

Sense and sensuality in people with disabilities

September 9 2021, by Ufrieda Ho



Credit: Curiosity, Wits University

Even though sex is a basic human need (even a human right in the Netherlands), it can be one of the overlooked needs for people living with disabilities.

Talking openly about sex, sexuality, [sexual desire](#) and [sexual identity](#), as well as navigating sexual relations and reproductive rights and contraception, is awkward enough for many people. Add to this the

burden of South Africa's hangover of a Calvinistic apartheid past where the Immorality Act policed sexual relations. On top of this is the harsh reality of being a person living with a disability in an ableist world. There are even more complexities, and experiences of exclusion, when the person with a disability is queer identified, and/or gender non-conforming, or transgender.

"It amounts to a feeling like having a double discrimination—there's already stigma attached to disability and then if someone identifies as gay too, it's an added stigma and people also ignore that you have sexual needs or that you also fall in love," says audiologist Dr. Victor de Andrade in the Department of Speech Pathology and Audiology.

Let's talk about it

Sometimes just starting a conversation can move mountains and shatter taboos—even about sex. De Andrade says that in 2015, at a seminar he arranged titled "Double Discrimination," a conversation ensued about addressing the needs of the disabled community and thinking through solutions.

In 2017, De Andrade and colleague Dr. Joanne Neille, also from the Department of Speech Pathology and Audiology, Dr. Haley McEwen and (the late) Dr. Paul Chappell from the Wits Center for Diversity Studies, and others, began to gather data, through a series of conversations and engagements, to better understand what people living with [disabilities](#) need to enjoy the right to live their lives as sexual beings.

The project team also included members of the Wits Disability Rights Unit, the GALA Queer Archives, and individual activists to create a team with adequate expertise to address this very important, yet complex, issue.

The researchers cast the net wide—deliberately, to be as inclusive and unfiltered as possible in their approach. Neille says: "Historically, research into disability has relied on proxy accounts or has excluded persons with cognitive or communicative disabilities, resulting in a biased understanding of lived experience. For this reason, we included a wide variety of participants with different sexual identities, disabilities, cultural and linguistic backgrounds."

As a result, resources for information about sex have been largely confined to speaking to friends, picking up something from the odd magazine articles that they came across, the variability of internet content, and pornography, she says.

Getting past the gatekeepers

De Andrade says they found that in residential care homes for people with disabilities, [sexual relations](#) and intimacy became formalized arrangements—like having to schedule access to designated intimacy rooms and relying on third parties to arrange contraceptives, where such possibilities did exist.

Along with a dearth of information and resources, was also a censure or judgment. "We found that there are many gatekeepers to people living with disabilities' sex lives, and their abilities to access information about sex, sexual health, and relationships, such as parents, teachers, and other caregivers," McEwen says.

"Participants suggested that they could get information about how not to get pregnant or how not to get HIV, but there was nothing about negotiating relationships or consent, and sometimes there was punishment involved or a punitive attitude when the person was trying to find out more."

The research project takes the bold step to place and keep the agenda on the table. What has made the difference in particular is the team's action research approach. It involves deep engagement, reflexivity and letting participants shape the concept and design and outcomes of the research. This has enabled the data gathered since 2017 to be stronger, more nuanced and complex. In turn, the insights seem richer and more valuable.

The trio will publish their findings and research in the coming months, accompanied by a corresponding online guide for caregivers to ensure that more people have access to the kinds of information that participants in the study required.

"We're not saying this guide will solve all the problems, but often people just feel directionless and this is a step in the right direction," De Andrade says.

Using the research findings to change lives, and the approach to reshaping teaching, is transformative. As McEwen says: "This research project was not about developing fancy theory or building our academic careers—there is a social justice imperative because these are huge forms of exclusion that affect all people."

Safe spaces

Gender-based violence and sexual harassment affects everyone, but when you're a person living with a disability, getting help and being heard can be such an overwhelming challenge that staying silent seems to be the better option.

The Wits Center for Deaf Studies has been working to fight stigma and invisibility of people living with disabilities, particularly when it comes to accessing help at a police station. One of the Center's initiatives has

been to team up with state-run rape crisis centers in a campaign to push for the National Prosecuting Authority to address the lack of accessible services for people with disabilities.

"The system does not acknowledge the needs of the victim and is inaccessible to Deaf victims or anyone who does not fall into the mainstream," says Professor Claudine Storbeck, Director of the Center.

Through the Center's Safe Spaces program, Storbeck says that they are also working to develop vocabulary to help Deaf children and teenagers to have the correct signs to ask and express about their bodies, about sex and sexuality. It is the foundation for understanding concepts about "sex as power, rights, privilege."

Importantly, Storbeck says that the able-list view of parachuting in to sort out something for the person living with a disability needs upending.

"The aim should be to create platforms so that these issues don't stay low priorities. But once these platforms are in place, people with disabilities are very effective in self-representing. They know exactly what they need," she says.

Provided by Wits University

Citation: Sense and sensuality in people with disabilities (2021, September 9) retrieved 3 July 2024 from <https://phys.org/news/2021-09-sensuality-people-disabilities.html>

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