

**The myth of asexuality? Disability stigma as a barrier to sexual
relationships in South Africa**

SUMMARY REPORT

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Project website: www.disabilityandsexualityproject.com

1. BACKGROUND AND PROJECT AIMS

Sex and sexuality is a concern for everyone growing up. But for many people with disabilities, sex and sexuality is often a site of oppression and discrimination. There are many myths and misconceptions about the sexuality of people with physical disabilities, including that they are non-sexual or have reduced capacity for, or interest in sexual relationships (Milligan & Neufeldt, 2001). As a result, people with physical disabilities are regularly excluded from matters of sexuality and access to sex education and sexual and reproductive health care.

Few published studies have focused on the sexuality, and sexual and reproductive health concerns of people with physical disabilities in South Africa (Carew et al., 2017). Most of the existing evidence in this field focuses on these issues from the perspective of persons with disabilities themselves, where disability stigma and discrimination from the so-called 'non-disabled-population' are highlighted as crucial factors for a negative construction of sexuality among persons with disabilities. Given the general scarcity of empirical evidence on sexuality and disability, particularly from low-income-contexts and from countries with high prevalence of HIV/AIDS, this project fills a much-needed gap in knowledge. The project aimed to explore societal attitudes about disability and sexuality, and issues of sexuality and disability from the perspective of persons with physical disabilities themselves.

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2. METHODOLOGY

The project adopted a mixed method design, involving two complimentary studies. Ethical approval for the research was obtained from institutional ethics panels in the United Kingdom and South Africa.

Study 1: Survey study of societal attitudes.

A survey of societal attitudes towards the sexuality of people with physical disabilities in South Africa was conducted. The survey questionnaire was developed with the input of people with physical disabilities themselves. The survey was administered online and as paper questionnaires between April 2016 and August 2016. The survey was translated in to 4 of the most dominant languages spoken in South Africa: English, Afrikaans, isiXhosa, and isiZulu. The survey was advertised through various channels, including social media, advertisements in press and through email lists. To ensure that the survey also reached people who did not have access to internet or were from more deprived socio-economic backgrounds, three field data collectors were trained and employed to collect paper and pen responses in a large low socio-economic area in Cape Town. A total of 1990 people responded to the survey. Of these, 125 reported having a disability, and 1865 reported being non-disabled (Table 1).

Table 1. Demographics of survey respondents

	PWD only (N = 125)	Non-disabled only (N = 1865)
Age range	18 to 76	18 to 59
Mean age	26 yrs	24.4 yrs
Gender	35% male 65% female	43% male 57% female
Sexual orientation	68% heterosexual 7% gay or lesbian 10% bisexual 15% asexual	75% heterosexual 3% gay or lesbian 4% bisexual 18% asexual
Race	33% Black 46% White 9% Coloured 8% Indian 4% Other	46% Black 40% White 8% Coloured 4% Indian 2% Other
Most common languages spoken	44% English 25% Afrikaans 7% Zulu 7% Tsipedi	35% English 24% Afrikaans 10% Xhosa 9% Zulu
Education	57% had completed high school 23% had at least one degree qualification	51% had completed high school 23% had at least one degree qualification

Study 2: Study of the experiences of persons with physical disabilities.

A qualitative interview-based study explored persons with physical disabilities' experiences of sexuality. The study made use of Photovoice (Wang & Burris, 1997) techniques. Photovoice is a participatory research technique in which participants are trained as co-researchers and photographers.

The Southern African Federation for the Disabled (SAFOD) issued a call for participants to the project to partner disability organisations and affiliates in South Africa during June/July 2015. Interested persons were invited to contact the research team for further information. Potential participants were invited to an initial planning workshop held in December 2015 in Cape Town, where the project was introduced.

A total of 13 participants were interviewed (7 men and 6 women) during March/April 2016. Of the 13 participants, 11 made use of wheelchairs, one made use of crutches. Three participants were born with a disability; two had acquired a disability in early childhood. Participants were asked to take photographs that represent their everyday experience related to sexuality, and were then invited to provide narrative discussion in relation to illustrative images. Participants were invited to produce other creative materials, if they preferred, such as drawings and poetry. The photographs and other materials were used as both visual data and as stimuli to elicit personal narratives during an individual interview. The interviews explored participants' experiences of their sense of sexual self, intimate relationships, and engagement with sexual and reproductive health care. The interviews were audio recorded and later transcribed. Photographs and other creative materials were collected from participants, with their consent. Some of the photographs are available to view on the project website (www.disabilityandsexualityproject.com).

An initial analysis of the interview transcripts was done using the technique of thematic analysis. Common themes related to sexual self-esteem, self-image, dating and relationships, sex and sexuality, reproduction and parenthood were identified across the data.

3. RESULTS

Study 1: Survey of societal attitudes

Beliefs about the sexual rights of people with disabilities

In the responses provided by non-disabled people to the survey (N=1865), we found some clear differences between what views were held towards people with disabilities when compared to views held towards non-disabled people. The survey contained questions about respondents' beliefs about the sexuality and sexual rights of people with physical disabilities and the non-disabled (general) population. Respondents were asked to indicate what percentage of people with physical disabilities a set of statements applied to (see Table 2). They were also asked to indicate the percentage of the general population these differences applied to.

Table 2: Percentage of (1) people with physical disabilities, (2) the general population to whom the following statements apply:

	People with disabilities (% and SD)	General population (% and SD)
<i>capable of expressing sexuality</i>	61.47% (SD = 30.47)	72.49% (SD = 26.21)
<i>sexuality is a basic human need</i>	66.21% (SD = 31.00)	73.03% (SD = 26.81)
<i>should be allowed to have children</i>	74.22% (SD = 29.99)	74.38% (SD = 27.34)
<i>benefit from sexual healthcare services</i>	61.80% (SD = 34.25)	70.25% (SD = 29.42)
<i>benefit from reproductive healthcare services</i>	59.04% (SD = 34.32)	69.60% (SD = 29.41)
<i>benefit from sexual education services</i>	60.26% (SD = 35.47)	69.07% (SD = 30.92)

In the above table, we can see that respondents, on average, felt that these statements applied less to people with disabilities than to the general population. So, for example, respondents, on average, felt that 61.47% of people with disabilities are capable of expressing sexuality compared to 72.49% of the general (non-disabled) population being seen as capable of expressing their sexuality. These differences were statistically significant. These results indicate that on average, people with disabilities are viewed as less sexual and having less sexual and reproductive health care needs than non-disabled people.

Attitudes towards contact, relationships and dating

Respondents were also asked their feelings about contact with people with physical disabilities in the following 4 questions (social distance scale: Tables 3 to 6)

Table 3: Social Distance Scale Q1: *To what extent would you feel comfortable befriending a person who has a physical disability?*

Scale		Frequency (N=1861)	Percent (%)
Very uncomfortable	1	46	2.5
	2	21	1.1
	3	46	2.5
	4	180	9.7
	5	240	12.9
	6	369	19.8
Very comfortable	7	959	51.5

Table 4: Social Distance Scale Q2: *To what extent would you feel comfortable going on a date with a person who has a physical disability?*

		Frequency (N=1860)	Percent
Very uncomfortable	1	96	5.2
	2	135	7.3
	3	196	10.5
	4	362	19.5
	5	373	20.0
	6	312	16.8
Very comfortable	7	386	20.7

Table 5: Social Distance Scale Q3: *To what extent would you feel comfortable being in a relationship with a person who has a physical disability?*

		Frequency (N=1858)	Percent
Very uncomfortable	1	141	7.6
	2	187	10.0
	3	215	11.6
	4	368	19.8
	5	324	17.4
	6	279	15.0
Very comfortable	7	344	18.5

Table 6: Social Distance Scale Q4: To what extent would you feel comfortable if a person who has a physical disability married into your family?

		Frequency (N=1859)	Percent
Very uncomfortable	1	40	2.1
	2	33	1.8
	3	49	2.6
	4	146	7.8
	5	222	11.9
	6	381	20.5
Very comfortable	7	988	53.1

In Tables 3 to 6 above there were more negative feelings expressed by non-disabled respondents with regards more intimate contact (going on a date or being in a relationship) with a person with physical disabilities, than being a friend or having a person with disability marry in to the family. A majority expressed positive feelings.

Study 2: Study of the experiences of persons with physical disabilities.

The 13 interviews we have conducted have yielded a large amount of rich and detailed qualitative data. Our initial analysis of the interviews revealed the following 5 core themes: Feeling different and excluded; Sexuality being questioned by others; Impacts on sense of femininity and masculinity; Reclaiming a sexual sense of self; and Experiences of accessing sexual health education and care.

1. Feeling different and excluded

All participants spoke of general disability stigma and various experiences of being perceived and treated as different, abnormal, and ‘other’ by non-disabled people. Participants spoke about physical barriers to places, but this was also symbolic of access to relationships and society. This was spoken about by all participants, who referred to being excluded by others. Some example quotes from interviews were:

“this is what people do to you when you are disabled – they mean well, but they don’t approach you.” (Fatima¹)

“the boys at school, you know girls and boys, that thing, the boys would say, no, we mustn’t go to this one because she’s got...and then I would feel like, shoo.” (Pride)

¹ Participants selected which names to use in any reporting of results

Two participants, a Xhosa man and a Xhosa woman, spoke about cultural beliefs of disability that constructed them as a feared 'other' in their community:

"In our society, when you are sitting in a wheelchair, people think that you are bewitched. Now if you are bewitched, no one wants to come close to you. No one wants to be your friend. No one wants to be your family. No one wants to be close to you at all because you are going to curse them. The curse that you are under is going to affect them. So they don't want to come close to you." (Mzukisi)

2. Sexuality being questioned by others

All participants spoke about how others often tend to assume that they, as people with physical disabilities are asexual. For those growing up with a disability, this assumption of asexuality was prevalent within the family where it was assumed that the child with disability would not be a sexual, be married and have children.

"For the family it's like, I'll never get married. It was said...So for them it was just a friend. No idea about the wishes or dreams of this young woman to one day get married, because it's impossible." (Fatima)

Other participants spoke about perceptions from others about disability and non-sexuality:

"Most of the ladies like to tease me and they say, come, I want to marry you. And then they say, if I marry you, how are you going to satisfy me sex-wise?" (Mzwandile)

"people don't expect me to be in a relationship or be able to do anything because I'm in a wheelchair" (Vic)

3. Impacts on sense of femininity and masculinity

Participants spoke about how societal attitudes about disability, attractiveness and 'normal' bodies, impacted on their sense of self in terms of femininity and masculinity. For women, femininity was very much linked to ideals of being a wife, a lover, and a mother. The females participants also spoke about their bodies, and the impact that this had on feeling attractive and feminine. Some of the women spoke about the importance that having long hair had for retaining a sense of femininity:

So I was told that your hair is your beauty and, if you die, it covers you. So I'm trying to illustrate the importance for me of wearing a scarf and being dressed in a certain way. But other than that, that's all that I'm holding onto, it's my beautiful long hair. It still makes me feel that I'm a woman. (Fatima)

For the men, many spoke about societal views on disability challenging notions of masculinity in relation to strength, independence and being a provider. Typical comments to this effect were:

“is she going to be able to perceive this person as a complete male? Or, is it like a...I don't know...a diluted or minimised version of a man?” (Bongani)

In terms of sex, many men spoke about having little sensation in their genitals, and difficulties with gaining an erection. Many men resorted to using medication, typically Viagra, but this was not always financially accessible. This impacted on their sense of masculine self, and their attractiveness as a potential partner:

“You know, at first I couldn't get an erection. The nurses would usually tease me about it. So it felt like my manhood was taken away from me.” (Tazz)

However, most participants talked about having fulfilling relationships, and finding a way to reclaim a sense of themselves as sexual.

4. Reclaiming a sexual sense of self

Particularly for those who had acquired a disability, becoming disabled meant having to renegotiate a sense of themselves as sexual. For some, this meant focusing on appearance, and a sense of confidence about themselves. For example, Cleone spoke of her journey towards reclaiming a positive sense of herself as a woman:

“I can't hide my flaws and imperfections like other people can. Mine is there for the world to see. In the process of rediscovering my sexuality, I have learned to use what I have to seduce and entice. The silent battles I have fought of self-acceptance and validation has left me with the realisation that I no longer have to hide the naked beautiful truth of who I am...a woman in every essence of the word” (Kate)

A male participant, Tazz, spoke of how looking and feeling good mattered for his sense of self as a sexual being:

“I feel as a person with a disability you still need to dress up and look attractive, especially when it comes to women. I still dress up. I still dress up to impress females. When a female sees me, I believe that she needs to admire me when she looks at me, not just for being dressed up nicely, but also for my attitude as well.”

5. Experiences of accessing sexual health and reproductive health care

Some of the participants had had children. Of those that had, most had reported having received good reproductive health care. However, some of the participants reported on negative attitudes received from sexual and reproductive healthcare staff, either from personal experience, or knowing others who had experienced it:

I have heard of staff that have been very nasty to disabled women who go in: “why do you want to be pregnant again? You can hardly help yourself!” (Rosabelle)

Some people ask what you want to do with condoms, ja [...] As far as sexual health and reproductive clinics are concerned, I usually go once a year for bladder check-ups. But I don't really attend such clinics. There aren't really sex clinics to look at stuff. It's almost like sex is non-existent for people with disabilities. (Tazz)

4. CONCLUSIONS AND RECOMMENDATIONS:

This project has produced the first empirical data of the existence of societal asexuality myths of people with physical disabilities in South Africa. Furthermore, the project has given voice to a small, but varied group of people with physical disabilities who have had the opportunity to share their stories and photographs, as well as their concerns and wishes, in a variety of ways. The following recommendations can be made:

1. There is a need for increased education and awareness about disability and sexuality at schools and media.
2. For people with disabilities in lower socio-economic circumstances, there needs to be improved affordability and access to sexual and reproductive health care.

3. The experiences of sexual minorities (lesbian, gay, bisexual, queer and transgender) with disabilities remain unexplored.
4. Research on sexuality and other forms of disability (e.g. developmental and sensory) remain relatively unexplored.
5. There is a need for more research and attention about the various structural, attitudinal, and sociocultural barriers to sexual and reproductive health for people with disabilities across diverse contexts.

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