

Including People Who Use Augmentative and Alternative Communication in Qualitative Research: Can You Hear Us?

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Abstract

People who use augmentative and alternative communication (AAC) are frequently excluded from research, yet their voices can significantly enhance the applicability, acceptability, and translation of qualitative research findings. Accessible and adapted research methods welcome and empower participants who use AAC, and enable meaningful involvement. In this article, we describe the collaborative development of a framework to conceptualise inclusive research and aspects of an accompanying inclusive research toolkit. The framework identifies balancing power as a critical factor, primarily achieved by ensuring that research methods and materials are accessible to people who use AAC. We propose that this is achieved through three interacting elements: collaboration with AAC users, skills and knowledge to achieve accessibility, and ensuring adequate time is available to achieve involvement. We identify five areas where applying these elements has impact for AAC users: recruiting AAC users, working with communication supporters, adapting research methods, securing ethics approval, and consent. In presenting the framework, we demonstrate how qualitative researchers can foster a research environment that values and actively includes AAC users, ultimately advancing the field towards more comprehensive and inclusive research practices. While our work is situated in the cerebral palsy and AAC communities, our proposed framework and toolkit can be applied by researchers seeking perspectives from individuals with communication disabilities more broadly. We have created a corresponding plain language video of this article as an additional means of optimising accessibility of the content. See [supplemental material](#).

Keywords

augmentative and alternative communication users, inclusive research, consumer involvement, complex communication needs

Introduction

This article describes a framework for involving individuals with cerebral palsy who use augmentative and alternative communication (AAC) as consumer research partners and research participants. AAC encompasses any form of communication that is not speech. AAC may be used as an alternative to, or to supplement (augmentation), spoken communication as well as to support comprehension in those who have difficulty understanding spoken communication ([Speech Pathology Australia, 2016](#)). Examples of AAC include picture communication books, text to speech apps on computers and mobile devices, Key Word Sign ([Key Word Sign Australia](#)), and electronic communication devices. AAC use is frequently multi-modal, involving two or more modes of communication, such as gestures, pictures, symbols, and voice

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output devices (Paterson & Carpenter, 2015; Speech Pathology Australia, 2016).

The collaborative methods used to develop the framework integrated the lived experience of consumers and the expertise of speech pathologists and consumer involvement experts, along with relevant information and resources. The framework and resultant inclusive research toolkit aim to support researchers to develop skills and knowledge to optimise involvement of people with cerebral palsy who use AAC in research. Although this work has a focus on AAC users who have cerebral palsy, the framework will be valuable for researchers involving other people with communication disabilities. The focus of this paper is the framework; for a copy of the inclusive research toolkit, please contact the authors.

Five of the authors on this article are people with cerebral palsy who have unclear speech or no speech, and communicate using AAC. Each of these authors emphasised the importance of involving AAC users in research, while reflecting that they often feel excluded from participation. As one author (PM) stated:

I believe it's important to be a part of the research as it helps identify the needs and wants of the AAC user. It allows us (AAC users) to have an opinion based on our lived experience and what helps us the most in communicating and having a voice. It helps improve the research so it can be understood by others to know what we prefer and what isn't working when it comes to being a [sic] AAC user.

Communication Considerations for People with Cerebral Palsy

Cerebral palsy is a lifelong disability involving movement and posture difficulties resulting from a brain lesion sustained prenatally or in early life (Rosenbaum et al., 2007). People with cerebral palsy may have mild to profound physical disability. They can experience comorbidities including pain, intellectual disability, epilepsy, hearing and vision impairment, feeding difficulties, learning disabilities, and speech and communication difficulties (Novak et al., 2012). Of those who have cerebral palsy, up to half have difficulty speaking and as many as one-third do not use speech for communication (Nordberg et al., 2013; Novak, 2014).

The physical difficulties present in cerebral palsy can pose challenges for people in accessing an AAC system (Griffiths & Addison, 2017). People with cerebral palsy who have significant physical disability will access AAC using their most reliable movements. Examples are operating a device using eye-gaze or a foot operated switch. Physical disability can also impact how quickly people can communicate using AAC and their endurance for accessing these systems. AAC should aim to enhance participation in daily and community life when individualised to the needs, preferences and goals of the user (Light & McNaughton, 2015). The success of AAC implementation often depends on factors beyond the individual and their technology: AAC users frequently require skilled communication supporters (Dee-Price,

2023), and inclusive and accessible environments to ensure participation (Taylor & Balandin, 2020).

Various terminology is used to describe people for whom speech is not their primary means of communication. Terms include people who are non-verbal or minimally verbal, non-speaking or semi-speaking, people who have complex communication needs or complex communication access needs, and AAC users. Zisk and Konyon (2023) recommend asking individuals who use AAC about their preferred terminology to describe themselves and their communication. This includes their preference for person-first or identity-first language (e.g., person who uses AAC or AAC user). In this article, the authors who use AAC considered the key terms for literature searches, reader familiarity, and their own identities, to recommend we use "AAC user" or "person who uses AAC."

Mansell (2011) has described strategies to include people who do not communicate intentionally in research. In this paper, however, we focus on people who communicate intentionally using AAC systems.

Our Context: CP-Achieve and People Who Use Augmentative and Alternative Communication

The authors of this article are affiliated with CP-Achieve, the Australian Centre for Health, Independence, Economic Participation and Value Enhanced Care for Adults and Young Adults with Cerebral Palsy (CP-Achieve Centre of Research Excellence, 2020). CP-Achieve is a Centre of Research Excellence funded by the Australian Government through the National Health and Medical Research Council, with a primary focus on the health, well-being and participation of adolescents and young adults with cerebral palsy.

CP-Achieve is committed to consumer involvement in research, that is involvement of adolescents and young adults with cerebral palsy and their support networks. Individual consumers collaborate with research teams as consumer research partners. In addition, four advisory groups consult with researchers to inform their work. The advisory groups comprise consumer research partners who are: i) young adults with cerebral palsy, ii) adolescents with cerebral palsy, iii) parents of individuals with cerebral palsy, and iv) people with cerebral palsy who use AAC. This fourth advisory group, self-titled *One Group Our Voice* was convened to promote inclusion of AAC users in research. A key role of One Group Our Voice was to co-develop a toolkit that supports researchers to involve AAC users as both research participants and consumer research partners.

The Importance of Involving People Who Use Augmentative and Alternative Communication in Qualitative Research

The most obvious reason for involving AAC users in research is to hear, explore and understand their perspectives. This knowledge is critical to identifying and addressing issues that

frequently compound AAC users' equitable access to good health and involvement in the community. Proxy-report by family and support people is often used in lieu of making research accessible for AAC users. Proxy-report, however, is an inferior option when there are ways to obtain perspectives from AAC users themselves (Dee-Price, 2023; Dee-Price et al., 2021).

Broader issues prevail. Both the Convention on the Rights of Persons with Disabilities (United Nations, 2006) and the Universal Declaration of Human Rights (United Nations, 1948) embody principles which demand that people with communication needs are involved in research and have equal opportunity for full participation and inclusion in an accessible world, without discrimination, and with respect for their autonomy. AAC users, like everyone else, have a wish and a right to express their views, opinions, perspectives, and unique lived experience. Researchers have an obligation to foster inclusive and accessible environments to enable AAC users to be involved as both research participants and consumer research partners.

We argue that involvement of AAC users as research participants demands collaboration with people who use AAC as consumer research partners. The aim of consumer research partners as co-investigators and/or collaborating on advisory groups is to harness their lived experience to design and implement research that is accessible to AAC users as participants. Accessible research will enable AAC users to be fully included, ensure the research is applicable and acceptable to AAC users, and the findings are meaningful and translatable.

Involvement of People with Cerebral Palsy Who Use Augmentative and Alternative Communication in Qualitative Research

What is Involvement?

AAC users can be involved in qualitative and other types of research as consumer research partners and as research participants. These are distinct roles. Research participants are the 'subjects' in research, for example participating in interviews or focus groups, and their responses are the data which are collected for analysis.

In contrast, consumer research partners can influence every aspect of the research process from determining research priorities, through to translating the findings. The potential influence of consumer research partners spans a continuum (Smits et al., 2020) and depends on the nature of the research, available resources, the skills and confidence of the researchers and preferences of consumer research partners. For instance, substantial influence will be exerted by consumer research partners who are co-researchers immersed in the research team, while less influence may be exerted by partners who are consulted as part of an advisory group.

Involvement of consumer research partners optimises the applicability of the research to the field, its acceptability to potential research participants, and the team's ability to translate the findings to end-users to inform future decision making

(Brett et al., 2014). In our work, one example of consumer partner influence was in the development of recruitment materials which feature AAC users and explicitly state that they are welcome. Another example is collaborating with a researcher to develop an interview schedule that was accessible for people who use AAC (e.g., language, font size, screen readability).

Terminology used to describe the process and practices of involving people with lived experience in research varies considerably. Terms include consumer involvement, public and patient involvement, citizen engagement, community and consumer involvement, and involvement of people with lived experience. The terms consumer involvement and consumer research partner have been selected by CP-Achieve, in consultation with people with cerebral palsy and their families. Their advice is that the word 'consumer' is empowering. In a market economy, consumers have an important role in driving demand, price, innovation and choice. Consumer involvement is intended to drive the kind of research we do to ensure our research meets the needs and priorities of consumers. In addition, 'consumer' is the terminology used by influential organisations in Australia (Australian Clinical Trials Alliance, 2019) and the funder of our research group, the National Health and Medical Research Council (NHMRC, 2016).

Advisors from One Group Our Voice have echoed other reports (Dee-Price, 2023; Taylor & Balandin, 2020) reinforcing that AAC users are often explicitly excluded from involvement in research at any level, as either consumer research partner or research participant, because researchers are unwilling or unable to support them. Consequently, we developed a framework to guide researchers in conceptualising the barriers and enablers of involving AAC users in research. The framework positions power and power imbalances as an overarching consideration. The framework offers accessibility as a major means for addressing power imbalance and outlines areas of accessibility which specifically apply in involving AAC users in research. The framework informed development of a toolkit, which used alongside the framework aims to assist researchers to address the disparity in access to the perspectives and expertise of AAC users. The aim of this paper is to describe the framework and its development, and provide practical guidance for involving AAC users in research.

Methods Used to Develop a Framework and Inclusive Research Toolkit to Support Researchers to Involve Augmentative and Alternative Communication Users in Research

Several sources of information were explored to identify and address knowledge and information needs. We completed a review of the literature, interviewed researchers, consulted with consumers (people with cerebral palsy and parents), and engaged in an iterative and reflective cycle with One Group

Our Voice to seek their expertise. See [Figure 1](#) for an outline of our collaborative process. Although presented in a stepwise fashion, we completed the information gathering and synthesis synchronously. We triangulated our learnings from the literature, researcher interviews, lived experience, clinical experience and experience of consumer involvement. Drawing from these multiple sources, we developed strategies and ideas, which we workshopped with One Group Our Voice. We anticipate that by describing our collaborative process, readers can see the framework being implemented as it was being developed. This paper does not describe research, rather we present the iterative process we used to integrate knowledge from the literature, and the personnel and people with lived experience in our research group, CP-Achieve.

Project Team Experience

The project team consisted of four people with lived experience of cerebral palsy (One Group Our Voice), five clinicians and researchers with speech pathology, occupational therapy and medical discipline-specific knowledge of disability and cerebral palsy, and one researcher (DS) with cerebral palsy (see [Sellwood, 2019](#); [Sellwood et al., 2017](#); [Sellwood et al., 2022](#)). The team collaborated to pool knowledge and experience, identify and share resources, and to reflect on our learnings, progress and direction.



Figure 1. The collaborative process used to develop the framework and inclusive research toolkit. Alt Text: A diagram showing that information from a literature review, a parent advisory group, interviews with researchers and project team experience all combined, along with collaboration with One Group Our Voice to develop an inclusive research toolkit. The figure also shows that the collaboration with One Group Our Voice was collaborative, iterative, and reflective.

With his extensive professional and personal experience, DS supported our broader understanding of disability and ensured that AAC users were at the centre of our research partnership approach.

Literature Review

We reviewed the literature in August 2022 to identify how AAC users and other people with complex communication needs were involved in research, barriers and enablers to their involvement and strategies to support their involvement. This literature review was not systematic nor publishable, it was a review to inform our practice. Broad search terms around complex communication needs were included in our literature search to capture related work, as our preliminary searches indicated little research specific to AAC users. The search yielded 10 articles associated with a range of diagnoses, including cerebral palsy and people with profound intellectual and multiple disability ([Dada et al., 2022](#); [Dee-Price et al., 2021](#); [Hemsley et al., 2008](#); [Ibrahim et al., 2021](#); [Lutz et al., 2016](#); [Paterson & Carpenter, 2015](#); [Pennington et al., 2007](#); [Taylor & Balandin, 2020](#); [Van Goidsenhoven & De Schauwer, 2022](#); [Watson et al., 2007](#)).

We completed a narrative synthesis of the information contained in the 10 articles. The review identified the frequent exclusion from research of people who use AAC, with many authors advocating for action to redress this inequity. We identified power imbalance as a major theme impacting involvement in research ([Ibrahim et al., 2021](#); [Lutz et al., 2016](#); [Van Goidsenhoven & De Schauwer, 2022](#)) and that creating accessible research was critical to address power imbalance. These issues are elaborated later in this article.

Interviews with CP-Achieve Researchers

Six CP-Achieve personnel, including researchers, participated in informal interviews to share their experiences and perceptions of working with AAC users. We also sought to understand what information they required to involve AAC users as research participants and consumer research partners. Audiorecorded interviews were transcribed and informally content analysed guided by the aims for the interviews. The project team met several times to review findings and collaboratively identify how the information obtained could be integrated with other information to inform the framework and toolkit.

Most interviewees had little experience working with AAC users in a research role, although some had clinical experience working with people who use AAC. Interviewees recognised the importance of involving AAC users in research, and wished to build their confidence and knowledge to do so. They identified key barriers to involving AAC users as research participants or consumer research partners, including their own limited knowledge about authentic involvement with AAC users, and concerns about the potential of “getting it

wrong” during the involvement process. Interviewees also identified that time was a barrier – specifically, time needed to learn about effective and inclusive involvement, adequately prepare accessible and tailored resources and research materials, and ensure AAC users authentically shared their perspectives.

Consultation with CP-Achieve’s Parent Advisory Group

We consulted with CP-Achieve’s parent advisory group, which included six parents of young people who use AAC. Parents play a critical role in supporting their young person who uses AAC to participate in research (Dee-Price, 2023; Van Goidsenhoven & De Schauwer, 2022; Watson et al., 2007). Meeting with the parent advisory group provided parallel insight into language accessibility and recruitment considerations for parents themselves, as well as the role of parents and other communication supporters when AAC users with cerebral palsy choose to engage in research as a participant or research partner.

Collaboration with One Group Our Voice

One Group Our Voice actively engaged in an iterative and reflective series of one-hour meetings, held every three weeks over more than 12 months in 2022–2023. As we gained additional insights, refined our knowledge, learned new information and reflected on the process, we returned to the collaborative process with One Group Our Voice to trial, seek further input, and continuously refine our framework and toolkit.

Findings and Application to the Inclusive Research Toolkit

We identified power as a critical perspective, often manifest through paternalism and ableism (Ibrahim et al., 2021; Lutz et al., 2016; Van Goidsenhoven & De Schauwer, 2022). We also identified that creating accessible research was critical to addressing power imbalance. This could be achieved when researchers developed the knowledge and skills to accommodate or modify the research processes for people who use AAC and allowed sufficient time for preparation and engagement with AAC users (Dada et al., 2022; Dee-Price et al., 2021; Hemsley et al., 2008; Ibrahim et al., 2021; Paterson & Carpenter, 2015; Watson et al., 2007). These issues are elaborated later in this article. The knowledge synthesised following the process described above has been integrated into a framework for involving individuals who use AAC as research participants and consumer research partners (Figure 2). This framework aligns with best practices in qualitative research, emphasising researchers’ reflexivity concerning power dynamics and their commitment to uphold individuals’ rights to participate in research concerning their own experiences.

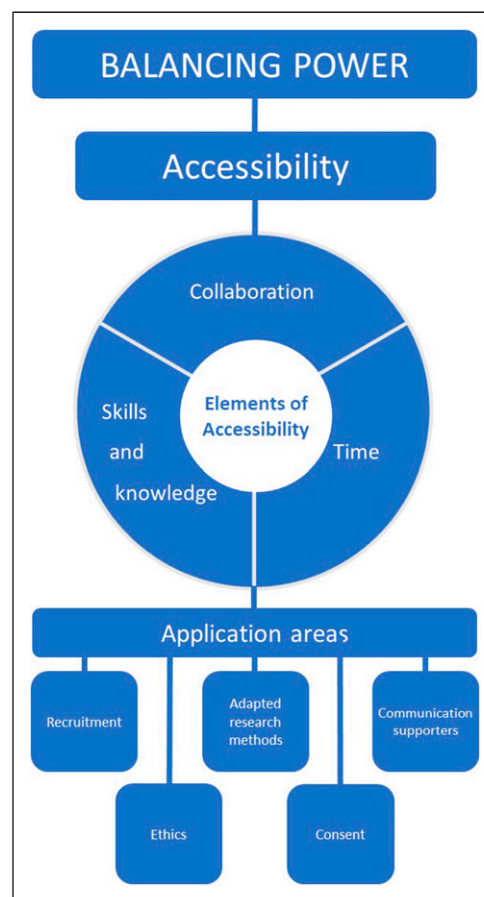


Figure 2. Framework for involving people who use AAC as research participants and consumer research partners. Alt Text: A diagram showing that balancing power was an important part of the framework and sits at the top of the diagram. Underneath is accessibility was a way of addressing power. The diagram then shows that there are three elements of accessibility: collaboration, time and skills and knowledge which are needed to be considered together. Then, there are five areas where accessibility is important to address with AAC users: recruitment, adapted research methods, communication supporters, ethics and consent.

Power is a critical perspective in this framework, specifically, understanding and balancing power and its impact on involving AAC users in participant and consumer partner roles. Researchers can mitigate these effects by addressing power imbalances and designing accessible research and research materials.

Accessibility, in this framework, revolves around three elements: *collaboration* with AAC users, acquiring the necessary *knowledge and skills* to adapt research and materials to cater to AAC users’ needs, and dedicating sufficient *time* to enable meaningful contributions from AAC users. We also identified five areas where applying these three elements can yield the most substantial impact for both researchers and AAC users: recruitment, working with communication supporters, adapted research methods, ethics, and consent. Elaboration on each component of this framework follows.

Power and Power Imbalance – the Critical Perspective

Power imbalances refer to unequal distribution of authority and influence between researchers and participants, potentially marginalising certain voices and experiences, hindering genuine participation, and impacting the applicability and inclusivity of research findings. The AAC user-researcher relationship is fraught with potential power imbalances and hierarchies which, when unchecked, impede authentic AAC user involvement in research (Ibrahim et al., 2021; Van Goidsehoven & De Schauwer, 2022; Watson et al., 2007). As a One Group Our Voice advisor reflected: “You have to be brave and take a risk, because you don’t know if it will be safe or fun.” This quote exemplifies the perception that power imbalance may be present in research interactions and should galvanise researchers to address power.

One aspect of power imbalance we identified related to ableism, a form of social prejudice and discrimination underpinned by the assumption that possessing typical ability is superior. Ableism reflects negative implicit and explicit attitudes about people with disability (Bogart & Dunn, 2019; Dirth & Branscombe, 2019). AAC users often experience ableism in interactions with researchers, health professionals, and the public. They report feeling underestimated, and many face assumptions that they have an intellectual disability which is perceived by others to impact their ability to be involved in research (Taylor & Balandin, 2020). While some AAC users have a concomitant intellectual disability, not all do; further, the presence of intellectual disability does not preclude participation in research. When asked what researchers should know about working with AAC users, One Group Our Voice advisors offered: “I am smart and I am funny”; “I understand but need time to process things” and “I’m not deaf, so don’t yell at me.” These responses reflect the legacy of common stereotypes ascribed to AAC users by professionals and community members, likely fed by underlying ableism (Bogart & Dunn, 2019).

Paternalism is another form of power imbalance that many AAC users, including One Group Our Voice Advisors, report experiencing throughout the research process. Paternalism reflects a societal attitude whereby non-disabled people assume responsibility for looking after the best interests of people with disabilities, thereby taking choice and control away from people with disabilities (Carney et al., 2021; Van Goidsehoven & De Schauwer, 2022). Taylor and Balandin (2020) provide an example of paternalism where a disability service withheld study recruitment information from AAC users, assuming they were ineligible, incapable, or uninterested. On the opposite end of the spectrum, people with disabilities are empowered to make decisions, realising their preferences, and securing their rights.

Ethics committees may display paternalism by considering AAC users to sit within a narrow definition of vulnerability. These committees are tasked with safeguarding the rights of

vulnerable populations, including those with physical, cognitive, or intellectual disabilities, or medical fragility (National Health and Medical Research Council et al., 2023). Categorising AAC users as vulnerable can amplify the perception of risk, leading ethics committees to impose more stringent recruitment, methodological, and consent requirements and thus creating barriers to involving AAC users (Dee-Price et al., 2021; Taylor & Balandin, 2020, Walsh et al., in press)

Many AAC users are supported by communication supporters, either informally (e.g., parents, guardians, and friends) or formally through paid support workers. Paternalistic actions of support people can disempower participants who use AAC by underestimating their abilities, speaking on their behalf, or acting as gatekeepers to information (Dee-Price, 2023; Lutz et al., 2016). Conversely, supportive and empowering relationships with communication supporters can be instrumental in ensuring AAC users’ genuine participation in research, enabling their voices and perspectives to be heard and valued (Dee-Price, 2023; Lutz et al., 2016). Researchers need to be mindful of the potential disempowering impacts of paternalism and implement strategies to mitigate these issues while recognising and harnessing the positive contributions that communication supporters can bring to the research process.

The impact of power imbalances can be evident at every stage of the research process, when working with either consumer research partners or research participants. Some advisors in One Group Our Voice were hesitant to share their opinions during the first few advisory group meetings, particularly if they thought their opinion countered the group’s coordinator (Walsh). This reluctance may have been founded in past experiences where their perspectives might not have been sought or valued. They expressed surprise that their views were invited, respected, and influenced the outputs of the project. We implemented strategies aimed at building the advisors’ confidence in expressing their opinions. For instance, the coordinator provided opportunities for the advisors to practice voicing their opinions on minor topics, such as pop culture, and consistently reinforced that the group purpose was to obtain their views, regardless of whether their opinions were different from the coordinator or other advisors. Over time, advisors confidently expressed their opinions, offered comments, and asked questions. When asked what is needed for AAC users to participate in research, one advisor responded, “you have to have the confidence to share your opinions, especially to people without disabilities.” This insight underscores the significance of cultivating an inclusive and empowering environment to facilitate genuine AAC user involvement in research.

The researchers we interviewed were knowledgeable about power, particularly power imbalance and disability. They knew that AAC users have a right to participate in research and recognised their own responsibility to ensure inclusivity. While these researchers embraced the values of inclusive research, they expressed a need for more knowledge on how to make their research accessible to AAC users. Their lack of

knowledge, skills and time negatively impacted their ability to include AAC users in their research.

Qualitative researchers endeavoring to include AAC users in their research will optimise involvement by constantly interrogating the potential for power imbalances and the impact of ableism and paternalism. Collaborating with consumer research partners who use AAC is an impactful strategy in keeping researchers attuned to the complexities of power dynamics.

Accessibility of Research and Research Resources

Inclusive research practice respects AAC users' rights, perspectives and experiences and, in doing so, reduces ableism and paternalism. Accessible research and research materials encompass a range of approaches and strategies that minimise barriers to AAC users' involvement in research, and empower their authentic participation in the process. Researchers should create accessible research materials that cater to the needs of individuals with varying physical, communication, intellectual, reading, and language abilities, as well as those with hearing and vision impairments.

The three elements of accessibility can be applied synchronously to address accessibility (Figure 2). Researchers will *collaborate* with AAC users to identify and understand accessibility needs. Researchers will develop and apply *knowledge and skills* about accessibility. *Time* is needed for this collaboration, to develop accessible resources and to optimise involvement of people who use AAC as research partners and participants. Focusing on these elements of accessibility empowers AAC users and authentically captures their ideas, perspectives, views, and lived experiences. These elements are detailed below.

Elements of Accessibility to Address to Optimise Augmentative and Alternative Communication User Involvement in Research

Collaboration Between Researchers and Augmentative and Alternative Communication Users

Collaboration between researchers and AAC users applies to two broad aspects of interaction – collaboration as consumer research partners throughout the research cycle and collaboration to understand individual AAC users' unique communication access needs, whether as consumer research partners or participants.

As consumer research partners, AAC users can advise researchers at every stage of the research process, promoting inclusivity and ensuring authentic involvement of research participants who use AAC. Collaboration can take various forms, such as consulting with an advisory group, closely

collaborating with a group like One Group Our Voice, or involving AAC users as part of the research team. These options represent different levels of influence (Dada et al., 2022; Smits et al., 2020). Ideally, collaboration will be embedded at each stage of the research, starting from identifying research priorities and questions. A research direction that aligns with the needs of AAC users enhances recruitment, retention, and participant motivation, contributing to meaningful implementation of findings in practice (Dada et al., 2022). By involving AAC users in the development of research methods, researchers can create feasible and accessible participant information materials and interview schedules that respectfully address important topics. Data collection facilitated by consumer research partners is likely to enhance participant engagement and authenticity. Collaborating with AAC users during data analysis and interpretation brings the perspective of lived experience, and a deeper understanding of the data and research findings, contributing to impactful, translatable outputs (Dada et al., 2022). Finally, collaboration will identify and implement the most impactful knowledge translation strategies (Dada et al., 2022).

The second aspect of collaboration is to understand individual AAC users' communication access needs and preferences (Dada et al., 2022; Paterson & Carpenter, 2015). This understanding is necessary whether the AAC user is a research participant, consumer research partner or, in participatory action forms of research, fills both roles. Each AAC user employs a unique combination of communication modalities aiming to optimise their ability to communicate with diverse communication partners in a variety of contexts (Speech Pathology Australia, 2016).

The experience of authors on this article who have cerebral palsy and use AAC is that researchers make assumptions about which communication modalities will be easiest for the AAC user. These assumptions further reinforce power imbalances, limiting the opportunity for AAC users to fully express themselves. For example, surveys are often used by researchers who assume that these are less taxing for an AAC user; however, for some AAC users typing is not possible or may be more fatiguing than communicating with the support of a communication supporter. Collaborating with AAC users to explicitly identify communication needs and preferences will avoid such unhelpful assumptions. Understanding an individual's communication style and their support needs can be facilitated by collaboratively completing an Access Profile. Developed in collaboration with One Group Our Voice, the Access Profile identifies the communication and access considerations for an individual AAC user in the research context, strategies to optimise their involvement as a research participant or consumer research partner, and information about their communication supporters and how to involve them (see Access Profile template in Appendix and Supplemental Material). Research teams can use the completed profile to guide interactions with AAC users, allowing

the AAC user to specify the communication modes they want to use throughout the process.

Customised and co-defined accessible communication strategies and materials are needed to accommodate communication, language, intellectual, hearing and vision difficulties, and these take time to refine and implement. Failure to invest the necessary time will contribute to a power imbalance because an AAC user is not provided adequate opportunity to communicate their perspectives.

Our experiences working on this project exemplify the aspects of collaboration described above. Understanding each individual One Group Our Voice advisor's communication access needs was fundamental to optimising their involvement in the collaborative process. Concurrently, advisors' lived experience was crucial to conceptualising the framework for involving AAC users in research. Advisors provided examples from their lives to illustrate the power imbalances experienced by AAC users that we identified in the literature. We collaborated to develop strategies for addressing these. One Group Our Voice provided practical examples of ways of adapting or developing research materials to be accessible to people who use AAC and provided us the opportunity to implement these in the advisory group meetings and collaboratively evaluate and refine them.

Skills and Knowledge

The means and resources to adapt and modify methods to make research and research resources accessible based on individual AAC users' needs is only one aspect of knowledge and skills. Researchers should also understand the diversity of the AAC user population more broadly. This includes factors beyond communication, communication systems, and access needs, and the myriad environments in which communication takes place, that impact the accessibility of research materials. For example, many AAC users experience a range of health comorbidities, including pain, fatigue, hearing, vision, and/or mild to profound motor disabilities (Pennington et al., 2007).

AAC users as a group have lower literacy (Machalicek et al., 2009; Taylor & Balandin, 2020) which can reflect exclusion from accessible literacy education. While some AAC users may also have an intellectual disability or language difficulty, literacy ability may not accurately reflect an AAC user's intellectual ability. AAC users often experience social isolation, including a smaller online presence (Ibrahim et al., 2021; Paterson & Carpenter, 2015; Raghavendra et al., 2013; Taylor & Balandin, 2020). Physical disability, communication difficulties, physical and social environmental barriers, and lack of availability of a support person can contribute to social isolation (Pashmdarfard et al., 2021). Isolation can impact AAC users' access to involvement throughout the research cycle, including access to invitations to participate in research, through to comfort and confidence with sharing opinions with researchers, due to literacy barriers and lack of practice in interaction with researchers and others. Understanding these

broader factors can assist researchers to involve AAC users in inclusive research.

Another essential area of knowledge and skills is AAC etiquette. Etiquette guidelines which are unique to communicating with AAC users are designed to optimise the flow and dynamics of conversations. AAC etiquette contributes to a sense of welcome and belonging, particularly in group settings. Several readily available resources on AAC etiquette exist, including the International Society for Augmentative and Alternative Communication's "AAC etiquette" (2012) and AssistiveWare's "How to be a respectful communication partner" (2023). Many of the AAC etiquette guidelines address power imbalances (e.g., speak directly to the AAC user, not to their support person) or accessibility considerations (e.g., provide questions to the AAC user before a meeting so that they have time to prepare their answers).

Finally, practical skills in amending research materials for accessibility and knowledge about the AAC user population can be applied to make accessible research resources tailored to the individual needs of AAC users and aligned with the research context. In meetings with One Group Our Voice, practical adaptations included providing materials in advance in an accessible format. These included a video-recording of the group coordinator summarising major topics, along with a plain language agenda supplemented with visual supports. These materials were accessible to all advisors and allowed them sufficient time to prepare their responses. We also facilitated discussions by offering a variety of response options including the Emotional Faces Scale (as described in Lutz et al., 2016).

Time

A consistent theme in the literature and reinforced throughout our information gathering was the importance of time. Adequate time is needed to involve AAC users as consumer research partners or participants and to ensure that research and research materials are accessible (Dada et al., 2022; Dee-Price et al., 2021; Hemsley et al., 2008; Lutz et al., 2016; Paterson & Carpenter, 2015). Advisors repeatedly raised time as a critical perspective when asked what they want researchers to know about working with AAC users. Comments included: "take the time to listen to us," "take the time to know me," and "we need more time so please be patient."

Communication using AAC systems takes more time than speaking, particularly when the AAC user has a physical disability impacting how they access their AAC systems. One advisor suggested including a video in their Access Profile to demonstrate to researchers the time needed to formulate information they wished to convey. Advisors expressed the need for ample time to prepare for meetings as they often pre-programmed their responses to questions in their communication devices to streamline in-meeting discussions. They also identified the importance of adequate time during meetings to actively contribute and additional time for correspondence

between meetings. Advisors reported that when researchers allowed sufficient time, they felt empowered and appreciated.

Ensuring research is accessible for AAC users also demands a significant investment of researcher time. Researchers must carefully plan and allocate resources to create or modify materials and methods to meet the specific needs of AAC users. This may entail developing more accessible materials, designing protocols that incorporate multiple and adapted response options, conducting research activities across multiple occasions, or budgeting for advisor remuneration for time advisors commit to preparing for and attending meetings and completing other research related activities.

Our experiences working on this project reinforced, in the strongest of terms, the critical importance of time – time to collaborate, to develop skills and knowledge, and to develop accessible research and materials. Time is necessary to mitigate power imbalance and optimise authentic involvement of AAC users as research participants and consumer research partners.

Application Areas – where Applying the Elements of Accessibility Will Have Impact

This project identified five areas (Figure 2) which have accessibility considerations unique to AAC users' involvement in research. These are recruitment, working with communication supporters, accessible research methods, ethics, and consent.

Recruitment

Recruiting AAC users into consumer research partner and research participant roles requires particular attention to the elements of accessibility. AAC users may not receive invitations to be involved due to gatekeeping by support people, limited online presence, and social isolation. Moreover, recruitment materials may not be accessible, considering the lower literacy rate in this population, along with the potential presence of intellectual disabilities and hearing or vision impairments (Machalicek et al., 2009; Taylor & Balandin, 2020). AAC users may hesitate to respond to invitations for a number of reasons including previous experiences of exclusion from research, lack of confidence in their own ability to contribute, uncertainty about whether the research will be accessible, and conflicting demands on their time.

One Group Our Voice reported that they assume they are not invited to participate in research or consumer partnerships, unless the invitation explicitly states that AAC users are welcome and will be supported in their role. On the advice of One Group Our Voice and the parent advisory group, invitations should overtly invite AAC users, clarify that their contribution is sought and valued, and reinforce that the supports needed for their involvement will be available. Invitations can be provided in multiple modalities such as

pictures, words, Easy English (Access Easy English, 2023), and video messages from researchers and, particularly, other AAC users. Invitations can reinforce inclusion of AAC users by using images which portray people who are AAC users, that is, they “see themselves” in the invitation. These principles apply to the development of participant information letters and consent forms.

Given the important role of support people in AAC users' participation in research, recruitment materials should also target support people (e.g., parents, support workers) and disability organisations (as in Watson et al., 2007). This strategy mitigates the decreased online presence and decreased literacy rates amongst the AAC user population, providing another avenue that AAC users can be informed about research opportunities. Awareness of the research and a sense of trust may be fostered when invitations are distributed and endorsed through trusted networks who can attest for the research's accessibility, its importance and the value placed on involving AAC users. On the other hand, researchers must consider the potential power imbalance of third-party recruitment, and prepare recruitment materials and messaging which addresses those potential pitfalls (Taylor & Balandin, 2020; Watson et al., 2007).

Working with Communication Supporters

Communication supporters play various roles in promoting AAC users' participation in research, such as ensuring that an AAC user comprehends the researcher's message, supporting the AAC user in conveying their thoughts, or signaling to the researcher when the AAC user wants to communicate (Dada et al., 2022; Dee-Price, 2023; Lutz et al., 2016). This can include re-voicing statements made by the AAC user to ensure researchers are clear about what was communicated (Sellwood, 2019). Communication supporters can be an asset to AAC users' participation, especially when navigating interactions with an unfamiliar conversational partner, such as a researcher (Dee-Price, 2023; Lutz et al., 2016; Watson et al., 2007). Conversely, communication supporters can pose a barrier to AAC users' involvement in research, particularly if the supporter's biases or assumptions influence how they interpret and convey the questions asked or the AAC user's responses (Lutz et al., 2016).

Researchers and AAC users should discuss the role of the communication supporter as part of research-related interactions. Communication supporters may not be familiar with research and conversations can assist them to understand their role in optimising AAC users' involvement while minimising their own influence in the interactions. Just as qualitative researchers reflect on their own positionality, it is important to consider the communication supporter's relationship with the AAC user and potential impact on the conversation. In an interesting parallel, Watharow and Wayland (2022) argue that researchers working with people with Deafblindness should acknowledge that the presence of an interpreter inevitably influences the narrative. Building on this precept, one co-author with cerebral palsy who uses AAC identified that an

AAC user is managing a relationship with two people during interactions with researchers – the researcher and the communication supporter. One Group Our Voice advisors were clear that “you have to work with your support people, so they help you in the right way”.

Adapted Research Methods

Researchers are encouraged to be creative in selecting or adapting accessible qualitative research methods and materials to optimise AAC users’ opportunity to share perspectives as research partners or participants. Author DS’s research (Sellwood et al., 2022) and several articles from the literature review describe research methods accessible to AAC users (Dada et al., 2022; Dee-Price et al., 2021; Hemsley et al., 2008; Ibrahim et al., 2021; Paterson & Carpenter, 2015; Watson et al., 2007). Some examples of adapting qualitative methods recommended by One Group Our Voice include:

- providing interview schedules in advance to enable AAC users time to seek communication supporter assistance and prepare responses;
- enabling asynchronous responses to interview questions through emails or online platforms;
- offering multiple interview or focus group occasions to minimise fatigue and allow participants time to contribute;
- including the option to seek additional information by email after an interview or focus group;
- videorecording interviews and focus groups to capture non-verbal communications (e.g., gestures and facial movements) which provide data and elucidate other responses;
- clarifying participant responses throughout interviews and focus groups to ensure responses are not misinterpreted;
- modifying response options to enable AAC users to indicate yes/no responses, or strength of agreement or feelings towards issues using scales like the Emotional Faces Scale mentioned above; and
- adapting transcription methods to minimise impact of communication breakdowns and subsequent resolutions on the quality of the information obtained.

Ethics

Navigating ethics governance to include AAC users requires consideration of the power issues described above as well as all three elements of accessibility. Walsh et al. (in press) document several key tensions which may arise in research including AAC users and provide recommendations for researchers, ethics committees, and institutions in navigating the ethics process to develop safe and inclusive protocols. Researchers and research partners may encounter paternalistic or ableist attitudes from research ethics committees (Taylor &

Balandin, 2020), and application processes may automatically deem AAC user participants or research collaborators as being “vulnerable” or classify projects as “high risk.” Researchers should look for ways to communicate the dynamic and intersectional factors which impact on individual AAC user participants’ vulnerability, rejecting the mass categorisation of this group as vulnerable (Gordon, 2020; Walsh et al., in press). Clearly addressing issues of capability, accessibility, and power in ethics applications can facilitate collaboration amongst the AAC user community, researchers and ethics committees as well as serve as a learning opportunity for ethics committee members. Ethics committees may raise similar concerns about involvement of consumer research partners who use AAC. In addressing these concerns, researchers can document the considerations taken to make the research safe and inclusive for research partners and delineate the consumer research partner role from that of a research participant.

Many accessibility considerations require flexibility during implementing research protocols, which can be at odds with the expectations of ethics committees that protocols will be prescriptive and pre-determined. To address ethics committee concerns about a flexible protocol, researchers and consumer research partners can cite the best practice frameworks behind their accessibility decisions, and refer to theoretical frameworks which support iterative, community-based research. See Walsh et al. (in press) for a critical understanding of the ethics process for research including AAC users, as well as for practical strategies for navigating those processes. If researchers are mitigating power imbalances and engaging in the three components of accessibility, they can develop safe and inclusive protocols.

Consent

Inseparable from ethical conduct of research is the critical nature of consent for inclusive research. Consent processes which allow for all people with complex communication needs to be supported in making decisions about their involvement are well documented. Dee-Price et al. (2021), Sellwood et al. (2022) and Paterson and Carpenter (2015) document consent processes for AAC users who can indicate “yes” and “no” responses, including videorecording the response (Paterson & Carpenter, 2015). As Watson (2017) observes, all humans make decisions supported by people who know them well; supported-decision making techniques are an extension of this premise. AAC users who are young, have an intellectual disability, or have complex support needs may require more support in their decision-making. As described earlier, communication supporters can play a significant role in AAC users’ participation in research, including supporting the AAC users’ decision to participate, if needed. Van Goidsenhoven and De Schauwer (2022) provide detailed information about informed consent and informed assent in participatory research with children with complex communication needs, using a case example to

highlight the relational aspects of the consent and assent process.

Conclusion

Our framework and accompanying inclusive research toolkit add to available practical guidance for involving people in research who are living with deafblindness (Watharow & Wayland, 2022), autistic adults (Nicolaidis et al., 2019) and people with disability more generally (Williams & Moore, 2011). By investing in genuine partnerships with lived-experience experts, our work aims to facilitate the involvement of individuals with cerebral palsy who use AAC as research participants and consumer research partners. Power is the overarching concept of this framework, driving an imperative to identify sources of power imbalance and empower AAC users. Accessibility is a pivotal factor in addressing power imbalance.

We identified three elements of accessibility needing to be addressed to optimise AAC user involvement in research. One element is collaboration with AAC users to understand their unique access needs and identify effective ways to involve them in research, preferably across the entire research cycle. A second element involves the skills and knowledge needed to adapt research methods and resources to respond to individual needs of AAC users and meet the demands of the study. The third element is the importance of time to engage with AAC users, implement accessibility measures, and truly listen to their voices. We have also identified five areas of accessibility that require particular consideration concerning power dynamics and accessibility when involving AAC users in research.

Our aim in sharing the framework and inclusive research toolkit is to empower qualitative researchers to involve people with cerebral palsy who use AAC as research participants and consumer research partners. By doing so, we anticipate that the inclusion of people with cerebral palsy who use AAC will result in authentic impacts on the research. We hope to read research which explicitly includes people who use AAC in study samples, and we also expect to see research about people who use AAC which elicits AAC users' perspectives, rather than those of proxies. We believe that our framework and inclusive research toolkit will have relevance for researchers seeking perspectives from people who have communication difficulties associated with diagnoses other than cerebral palsy. We also believe that the framework and toolkit will be relevant for quantitative, as well as qualitative research.

By including AAC users as consumer partners and participants, giving access to research materials, and explicitly addressing power imbalance, researchers can give voice to AAC users who have conventionally been under-included in research. Fundamentally, inclusion is a human right. Such inclusion can drive meaningful and impactful research and serve as a catalyst for targeted health, disability, social, and

policy interventions, ultimately optimising outcomes for people who use AAC.

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Supplemental Material

Supplemental material for this article is available online.

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