Macrothink Institute™

Issues in Social Science
ISSN 2329-521X
2022, Vol. 10, No. 1

Recruiting Participants with Complex Communication Access Needs in Social Science Research: Issues of Capacity and Consent

Betty-Jean Dee-Price

College of Medicine and Primary Health, Flinders University

Sturt Rd, Bedford Park 5042, Adelaide, South Australia

Tel: 6-043-419-2392 E-mail: bj.deeprice@flinders.edu.au

Received: June 7, 2022 Accepted: June 23, 2022 Published: June 25, 2022

doi:10.5296/iss.v10i1.20019 URL: http://dx.doi.org/10.5296/iss.v10i1.20019

Abstract

Qualitative research assumes verbal and written communication ability from participants. Legitimised by the ethical pillars of 'capacity' and 'consent', articulate speech acts are the *hidden* ticket to research inclusion. The knowledge contribution of people with complex communication access needs is left off; a situation that undermines social science, reinforces disability exclusion paradigms and bypasses opportunities to remediate the problem. In this study, an important part of capacity assessment was transferred from the researcher to the prospective participants to *sign off* on the investigators' capacity to communicate using alternative augmentative communication. The article begins with an exploration of the problem before describing the adaptations made and implemented in this study and their implications for social science.

Keywords: communication disability, research inclusion, consent, capacity, qualitative, ethics

1. Introduction

Communication is the process of understanding and sharing meaning (Pearson & Nelson, 2000) yet a much narrower interpretation of communication as ‘spoken’ governs qualitative research. (Dee-Price, 2019) This situation presents a problem because not all people have access to spoken communication. In view of this dilemma, the social model of disability formed the primary theoretical framework for the adaptations made to the ‘consent-to-research’ process described in this article. The social model of disability locates disability as a consequence of disabling conditions (McLeod, 2018, Emerson et al., 2011) rather than exclusively as an individual medical problem or a ‘personal tragedy’ as presented by Western culture (Barnes, 2020). By taking this approach the investigation was liberated to consider the communicative exchange between the potential research participant and researcher as ‘a two-way street’; to allow the expansion of the notion of ‘communicative competence’ (Light, 2014) to include the social scientist and their *ability* (or not) to understand and incorporate alternative forms of communication when seeking consent with potential research participants.

There are several terms used to refer to people who do not speak (or speak clearly enough to be understood). ‘Communication disability’ is used by Hemsley et al. (2016) as an umbrella term for communication impairments, communication activity limitations, and restrictions in communicative participation. It is also used by the Australian Bureau of Statistics (ABS, 2015) when estimating the 1.2 million Australians who either require a communication aid to get their message across or cannot be understood at all. The phrase ‘complex communication needs’ is common within the field of augmentative and alternative communication (AAC) which Sigafoos et al. (2014) refer to as a clinical specialization within the broader field of speech-language pathology). ‘Complex communication needs’ describes those for whom spoken language is not sufficient to meet their communication needs due to congenital or acquired disabilities (Therriena & Light, 2018) often associated with conditions such as cerebral palsy, intellectual disability, multiple sclerosis, autism, brain injury and stroke (Beukelman et al., 2012) and sometimes with mental illness (García-Mieres et al., 2020; Cohen et al., 2014). Predominantly the professional domain of speech and language therapy, AAC has developed into a specialized area of research and provision in recent decades (Schlosser, 2003) in this context there is a therapeutic focus on treating client needs. Clinical in nature, the communication problem is largely perceived as existing with the individual rather than the communicative situation or setting (Dee-Price, 2020). Herein the expansion of the term to include the word ‘access’ (complex communication *access* needs) shares the problem and solution responsibility across all potential stakeholders in the communicative exchange (Dee-Price, 2019).

1.1 Research Barriers

Research and its philosophical pillars of ontology, epistemology, methodology and methods (Zukauskas et al., 2017) is an exclusively human endeavour directly impacted by those sociological forces applied throughout the social universe, including the scientist’s social location. (Michalski., 2020). Like the rest of the community, researchers swim in a melting pot of experience (author removed) that guides their research approach (Zukauskas et al., 2017). In parts of the social universe (where disability is experienced), alternative forms of expression and communication may appear vastly different from the realm of everyday speech and writing. People may use different ways to convey meaning and/or use alternative and augmentative communication (AAC) which may be unfamiliar to the social scientist. Verbal, written, and textually agentive communications are presumed to be the most valid qualitative-research data (Jones & Cheuk, 2021) with significant communication challenges faced by the researcher to include participants (Nind, 2008) which results in viewpoints not being collected and, therefore, not present amongst research findings (Stafford, 2017; Ison, 2009). Scant attention is given to how "voice" is conceptualized in interview-based research with persons who communicate in ways other than speech; nor does it address the effects of normative judgments in qualitative research about which types of "voices" are valid and authentic. (Teachman & Gibson, 2018). Yet there is evidence of successful qualitative studies involving direct communication with participants including those with severe and profound intellectual disability (Mietola et al., 2017, 2012, Cocks).

The absence of research governance acts in such as way as to legitimise participation gaps, hindering the inclusion of people with impaired capacity (Ries et al., 2017). It includes the absence of guidelines supporting consent-to-research processes for people with complex communication access needs (Cascella & Aliotta, 2014). Instead, a 'protection versus empowerment' situation emerges where people with CC(A)N are subject to overtly protective structures within research ethics committees (Ryan et al., 2020, Iacono, 2006).

As outlined earlier, people with CCAN might also have other conditions affecting the presentation of the body and behaviours such as involuntary movements, hypersalivation (drooling) etc. Stafford (2017) suggests that societal assumptions about body movement, speech, and social interaction as befitting an accepted *norm* have led to perceptions of the legitimacy of the prospective research participant. Awareness gaps suggest notions of communication access have tended to lag behind other types of disability whereby access is often limited to understanding physical barriers such as parking spaces, curb cuts, and ramps (Collier et al., 2012). Without supportive research processes, researchers are free to act on assumptions such as people who cannot speak or write are without thought and that people with severe intellectual disability lack capacity to communicate (Dee-Price, 2019).

1.2 Capacity

The Mental Capacity Act (United Kingdom) provides the framework for acting and making decisions on behalf of individuals who lack the *mental capacity* to make decisions for themselves (Johnston & Liddle, 2007). An applied example of similar legislation can be found in the South Australian Office of the Public Advocate (2020), which states that having mental capacity means to (i) understand information. (ii) weigh up the information available to make that decision and (iii) retain that information long enough to be able to make a decision and (iiii) communicate their decision to others. The current study was particularly interested in the last point and the onus on the person with CCAN to somehow be ready and able to communicate on the closest possible terms of the communication partner (without disability).

The responsibility to demonstrate capacity appears heavily one-sided.

For the recruiting social researcher attempting to discern decisional capacity, the lack of familiarity of communication outside of spoken and written language may be enough to dissuade inclusion altogether. (Dee-Price et al., 2020). Some disability focussed research projects may consider the funding of, for example, speech pathologists trained in AAC, but resource restrictions (including time) and institutional pressures are often extensive. ‘When one is working with deadlines and tight budgets, it is not always possible to use emancipatory or even participatory approaches. One must generally be pragmatic’ (Castrodale & Crooks, 2010, p. 96).

As (Biros, 2018) highlights, informed consent is often considered a document and not a process and that it may not involve the robust two-way communication needed to ensure adequate contemplation and comprehension of capacity.

There is also a ‘rights-based’ issue to consider. Article 19 of the (UNCRPD) protects the *right* to express opinions and *communicate* information and ideas in different ways (regardless of frontiers), but without the necessary adaptations, qualitative inquiry risks overlooking this right in favour of researcher-friendly practice. There is lost opportunity here; as highlighted by Oliver (1997), research can contribute to combating the oppression of people with disabilities by the development of emancipatory methodology and techniques, but this is not possible when people are excluded from the outset. (Dee-Price et al., 2020) argues that qualitative research must be compelled to make adaptations, not just based on rights and ‘research inclusion’ but with an epistemological investment in research innovation.

1.3 Consent

The consent process adapted in this study was part of an investigation of adults with complex communication access needs and their experiences of ‘home’. To give valid informed consent, potential participants should understand their options, the risks, potential benefits, procedures, and alternatives to the study in question (Wendler & Grady, 2008). The challenge was to find a corridor for this to occur for potential participants with CCAN.

From the field of augmentative and alternative communication Iacono and Murray (2003) summarise three important steps to gaining consent from a prospective participant with complex communication (access) needs: (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. According to Iacono and Murray (2003), staff members who were familiar with the residents were generally able to assess their ability to provide consent.

In a study of participants with intellectual disability, Horner-Johnson and Bailey (2013) suggest assessment of consent capacity can be a relatively informal screening process during the initial phases of a consent discussion; the focus being to identify individuals who may have problems understanding consent-related issues. Depending upon the risks and requirements of the particular study, options for participants who have difficulty answering questions might include - exclusion from the study, being provided with additional information and screening, or enrolled with the consent of an authorised representative such as an authorised person or someone familiar to the individual (Horner-Johnson & Bailey, 2013). Kindell et al. (2016) refer to the crucial role communication partners have in scaffolding the conversational abilities of people with dementia but as noted in the literature risks can be present in care and support relationships, such as the urge to meddle or control others (Sevenhuijsen, 1998). As indicated in a recent study by Sellwood (2019), if participants chose to use a communication assistant, they were encouraged to have a competent person whom they trusted to support them, and that the researcher needed to ensure the predominant voice of the participant with complex communication (access) needs.

Also influential in shaping consent for this investigation was a publication of recommendations for improving communication between General Practitioners (GPs) and people marginalised by barriers to communication. Chew et al. (2009) provide the following list (the language of ‘patient’ and ‘research participant’ can be interchanged):

- Speaking directly to patients (or *research participants*), regardless of the severity and aetiology of the disability
- Using short sentences and clear age-appropriate language
- Encouraging patients (or *research participants*) to be actively involved – either verbally or nonverbally – regardless of communication difficulties
- Using pictures and diagrams to clarify explanations
- Ensuring adequate time is available for the consultation
- For patients who communicate with an augmentative and alternative communication system (AAC) systems, medical practitioners (researchers) can: - Ensure that the patient (or *research participants*) has access to his/her AAC system
- Find out how the patient’s (or *research participants*) particular AAC system is used.

Enacting the above recommendations required time, thoughtful preparation and planning. Added to the list were suggestions made by colleagues from the field of augmentative and alternative communication. This led to the inclusion of Talking Mats© (an evidence-based tool for helping people with communication difficulties to participate in conversations and communicate effectively). It also emphasised the need to allocate enough time for potential participants to prepare their responses to questions, and to be comfortable with re-clarifying with participants that their messages have been understood (not pretend to understand something communicated when it is not understood). It also highlighted the importance of researching and valuing communication devices and tools used by the potential participant, and to monitor participant fatigue.

A technique described in a resource for parents of children with speech delays (Pepper et al. 2004) offered another resource for the study wherein the acronym OWL (*observing, waiting and listening*) urged the researcher to slow down, learn and demonstrate 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.

For people with intellectual disabilities and complex communication needs, Heal and Sigelman (1995), state that yes-no questions produce the highest response levels for persons with intellectual disabilities. Figure 1. Shows the tools that were included in the study to support conversations about consent. Talking Mats© with icons of yes, no, and unsure/neutral were available for participants to indicate their choice-making, as were the push buttons (purchased at a local stationery store). The investigation was aware that consent issues could arise at any time during the interview(s) and were not restricted to the ‘consent-to-research’ process undertaken at the time of recruitment. Icons such as ‘Stop’ and ‘Finish’ offered a quick way to end the consent process or interview at any time. These were available to participants utilising pointing (‘finger’-or ‘eye’ pointing’). Talking Mats©

Figure 1. Tools used during the consent process

The Flinders University of South Australia HREC approved the study of adults with complex communication access needs. The recruitment process involved advertising on the AGOSCI (Note 1) website and its on-line list-serve and contact with to a leading state-wide day-options service provider and a series of group homes in South Australia. The researcher attended some staff meetings of service agencies to help increase opportunities for people with complex communication access needs to be linked to the project. This was beneficial as it resulted in several prospective participants being well-prepared and informed of the study before meeting with the researcher. At this point another barrier was identified as reflected in this comment by an AAC provider. *“I haven’t approached any AAC* (augmentative and alternative communication) *users about being involved in your research, as most of the people I would like to approach might be controversial in one way or another. Many are in State care.”* Statements such as this suggest participation barriers may exist preventing the advertising of the proposed research from ever being made known to potential research participants; in itself a different (but related) problem.

2. Method

With support from disability agencies and AGOSCI, a cohort of 10 study participants; four female and six male participants ranging in age from 23 to 77 years were recruited. They came from diverse backgrounds with vast differences in levels of education and research participation experience. Four were people with cerebral palsy, two with stroke, and one with an unknown neurological condition. Three participants had an intellectual disability, with one of these persons with severe to profound disability. A form was created for the study that outlined the role of an accompanying support person (or communication assistant) and required their name and signature as part of the initial consent process. Access adaptations included a large space for participant signing and the ‘sign off’ of the participant and/or their communication assistant on the communication capacity of the researcher. The form was adapted to include an ‘Easy-Read’ version (Easy Read is a simplified and pictorial version of English suitable for adults who have s trouble reading or where English is a second language).

After initial greetings, prospective participants were reminded of the essential first step in the research process: they (the prospective participant) needed to indicate they felt comfortable and confident in the researcher’s ability to communicate with them. The participant also needed to indicate their sense of the researchers’ understanding of how they communicated and identified and used their ‘yes’ ‘no’ and ‘neutral/unsure’ communication. Overall, the study required indication that the participant felt confident they would be understood during the research process.

An essential initial question asked of participants was ‘could you show me *your way* of saying yes?’ which involved the OWL acronym, described in Weizman, (2006) of careful ‘observing’, ‘waiting’ and ‘listening’ for responses which were then repeated with ‘small talk’ using yes and no questions. The talking mat, ‘yes’ ‘no’ buttons and the ‘stop’ ‘finish’ icons were unnecessary but proved to be a fun way to double-check intent. For example, after showing his ‘thumbs up’, a participant with a neurological condition followed it by pressing the green ‘yes’ button.

3. Findings

Each of the ten participants possessed unique ways of conveying yes and no. For example, saying ‘yes’ could include vocalisation where letter sounds were distinguishable (‘naya’ ‘nya’) or humming. Eye movements such as looking up and left or looking down and left at a ‘yes’ symbol on the tray of their wheelchair conveyed ‘yes’ as did gestures such as ‘thumbs up’; or a forced/fixed smile.

Upon meeting individually with each prospective participant, it took between five and 20 minutes for the researcher to become familiar with the ‘yes’ ‘no’ responses of each participant and to be ‘signed off’ as having the capacity to communicate effectively enough to continue with the consent process. The researcher was required to maintain an open approach to how ‘yes’ or ‘no’ might be expressed. Gestures, body movements, and staring in a particular direction all required observation, not just listening.

The consent process took more time than what might otherwise be the case which included gathering background information about how the prospective participant communicated, greeting the prospective participant, discerning 'yes' 'no' and 'unknown/undecided' responses, and greeting/outlining the role of the communication assistant (if they used one). Seven of the 10 participants included a third-party support person who, to varying degrees, assisted with communication.

The role of the supportive third party, well known to, and with good knowledge of, the participant, was, in some situations, an essential element, particularly since the prospective participant did not have independent use of their communication device(s). For example, being informed by the parents of a young that his looking straight up to the sky was his way of saying 'I do not know' provided valuable information. On the other hand, family and other supports sometimes 'spoke for' the prospective participant, which required the researcher to request for them not to do this. Two of the participants had higher degree qualifications with refined skills in bridging the limited AAC skills (and ability to understand dysarthric speech) of the researcher. One of the participants mentioned being overlooked for research participation, in the past, due to the assumption they were incapable and had nothing to say.

Not all of the yes and no communication was easy to discern. The following journal extract describes a significant challenge when attempting to gather consent from a man with a severe to profound disability. *I asked (name of participant) to show me how he says his '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, having a visitor is a rare treat. After some minutes, the Nurse requested that the man be allowed to participate in the research as he was repeatedly indicating 'yes'.* As noted by Iacono and Murray (2003), staff members familiar with the residents were generally able to assess their ability to provide consent. On this basis, the prospective participants 'yes' was accepted as consent to the study.

Three of the participants were able to sign the consent form (all with some difficulty); five could make a mark, and two could not use the paper at all. The space allocated for signing was more than half a page in size, allowing participants without fine motor skills.

*There was an embarrassing moment when I grabbed (*name of participant*'s) arm to help him get his hand to the paper to sign the form. I could see how he was struggling to bring it down to the paper, but he didn't want me to steer his arm and appeared understandably annoyed by this.*

In situations where a signature was unattainable, the consent form included a provision for the participants' attendant or communication assistant to sign as a witness of the consent provided. Despite the adaptations, the consent form was cumbersome.

Nine of the 10 participants confirmed 'yes'; they believed the researcher was able to communicate effectively with them. The participant with a severe to profound disability did not answer the question. The cohort appeared to welcome the opportunity to assess the researchers' capacity to communicate with them (participants) and all displayed great patience with the process. One participant contributed to the assessment by offering a score out of 10 on the researcher's ability to understand their dysarthric speech. A crucial outcome of the study was the knowledge that the capacity to communicate in more diverse ways was a learned experience and, as such, not beyond the scope of other researchers in other studies.

4. Discussion

Effective, first-person communication between people with complex communication access needs and social science investigators is vital to authentic and inclusive data collection, but researchers-have several barriers to surmount. On one hand, there are the capacity-built skills of the researcher; values, insights and abilities to build and work with communication access strategies such as – incorporating augmentative and alternative communication to open the door for the consent to research process. On the other hand, are the contextual barriers such as the absence of guidelines and resources such as the time needed to give people the opportunity to communicate.

Study findings reveal that potential participants with complex communication access needs rely upon the capacity of researchers to acknowledge, learn, and use diverse communication. Achieving this requires an awareness of alternative and augmentative communication and a willingness, as a research project and as individual researcher(s) to provide the time and commitment to adapting to new ways of communicating; weaving new knowledge into tangible, inclusive, research practice. Other barriers were identified in the study, such as the gatekeeping of agencies and the authorities overseeing the care and protection of people with disabilities, however, these were outside the scope of the study.

The philosophical and expanded perception of communication and the reflexivity of questioning one's perception of what 'counts' as valid communication was the fundamental first step in the study. It meant engaging in a different form of 'vulnerability' which urged the researcher to consider their own limitations of communication experience; to learn, adapt practice and then be assessed, by the prospective participant on the learned practice. In this study, by understanding how each participant communicated, applying the many recommended strategies, and ensuring the inclusion of personal AAC and communication assistants (where relevant) it was relatively simple to identify the 'yes' 'no' and 'unsure' of most of the participants. In the situation of uncertainty (the potential participant with severe to profound disability), the recommendations made by Iacono and Murray (2003) were particularly helpful.

It seems plausible that the consent process might translate more broadly across more diverse cohorts of people with CCAN, however, it is too early to suggest the adaptations made in this study (in particular, the participant signing off on the researcher's communication capacity) might apply to all groups of people with complex communication access needs. Nonetheless, the study confirmed the value of adaptations described in the literature as well as the types of recommendations made by researchers from the field of alternative and augmentative communication. This included the critical element of researcher(s) identifying and understanding the type of AAC used by the participant and responding to diverse and unique ways of saying 'yes 'no' and 'neutral' (or undecided); slowing down the communication process by allowing time to observe, wait and listen to the participant.

Other skills were required of the researcher such as managing power differences between the person with complex communication access needs and others present. At times the researcher was required to be assertive, ensuring participant communication assistants or supports refrained from speaking 'for' or 'over' the participant. The reflexive practice was also crucial in the study as there was the potential to fall back into the familiar and expedient practice of spoken and written language; recognising the researcher might also 'speak for', 'gloss over' or misinterpret the participant was important. The use of a research journal helped maintain reflexivity and to record and build upon practice.

The study reinforced a propulsion to move beyond the traditional processes of seeking research consent to a process of interactive communication between the participant and researcher. It led to a re-thinking of the *use of a signature as part of the consent* process (as performed on paper) which may be a barrier for some people with complex communication access needs. As experienced in this study, the physical signing of a consent form was a requirement of the research ethics process, yet several participants could not physically do this.

The knowledge that well over one million Australians have complex communication access needs suggests the need to ensure a similar targeted representation of research participants as afforded to other diverse and marginalised populations. Herein, an obvious challenge for future studies is equipping social scientists with the necessary insight, skills and tools to undertake inclusive research. Cultural shifts in awareness, workforce training and intersectoral capacity building between multiple platforms of research and the field of augmentative and alternative communication are some obvious implications. In the interim, social scientists can, at least, question the framework of social-universe assumptions about communication; to similarly draw upon what is already available.

Potential participants with complex communication access needs rely upon the capacity of the researcher; herein to acknowledge, learn, and use diverse communication. It requires an appreciation of communication as extending well beyond speaking and writing and a willingness to demonstrate that understanding in active research practice. This study demonstrates that it can be done. Yet there were limitations that require consideration. The sample was small and did not include people with all types of impairments such as sensory disabilities (vision and hearing impairments), mental illness or dementia. While it seems plausible that the consent process might translate more broadly, it is too early to suggest the adaptations made in this study (in particular, the participant signing off on the researcher's communication capacity) might be applicable to all groups of people with complex communication access needs. Nonetheless, the work confirmed the relevance of the adaptations made to the literature as well as the types of recommendations made by researchers from the field of alternative and augmentative communication. This included the critical element of researcher understanding and responding to diverse and unique ways of saying ‘yes ‘no’ and ‘neutral’ (or undecided) communication as an essential component of the study. The learning different ways people communicate helped the researcher to push beyond familiar boundaries and rethink how to practice outside the spoken language’s social universe hegemony. It meant being open to new ways of communicating, slowing down the communication process by allowing time to observe, wait and listen to the participant.

Other skills were required of the researcher, which had implications for managing power differences between the person with complex communication access needs and others present. At times the researcher was required to be assertive, ensuring participant communication assistants or supports refrained from speaking ‘for’ or ‘over the person. Reflexive practice was crucial in this study as the potential to fall back into the familiar and expedient practice of spoken and written language; recognising the researcher might also speak ‘for’, ‘gloss over’ or misinterpret the participant was important. The research journal helped maintain and record this awareness.

The obvious need to recognise communication diversity within research practice points to broader implications. Communication-diverse practice across qualitative research requires multi-tiered inroads such as the development of research standards, guidelines and more richly informed and nuanced ethical processes. There is also the significance of researcher training and supervision and the building of the capacity of investigators. Other implications for social researchers which might include the installation of appropriately trained advanced communication assistants within large projects and the development of protocols of inclusion for informal communication assistants.

The study highlights a need to move beyond the traditions of the written *signature of consent*, as a document filled with words that may be physically not accessible and unreadable for some people with complex communication access needs (and others). As experienced in this study, the physical signing of a consent form was a requirement of the research ethics process, yet several participants could not physically do this. Social science exists in a burgeoning digital world; herein there is opportunity to embrace new inroads to communication access and pathways for inviting conversations about consent. Yet the consent paperwork in this study, especially at the sensitive stage of meeting prospective participants, seemed ableist, especially in the face of available access technologies.

An obvious challenge for future studies is equipping social researchers with the necessary awareness, skills and tools to undertake inclusive research of this nature. Research ethics and guidelines have a role to play, and so too does workforce training and access to resources. The field of augmentative and alternative communication has forged inroads into communication access, however, significant intersectoral practice and capacity building is required.

5. Conclusion

At present, without the necessary regulations or guidelines in place to support the inclusion of people with complex communication access needs as research participants (or as researchers) it is left up to researcher(s) to invest the interest, time and commitment to undertake inclusive work. Without a supportive infrastructure to adapt to participants' needs, the responsibility of overcoming research barriers falls upon discretionary impetus or the epistemology of 'pot luck'. From their position in the social universe, social scientists *might* have familiarity with complex communication access needs or have the willingness to learn and the wherewithal to push for the time needed to investigate thoroughly and inclusively. There is also a challenge to research to help find better avenues of learning about the parts of the social universe where spoken and written communication is not available, at least enough to reconceptualise the concept of who 'can' and 'cannot communicate. Without these features, there is little to compel the inclusion of people with complex communication access needs (either in general or specific cohorts) within qualitative research.

The investigation required several necessary adaptions, including allocating the time for preparation and learning about complex communication access needs. Inclusive research requires active attitudinal, skills-based, environmental-based and process adaptations. Making space for the research participant with complex communication access needs research relies upon a range of progressive shifts, in particular, the advancement of the consent process. Until these advancements are manifested inclusive research relies upon the adaptive acumen of individual researchers and research bodies, who may or may not, seek to ensure an accurate reflection of community representation in social studies. Without these necessary adaptions, social science will likely continue to overlook real data from real people, a practice that appears as unscientific as it does unjust.

Acknowledgements

Gratitude is extended to the participants involved in this study for their generosity, patience, and assistance.

References

ABS. (2015). *Disability, Ageing and Carers, Australia: Summary of Findings*. Cat. No. 4430.0. Australian Bureau of Statistics.

AIHW. (2008). *Disability in Australia: Intellectual Disability.* Australian Institute of Health and Welfare.

Biros, M. (2018). Capacity, Vulnerability, and Informed Consent for Research. *Journal of Law, Medicine & Ethics*, *46*(1), 72-78. https://doi.org/10.1177/1073110518766021

Butler, C. (2013). Identity and stammering: Negotiating hesitation, side-stepping repetition, and sometimes avoiding deviation. *Sociology of Health & Illness*, *35*(7), 1113-1127. https://doi.org/10.1111/1467-9566.12025

Cascella, P., & Aliotta, F. (2014). Strategies to Enhance the Informed Consent Process for Communication Disorders Researchers. *Communication Disorders Quarterly, 35*(4), 248-251. https://doi.org/10.1177/1525740114524589

Castrodale, M., & Crooks, V. (2010). The production of disability research in human geography: An introspective examination. *Disability & Society*, *25*(1), 89-102. https://doi.org/10.1080/09687590903363415

Chew, K. L., Iacono, T., & Tracy, J. (2009). Overcoming communication barriers - working with patients with intellectual disabilities. *Australian Family Physician, 38*(1-2), 10-14.

Cocks, A. (2008). Researching the Lives of Disabled Children. *Qualitative Social Work, 7*(2), 163-180. https://doi.org/10.1177/1473325008089628

Cohen, A., McGovern, J., Dinzeo, T., & Covington, M. (2014). Speech deficits in serious mental illness: A cognitive resource issue? *Schizophrenia Research, 160*(1-3), 173-179. https://doi.org/10.1016/j.schres.2014.10.032

Collier, B., Mcghie-Richmond, D., & Self, H. (2010). Exploring Communication Assistants as an Option for Increasing Communication Access to Communities for People who use Augmentative Communication. *Augmentative and Alternative Communication*, *26*(1). https://doi.org/10.3109/07434610903561498

Dee-Price, B. (2019). Making space for the participant with complex communication (access) needs in social work research. *Qualitative Social Work*, *19*(5-6), 827-844. https://doi.org/10.1177/1473325019856080

Dee-Price, B., Hallahan, L., Nelson Bryen, D., & Watson, J. (2020). Every voice counts: exploring communication accessible research methods. *Disability & Society*, *36*(2), 240-264. https://doi.org/10.1080/09687599.2020.1715924

García-Mieres, H., Lundin, N., Minor, K., Dimaggio, G., Popolo, R., Cheli, S., & Lysaker, P. (2020). A cognitive model of diminished expression in schizophrenia: The interface of metacognition, cognitive symptoms and language disturbances. *Journal of Psychiatric Research*, *131*, 169-176. https://doi.org/10.1016/j.jpsychires.2020.09.008

Harris, J., & Roberts, K. (2003). Challenging Barriers to Participation in Qualitative Research: Involving Disabled Refugees. *International Journal Of Qualitative Methods*, *2*(2), 14-22. https://doi.org/10.1177/160940690300200202

Heal, L., & Sigelman, C. (1995). Response biases in interviews of individuals with limited mental ability. *Journal of Intellectual Disability Research*, *39*(4), 331-340. https://doi.org/10.1111/j.1365-2788.1995.tb00525.x

Horner-Johnson, W., & Bailey, D. (2013). Assessing Understanding and Obtaining Consent From Adults With Intellectual Disabilities for a Health Promotion Study. *Journal of Policy and Practice in Intellectual Disabilities, 10*(3), 260-265. https://doi.org/10.1111/jppi.12048

Iacono, T. (2006). Ethical challenges and complexities of including people with intellectual disability as participants in research. *Journal of Intellectual & Developmental Disability, 31*(3), 173-179. https://doi.org/10.1080/13668250600876392

Iacono, T., & Murray, V. (2003). Issues of Informed Consent in Conducting Medical Research Involving People with Intellectual Disability. *Journal of Applied Research in Intellectual*

Disabilities, 16(1), 41-51. https://doi.org/10.1046/j.1468-3148.2003.00141.x

Johnston, C., & Liddle, J. (2007). The Mental Capacity Act 2005: A new framework for healthcare decision making. *Journal of Medical Ethics, 33*(2), 94-97. https://doi.org/10.1136/jme.2006.016972

Kindell, J., Keady, J., Sage, K., & Wilkinson, R. (2016). Everyday conversation in dementia: a review of the literature to inform research and practice. *International Journal of Language & Communication Disorders, 52*(4), 392-406. https://doi.org/10.1111/1460-6984.12298

Light, J., & McNaughton, D. (2014). Communicative Competence for Individuals who require Augmentative and Alternative Communication: A New Definition for a New Era of Communication? *Augmentative and Alternative Communication, 30*(1), 1-18. https://doi.org/10.3109/07434618.2014.885080

Michalski, J. (2020). The sociological determinants of scientific bias. *Journal of Moral Education, 51*(1), 47-60. https://doi.org/10.1080/03057240.2020.1787962

Mietola, R., Miettinen, S., & Vehmas, S. (2017). Voiceless subjects? Research ethics and persons with profound intellectual disabilities. *International Journal of Social Research Methodology, 20*(3), 263-274. https://doi.org/10.1080/13645579.2017.1287872

Nind, M. (2008). *Conducting qualitative research with people with learning, communication and other disabilities: Methodological challenges*. ESRC National Centre for Research Methods Review Paper. National Centre for Research Methods.

Oliver, M. (1997). Emancipatory research: Realistic goal or impossible dream? In C. Barnes, & C. Mercer (Eds.), *Doing Disability Research* (pp.15-31). Leeds: Disability Press.

Pearson, J., & Nelson, P. (1998). *An introduction to human communication*. Boston: McGraw-Hill.

Pepper, J., Weitzman, E., & Manolson, H. (2004). *It takes two to talk*. Toronto: Hanen Centre.

Ries, N., Thompson, K., & Lowe, M. (2017). Including People with Dementia in Research: An Analysis of Australian Ethical and Legal Rules and Recommendations for Reform. *Journal of Bioethical Inquiry, 14*(3), 359-374. https://doi.org/10.1007/s11673-017-9794-9

Ryan, H., Heywood, R., Jimoh, O., Killett, A., Langdon, P., Shiggins, C., & Bunning, K. (2020). Inclusion under the Mental Capacity Act (2005): A review of research policy guidance and governance structures in England and Wales. *Health Expectations, 24*(1), 152-164. https://doi.org/10.1111/hex.13165

Schlosser, R., & Koul, R. (2015). Speech Output Technologies in Interventions for Individuals with Autism Spectrum Disorders: A Scoping Review. *Augmentative and Alternative Communication, 31*(4), 285-309. https://doi.org/10.3109/07434618.2015.1063689

Sellwood, D. (2019). *Lived experiences of people with complex communication needs: Romantic and sexual relationships*. Flinders University, College of Nursing and Health Sciences. https://doi.org/10.1080/07434618.2022.2046852

Sevenhuijsen, S., & Savage, L. (1998). *Citizenship and the Ethics of Care*. Routledge. https://doi.org/10.4324/9780203169384

Stafford, L. (2017). What about my voice': Emancipating the voices of children with disabilities through participant-centred methods. *Children's Geographies, 15*(5), 600-613. https://doi.org/10.1080/14733285.2017.1295134

Stalker, K. (1998). Some Ethical and Methodological Issues in Research with People with Learning Difficulties. *Disability & Society, 13*(1), 5-19. https://doi.org/10.1080/09687599826885

Teachman, G., & Gibson, B. (2018). Integrating Visual Methods With Dialogical Interviews in Research With Youth Who Use Augmentative and Alternative Communication. *International Journal of Qualitative Methods, 17*(1). https://doi.org/10.1177/1609406917750945

UNCRPD. Article 12 of the United Nations Convention on the Rights of Persons with Disabilities (UNCRPD).

UNCRPD. Article 19 of the United Nations Convention on the Rights of Persons with Disabilities (UNCRPD).

Walmsley, J. (2004). Inclusive learning disability research: The (nondisabled) researcher's role. *British Journal of Learning Disabilities, 32*(2), 65-71. https://doi.org/10.1111/j.1468-3156.2004.00281.x

Wendler, D., & Grady, C. (2008). What should research participants understand to understand they are participants in research? *Bioethics, 22*(4), 203-208. https://doi.org/10.1111/j.1467-8519.2008.00632.x

Žukauskas, P., Vveinhardt, J., & Andriukaitienėukaitienė, R. (2018). Philosophy and Paradigm of Scientific Research. In *Management Culture and Corporate Social Responsibility*. IntechOpen. https://doi.org/10.5772/intechopen.70628

Note

Note. AGOSCI is the Australian Chapter of the International Society for Augmentative and Alternative Communication

Copyright Disclaimer