Research and Practice in Intellectual and Developmental Disabilities

ISSN: (Print) (Online) Journal homepage: https://www.tandfonline.com/loi/rpid20

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To cite this article: Betty-Jean M. Dee-Price (2020): Social researchers and participants with intellectual disabilities and complex communication (access) needs: whose capacity? Whose competence?, Research and Practice in Intellectual and Developmental Disabilities, DOI: 10.1080/23297018.2020.1788418

To link to this article: https://doi.org/10.1080/23297018.2020.1788418

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https://doi.org/10.1080/23297018.2020.1788418

Social researchers and participants with intellectual disabilities and complex communication (access) needs: whose capacity? Whose competence?

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ABSTRACT

Despite the evolution of inclusive research and augmentative and alternative communication, there is an ongoing absence of people with intellectual disabilities and complex communication (access) needs from sociological cohorts. In an in-depth study of 10 individuals with complex communication access needs, the involvement of three participants with intellectual disabilities was highlighted. The purpose of this article is to describe how the investigation was conceptualised, designed, and adapted to maximise the participation of adults with intellectual disabilities and complex communication access needs. Revealed are the adaptations and approaches made to the core elements of the study: communication access, research design, consent-to-research, and methods. Also described are subsequent participant insights on the topic of inclusion of people with complex communication access needs in research. The investigation contributes to an evolving body of literature on inclusive research, highlighting tensions of competence and capacity, as well as capacity-building challenges more broadly.

ARTICLE HISTORY
Accepted 24 June 2020

KEYWORDS
Intellectual disability; ethics; inclusion; complex communication access needs; augmentative and alternative communication; research inclusion

The proportion of Australians with intellectual disabilities and complex communication access needs (as well as the dynamic interrelationship between the two) is largely unknown. The insights of people with complex communication (access) needs are often not collected and therefore not present among research findings (Ison, 2009; Stafford, 2017). People with severe, multiple disabilities are virtually missing from key theoretical and methodological discussions (Mietola et al. 2017), with evidence of ongoing bias leading to the research exclusion of participants with intellectual disabilities, such as in all forms of autism research across the field of disability (Russell et al., 2019). The Australian Bureau of Statistics (ABS, 2015) estimated 1.2 million Australians have a communication disability, ranging from those who can get their message across with assistance of a communication aid to those who cannot be understood at all. The Australian Institute of Health and Welfare (AIHW, 2008) revealed that 60% of people with intellectual disabilities have severe communication limitations,

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commonly referred to as complex communication needs (not complex communication *access* needs).

Hodge (2007) noted that the discipline of augmentative and alternative communication is situated within the domain of speech pathology, a field dedicated to improving the communication ability of people with disabilities. The inherent philosophical tension between the roles of service providers in responding to the "needs" of clients, and addressing the social and structural barriers to "access" in the environment is not well documented. As Dee-Price et al. (2020) suggested, the term *complex communication needs* is deficit-oriented, situating the problem of communication with the individual with impairment. This is because "needs" are generally not attributed to persons with the ability to speak but are otherwise unable to use augmentative and alternative communication. For example, we do not usually refer to health professionals as having "augmentative and alternative communication needs" if they lack skills in this mode of communication and are providing services to persons who do not communicate verbally.

There is also the notion of *communicative competence*. Light (1989) described the phrase as having evolved from clinicians and researchers seeking more constructive approaches to evaluating the communicative competence of individuals using augmentative and alternative communication. In order to demonstrate communicative competence, individuals who required augmentative and alternative communication had to develop and integrate knowledge, judgment, and skills across four interrelated domains: linguistic, operational, social, and strategic (Light & McNaughton, 2014). Despite an emerging re-conceptualisation of the phrase as dyadic, learned, and co-constructed (Tsai, 2016), a problem arises in that communication competence is measured with a normative yardstick. When the person (without speech) can adapt no more, there is little that compels disability services to measure communication access.

Potential for measuring communication access is illustrated in Dee-Price's (2020) study in which various environmental communication elements were coded for frequency and intensity and compared with participants' home type (independent living, living with immediate family, or living in a group home). In utilising the social model of disability, this study re-conceptualised communication "needs" and "competence" by focusing on the research environment and the researcher as equal partners in a "communication needs situation." With notions of access tending to be limited to physical barriers and communication barriers not understood in the same way as parking spaces, curb cuts, and ramps (Collier et al., 2012), the study was interested in shaping an accessible communication platform. It began this process by conceptualising the notion of communication from the position of access.

While emancipatory disability research has emerged in recent years, it has often not translated beyond its particular niche within the disability field (Dee-Price et al., 2020). As highlighted by McNaughton et al. (2019), the capacity gaps beyond the field of augmentative and alternative communication are significant. Little information is available to guide the selection and modification of methods for research with people with communication impairments (Teachman & Gibson, 2018), and there is an absence of ethical research standards and methodological guidance specific to this group (Cascella & Aliotta, 2014). It is not unusual for studies to list the ability to provide informed consent as an inclusion criterion, a situation whereby people with intellectual disabilities may simply be assumed to lack the capacity to participate and thus ineligible (Horner-Johnson & Bailey, 2013). Goodyear-Smith et al. (2015) suggested that ethics committees should acknowledge and celebrate the diversity of research by ensuring their members receive broad training in the full range of research methods, study designs, and the rationale for these approaches. Until this occurs, the complex challenges of managing the cross-cutting issues of capacity and self-determination, vulnerability, and need for protection, will be overlooked, with few exceptions.

From the perspective of *inclusive research*, a phrase first used by Jan Walmsley in 2001, social work scholars Bigby et al. (2013) have pointed to an emerging (in principle) inroad with Australia's first National Disability Research And Development Agenda (Australian Government Department of Social Services, 2011). Supporting this is the known capacity of people with severe to profound intellectual disabilities to communicate and interact with others as is demonstrated in studies from the field of intellectual disability, such as Watson et al. (2017), Johnson et al. (2012), Clement and Bigby (2013), and in studies located outside of the field, such as Mietola et al. (2017) and Cocks (2008). Johnson et al. (2012) pointed to the need for recognition of the diverse communication skills and preferences of people with severe to profound disabilities, as well as the extensive support (that may be) required to assist this. With communications of people with profound intellectual disabilities being non-symbolic (Griffiths & Smith, 2015; McLean et al., 1999), engagement and interactions between them and support worker(s) have been described as a continuous process of perception and action (Griffiths & Smith, 2017), with interactions of movement, facial expression, vocalisations, and touch.

The aim of this article is to describe how the study conducted by Dee-Price (2018) was conceptualised, designed, and adapted to maximise the participation of adults with intellectual disabilities and complex communication access needs. The study took a critical approach to the notion of competency and capacity as often applied to people with intellectual disabilities in research settings. The supporting literature helped form the decision to *not* use intellectual capacity as an exclusion criterion of potential participants. Instead, several important adaptations were made to obtaining consent, shaping methods with low reliance upon spoken and written language, incorporating communication tools, and introducing participant supports. These are described in the following sections.

Method

Consent

The study received ethics approval from the Human Research Ethics Committee of Flinders University, South Australia, to recruit adults with complex communication access needs, including people with profound intellectual disabilities. The total cohort consisted of 10 study participants, who were recruited with the support of disability agencies and an Australian Augmentative and Alternative Communication list-serve advertisement. The four female and six male participants recruited ranged in age from 23 to 77 years; seven were people with cerebral palsy, two with stroke, and one person with an unknown neurological condition. The three participants with known intellectual disabilities were all males, two with cerebral palsy and one with an unknown neurological syndrome. The types of disability and communication used by the participants were identified prior to meeting with them. In relation to the participants with intellectual disabilities, this information was conveyed via telephone by the sister of one participant, and a co-ordinator of a disability agency in respect of the two people living in a group home. Documentation from the group home was later shown to the researcher; although this had not been requested.

The researchers were keen to avoid proxy interviewing. As Ison (2009) explained, proxies such as caregivers and healthcare providers often have a different perspective from the person with a disability. Yet in the absence of guidelines supporting the gaining of the consent-to-research process (Cascella & Aliotta, 2014), the current investigation attempted to make deeper inroads into the literature. Iacono and Murray (2003) summarised three important steps required to gain consent from a prospective participant: (i) accurate and balanced information about the project is conveyed to the person; (ii) the person is capable of making a decision about his/her participation in the research; and (iii) the decision is made autonomously or voluntarily. Iacono and Murray (2003) noted that members of staff who were familiar with the residents were generally able to assess their ability to provide consent.

Criteria of capacity and competence were inverted in this study. Instead of the potential participant demonstrating their capacity to communicate, it involved the researcher learning and demonstrating to the participant, their (researcher's) ability to identify and respond to the individual's "yes," "no," and "neutral" communication signals in any form of interaction. Heal and Sigelman (1995) highlighted the fact that yes-no questions produced the highest response levels for persons with intellectual disabilities. The use of yes-no questioning should be considered potentially valuable as a question format option providing acquiescence is adequately assessed (Ramirez, 2005).

The questions in this study primarily centred on yes, no, or neutral responses, with scope to ask questions supported through augmentative and alternative communication, including the use of Talking Mats©. Only once the researcher had demonstrated and was "signed-off" by the participant (with support from their attendant/friend) as having a clear understanding of the participant's "yes," "no," or "neutral" responses were the rest of the consent questions presented to the potential participant. Access to icons such as "stop" and "finish" were available throughout the study, allowing the participant a quick way to end the consent process *or* interview.

A plan to manage the possibility of acquiescence of participants was a feature of the investigation's ethics proposal. It involved a range of strategies including triangulation of responses, cross-checking video for body language, and inviting the presence of a trusted person chosen by the participant. Recruitment material for the study was explicit in including prospective participants with intellectual disabilities, and an outline of the consent process was made available to recruiting agencies/persons.

Figure 1. Tools to support communication during the consent process.

Measurement and tools

Talking Mats® (an evidence-based tool for helping people with communication difficulties to participate in conversations and communicate effectively) was used to help ask questions. The researchers had consulted with a representative from Talking Mats® who advised on the various ways the tool could be adapted in a research context to support the diverse needs of individuals. As shown in the literature (Murphy & Cameron, 2008) Talking Mats® has been effective for use in studies with people with intellectual disabilities. However, in the current study, the tool served primarily to display visual options to some research questions and not necessarily to broaden communication.

Incorporated into the study were visual and sensory ethnography methods. Photographs of hands in different postures to reflect quality of life meanings as related to “home,” such as “comfort” and “safety” were developed. Added to Talking Mats® were picture communication symbols from Boardmaker®. Answering questions involved the use of adapted icons, and picture communication symbols such as “housemates,” “pets” were used to help collect the insights of participants about what was more or less important about “home.” Participants were invited to make choices from photographs and icons and to either use their augmentative and alternative communication to clarify meaning or “yes” or “no” responses with the researcher. As seen in Figure 1, participants could choose from the simple icons shown: thumbs up (consent) on the left, unsure in the middle, and thumbs down (do not consent) on the right.

Although it was anticipated that participants would have access to their own augmentative and alternative communication, some generic tools were brought to the interviews in case they would be of benefit. In addition to the availability of Talking Mats® for back-up communication, the researcher also brought versions of Pragmatic Organisation Dynamic Display books (a system of organising and selecting picture communication symbols). The books varied from those with only a few symbols to those with many pages of symbols. Also available were push-buttons of "yes" and "no" (purchased at a local stationary store) if participants preferred to use these. The buttons (like the earlier mentioned "stop" and "finish" icons) could also be accessed by eye-gaze with participants staring at, rather than manually pushing the chosen button.

Augmentative and alternative communication used by participants

Only one of the three participants with intellectual disabilities included communication tools or devices in the interview and this consisted of approximately 20 picture communication symbols adhered to the clear plastic tray on his wheelchair. The key worker, a nurse, attending a man described as having "profound cognitive impairment" stated that he did not use any augmentative and alternative communication. The family of another participant described a history of Bliss Symbols[1] communication. This ceased when he moved into an accommodation care agency, which invested, instead, in his learning Auslan sign language. However, due to the degenerative nature of his condition (unknown syndrome) this participant had gradually lost much of his physical capacity to sign and appeared to have not been referred to a speech pathologist to support his communication.

Findings and learnings

A series of adaptations to research processes were effectively utilised. The process of obtaining consent, although requiring considerable preparation, was particularly successful. By placing the emphasis upon the researcher's capacity to communicate (using augmentative and alternative communication and identifying sensory input) the consent process appeared to be enjoyed by participants. Participants helped support the learning and capacity of the researcher by sharing their (participant's) use of augmentative and alternative communication. Two of the participants with intellectual disabilities used a combination of vocalisation with clear sounds for "yes" and "no" as well as gestures. The participant who had lost much of the capacity to sign, used a thumbs up to indicate yes to the researcher (and to his support attendant). This participant also effectively used a Pragmatic Organisation Dynamic Display book (of approximately 160 symbols) shown, and made available, to him by the researcher, to elaborate on a choice made and to just chat. The participant with picture communication symbols on his tray, used eye-gaze and some hand pointing to indicate messages. He also vocalised words and gestured with his arms.

The ability to understand and respond to participants "yes," "no," and "neutral" (or undecided) communication was an essential component of the study. For all of the participants (10), it involved asking the question "Could you show me *your way* of saying *yes*?," and then the researcher waiting and observing. For some, it meant re-checking at times with their attendant, for example: did that drop of the head mean *yes*, or was he trying to clear his throat?

Obtaining consent from a participant whose group home file (shown to the researcher upon arrival) described him as having a profound intellectual disability, was not straightforward, as this excerpt from the field notes illustrates:

> I asked [participant] to show me how he says *yes*, and his eyes rolled left and up. He said *yes* to the interview, but a few minutes later, (nurse) informed me the participant often says *yes* to everything. Presented with a dilemma, I asked [nurse] for examples of when [participant] will say *no* to things. [Nurse] offered that if there is unknown meat at dinner, he will say "No pork" but that he often said it out of the context of mealtimes… .There was also the possibility of coercion for the interview – as indicated by his nurse that having a visitor is a rare treat and that [participant] liked receiving things like the shopping voucher (token of appreciation for research participation).

The dilemma led to a decision to give the participant the shopping voucher, terminate the interview, and to "just chat." After some minutes, the nurse requested that the man be allowed to participate in the research as he was repeatedly indicating "yes." Due to his fatigue, only one question was presented; however, in a single response, the participant told a story of what home means to him, specifically, that "home" was not the group home.

The visual research methods used in this study were effective. With the exception of the person with a profound intellectual disability, all participants (including those without intellectual impairment) made meaningful selections from an adaptation to Talking Mats©. The photographs of hands were effectively used by all participants to reveal meaning and were also consistent with the choices made using Talking Mats©. The following provides an example of how the photographs were used:

> The board of photographs was held aloft by [nurse] and myself. [Participant] lying beneath, scanned each of the images and then stopped at the image of hands cradling a mug, one wearing a crocheted glove. Staring at this image, he called out a word, which we recognised as "Mum", and then turned to the nurse and made other vocalisations. "Oh, you want to go home, but you are home, here with [names of others]" the nurse said. The participant became agitated and vocalised his desire to go home. The selected photograph represented home – a place where he had lived his Mother but, as explained by his nurse, his Mother had passed away years ago.

There was a sensory physicality (loud vocalisations) evident in the participant's responses to the image. Similar responses (exaggerated body movements and loud voices) appeared in the responses of the other participants with intellectual disabilities.

When answering the question, *what do you think could help researchers (people like me) to interview people who do not speak or write easily?*, the youngest of the three participants, a man living with his parents, first looked to the ceiling, which conveyed his "I don't know." He stared at the hand photographs to indicate they were helpful and then at the "researcher." The participant's Mother interpreted this as his affirmation of an augmentative and alternative communication informed researcher; however, it was clarified in this way:

> (R) Do you mean me [pointing at self] or all or any researchers knowing about disability and AAC (augmentative and alternative communication)?

(Mother) This hand is all researchers – this hand is just her.
(P) (Stares at Mother's hand indicating all researchers.)

One of the participants living in a group home answered the question by flinging his hand onto the shoulder of his support worker/attendant sitting next to him and said the word "him":

Researcher (R) Are you saying it's important to have a support worker with you to help explain things?

Participant (P) (vocalisation meaning "yes, him" indicated the icon "great").

(R) Just about you or should everyone have someone like [attendant]?

(P) (waves arm in a circle to indicate "everyone").

The presence of a trusted support person was an essential element of the study. A support person was present during the consent process and interviews with all three of the participants and also with a few of the cohort without intellectual disabilities.

Discussion

All participants regardless of their intellectual and communication status provided rich insight into what *home* meant to them. The use of photographs and picture items, a trusted support person, and a researcher who understood communication disabilities and augmentative and alternative communication were important features of the study. These closely aligned with the recommendations made by the three participants, and several others in the cohort (without intellectual disabilities) also recommended these features. The use of *yes-no* questions was an essential component of the successful inverted consent process (and study). Of the 10 participants, nine effectively utilised *yes-no*. However, the consent of the participant with a profound intellectual disability was derived from a combination of the man's display of interest and his nurse requesting his participation. Unlike most of the cohort, the participants with intellectual disabilities were without regular access to a computer. However, half (five) of the participants had self-referred by responding to computer-based notifications of the study. This was noted as a possible barrier to access to research participation by people with intellectual disabilities.

Participation in this study was not shaped by intellectual status; rather by adapted praxis, which sought to plan for and adapt methods and to welcome augmentative and alternative communication. Herein notions of capacity and competence were shared by the researcher. Not only in the re-shaping of the consent process but in the shared willingness of the participants to repeat messages (sometimes several times over) and that of the researcher to frequently seek clarification, to patiently observe and learn. The extended time and effort it took to convey responses and have them understood, was a common experience for all of the participants, not only those with intellectual disabilities.

The ethical dilemma of consent presented the greatest challenge to the study. While one of the participants may not have known *what* he was participating in, there was a clear indication (to the researcher and the participant's nurse) that he knew his view or opinion about photographs was being sought, and that he wanted to offer that opinion. It was also evident that the participant knew the meaning of “home,” not necessarily in a way that required identifying symbols to reveal his thoughts but rather through an emotional response to a photograph. The memory of home, its meaning supported by his brief utterances, represented a relationship he had with his Mother. His distress upon confronting that memory concerning his current life in a group home was felt by the researcher and nurse, propellingS further ponderings of ethics. The man’s Mother had died several years ago, leaving no opportunity to go back to “home.” This question led the participant to an experience of “loss” and an acute awareness of his current accommodation as not being “home.” However, it also led the researcher to “knowing.” To avoid or overlook the pathway toward meanings such as these, in case they lead to unpredictable or painful memories potentially denies information from which services, such as disability housing, might be shaped. Noted too, was the important role of the support person (nurse) in caring for the participant in this situation.

Incorporating the various modes of communication used by participants (formal such as communication devices; informal such as body movements), and developing research questions into research tools such as Talking Mats® was beneficial. The photographs and icons provided a useful focus for asking questions and in capturing meaning with minimal need for discussion or dialogue. Two of the three participants frequently relied upon their own augmentative and alternative communication that included eye-gazing icons attached to the tray of their wheelchair and gesturing. With the exception of the Pragmatic Organisation Dynamic Display, used briefly by one participant, the communication tools brought into the interview by the researcher were often not required by these participants. Still, in preparing these tools, the researcher gained an increased awareness and confidence in using augmentative and alternative communication was gained. Access to participation in research for many of the participants was by way of the Internet; a tool that was not available to the three participants with intellectual disabilities. This highlighted the value in explicitly targeting agencies and services to increase opportunities for recruiting participants with intellectual disabilities. It also raised the question of how electronic media might be adapted to better suit people with diverse needs, including those with severe and profound intellectual disabilities. This is a topic deserving of further investigation

There were limitations to the study. As a secondary analysis of a very small number of participants, the findings are preliminary at best. Participant and researcher reliance upon senses (vision and hearing) was another problem. Adaptations made to methods were mostly visual. Further exploration of methods that include people with vision impairment is needed. Central to this study were notions of communication competence and capacity but viewed from the perspective of *how* to build the capacity of researchers outside the field of intellectual disability and augmentative and alternative communication. Research ethics committees also have a role to play in developing standards and guidelines so as to support inclusion.

Conclusion

An investment in including research participants with complex communication needs and intellectual disabilities in qualitative investigations relies upon a range of progressive shifts. Addressing gaps in knowledge, researcher training, inroads to guidelines and ethical practices, and capacity building between fields and disciplines are likely to assist progress in this area. The participants in this study highlighted the importance of adapting methods such as the use of photographs and icons to convey meaning. Highlighted too was researcher insight and the significance of involving a trusted, supportive attendant or friend. Fundamental to all of these features is a deeper re-conceptualising of inclusive research to disrupt underlying concepts of people who “can” and “cannot” communicate. Research itself must explore notions of its own capacity and competence; to challenge its ability to shape ethics and standards so as to accommodate the “voices” of people who communicate outside the status quo.

Note

1. Bliss Symbols are a constructed symbolic language consisting of several hundred basic symbols that can be used alone or in combination to form new words.

Acknowledgements

Deep gratitude is extended to the participants of this research for their generosity, patience, and willingness to go the extra mile to get their messages understood (for the benefit of the study). Heartfelt appreciation to Associate Professor Kathy Arthurson and Associate Professor Lorna Hallahan from Flinders University for their wisdom and humanity, and to the Southgate Institute for Health, Society and Equity, Flinders University. Thank you also to the exceptional journal reviewers who challenged and encouraged this work in equal measure. Finally, gratitude is extended to Max Saul—the best of teachers.

Disclosure statement

No potential conflict of interest was reported by the author(s).

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