

## **Navigating Sexuality Support for Adolescents with Cerebral Palsy who use AAC: Perspectives, Challenges, and Key Themes**

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### **Short Abstract**

### **Plain Language Abstract**

Our study explored how teenagers and young adults (adolescents) with cerebral palsy who use augmentative and alternative communication (AAC) discuss sexuality. We interviewed five adolescent AAC users with cerebral palsy and 12 parents of adolescents with cerebral palsy who use AAC.

In our workshop, we will share what the adolescents and parents told us about these conversations. A major finding from this work is about how people support adolescents in conversations about sexuality, especially when those conversations are about or during sexual activity (for example masturbation, kissing, or sex). We identified four main themes:

1. choosing support workers,
2. support workers as friends,
3. who should provide support for sexuality, and
4. safety concerns.

We will discuss these themes and roles as a group. There will be opportunities for everyone to be involved in the discussion, including AAC users. By the end, you will:

- understand the perspectives of adolescents with CP who use AAC and their parents regarding sexuality support,
- learn about research and guidelines for supporting sexuality in adolescents with physical or communication disabilities,
- recognize key issues in this area, and

- gain skills and confidence to initiate conversations about sexuality support with AAC users and their supporters.

This workshop will be delivered by a researcher, an AAC user with cerebral palsy, and the parent of a child who uses AAC and has cerebral palsy.

## **Long Abstract**

### **Academic Language Abstract**

Our research aimed to understand interactions about sexuality for adolescents with cerebral palsy who use augmentative and alternative communication (AAC). We carried out participatory research with five adolescents (ages 10-24) and 12 parents. Both adolescent and parent participants identified important issues around the role of supporters (both paid and unpaid) in interactions about sexuality.

Prior to commencing our research, we carried out a systematic scoping review to understand interactions about sexuality for adolescents with cerebral palsy and/or complex communication needs (Walsh et al., 2024). We found no evidence describing interactions with paid support workers around sexuality, despite adolescents with cerebral palsy who could speak reporting the need for assistance with sex (e.g. undressing, positioning on the bed) (Wiegerink et al., 2011; Wiegerink et al., 2008). In some of the literature, parents of adolescents expressed unease about who the most appropriate and safest person was to support their adolescent's sexual and romantic interactions (Cummins et al., 2020; Davis et al., 2009; East & Orchard, 2014; Power et al., 2023; Power et al., 2020; Shikako-Thomas et al., 2013).

Research about romantic and sexual relationships with adults with congenital physical disabilities who use AAC identified several findings related to the paid support workers supporting the AAC users. These findings included that:

- paid support workers could be either a barrier or facilitator to engaging in romantic or sexual relationships, depending on attitude and willingness to help;
- bureaucratic barriers exist which prevent paid support people from supporting sexuality; and
- high staff turnover rates make it difficult for AAC users to find paid support workers they could trust. (Sellwood et al., 2022)

We analysed the adolescent and parent data from our research using reflexive thematic analysis (Braun & Clarke, 2022). Four research partners, including two AAC users with cerebral palsy, contributed to the data analysis. We found that the role of the support person was significant in interactions about sexuality for these young people. We developed four themes, which we will present in detail:

1. choosing support workers,
2. support workers as friends,
3. who should provide support for sexuality, and
4. safety concerns.

From our collective lived, clinical, and research experience, we understand that there are tensions around these themes, including around people with disabilities forming friendships with their paid support workers. Following a review of the current literature and our research results, we will facilitate community discussions with the audience around these key themes as they relate to adolescent AAC users. This workshop will be presented by a clinician-researcher, AAC user, and parent of a child who uses AAC.

### **Learning objectives:**

By the end of the workshop, participants will

- understand the perspectives of adolescents with CP who use AAC and their parents regarding sexuality support,
- learn about research and guidelines for supporting sexuality in adolescents with physical or communication disabilities,
- recognize key issues in this area, and
- gain skills and confidence to initiate conversations about sexuality support with AAC users and their supporters.

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