CCN) to join research in augmentative and alternative communication (AAC) as partners or participants. Despite the relevance of the field of AAC research to those with CCN, there is limited research into the lived experience of people with CCN who use AAC devices (Collier, Blackstone, & Taylor 2012; Howe, Worrall, & Hickson 2008; Taylor, Balandin, Wilson, & Murfitt 2019) and their voices are rarely heard in research studies that may impact on their lives. People with CCN may communicate using AAC systems, or may use limited natural speech with some augmentation (e.g., signing, speech generating device [SGD]). There are many different types of AAC systems, including AAC technology that provides computerized speech output (i.e., computers, mobile phones or SGDs that talk). AAC also includes non-technological systems such as sign and gesture, letter boards, picture boards and writing. Researchers in the field of AAC may encounter challenges in conducting studies that involve people with CCN. For example, ableist assumptions may limit the involvement of people with CCN in AAC research, thus negatively influencing the conduct of fair and equitable research that benefits people with CCN and other stakeholders (e.g., family members).

Approximately 80% of adults with CCN (e.g., those with cerebral palsy or severe cognitive impairment) have lived with the impairment since birth and have never developed functional speech (Australian Institute of Health and Welfare, 2003). Thus, they differ from the 20% of people with CCN who acquired the impairment later in life (Australian Institute of Health and Welfare 2003), usually as a result of degenerative neurological conditions such as Alzheimer's or Parkinson's Disease, or because of stroke or acquired brain injury (Speech Pathology Australia 2010). Nevertheless, whatever the underlying cause of the communication impairment, the voices and experiences of these people are rarely included in AAC research. It is even rarer for them to be included as investigators on research teams.

Disability research was influenced by the emergence of disability rights activists in the 1970s, at a time when most studies took a clinical or medical approach using a deficit perspective of disability. These traditions continue to exist, but are challenged by approaches that emphasize that, although medical issues cannot be overlooked (Shakespeare 2006), disability is a social phenomenon (Oliver 1996). Disability advocates have long argued that people with disabilities have the right to participate in research as well as to participate equally in setting the research agenda and controlling research projects (Iacono 2006; Oliver 1992; Oliver & Barnes 2010). Yet the rights of people with little-known and under-researched disabilities such as CCN have to date not been strongly advocated in the literature. These rights are upheld by the United Nations Convention on the Rights of Persons with Disabilities [UNCRPD] (2006). Article 19 asserts the right of people with disabilities to be included in the community, and Article 21 upholds freedom of opinion and expression.

Yet, some authors have noted a growth of conservatism in Human Research Ethics Committees' (HRECs) decisions that may prevent people with CCN from participating in projects that utilise qualitative research methodologies (Boxall & Ralph 2011; Iacono 2006) that would enable them to contribute their own experience to research studies as participants or investigators. Iacono (2006) linked this conservatism with the make-up of HRECs, where the representation of multiple interests may preclude disability expertise, and which may contribute to a shift toward risk aversion in reaction to feared research misconduct. Researchers and research institutions are required by standards of ethical review to balance the benefits and risks of human research (World Health Organization 2011). Ethical review conducted by HRECs must assess whether potential risks are justified and balanced by the benefits brought by gains in knowledge and skill in the area being researched, or by improved wellbeing for individuals of the population being studied. Assessment of risks is influenced, among other factors, by the extent to which HREC members understand the population group to which research applies. Risk assessment includes a number of components such as recruitment and participant consent.

Participant Recruitment and Data Collection Methods

Research institutions' standard ethical review processes may unintentionally require participant recruitment and data collection methods that make it more difficult to reflect the perspectives of people with some disabilities (Boxall & Ralph 2011; Schlosser 1999), including those with CCN. The number of adults with CCN is relatively small (Beukelman et al. 2013), and potential participants may be socially isolated (Trembath et al. 2009) making it difficult for AAC researchers to recruit participants. Also, qualitative research methods that require conventional ways of communicating, such as answering questions in in-depth interviews or focus groups without accommodation for different communication modes have frequently excluded participants with CCN (Singal 2010).

Some researchers, including the authors of this paper, have overcome these potential barriers to research participation. For instance, Ashby and Causton-Theoharis (2012) reported that they used purposive sampling to recruit post-secondary students who had CCN and typed to communicate, in the interests of 'honouring the voices of people often rendered silent in higher education' (Ashby & Causton-Theoharis 2012: 265). The researchers interviewed 14 student participants, as well as 10 other people involved with the students. They also used observation and documentation of student presentations and assignments. Importantly, their research report detailed inclusive data collection methods that accommodated the communication difficulties experienced by participants. For instance, they provided interview questions ahead of the interview to enable participants time to prepare. The number of questions was limited, and the wait time for responses was extended because of the time needed by participants using AAC to respond. Paterson and Carpenter (2015) also reported using purposive sampling in their research exploring how people with severe acquired CCN experienced, and made decisions about, the communication methods they use. The researchers aimed to recruit people with CCN who could provide 'rich descriptions of the experience of living with communication difficulties' (Paterson & Carpenter 2015: 1523). Participants were able to use their communication method of choice during their interview. In using and detailing these inclusive methods of participant recruitment and data collection, the researchers ensured their research reflected the perceptions and experiences reported by the participants with CCN. Similarly, the authors of this paper have used purposeful sampling and semi-structured interviews, limited in time, to collect data from participants with CCN.

However, some AAC researchers have offered reasons for not recruiting participants with CCN. Such practices are not without controversy (Alant, Bornman, & Lloyd 2006). Exclusion from research participation, whilst acceptable in some circumstances (e.g. when the use of proxies is justified), can have unintended social costs (Clements, Rapley, & Cummins 1999; Griffin & Balandin 2004). If researchers exclude participants with CCN, they risk contributing to the perpetuation of stigma and societal oppression (McVilly & Dalton 2006; Shivas 2004; Smith-Chandler & Swart 2014) and producing research findings that contribute to stereotyping (Iacono & Carling-Jenkins 2012). Thus, we would argue that AAC researchers have an obligation to justify research design that automatically or deliberately excludes people with CCN from research participation, and that such reasons should be both well-defined and overtly stated in research proposals. For instance Dukhovny and Zhou (2016) argued in their study comparing SGD training methods that there were practical benefits to excluding participants who use SGDs in the initial stage of their research. They argued this method enabled researchers to 'explore the strengths and limitations of new technology or theoretical models in a controlled setting, prior to attempting intervention with individuals who rely on aided AAC to communicate' (Dukhovny & Zhou 2016: 244). It is beyond the scope of this paper to debate this decision, but in any such decision by AAC researchers to exclude participants with CCN, care must be taken to balance the rights of people with CCN with effective research methods.

Third Party Recruitment

The authors of this paper have encountered difficulties including people with CCN as research participants, due in part to their relatively small numbers (Beukelman, Beukelman, & Miranda 2013) and the social isolation experienced by many people with CCN (Trembath, Balandin, & Togher 2009). However, other obstacles attributable to the research environment rather than to the experience of disability have also occurred. For instance, stakeholders who misunderstand the nature of CCN may not provide individuals with CCN the choice to participate, erroneously believing

that people with little or no functional speech cannot participate in a spoken interview. Furthermore, if only a limited choice of suitable participant consent procedures are available, people with CCN who are not literate may be excluded.

Because of the difficulties in finding people with CCN who may participate in research, some researchers propose recruiting participants through third party organizations (Goldsmith & Skirton 2015; Lennox et al. 2005; Stalker 1998; Taua, Neville, & Hepworth 2014), and this strategy was attempted by the authors of this paper. For AAC researchers, third parties may be health services, speech pathology services or disability support services used by people with CCN. An example of this approach to sampling can be seen in an AAC study by Balandin, Berg & Waller (2006). The researchers compared the loneliness experienced by older people with cerebral palsy who used natural speech, with that experienced by people with cerebral palsy who used AAC. They recruited participants with CCN through a disability organization that provided services to people with cerebral palsy. The organization identified participants who met the selection criteria and informed them about the research. People interested in participating could then either contact the researchers independently, or through a speech pathologist employed by the organization.

Whilst third party recruitment of participants may provide opportunities for people with CCN to find out about a research project, researchers must consider potential difficulties. The authors of this paper have found that third parties may take a less inclusive approach than researchers to people with CCN participating in research. For instance, third party recruitment may bias the sample away from those living independently in the community (Durham, Brolan, & Mukandi 2014). Third parties may decide not to include some people in recruitment for reasons not discussed with the researchers. Organizations are able to develop and use their own ethics procedures that may differ from national ethics statements, although duplication of the ethics approval process is discouraged in some national statements as it delays the research process and also leads to exclusion [e.g. the Australian National Health and Medical Research Council (NHMRC) National Statement clause 5.3.1] (National Health and Medical Research Council 2018). Organizations may, therefore, have their own HRECs, governed by different demands than a University or national ethics committee (Iacono 2006; Ramcharan 2006). There has been a burgeoning of HRECs in individual disability service provider organizations (Ramcharan 2006), without HREC status (Iacono 2006).

As a consequence of these additional committees, requests for assistance with participant recruitment may entail application to the organization's HREC for assessment of risk. Some AAC researchers, including the authors of this paper, have found disability organizations are a major obstacle in the recruitment of participants, with organizations acting as gatekeepers in their communication with potential participants (Jepson, 2015; Lennox et al. 2005; Stalker 1998). An organization may, for instance, consider that the research project does not sit within their Strategic Plan. Organizations may assume that the clients would not be interested, without discussing it with the relevant client groups. Researchers in cognitive impairment have found disability service providers have preconceived opinions about the nature of research (Lennox et al. 2005), or make assumptions about participant capacity to consent, perhaps not fully understanding the concept of informed consent (Jepson 2015; Stalker 1998). Having experienced these difficulties, both Lennox (2005) and Stalker (1998) recounted resorting to using non-government disability advocacy organizations as neutral parties who could recruit participants from disability provider organizations. Both Lennox and Stalker's experiences, and those of the authors of this paper, suggest a sense of ownership of clients by some, but not all, disability providers, and a lack of respect for people's right to be informed about opportunities to participate in research, and their right to make their own decisions whether or not to consent and to participate. AAC researchers must be aware of these risks.

In general research, participation of marginalized groups is higher where the researcher is able to make direct contact with potential participants and engender confidence in the research process (Cleaver, Ouellette-Kuntz, & Sakar 2010; Jepson 2015). However, there are instances where recruitment by third parties has reduced the possibility of pre-recruitment contact between potential research participants and researchers. For instance, the organization's ethics approval may prevent researcher contact with potential participants until consent forms are signed (Lennox et al. 2005). Other recruitment barriers encountered by researchers, including the authors of this paper, may be attributed to financial constraints, workload priorities, and service models that entail time-consuming decision making processes. Limited time for, and exposure to, research within non-government organizations was also identified as contributing to recruitment barriers (Balandin & Raghavendra 1999; Booth & Booth 1996; Lennox et al. 2005).

Participant Consent

As in all research, ethical concerns centre on the protection of the rights of participants considered vulnerable. Disability is often associated with vulnerability and diminished capacity to give informed consent to participate (Iacono & Carling-Jenkins 2012). These are considerations that may raise concerns for researchers and HRECs with little understanding of people with CCN. Concerns are derived from two assumptions. Firstly, the authors of this paper have found a tendency among researchers to assume that any cohort of people with CCN will include people with cognitive impairment. This assumption is erroneous, as people with CCN are not a homogeneous group. Consequently, they may or may not have associated cognitive impairment. Having a cognitive impairment automatically signals to HRECs a vulnerability to risk of harm as a research participant. This occurs no matter what the research topic or method. However, the assumption of vulnerability in this context is challenged by many (Iacono & Carling-Jenkins 2012; Lai, Elliott, & Ouellette-Kuntz 2006). Its use as a rationale for exclusion from research participation is arguably

in contravention of the UNCRPD (2006). Furthermore, as noted, HRECs cannot assume that CCN signals cognitive impairment.

Secondly, many people with CCN have low literacy levels. A history of exclusion from literacy learning at school and limited social stimulation may lead to a failure to develop functional literacy skills regardless of intellectual ability (Koppenhaver, Evans, & Yoder 1991). The absence of functional speech and limited or no literacy skills can lead others to assume, wrongly, that individuals are not eligible for research participation. For instance, those not familiar with people with CCN may believe an inability to read the consent forms equates with an inability to understand the information provided, resulting in an increased risk of harm. We contend these assumptions are wrong, and, in our experience, lead unnecessarily to the ongoing exclusion of people with CCN from research participation. This amounts to wrongful discrimination on the basis of assumptions about possible cognitive limitations that are not applied to the general population. Concerns about informed consent are further complicated by a lack of consensus in the literature about the criteria and processes for obtaining informed consent from people with disabilities (Iacono & Carling-Jenkins 2012; Ramcharan 2006).

The most commonly followed process for obtaining informed consent in research is to have participants read and sign a Plain Language Statement and Consent Form. Conventionally, the statement is a multiple paged document explaining the research and setting out the potential risks and benefits of participation. Even plain language statements are often written in language difficult for people with low literacy levels or those who have no functional literacy (Aman & Handen 2006), as may be the case for potential participants with CCN. Potential participants are asked to sign the form to indicate they understand their role as research participants and confirming their participation. This approach to obtaining consent was adopted from consent for medical research procedures by universities and other research organizations (Bosk 2010), and has been criticized for focusing inordinately on protection of research organizations rather than participants (Boxall & Ralph 2009; 2011). Such a structured approach to consent has also been blamed for hampering researchers' ability to develop personal relationships between researcher and participant that can be instrumental in social science research (Bosk 2010).

However, HRECs with an understanding of the importance of including people in AAC research may agree to flexible ways of obtaining informed participant consent. For instance, they may agree to modify the language and length of the Plain Language Statement or its equivalent (Aman & Handen 2006; Boxall & Ralph 2011; Clements et al. 1999). Alternative methods have been used by researchers and HRECs who understand consent not to be a dichotomy between 'yes' and 'no' (Dye, Hendy, Hare, & Burton 2004), or who assume that all participants have the capacity to consent unless the researcher discovers otherwise (Dalton & McVilly 2004; Iacono & Carling-Jenkins 2012). Studies using alternative methods of obtaining informed consent such as assent, progressive consent (Dalton & McVilly 2004; Griffin & Balandin 2004; McVilly & Dalton 2006; Ramcharan & Cutcliffe 2001), supported decision making (Iacono 2006; Iacono & Carling-Jenkins 2012), the use of pictorial communication (Boxall & Ralph 2009), or video recording participant consent (Paterson & Carpenter 2015), reframe the purpose of obtaining informed consent toward inclusion rather than exclusion, and are highly applicable to AAC research.

There are ways in which HRECs, and indeed disability organizations with whom AAC researchers seek to collaborate, can take a strong role in promoting ethical and inclusive research practices (Lai et al. 2006). For instance, clear and regular reporting back to HRECs and organizational boards on research procedures and outcomes (Cleverly et al. 2010). Also, inclusion on HRECs and boards of at least one member that can 'represent and advocate for the interests of those persons identified as potential participants for the study' (Dalton & McVilly 2004: 59). These approaches have been recommended as ways of improving understanding by HREC members about ethical research with people with cognitive impairment, and could also be applied to AAC research. Dialogue between HRECs and AAC researchers, and disability organizations and AAC researchers, on matters such as negotiating methods for participant recruitment and consent that suit research objectives (Moore 2002), may assist in informing and educating on ethically sound research (Iacono 2006; Iacono & Carling-Jenkins 2012). HRECs, boards of collaborating service provider organizations and AAC researchers need to be familiar with the fairness clauses in any national ethics statements because they emphasize transparency in the selection of participants and the reporting of results. Requiring ethics approval applications to document why participants with CCN are relevant or not relevant as participants would encourage HRECs, non-government organizations and researchers to include participants. HRECs and researchers may also be influenced by a more systematic approach to publishing research reports. For instance, data on participant selection processes and profiles may reflect on the roles and responsibilities of participants, and identify potential sources of bias in recruitment (Bigby & Frawley 2010; Clements et al. 1999). Finally, AAC researchers would be assisted if HRECs and collaborating disability organizations provided their members with regular training in current research methods. This may include options for participant consent (Jepson 2015).

Participation in research projects is voluntary, and people with CCN are as interested as others in participating in research that they perceive to be worthwhile (Alm 1994; Balandin & Raghavendra 1999). Twenty years ago, Balandin and Raghavendra (1999) reflected that 'The field of AAC is moving slowly towards using different research paradigms that will help ensure that augmented communicators have a more equal voice in the research process' (p. 276). Examination of recent AAC research supports the assertion that change is occurring. For example, researchers are including people with CCN as respondents to surveys (Parr 2007; Worrall et al. 2011); as participants in the development of research tools (Paterson & Carpenter 2015); in member checking (Caron & Light 2015, 2016; Hemsley, Dann, Palmer, Allan, & Balandin,

2015; Trembath et al., 2009); and in feedback on research process and tools (Raghavendra, Newman, Grace, & Wood 2015). However, despite these indications of change, the authors of this paper have found the issues discussed above continue to militate against including people with CCN in research (Hynan, Goldbart, & Murray 2015).

Although this paper focuses on AAC research, a similar argument may be made about the inclusion of people with CCN in all research, not only disability research. People with CCN, in common with their nondisabled peers, are entitled to participate in research that is relevant to any aspect of their life, free from ableist assumptions that exclude them. Research methods should accommodate their needs in terms of sampling, consent and accessible communication. It is incumbent upon researchers and upon HRECs to ensure that research methods are inclusive, or that rationales are provided for excluding people with CCN and others perceived to be members of vulnerable groups from research.

Conclusions

The authors of this paper recommend research organizations and AAC researchers adopt new approaches to ethical recruitment of research participants with CCN. Recruitment needs to focus on inclusion rather than exclusion of participants. Flexible methods of obtaining consent, where the approach is to incorporate and support a range of participants, will encourage and support people with CCN to participate not only in AAC research projects but also other research projects. HRECs and collaborating disability organizations need to accept the capacity of participants to consent to participate in research if the research is explained in an accessible format. They could also appreciate the benefits that participating in research can deliver to participants with CCN and to the broader community. Researchers could detail in research reports and articles why and how participants with CCN were included in research, how informed consent was obtained, and how data was obtained. Data collection methods may need to accommodate accessible communication. Finally, more inclusive methods of informed consent are inextricably linked with more inclusive methods of conducting AAC research projects, such as participatory research methods. Research reports demonstrating successful engagement of people with CCN in participatory research, or reflecting on difficulties experienced, such as Balandin and Morgan (1997), may assist. Expert ethical review is essential for people with CCN to claim their right to be included and to have their voices heard. Having little or no speech and low literacy levels should not be a barrier to expression.

Acknowledgements

This manuscript is part of the first author's doctoral dissertation. The authors would like to thank Professor Patrick Kermit, Institute of Mental Health, NTNU, Trondheim, Norway, for his expert and valuable contribution to the manuscript.

Competing Interests

The authors have no competing interests to declare.

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How to cite this article: Taylor, Susan and Susan Balandin. (2020). The Ethics of Inclusion in AAC Research of Participants with Complex Communication Needs. *Scandinavian Journal of Disability Research*, 22(1), pp. 108–115. DOI: <https://doi.org/10.16993/sjdr.637>

Submitted: 15 March 2019 **Accepted:** 29 November 2019 **Published:** 10 April 2020

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