Insights from the co-design of a website about sexuality for people with Communication Access Needs

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Short Abstract

Sexuality has long been an overlooked component of inclusion for people with a disability, especially people with Communication Access Needs (CAN). Most limited sexuality education that does exist follows the well worn paths of protectionism, even though organisations such as the United Nations and the World Association of Sexual Health advocate for inclusion at all levels. Sexual education in school settings for people with CAN is limited or non-existent, and often people have no pathway to engage in this discussion as the vocabulary of sexual health, expression and engagement is usually missing from Alternative and Augmentative (AAC) systems.

Approaching sexuality with a sexological sex-positive lens opens up the access and awareness of information to a much broader framework that also includes such things as pleasure, body awareness, sensuality, identity, spirituality and the politics of disability and sexuality. This presentation will present key learnings from a project by Microboards Australia to create an accessible website, co-designed with people with disability who use AAC, which gives people with CAN and their communication partners access to the understanding, vocabulary, and supports needed to explore their sexuality. We will share what we have learned about navigating common concerns about sexual consent, capacity and safety, and invite enrolment in a vision for the rights for people with CAN to fully realise their sexual identity and to experience sexual expression on their own terms.

Long Abstract

As an organisation committed to finding ways to uphold the Human Rights of people with disability, and particularly people with Communication Access Needs (CAN), Microboards Australia has long had an interest in supporting sexuality. In our work we have noticed many barriers which include lack of access to education, fears about consent and safety, and uncertainty about when and how to start having conversations with people with CAN about sex. Where people with CAN also have high physical support needs, it seems to be rare that they have had any opportunities to explore sexuality.

In this presentation we will share what we have learned so far from codesigning a website which hosts resources, AAC communication pages and processes, with people with CAN and their supporters, to access and explore sexuality. Our presentation will include discovery of

some perhaps surprising gaps in knowledge for AAC users, things we have learned from them in terms of their sexuality access needs, as well as realisation of some significant barriers which are yet to be overcome.

This project uses the sexuality flower model to inform and provide a framework for education and learning for AAC users with a cognitive disability. South Australian sexologist Lud Allen introduced us to the sexuality flower model (created by Jo Adams in partnership with Carol Painter (Adams & Painter, 2004)) and which invites us to view sexuality as a flower full of petals. Each petal encompasses an aspect of sexuality (sex practice/self image/sensuality/politics/emotions and spirituality). Every petal interacts with the others and is essential to overall wellbeing.

We are embedding this model in a website co-designed with people with disability who use AAC, which gives people with Complex Communication Needs (CCN) access to the understanding, vocabulary, and supports needed to explore their sexuality. Learning about sexuality encompasses much more than the reproductive system and how it functions. This project aims to translate human sexuality education into a comprehensive, sex positive AAC accessible user friendly space.

In reviewing the reasons why access to sexuality for people with CAN is complex, we have learned that there appear to be number of foundational understandings and processes that need to be in place for this to happen, other than just access to sexual information. Support for communication partners to understand their role in conversations about sexuality and to have confidence to know how to talk about sexuality with an AAC user has turned out to be critical, and consequently our website design reflects this. Understanding the fluid nature of consent and the ways that people give consent is also essential for supporters to understand in order to be able to support sexuality, and we will share our approach to building capacity to support consent practice in communication partners.

People with CAN have often missed out on developmental stages that their typical peers have had access to and consequently these may need to be addressed. For example, people with CAN may need opportunities to understand and improve their self-image, including their relationship with their disability and how this affects the way they see and value themselves, before exploring the possibility of romantic or sexual relationships with others.

People with CAN may also have missed out on awareness and exploration of sensuality, not just in the context of sexuality, but in terms of the person's experience of pleasure generally in their life, and how this is explored and supported. Whilst sensory processing is certainly important it can be experienced as a therapeutic approach which comes at the expense of exploring and embedding regular sensory experiences which bring pleasure.

Spirituality is another area of life which is often not explored with people with CAN, and needs inclusion in this conversation about sexuality as an important component for some people. This includes exploration of the role of spirituality in a person's life including the meaning of intimate connection, and the way their culture and values interact with their sexuality.

People with CAN co-designing the program have helped us to see the often significant gaps in vocabulary in AAC systems to be able to talk about sexuality including physiology and reproductive body parts and sensations associated with them. There can be a perception that this is 'adult' language rather than empowering language which should be accessible to

people from childhood. Words to describe the emotional experiences of relationships are also needed, not just the usual terms of love, anger but also contextual words like desire, crush, attraction etc.

Microboards Australia's sexuality website will be live later in 2025 and it is our hope that it helps to respond to common concerns about sexual consent, capacity and safety, as well as inviting enrolment in a vision for the rights for people with CAN to fully realise their sexual identity, and to experience sexual expression on their own terms.

References

Adams, J. & Painter, C. (2004). Explore, Dream Discover: working with holistic models of sexual health and sexuality, self esteem and mental health. https://www.sexualhealthsheffield.nhs.uk/wp-content/uploads/2015/03/Explore-Dream-Discover.pdf