Including AAC users in conversations about their own lives: what we learned from carrying out a research study with young people with cerebral palsy who use AAC

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Short Abstract

Plain Language Abstract

Augmentative and alternative communication (AAC) users are often excluded from participating in research. This is particularly true for AAC users who use a few picture symbols at a time and/or who have intellectual disabilities. Sometimes they are excluded from research because the research isn’t accessible. Other times, people make assumptions about their abilities. Our research focused on teens and young adults with cerebral palsy who use AAC and conversations about an important topic – sexuality. During our research, we saw that AAC users are also often excluded from discussions about important aspects of their lives like sexuality.

An advisory group of AAC users and parents of AAC users helped make our research accessible to a range of AAC users. It was also important to us to empower AAC users to take the lead and tell us what was important to them. In order to carry out the research, we needed approval from the university ethics committee. During the ethics approval process, we addressed assumptions about AAC users’ abilities and advocated for their right to participate in research.

Our inclusive methods allowed AAC users to initiate discussions about sexuality and to advocate for themselves. In this presentation, we will share the strategies we used to individualise support so that AAC users could participate in these important conversations. We will also share resources on advocating for AAC users' involvement in discussions about their lives and identities. This will include addressing assumptions about their ability to participate in research.

Long Abstract

Academic Language Abstract

Augmentative and alternative communication (AAC) users are often excluded from being active participants in research about their lives (Dee-Price et al., 2021; Taylor & Balandin, 2020; Walsh et al., 2024). When research is done with AAC users, particularly those with limited literacy or with an intellectual disability, it is often done via proxy reporting (Dee-Price et al., 2021; Taylor & Balandin, 2020; Walsh et al., 2024). While familiar and trusted communication partners can contribute to our understanding of AAC users' lives, we cannot understand AAC users' experiences and perspectives without directly involving them. Excluding a group from participation in research about their lives leads to what Shepherd calls "evidence-biased care" (Treweek et al., 2022). Encouragingly, AAC users are being included more and more as research participants and as members of the research team.

Our participatory research was with adolescents (10-24 years old) with cerebral palsy who used symbolic AAC (e.g. signs, picture symbols, yes/no, spelling). The research aimed to understand the adolescents' experiences of and priorities about conversations about sexuality. Doody notes a hierarchy of disability inclusion in research, with those with mild impairments more likely to be included (2018). With this in mind, we developed research methods which would be accessible to all adolescent symbolic AAC users with cerebral palsy, including young people who might be considered "early" symbolic communicators, those with complex access needs, and young people with intellectual disabilities. In addition to a focus on access, we designed our protocol to maximise the adolescent participants' agency; they drove the conversations and identified knowledge translation priorities. Consumer research partners, including AAC users and parents of AAC users, were key to developing these accessible, innovative, and participatory research methods.

We faced numerous barriers during the ethics approval process for this research. We worked with the chair of the university's human research ethics committee to address assumptions about capacity and vulnerability with this group and the sensitive topic. Following this protracted and at times tense process, we collaborated with the chair to publish a practice reflection that identified tensions around the ethical approval of participatory research with people with disabilities. In this presentation, we will share the strategies we used to communicate about AAC users' access needs and advocate for their inclusion in research. These strategies may be useful even for those outside of research who need to counter assumptions about AAC users and advocate for their inclusion.

A finding of the research is that in their daily lives, these adolescents often do not have the opportunities to engage in conversations about sexuality or gender identity. One aspect of our methods was offering multiple sessions with the young people. This allowed them time to communicate and for them to develop rapport with the researcher. As the sessions went on, the adolescents initiated more of the conversations about sexuality, not only within the research sessions but in their lives outside of the research. Additionally, they began to advocate for themselves with regard to sexuality with health professionals, family members and support workers. We employed numerous communication support strategies to enable these adolescents to engage in these important conversations and saw the impact in their day to day lives.

Just as AAC users are often excluded from research, we found that they are often excluded from conversations about important aspects of their own lives. Through our research, we identified strategies to support symbolic AAC users with a range of expressive communication levels to lead conversations about their lives and identities. Presented by a clinician-researcher and a parent of a child who uses AAC, in this presentation we will:

- describe our individualisable, accessible, participatory research methods;
- provide recommendations for how those methods could be applied within AAC users' daily interactions;
- share the resources we developed to identify an individual AAC user's access needs around participating in conversations about sexuality or identity; and
- provide resources and recommendations for countering assumptions about AAC users' abilities and advocating for their inclusion.

References

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