

FINAL REPORT

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

Contents:

1. Research team	2
2. Background	2
3. Research aims and objectives	4
4. Methodology	4
<i>Study 1: Survey study of societal attitudes</i>	4
<i>Study 2: Qualitative study</i>	7
5. Results	10
<i>Study 1: Survey study</i>	10
<i>Study 2: Qualitative study</i>	17
6. Outputs and dissemination	30
7. Participant experiences on the project	35
8. Recommendations	38
9. Conclusion	38
10. References	39
11. Appendices	40

1. RESEARCH TEAM:

- Dr Poul Rohleder, Department of Psychology, University of East London (UEL), United Kingdom. Email: P.A.Rohleder@uel.ac.uk
- Mr Mussa Chiwaula, Director General of the Southern African Federation of the Disabled, Botswana. Email: mchiwaula@safod.net
- Prof Leslie Swartz; Department of Psychology; Stellenbosch University, South Africa. Email: lswartz@sun.ac.uk
- Dr Stine Hellum Braathen; SINTEF Technology and Society, Department of Health Research; Norway. Email: Stine.H.Braathen@sintef.no
- Dr Mark Carew, Research Assistant employed on this project at UEL (Now at the Leonard Cheshire Disability & Inclusive Development Centre, University College London). Email: m.carew@ucl.ac.uk
- Ms Xanthe Hunt, Doctoral student, Department of Psychology, Stellenbosch University, South Africa. Email: xanthehuntwrites@gmail.com

The team consists of 4 men and 2 women; 2 persons with disabilities and 4 able-bodied persons. A photograph of the research team is included as Appendix 1.

2. BACKGROUND

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 as well as access to sexual health education and sexual and reproductive health care (Rohleder & Swartz, 2012). There has been increased international attention given to the sexual health rights of persons with disabilities (e.g. the World report on Disability, WHO, 2011). The United Nations Convention on the Rights of Persons with Disabilities (UNCRPD) in 2006 introduced a human rights approach to disability. Article 25 of the UNCRPD emphasizes the need for states to recognize and ensure that people with disabilities have the right to the enjoyment of the highest attainable

standard of health without discrimination on the basis of disability. This includes sexual and reproductive health. Sexual health does not just refer to the absence of disease; it refers to wellbeing in the area of sexuality and sexual relationships more broadly (WHO, 2006). Despite this, the sexual lives of people with disabilities remain an under-researched area (Carew et al., 2016).

In the context of a significant HIV epidemic in sub-Saharan Africa, there has been a growing attention given to how exclusionary attitudes towards disability, may place persons with disabilities at increased risk for HIV. A review of the international literature relevant to HIV and disability (Groce et al., 2013) has highlighted the need to consider the inclusion of persons with disabilities in sexual health programmes (in the context of concerns such as HIV). HIV and AIDS are also very much linked to sexual reproductive health rights for women with disabilities in particular.

Few published studies have focused on the sexuality, sexual and reproductive health concerns of people with physical disabilities in South Africa (Carew et al., 2016). Research that has been conducted suggests that young persons with physical disabilities receive limited education and care on matters of sexual and reproductive health (e.g. Eide et al., 2011; Wazikili et al., 2009), and may thus not have the knowledge, skills and agency to engage in safe sex practices (Rohleder et al., 2012; Wazikili et al., 2006). Furthermore, persons with disabilities may experience sexual violence and rape, partly due to intersecting misconceptions about disability, sexuality and gender (Groce & Trasi, 2004; Hanass-Hancock, 2009; Kvam & Braathen, 2008). Women with physical disabilities may also experience attitudinal barriers to accessing sexual and reproductive health care (Becker et al., 1997; Mgwili & Watermeyer, 2006; Smith et al., 2004).

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 and sexual health among persons with disabilities (Kvam & Braathen, 2008). This is suggested by research reporting on the experiences of young people with physical disabilities in South Africa, where

they have reported that the need to feel accepted and loved was more important than the need to practice safe sex (Wazakili et al., 2006).

3. PROJECT AIMS AND OBJECTIVES

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 issues of disability and sexuality, and sexual and reproductive health from the perspective of persons with physical disabilities themselves. The project also aimed to explore these issues from the perspective of non-disabled people, to explore the realities behind this perceived stigma of persons with disabilities.

Specifically, the project aimed to:

1. investigate the attitudes of the general population towards the sexuality of persons with disabilities in South Africa;
2. explore the experiences of stigma and barriers to fulfilling sexual relationships among persons with disabilities in South Africa;
3. raise public awareness about the intersection between disability stigma and sexuality

4. METHODOLOGY

A participatory research approach was used for generating the research agenda, generating data, and disseminating findings. The project adopted a mixed method design, involving two complimentary studies, which used innovative visual as well as textual and numerical data:

Study 1: Survey study of societal attitudes.

Study 1 involved an online survey of societal attitudes towards the sexuality of people with physical disabilities in South Africa.

Survey design

At an initial workshop held at the start of the research project, the research team presented ideas about a survey to 18 people with physical disabilities (who were

recruited as participants for study 2 – see below) and a discussion was held to generate ideas about what sort of topics should be covered by the survey and what sort of questions should be asked. Based on this input and input from the research literature, a survey questionnaire was developed that included questions measuring attitudes with regards to disability and: Attractiveness; Dating; Sex; Sexual health; Reproductive health; and Sexual Orientation. The survey included both closed questions, generating statistical data, and open-ended questions that generated qualitative data. As the survey aimed to measure the attitude about the sexuality of people with physical disabilities, the survey was targeted primarily to non-disabled people, but people with disabilities were also invited to respond. The survey included the Washington Group set of questions on disability (see Appendix 2).

The survey was made available as an online survey (using Qualtrics as the host site) and a paper questionnaire. The survey was translated in to 4 of the most dominant languages spoken in South Africa: English, Afrikaans, isiXhosa, and isiZulu. The survey was first piloted by the participants recruited to the interview study, who inputted in the design of the survey questionnaire.

Ethical approval for the survey study was obtained from the Stellenbosch University National Health Research Ethics Committee (NHREC) (registration number REC-050411-032), and the University of East London Research Ethics Committee (reference number: UREC_1415_61).

Survey administration

The survey was administered between April and August 2016. In order to attract as wide a range of respondents as possible, the survey was advertised through the following channels:

- Social media – primarily Facebook, including a Facebook page for the survey (<https://www.facebook.com/Help-us-understand-the-world-a-little-better-988826751208532/?ref=bookmarks>)
- To the student email list of Stellenbosch University and the University of Johannesburg in South Africa, with institutional approval.

- The survey was advertised on the website pages of two prominent newspapers: The Sowetan and Times Live.
- To the alumni email list of a large high school in Cape Town, South Africa
- To colleagues at other universities across South Africa who distributed the advert for the survey to their students

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 Khayelitsha, a large low socio-economic area in Cape Town.

Survey respondents

A total of 1990 people responded to the survey. Of these, 125 reported having a disability, and 1865 reported being non-disabled. Table 1 details the demographics of respondents, split into people with disabilities and non-disabled cohorts. It is important to note that the sample tends to be less representative of the racial demographics and education level of the general population, with more white individuals and higher levels of education among the sample. This is partly due to recruiting via two universities.

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

Method of data analysis

Responses to the closed questions of the survey were analysed statistically using SPSS. Responses to open-ended questions were analysed using thematic analysis and content analysis, to identify commonly reported stereotypes and themes.

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

A qualitative interview-based study explored persons with physical disabilities' experiences of sexuality.

Study design

The study made use of Photovoice (Wang & Burris, 1997; Vaughan, 2014) techniques. Photovoice is a participatory research technique in which participants are trained as co-researchers and photographers. 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. An interview Guide is included in Appendix 3. The interviews were audio recorded and later transcribed. Photographs and other creative materials were collected from participants, with their consent.

The study received ethical approval from University of East London Research Ethics Committee (reference number: UREC_1415_61), and the Stellenbosch University National Health Research Ethics Committee (NHREC) (registration number REC-050411-032).

Study participants

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 provided with an information sheet and consent form (included in Appendix 4). Potential participants were invited to a planning workshop held on the 2 December 2015 in Cape Town, South Africa. Participants were each paid R200 (Two hundred South African Rands) to cover the cost of their attendance at the workshop. At the workshop, a presentation was given about the research project, its aims and objectives, and potential participants were provided with information about photovoice, and what would be expected of them if they participate. The workshops also included discussions about the survey study and the design of the survey questionnaire (discussed above). Eighteen persons with physical disabilities (9 men and 9 women) attended the workshop and agreed to participate in the study. Following this workshop 4 potential participants chose to withdraw from the study, either because they felt uncertain about discussing such a personal topic, or because circumstances prevented them from participating. One individual who attended the workshop did not actually have a physical disability, but rather a speech impediment, so he was not included in the study.

The interviews were held in Cape Town during March/April 2016. A total of 13 participants were interviewed (7 men and 6 women). The interviews took place in participants' homes, or at rooms at Stellenbosch University (at their request). Interviews lasted between 60 and 120 minutes. Nine participants took and shared photographs; one participant made drawings; and three participants chose to just talk. One participant also shared poems and text alongside her photographs.

Table 2 below provides descriptive demographics of the 13 participants. The names provided are those chosen by the participants themselves to be used for reporting purposes. 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.

Table 2: Description of participants

Name	Gender	Age	Race	Religion	Disability Description	Relationship	Children
Badien	M	25	Coloured	Christian	Acquired: accident at age 18- paraplegic	married	2 step-children
Bongani	M	Not provided	Black	Christian	Acquired: Accident at age 4 - paraplegic	single	none
Cleone	F	45	Coloured	none	Acquired: Accident age 26 – paraplegic	divorced	2 children
Fatima	F	50	Coloured	Muslim	Born with disability: Cerebral Palsy; quadriplegic	Married	1 child
Jacques	M	50	White	Christian	Acquired: Accident age 22 – paraplegic	Single	none
Martha	F	56	White	Christian	Born with disability: Achondroplasia	single	none
Mzukisi	M	28	Black	Christian	Acquired: accident age 23 – paraplegic	engaged	none
Mzwandile	M	Not provided	Black	Christian	Acquired: accident in 2010 – paraplegic	separated	yes
Nosisa	F	48	Black	Christian	Acquired: accident at age 24- paraplegic	single	yes
Pride	F	42	Black	Christian	Polio - one leg	single	none
Rosabelle	F	60	Coloured	Jewish	Polio - both legs	divorced	yes
Tazz	M	32	Coloured	Christian	Acquired: Quadriplegic after violent attack age 18	single	1 (prior to accident)
Victor	M	47	White	none	Acquired: Quadriplegic after car accident age 19	married	2 children

Method of data analysis

An initial analysis of the interview transcripts was done using Nvivo software, 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.

5. RESULTS

We present here some of the key findings from the survey study and the photovoice study. These are findings that have already been reported in academic publications (see details of publications below). Analysis of the data is still ongoing, and we have further publications planned.

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 the following statements applied to:

1. The percentage of the people with physical disabilities that are capable of expressing sexuality
2. The percentage of people with physical disabilities for whom expressing sexuality is a basic human need
3. The percentage of people who have physical disabilities who should be allowed to have children
4. The percentage of people with physical disabilities who benefit from sexual health care services
5. The percentage of people with physical disabilities who benefit from reproductive health care services

6. The percentage of persons with physical disabilities who benefit from sexual education services

They were then asked to indicate the percentage of the general population these differences applied to. The results are in Table 3 below:

Table 3: 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.

We grouped the first three items as a scale of sexual rights beliefs, and the last three items as a scale of beliefs about the benefit of sexual and reproductive health care. We did a factor analysis of these 2 scales and found them to be valid. When we did a statistical analysis of these responses as a group measure, we found that these percentages were significantly different:

- *Sexual rights beliefs.* There was a significant difference in sexual rights beliefs between the groups, $t(2022) = -12.1$, $p < .000$. $d = .54$. Specifically, 66.04% participants supported the idea that persons with physical disabilities deserved sexual rights, compared to 71.95% of the general population.
- *Benefiting from sexual and reproductive health care beliefs.* There was a significant difference in beliefs between the groups, $t(2022) = -9.23$, $p < .000$.

$d = .74$, with participants reporting that they believe 59% of people with physical disabilities would benefit from sexual and reproductive health care services, compared to 68.23% of the general population.

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. Much of the evidence as to the prevalence of the myth that people with disabilities are asexual has been anecdotal. To our knowledge, this is the first empirical finding establishing the existence of the perception that non-disabled have that people with disabilities have reduced sexual capacity and needs. Thus, this presents an important and unique finding.

Beliefs about the sexuality of people with disabilities

We also asked respondents to indicate what percentage of people with and without physical disabilities they think identify as asexual, gay or lesbian, bisexual or heterosexual. The results are presented in Table 4 below:

Table 4: Percentage of (1) people with physical disabilities, (2) the general population, who identify as...:

Percentage who identify as	People with disabilities (%)	General population (%)
<i>Asexual</i>	29.97	25.23
<i>Bisexual</i>	21.21	27.69
<i>Gay or lesbian</i>	23.12	32.12
<i>Heterosexual</i>	61.58	65.20

The important thing to note in this table above is that respondents assume more people with physical disabilities to be asexual than non-disabled people. Furthermore, fewer people with disabilities are assumed to be gay or lesbian, heterosexual or bisexual 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 5 to 8)

Table 5: 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 6: 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 7: 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 8: 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 5 to 8 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 more feelings.

Further questions about feelings and attitudes towards dating a person with physical disabilities were measured by 8 questions of a dating beliefs scale (Tables 9 to 16):

Table 9: Dating Beliefs Scale Q1: *I would NOT date a person who has a physical disability because I think having to take care of them might be too much work.*

		Frequency (N=1861)	Percent
Strongly disagree	1	488	26.2
	2	275	14.8
	3	264	14.2
	4	312	16.8
	5	249	13.4
	6	160	8.6
Strongly agree	7	113	6.1

Table 10: Dating Beliefs Scale Q2: *I would NOT date a person who has a physical disability because I would feel awkward and not know what to say or how to treat them.*

		Frequency (N=1860)	Percent
Strongly disagree	1	585	31.4
	2	309	16.6
	3	226	12.1
	4	252	13.5
	5	208	11.2
	6	158	8.5
Strongly agree	7	122	6.6

Table 11: Dating Beliefs Scale: Q3 *I would NOT date a person who has a physical disability because I would be afraid they would be sick or ill too often.*

		Frequency (N=1859)	Percent
Strongly disagree	1	557	29.9
	2	334	17.9
	3	248	13.3
	4	254	13.6
	5	208	11.2
	6	147	7.9
Strongly agree	7	111	6.0

Table 12: Dating Beliefs Scale Q4: *I would NOT date a person who has a physical disability because I do not think they would be able to satisfy me sexually.*

		Frequency (N=1853)	Percent
Strongly disagree	1	640	34.4
	2	281	15.1
	3	235	12.6
	4	271	14.6
	5	172	9.2
	6	133	7.1
Strongly agree	7	121	6.5

Table 13: Dating Beliefs Scale Q5: *I would NOT date a person who has a physical disability because I am just not attracted to people who have physical disabilities.*

		Frequency (N=1859)	Percent
Strongly disagree	1	594	31.9
	2	279	15.0
	3	256	13.8
	4	316	17.0
	5	153	8.2
	6	136	7.3
Strongly agree	7	125	6.7

Table 14: Dating Beliefs Scale Q6: *I would NOT date a person who has a physical disability because I think that people who have physical disabilities are not much fun.*

		Frequency (N=1855)	Percent
Strongly disagree	1	1128	60.6
	2	336	18.1
	3	138	7.4
	4	142	7.6
	5	55	3.0
	6	29	1.6
Strongly agree	7	27	1.5

Table 15: Dating Beliefs Scale Q7: *I would NOT date a person who has a physical disability because I would be afraid of what my friends and family might think or say.*

		Frequency (N=1857)	Percent
Strongly disagree	1	899	48.3
	2	287	15.4
	3	218	11.7
	4	178	9.6
	5	116	6.2
	6	72	3.9
Strongly agree	7	87	4.7

Table 16: Dating Beliefs Scale Q8: *I would NOT date a person who has a physical disability because I do not think that they would be capable of being a good parent.*

		Frequency (N=1857)	Percent
Strongly disagree	1	1202	64.6
	2	295	15.9
	3	131	7.0
	4	100	5.4
	5	61	3.3
	6	27	1.5
Strongly agree	7	41	2.2

Responses in Tables 9 to 16 above, while majority positive, indicated some feelings of ambivalence, uncertainty and discomfort.

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

The 13 interviews we have conducted as part of the photovoice study, have yielded a large amount of rich and detailed qualitative data, which we cannot present here in its entirety. Our analysis and write up of this data is still ongoing. We present here some of the core themes that emerged from the interviews, alongside a small selection of photographs taken by some of the participants. Further photographs are available to view from the website. We present here 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
- Experiences of accessing sexual health education and care

We will discuss each in turn, presenting some illustrative quotes from the data.

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. Many participants included photographs that depicted environmental barriers that

represented their general exclusion from full participation in society. For example, one participant, Badien, took the photo below, and explained:



“Most of the time people don’t understand the physically disabled. For example, for me going about on my routes on my way home, this is the only route that I can take to get off the main section of the main road. But for me going through there I have to go through stones and I have to go through sand. There are even potholes that sink in the sand. And most of the time as well, if I have to go through that section there, there are always cars parked on that side there. This is a workshop and, if I have to pass there, there’s always a person who would utter these words: “why are you on my property?” So I have no choice but to turn around and take the freeway. And what happened to me there also a few months ago, a taxi driver knocked me on my elbow and I fell from my chair. So I’m very sceptic about taking that route.” (Badien)

While Badien spoke about physical access, this was symbolic of access to relationships and society. This was spoken about by all other 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.” Fatima)

“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)

One of the participants, Bongani, depicted this in a photograph. He wanted to photograph a see-saw, but not being able to find one, he photographed a bench and spoke about it representing exclusion from relationships:



To be honest, I actually wanted a picture of a seesaw, a seesaw in the sense that one can’t really enjoy the full benefits of the seesaw unless there’s another person on the other side. So you might be in a park full of people with very high spirits and all of that, ja, you might go and sit on the seesaw, but it’s almost entirely useless until someone sees you as worthy of joining you. So that was my thought process behind that. So I just related that to participation within sexual engagements, that why I might for instance be eager to explore and find out more what sex has to offer. So just my own thoughts about how it makes me feel, or how it can unleash any form of potential or to explore further possibilities with my partner. Unless that partner is almost on a similar page as me, I’m not going to be able to fully capture that. But at the same time, the biggest challenge is to get to a point where someone is on the same page as you. It’s almost like get over the...how can I say...the barrier of how they perceive you. (Bongani)

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 community, in the black community, they are not aware of disability. Like if your child has got a disability, it’s got that myth as if you are cursed or you are bad luck, or something isn’t right with your family.” (Pride)

“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. They don’t want your help. Some believe that if they come across you and you say hello and you carry on with the conversation a little bit, you are planting that curse onto them. So if the situation is like that, then there is no way that you will have a friend in a society like that, not a girlfriend. A girlfriend is difficult to get while you are still walking, how if you are cursed?” (Mzukisi)

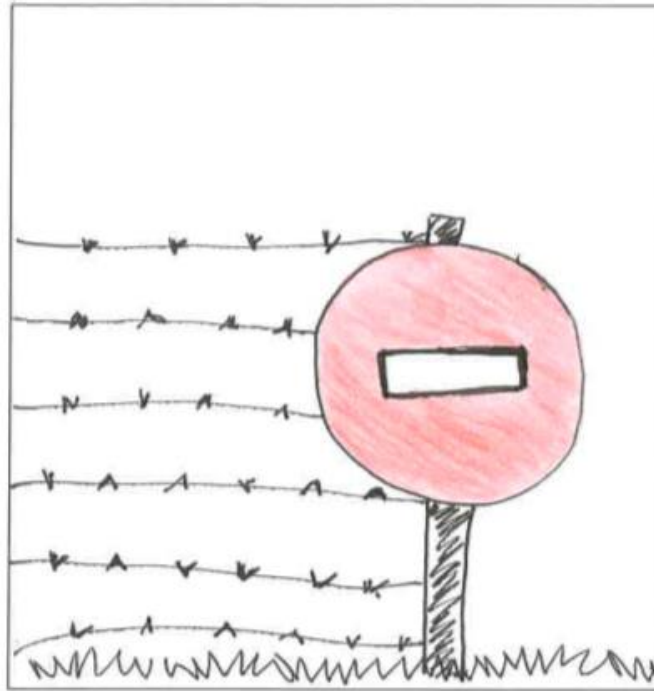
Alongside this disability stigma, participants spoke about being perceived as non-sexual or sexually inferior, as discussed in the next theme.

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 person in the form of being married and having children. For example, Fatima and Martha both refer to these messages they received while growing up:

“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)

Martha talked about growing up with a sense that relationships were not meant for her. She depicted this as a no-entry sign, and explained:



“The no-entry sign. I come from a conservative background, a conservative Christian background, so for me, as I was growing up, the whole thing of sexuality and even marrying was very closely tied to having children. And everybody just took for granted, because I couldn’t have children, I wouldn’t marry. So that’s something I rebelled against and struggled with. But at the same time, what it also did, it made me sort of...a few times that I started in friendships with boys or with young men, I would sort of put up the blockades earlier so that I wouldn’t get to that point. And ja, it was painful and I was angry a lot of the time. But this epitomises it, that yes, there is a way, and a lot of my friends...I mean, when I was in my twenties quite a few of them had been married and unfortunately marriages were breaking up, so I knew that marriage as such wasn’t an easy road, but for me it was this no-entry. You know, that was the message that I was getting. I mean, I always hoped. Even through all the time that I knew about the no entry sign, there was hope, but it was something that I wasn’t allowed to talk about.” (Martha)

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)

“most of the people I speak of, they always have got this question in their mind: do you still have sex? So it usually comes up in their conversation.” (Tazz)

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

For some participants, who had acquired a disability in adulthood, the loss of sexuality was something that they spoke about, echoing perhaps their own preconceived assumptions about disability and sexuality, but also the actual loss of sexual sensations:

“for me it was, I couldn’t feel anything, so why even try, that kind of thing. Just get it over and done with. So, no, he didn’t, but I also didn’t want to because I wasn’t feeling attractive. I didn’t feel attractive. For me, if I didn’t have sex, it would have been fine.” (Cleone)

This impacted on the participants sense of self as masculine or feminine and required some work in regaining their sense of sexuality. Both these themes are now discussed below.

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. As discussed above by Martha, this was an area of life that many young women grew up receiving the message that they did not belong to. The females participants also spoke about their bodies, and the impact that this had on feeling attractive and feminine:

growing up, apart from short arms and legs, everything is normal, absolutely normal, so I had all the trials and tribulations, if one can call it that, of growing up and adolescence, womanhood and all that, but I didn’t have benefits. I mean, I also realised that by the world’s majority standards that I wasn’t beautiful and I didn’t have a good body. I wasn’t attractive, and for any teenager, any young person, it’s hard. I’m delighted that it gets easier as one grows older, and that there is so much else.

Now it's easier, when I do see an inkling of something sensuous, I feel better equipped to respond. But in terms of how did it make me feel, well, I felt ugly. I felt rejected and that I missed out a lot. I felt angry, which is probably the overriding emotion that I felt. (Martha)

Interestingly, some of the women spoke about the importance that having long hair had for retaining a sense of femininity. For example, Cleone speaks of the impact that an acquired disability at first had on making her feel unsexualised, unattractive, until she had long hair:

As a woman, this was my life, terrible! And then I started going out and I saw that guys were actually interested in me. It was after my divorce. I met up with some old girlfriends. We would go to clubs, which I hated. But the thing is, at these places I saw that men were actually interested in me. I had long hair then. (Cleone)

Similarly, Fatima speaks about her long hair, an aspect of her feminine identity that was very important to her and she depicted in her photographs:



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)

“we were brought up to be independent and responsible, and that was taken away from me. It made me feel not worth it because I couldn't provide for myself. I had to rely on a disability grant solely. It really made me feel less than other people because people would say that I can't contribute to society when it comes to employment. [...] for me, part of bringing out my sexuality and part of being a man, it's to still contribute to society with employment and stuff. It makes me feel good. It makes me feel like I'm a man.” (Tazz)

In terms of sex, many 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:

“a physically-disabled person is more likely to end up in a short term, like I've mentioned, a short term relationship due to their challenges and intimacy. Why I'm saying intimacy phase, an intimacy phase from my perspective, because like now, I've got to use equipment or I have to use some medication to give me that stamina, that feeling back, that energy back, to be intimate with a partner. I mean, it's part of life. Sometimes, for example, I can't afford to get that specific treatment, then I'm stranded, which makes my partner stranded, and that same strandedness will make the partner look for someone else to fulfil her wants and needs.” (Badien)

“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 had a series of sensual photographs taken of herself, as part of her journey towards reclaiming a positive sense of herself as a woman and a sexual being:



“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 sexual:



“I believe that people with a disability, we still need to look good when you dress up. You need to look good. You need to look neat and present yourself in a clean and neat manner. So for me, 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.” (Tazz)

Some of the men spoke about how Viagra and being able to sexual please a woman, allowed them to retain their sense of masculinity and sexual self:

“I think mostly about my partner. You know why I’m saying so? Part of my body has got no sensation, it’s got no feeling, so if I have intimacy with my partner I don’t feel anything. But I have to think about her needs. I have to fulfil her needs, but then my

partner fulfils my needs in a different tactic or a different sensitive part of your body, for example, from the neck down, etc, etc. But in her case it's like the normal routine. Like I've mentioned, I don't feel anything, nothing, but she needs to feel. I'm working in her terms now." (Badien)

I met a girl here. We had a sexual relationship, but we never had penetrative sex. It was a good sexual relationship. I mean, there are lots of ways to have sex without having penetrative sex. [...] I in any case like not having penetrative sex. I like explorative sex, that's more my line. And in my life I have actually found that women prefer that. Most of the girls that I was with, a very small percentage of them preferred sex and rather would like to just fool around and have a good time. You know, so that's a different thing. (Jacques)

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. Some comments made about this were:

"I knew that I was functional and that I could do everything. In fact, I went to the geneticist while I was studying at university because I just wanted to find out for myself exactly what's going on here and with me. So, I went to the professor of genetics, and he was very cold. He said, well, if we had already found out the genes that cause achondroplasia, your abortion would be legalised. And I just remember reeling and then walking out of there thinking, that man thinks my life isn't worth living, that achondroplasia is a reason for abortion." (Martha)

[And what happened when you came to the clinic?] - Oh, the nurses were also like, why? What are you doing here? I came for prevention. And then? Why? Do you have a boyfriend? Yes, nurse, I have a boyfriend. No, this is not right. How can you have a boyfriend. You can't have a boyfriend if you have a disability. (Pride)

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. You know, it's like that. That is what friends have told me. (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. So these health facilities, they know very little about people with disabilities and sex. (Tazz)

However, many faced negative social attitudes about being pregnant, or having children, often by their identity as a parent being ignored:

"it's about awareness also to the people, that people who are physically-disabled can get pregnant and can have babies. So, it was really empoweredness into the community, as much as they didn't take notice; because when I'm pregnant, people won't take notice of me that I'm pregnant. It was worse then, because I was sitting in a wheelchair, so people won't take notice." (Nosisa)

One participant, Vic, took a photograph of pictures of his family and spoke about the social attitudes he often receives that focus on his disability and deny his identity as a father, and a husband:



“when you go out and meet other people, what are their first questions you ask each other?” It doesn’t take very long before they say, well, “who are you?”; “Are you in a relationship?”; you know, “Are you on FaceBook, in a relationship, and what do you do?” Those are the questions that everyone asks. That is what people want to know about you straightaway – “what do you do and are you a relationship?”. That is your identity and value in society. What do you think people ask me when they meet me? - “What happened to you?” And that is what sucks about being disabled. People don’t expect me to be in a relationship or be able to do anything because I’m in a wheelchair and so I have less value in society. So, these photographs are about inclusion. This is part of my life; I have some family photos on my bedroom mirror. So, this is a direct identity statement about being married, having kids, despite being disabled. I am a husband and a father first, that is my identity and how I see myself – my disability is secondary.” (Vic)

6. OUTPUTS AND MATERIALS

The project ended with a stakeholders' conference held in Cape Town in March 2017. At this event, all participants who took part on the study were invited, along with a guest, as well as representatives from various disability organisations, media, and disability researchers and health professionals. At the conference, the research team presented the project; what was done and what some of the preliminary results were. We also screened the documentary film, and invited discussion on the film.

The conference featured a display of posters of some of the participants photographs and accompanying narratives. The posters were then given to the participants as a gift for them to keep. The event ended with a dance performance by a group called Unmute, who feature dancers with disabilities. Appendix 5 includes photographs from the event and some of the posters that were on display.

The following outputs and materials were developed as part of this project:

6.1: Documentary video

Four individuals with physical disabilities (2 men and 2 women) who participated in the photovoice interview study (Study 2 described above) consented to take part in documentary film. Following their individual photovoice interview, they took part in a filmed individual interview and were asked question specific to their experience.

These questions were prepared and agreed to ahead of filming. Four individual video interviews were conducted. These were then used to construct a short 16-minute documentary film. A narrative for the film was constructed with a fifth participant, who agreed to be recorded as a narrator for the film. A storyboard was constructed based on important points taken from the four interviews and the theme of the project. This was discussed and agreed with the 5 participants who took part in the film (narrator and 4 interviewees). The film features: Bongani (see Table 2) talking about sexuality and dating experiences; Cleone talking about disability, sexuality and relationships, and pregnancy; Rosabelle talking about disability, body image and dating; and Vic talking about disability, sexuality, relationships and parenthood. The film is available in a version with subtitles for viewers who are hard-of-hearing, and a non-subtitled version. The films are freely available to view on the project website (see below) and has been screened at a number of conferences (see below).

6.2: Project website

We have developed a project website using Wordpress. This was not in our original proposal, but it was decided that it would be a more effective way of sharing the project materials with a wider audience than a book would. The website features a brief description of the project and introduces the core research team. It also features some of the photographs and drawings made by the participants and their accompanying narratives. The website also includes all the videos and the documentary film. Academic publications are also featured on the website as soon as they have been published. The website can be found at:

www.disabilityandsexualityproject.com.

The website went live at the end of April 2017. According to the website statistics, as of end of August 2017, the website has received 2739 views from visitors from 46 different countries (from Western and Eastern Europe, Africa, Asia, North America, Central America and Oceania). The un-subtitled film has been played in full 124 times, and the subtitled film has been played 49 times.

6.3: Book

We had originally proposed the development and publication of a non-academic book, co-authored with the participants on this project, featuring personal stories and photographs from the project. There was a budget (€7,000) for the production of this book to make it freely available as an electronic publication. A book proposal, with some draft chapters, was submitted to HSRC Press in South Africa in April 2017 for consideration by the editorial board. Unfortunately, HSRC Press declined the proposal, stating that they preferred a more academic publication.

Since then, we have approached the co-editors of a special book series: *Palgrave Studies in Disability and International Development* published by Palgrave MacMillan (see series website: <https://www.palgrave.com/br/series/14633>). The co-editors expressed their initial support for the proposed book, and we are currently compiling a formal book proposal to Palgrave. This will be a more academic publication than initially planned, but will still contained personal stories co-authored by the project participants, and their photographs. Some chapters will be co-authored by selected participants. The development of the website (which was not in the original project

proposal), has made the project materials freely available, and so we feel this has compensated for the original plans for a non-academic book. There is an option to contribute towards Palgrave's cost of production to make a free electronic version of the book available. Thus, the budget of €7,000 for book production remains as yet unspent (see accompanying report of final project budget and expenditure).

6.4: Academic publications

The following 5 academic publications have been produced to date. The first two have been published Open Access, paid for from the research budget.

- Carew, M., Braathen, S., Swartz, L., Hunt, X., & Rohleder, P. (2017). The sexual lives of people with disabilities within low- and middle-income countries: A scoping study of studies published in English. *Global Health Action*, 10:1, 1337342, DOI: 10.1080/16549716.2017.1337342.
Available as Open Access:
<http://www.tandfonline.com/doi/abs/10.1080/16549716.2017.1337342>
- Hunt, X., Carew, M., Braathen, S.H., Swartz, L., Chiwaula, M., & Rohleder, P. (2017). The sexual and reproductive rights and benefit derived from sexual and reproductive health services of people with physical disabilities in South Africa: beliefs of non-disabled people. *Reproductive Health Matters* 25:50, 66-79, DOI: 10.1080/09688080.2017.1332949.
Available as Open Access:
<http://www.tandfonline.com/doi/full/10.1080/09688080.2017.1332949?src=recsys>

The following are currently in press or under review, but will not be available as Open Access:

- Hunt, X., Carew, M., Braathen, S., Swartz, L., Chiwaula, M., & Rohleder, P. (in press). Dating persons with physical disabilities: the perceptions of South Africans without disabilities. *Culture, Health & Sexuality*.
- Hunt, X., Carew, M., Braathen, S., Swartz, L., Chiwaula, M., & Rohleder, P. (under review). Withdrawn, strong, kind, but de-gendered: Non-disabled South Africans' stereotypes concerning persons with physical disabilities. *Disability & Society*

- Hunt, X., Braathen, S., Swartz, L., Carew, M., & Rohleder, P. (under review). Physical disability and sexuality: Experiences of people with physical disabilities in a photovoice study from South Africa. *Journal of Health Psychology*

The papers that are first authored by Xanthe Hunt, form part of her PhD by publication which she is currently completing at Stellenbosch University, supervised by Prof Leslie Swartz, Dr Brian Watermeyer, and Dr Poul Rohleder. The dissertation is due to be submitted in 2018.

6.4: Conference presentations

The research team have given the following 7 conference presentations on the project:

- Hunt, X., Swartz, L., Braathen, S.H., Carew, M., Chiwaula, M., & Rohleder, P. (2017) Shooting back and (re)framing: Challenging dominant representations of the disabled body in the global South. Paper presented at the *2017 Disability Studies Conference: Disability as Spectacle*, at the University of California in Los Angeles, 13-14 April 2017.
- Hunt, X., Swartz, L., Braathen, S.H., Carew, M., Chiwaula, M., & Rohleder, P. (2017) Shooting back and (re)framing: Challenging dominant representations of the disabled body in the global South. Paper presented at a *departmental seminar at Berkeley University in San Francisco*, 18 April 2017.
- Hunt, X., Swartz, L., Braathen, S.H., Carew, M., Chiwaula, M., & Rohleder, P. (2017) Shooting back and (re)framing: Challenging dominant representations of the disabled body in the global South. Paper presented at *the 2017 Nordic Network for Disability Research*, at the University of Orebro in Sweden, 4-6 May 2017.
- Rohleder, P., Swartz, L., Braathen, S.H., Hunt, X., & Carew, M. (2017). Beliefs about the sexuality and sexual health rights of persons with physical disabilities in South Africa. Paper presented at the *10th Biennial Conference of the International Society of Critical Health Psychology*, Loughborough University, United Kingdom, 9-12 July 2017.

- Rohleder, P., Braathen, S.H., Swartz, L., Hunt, X., & Carew, M. (2017). Challenging the myth of asexuality of people with disabilities: A South African photovoice study. Pecha Kucha presentation given at the *10th Biennial Conference of the International Society of Critical Health Psychology*, Loughborough University, United Kingdom, 9-12 July 2017.
- Braathen, S.H., Rohleder, P., Swartz, L., Hunt, X., Carew, M., & Chiwaula, M. (2017). Disability, sexuality and gender: Stories from South Africa. Paper presented at the *5th Afrinead Conference on Disability and Inclusion in Africa*, at the Kwame Nkrumah University of Science and Technology (KNUST) in Ghana, 7-9th August 2017.
- Carew, M., Rohleder, P., Braathen, S.H., Swartz, L., Hunt, X., & Chiwaula, M. (2017). Understanding negative attitudes toward the sexual rights and sexual healthcare access of people with physical disabilities in South Africa. Paper presented at the *5th Afrinead Conference on Disability and Inclusion in Africa*, at the Kwame Nkrumah University of Science and Technology (KNUST) in Ghana, 7-9th August 2017.

In addition to the above conference presentations, the documentary film has been screened in its entirety or in part at the following conferences/meetings:

- *10th Biennial Conference of the International Society of Critical Health Psychology*, Loughborough University, United Kingdom, 9-12 July 2017
- Part screening at the *Global Disability Innovation Summit*, Queen Elizabeth Olympic Park, London, 13-14th July 2017.
- Plenary screening at the *5th Afrinead Conference on Disability and Inclusion in Africa*, at the Kwame Nkrumah University of Science and Technology (KNUST) in Ghana, 7-9th August 2017.

7. PARTICIPANT EXPERIENCES ON THE PROJECT

At the stakeholders' conference held in Cape Town in March 2017, we held a writing workshop for participants, where they were invited to write about their experiences on this project. Below are some of the feedback written:

"When I received an invitation to participate in this research, my thought were – at last! It's a topic that's been taboo for a long, especially if its not in an academic setting. The interview was great. It was extremely liberating to discuss sexuality from my perspective without fear of judgement, when the general assumption is that I am not or rather people / society find it difficult to relate to me as a sexual being. This was confirmed to me just last Friday again (3 days ago). I met a woman and we chatted about this and that to pass the time. I briefly mentioned that I have children and she could not hide her surprise. When I asked why she seemed to be shocked by me having children, she unhesitantly stated she assumed that because I was in a wheelchair she did not think I could have children. This is the general perception of society. So this project is critical to create awareness around disability. That persons with disabilities are much more than meets the eye, we are who encompass roles that makes us mothers, lovers, friends....the list is never ending. I'm so glad to have been part of this project. I'm glad that I could contribute to hopefully making a difference in how persons with disabilities are viewed."

"in this study I often forgot that I was a participant because of the learning / benefit / blessing for myself. The immediate value of the project to me, as a participant during the study was tremendous. Even just identifying under-solved issues in my own life – even without starting a formal therapeutic intervention, has been therapeutic. Participation in the project has encouraged / strengthened my resolve to be an advocate – albeit in an area that does not feel comfortable."

"It's my first time to become a member of such a group and I'm very much proud to participate to such a group that is the reason why I've told myself that I need to share whatever you are expecting to me and that is why I did share my history about my pregnancy being on a wheelchair. Being physically challenged too and by the time my baby has been born, yes I've experienced something new too because the two boys I do have they were born by the time I was walking, so I'm rally experiencing

something I never experienced before and I experienced that as we are physically challenged we are different too. I do see those who are different to me as I'm within this project and I love to treat each and every one fair, not to be rude and think that I'm better than the others, we are all human beings and we are created by God so we need to respect each other. I did not know that there'll be some people who would like to learn more about myself too and to have an interest to spend time with me and listen to my story and the experience I do have. As much as we are physically challenged we do have different stories too and different lives."

"I feel very good about this project. For me it is the first time to share my feelings about my disability. I've never shared my story with anyone even my family never had time to listen to my feelings. My community as well does not care, at work it is like you are making excuses if you try to explain what is bothering you. It is also a healing session for me because since I got involved in the project, I am able to speak out about myself. I'm not ashamed anymore and for me it is also a learning curve especially to meet other people with different disabilities. I feel that the work will also learn that we are also human and get feeling, needs and dreams. It is not about how I look but it's about who I am, not the physical appearance. It is also nice to interact with the team, it makes easy to communicate with. I feel proud and honored, I feel different and I know that I am unique. My family also feel proud of me when I told them about this project. They learnt something from me."

"It was awesome to be part of this project. I was impressed with the team of professionals who allowed in puts by participants from the word "go" felt comfortable throughout the research period. I had no hesitation to share knowing that my contribution would be respected. Continuous communication also meant a lot and privacy was guaranteed until I had given permission. Although I had no problem with use of info it was good that I could feel the positive involvement through the whole process. The interview were great and done in a relaxed atmosphere. I am sure that the result will have a positive impact on all who read and see videos and footage. The project and research portrays in my humble opinion, a true reflection over a broad spectrum of what happens in the lives of persons with disabilities. I have learnt more about other disabilities about views by both male and female and how my experiences differ. However, in the end we all cope with our specific challenges to

work towards finding solutions to live with or without finding a special bond in particular a sexual bond. Thank you team for including me on a further in-depth journey.”

“In the beginning it was exciting that someone somewhere took the initiative to run with this project and now today putting all that together. Only then can we tell how the general public is going to react to what is out there. I’m very optimistic that this project will prove to be outstanding as it is very important to the human race to love and be loved and to have a family if they choose to do so. One thing I’ve learned because of this project is the freedom of expression as a woman. To be out the feminist particularly the part where we took pictures. There’s no words to describe how grateful I am for the opportunity to express my sexuality as a woman without fear without being judged. The pictures component and the interview, there I could tell, I didn’t have to worry what people would say.”

“I just wanted to extend a heartfelt thanks to all the research team for a fantastic initiative and production – it seems we have already created a sound platform for much-needed research and debate – and I hope is a lot more to come as well. I am certainly keen to keep in touch and carry on working on further research in this area. Another thought I had – this has been quite a liberating experience for all of us in varying degrees and has had on it a big impact on many of the participants like Fatima – and I think it would be sad for her to lose that connection/momentum, especially if she feels unheard in her community etc. So, could I ask that the team think about arranging a reunion for next year – even if it is just a get-together that may help re acknowledge and validate this process and what we participants have been through. I think a lot has come out of this project already and I’ve been involved with projects and research before that ended quickly or just slowly dissipated – and when the project ends sometimes participants can feel kind of ‘spare’ for want of a better term.”

We are exploring possibilities for funding to indeed have a follow-up meeting, as the above participant suggests. However, we continue to have contact with participants about ongoing developments with the website, writing and publications.

8. RECOMMENDATIONS

On the basis of our findings and experience on this project, we can make the following provisional recommendations:

1. There is a need for increased education and awareness about disability and sexuality, at schools and through general media. At schools, education on disability and sexuality should not just take place at schools for learners with disability. It should also be incorporated into general sexual and reproductive health care education at all schools, so that non-disabled learners are made aware of disability issues. This might go some way towards challenging myths and stigma.
2. For people with disabilities in lower socio-economic circumstances, there needs to be improved affordability and access to sexual and reproductive health technologies, including, for example, access to medication such as Viagra, and access to fertility treatments.
3. The experiences of sexual minorities and alternative sexual identities (lesbian, gay, bisexual, queer and transgender) persons with disabilities remain unexplored. There is a paucity of research in this area internationally, and given the layers of discrimination and oppression, attention needs to be given to this.
4. This project has focused on persons with physical disabilities. 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, particularly in regard to emancipatory practices.

9. CONCLUSION

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 project has been a

creative and collaborative exercise, which has expanded beyond what was originally proposed, as a result of the enthusiasm and dedication of the participants we worked with. The project has delivered more than what was originally anticipated, particularly with the development of the short film and the website. We thank FIRAH for their generous support.

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11. APPENDICES

Appendix 1: Photo of core research team

Appendix 2: Survey questionnaire (English version)

Appendix 3: Photovoice interview guide

Appendix 4: Participant information sheet and consent form

Appendix 5: Photographs and posters from the stakeholders' conference

Appendix 6: Budget and expenditure

APPENDIX 1: PHOTO OF CORE RESEARCH TEAM



Figure 1: Research team: front row (L to R): Mussa Chiwaula, Stine Hellum Braathen, Poul Rohleder.
Back row (L-R): Leslie Swartz, Mark Carew, Xanthe Hunt

APPENDIX 2: SURVEY QUESTIONNAIRE (ENGLISH VERSION)

[Notes in brackets to indicate how survey will appear on survey platform]

This is the beginning of the survey

The following questions will be used to generate a unique code which you can use to identify your survey responses, should you need to.

Please state only the first letter of your first name:

Please state only the first letter of your father's first name:

Please state only the first letter of your mother's first name:

Please state your day of birth as two digits:

For example, if you were born on the 3rd October 1987, please put 03

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[Page break]

The following questions will just ask a bit about your background and lifestyle. Please answer them by selecting the appropriate option or writing in the box provided.

How old are you (in years)?

Are you:

Male

Female

How would you describe yourself in terms of your population group?

Black African	Coloured	Indian or Asian
White	Other	

Which language do you speak most often in your household?

Afrikaans	English	IsiNdebele
IsiXhosa	IsiZulu	Sepedi
Sesotho	Setswana	Siswati
Tshivenda	Xitsonga	Other

In which province do you usually live?

Western Cape	Eastern Cape	Northern Cape
Free State	Kwa-Zulu Natal	North West
Gauteng	Mpumalanga	Limpopo

What is your highest level of education obtained?

No schooling	Up to Grade 2/Sub B	Up to Grade 7/Std 5
Grade 10/Std 8	Grade 12/ Std 12 / Matric	Bachelor Degree/Higher Diploma
Honours Degree	Higher Degree/Diploma (Masters/PhD)	

How would you describe your sexual orientation?

Heterosexual	Asexual	Gay, lesbian or bisexual
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[page break]

Do you have difficulty seeing, even if wearing glasses?

1. No- no difficulty.
2. Yes- some difficulty.
3. Yes- a lot of difficulty.
4. Cannot do at all.

Do you have difficulty hearing, even if using a hearing aid?

1. No- no difficulty.
2. Yes- some difficulty.
3. Yes- a lot of difficulty.
4. Cannot do at all.

Do you have difficulty walking or climbing steps?

1. No- no difficulty.
2. Yes- some difficulty.
3. Yes- a lot of difficulty.
4. Cannot do at all.

Do you have difficulty remembering or concentrating?

1. No- no difficulty.
2. Yes- some difficulty.
3. Yes- a lot of difficulty.
4. Cannot do at all.

Do you have difficulty with self-care such as washing all over or dressing?

1. No- no difficulty.
2. Yes- some difficulty.
3. Yes- a lot of difficulty.
4. Cannot do at all.

Using your usual language, do you have difficulty communicating, for example understanding or being understood?

1. No- no difficulty.
2. Yes- some difficulty.
3. Yes- a lot of difficulty.
4. Cannot do at all.

[Page break]

Please respond to the following questions by selecting the number between 1 and 7 that best matches your opinion.

**Please indicate the extent to which you mix with people who have physical disabilities...
...in the area that you live in.**

Not at all 1 2 3 4 5 6 7 A great deal

...when socialising.

Not at all 1 2 3 4 5 6 7 A great deal

...when engaging in leisure activities.

Not at all 1 2 3 4 5 6 7 A great deal

...within your friendship group or family?

Not at all 1 2 3 4 5 6 7 A great deal

[Page break]

Please indicate the extent to which your past interactions with people who have physical disabilities have been...

...positive?

Not at all 1 2 3 4 5 6 7 Very much so

...personal?

Not at all 1 2 3 4 5 6 7 Very much so

...enjoyable?

Not at all 1 2 3 4 5 6 7 Very much so

...worthwhile?

Not at all 1 2 3 4 5 6 7 Very much so

[page break]

Do you currently, or have you ever had, romantic contact with a person who has a physical disability (e.g., dating, a relationship)?

Yes No

To what extent do you favour or oppose each of the ideas listed below?

We should do what we can to equalize conditions for different groups.

Strongly oppose 1 2 3 4 5 6 7 Strongly favour

We should work to give all groups an equal chance to succeed.

Strongly oppose 1 2 3 4 5 6 7 Strongly favour

Group equality should not be our primary goal.

Strongly oppose 1 2 3 4 5 6 7 Strongly favour

It is unjust to try to make groups equal.

Strongly oppose 1 2 3 4 5 6 7 Strongly favour

[Page break]

Please read the following scenario carefully and then answer the below question by writing in the box provided:

[The following question will be matched to participant gender. Words in brackets denote where changes will occur]

A group of [female] friends sits and chats about their dates over the weekend – including some intimate details of their sexual encounters. One of them is a [woman] who has a physical disability. The group eggs one another on to share, naming and coaxing each person in turn to share something until all have shared except the [woman] who has a disability. What happens next?

[page break]

Please read the following scenario carefully and then answer the below questions by writing in the box provided:

[John], who is non-disabled, meets [Jane], who has a physical disability, at a party. They have a nice chat together and seem to get along really well. At the end of the evening, [Jane] tells [John] that [she] really likes [him], and invites [him] to go out on a date the following weekend.

How does [John] react to this? How might [he] respond to [Jane]?

Why might [John] react in this way? What are [his] thoughts and feelings about the situation?

[page break]

Please list three traits that come to mind when thinking of men who have physical disabilities and three that come to mind when thinking of women who have physical disabilities. You can write these in the boxes below.

Disabled men:

Disabled women:

[page break]

To what extent would you feel comfortable...

...befriending a person who has a physical disability?

Very uncomfortable 1 2 3 4 5 6 7 Very comfortable

...going on a date with a person who has a physical disability?

Very uncomfortable 1 2 3 4 5 6 7 Very comfortable

...being in a relationship with a person who has a physical disability?

Very uncomfortable 1 2 3 4 5 6 7 Very comfortable

...if a person who has a physical disability married into your family?

Very uncomfortable 1 2 3 4 5 6 7 Very comfortable

[page break]

I would NOT date a person who has a physical disability because...

...I think having to take care of them might be too much work.

Strongly disagree 1 2 3 4 5 6 7 Strongly agree

...I would feel awkward and not know what to say or how to treat them.

Strongly disagree 1 2 3 4 5 6 7 Strongly agree

...I would be afraid they would be sick or ill too often.

Strongly disagree 1 2 3 4 5 6 7 Strongly agree

...I do not think they would be able to satisfy me sexually.

Strongly disagree 1 2 3 4 5 6 7 Strongly agree

...I am just not attracted to people who have physical disabilities.

Strongly disagree 1 2 3 4 5 6 7 Strongly agree

...I think that people who have physical disabilities are not much fun.

Strongly disagree 1 2 3 4 5 6 7 Strongly agree

...I would be afraid of what my friends and family might think or say.

Strongly disagree 1 2 3 4 5 6 7 Strongly agree

...I do not think that they would be capable of being a good parent.

Strongly disagree 1 2 3 4 5 6 7 Strongly agree

[page break]

There are many types of physical disabilities and some physical disabilities may be more severe than others. Please move the slider below to indicate what % of people with physical disabilities the following statements apply to. You can do this by moving the slider below to the number between 0 and 100 that best represents your view.

% of people with physical disabilities that are capable of expressing sexuality.

[There will be a slider under these questions on Qualtrics, to aid comprehensibility and ease of understanding for participants]

% of people with physical disabilities for whom expressing sexuality is a basic human need.

% of people who have physical disabilities that should be allowed to have children

% of people with physical disabilities who benefit from sexual healthcare services (e.g., HIV testing) in your area.

% of people with physical disabilities who benefit from reproductive healthcare services (e.g., pregnancy screening) in your area.

% of people who benefit from sexual education services (e.g., classes providing information about HIV) in your area

[page break]

Please move the slider below to indicate what % of the general population the following statements apply to. You can do this by moving the slider below to the number between 0 and 100 that best represents your view

% of the general population that is capable of expressing sexuality.

[There will be a slider under these questions on Qualtrics, to aid comprehensibility and ease of understanding for participants]

% of the general population for whom expressing sexuality is a basic human need.

% of the general population that should be allowed to have children.

% of the general population who benefit from sexual healthcare services (e.g., HIV testing) in your area.

% of the general population who benefit from reproductive healthcare services (e.g., pregnancy screening) in your area.

% of the general population who benefit from sexual education services (e.g., classes about HIV prevention) in your area.

[page break]

Please move the slider below to indicate what % of people with physical disabilities you think identify as:

...heterosexual.

...asexual.

...gay, lesbian or bisexual.

Please move the slider below to indicate what % of the general population you think identify as:

...heterosexual.

...asexual.

...gay, lesbian or bisexual.

[page break]

Please use the box below to write any additional thoughts you might have and then press the >> button.

[page break]

Dear Participant,

Thank you for completing this survey. Your participation is greatly appreciated.

This survey was designed to investigate your attitudes toward the sexuality of physically disabled people. There has been little research investigating these attitudes, especially within the South African context.

Results will be used to inform healthcare professionals, policymakers and disability organisations, as well as contexts where non-disabled people and physically disabled people are likely to interact.

If you have any questions about this study or would like to contact the researchers at a later date, please email Xanthe Hunt (*your email*) or Mark Carew (m.carew@uel.ac.uk).

If you would like to enter into a prize draw for the chance of winning a camera, please leave a contact email address below. Note that this email address will not be associated with the data you have provided on this survey. We will contact the winner of the prize draw, after data collection for the study has been completed.

Contact email address for the prize draw: _____

Please press the >> button to end the survey

APPENDIX 3: PHOTOVOICE INTERVIEW GUIDE

- Explain purpose of interview and what it would involve
 - Participants will have been asked to select 5 photographs that they have taken to discuss
 - Revisit consent
 - Thanks for participation
1. Initial exploratory questions
 - a. Occupation
 - b. Disability
 - c. Relationships
 2. You were asked to take photographs over the past 3 months- what was that like? What did you learn in taking these photographs?
 3. Choose a photograph that you took that you want to talk about. Tell me about this – what is this photograph about? What does it remind you of about yourself?
[Explore narrative in relation to sexuality, sexual and reproductive health as appropriate]
 4. Continue with other photographs
 5. If not specifically discussed in relation to photographs, then include the following specific questions:
 6. What feelings do you have about yourself as a sexual person?
 7. What sorts of things or people influence your feeling in this way?
 8. Have you had any sexual relationships? If so, what has your experience been like? If not, what are the reasons why not?
[ask probing questions about possible stigma or barriers to full intimacy etc]
 9. What have your experiences been of using sexual and/or reproductive health care services?
[ask probing questions about access, staff attitudes etc]
 10. What have been the most important relationships for you?
 11. Anything more that you wish to add?
- Revisit how data will be used (report, journal articles, educational material)
 - Revisit consent
 - Ask whether they would be happy to be contacted again to discuss their interest in participation in the book/ video – if they are positive, get email address and telephone number

APPENDIX 4: PARTICIPANT INFORMATION SHEET AND CONSENT FORM



UNIVERSITEIT • STELLENBOSCH • UNIVERSITY
jou kennisvennoot • your knowledge partner



STELLENBOSCH UNIVERSITY AND UNIVERSITY OF EAST LONDON CONSENT TO PARTICIPATE IN RESEARCH

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

You are asked to participate in a research study conducted by:

- Prof Leslie Swartz; Department of Psychology, Stellenbosch University, South Africa
- Dr Poul Rohleder; School of Psychology, University of East London, United Kingdom
- Mr Mussa Chiwaula; Director General of the Southern African Federation of the Disabled
- Ms Stine Hellum Braathen; SINTEF Technology and Society, Department of Health Research; Oslo, Norway.

You were selected as a possible participant in this study because you are an adult person who has a physical disability.

1. PURPOSE OF THE STUDY

The study will investigate the attitudes that people have about the sexuality of people with physical disabilities in South Africa through the experiences of people with physical disabilities themselves. The study aims to use what is learnt from participants to produce educational materials to raise public awareness about disability, stigma and sexuality. The study will also produce academic articles. The study has received ethical approval from the University of Stellenbosch in South Africa and the University of East London in the United Kingdom.

2. PROCEDURES

If you volunteer to participate in this study, we would ask you to do the following things:

1. You will be asked to attend a workshop in the Western Cape with other participants (8 men and 8 women) and some of the researchers mentioned above. At this workshop, you will be asked for your views about the topic and possible questions that we could ask able-bodied people about their attitudes towards people with disabilities. Your input will be used to create a survey questionnaire about disability and sexuality which will be used as an online survey which able-bodied people will be invited to complete.
2. At the workshop we will discuss your involvement in a study to explore your own personal experiences about sense of sexual self, intimate relationships, and engagement with sexual and reproductive health care. We will ask you to share your experiences by taking photographs of things that *represent* or *remind* you of these experiences or thoughts. You are not asked to take photographs that are of a sexual nature. You will be provided with a camera which you can use, or you can ask a friend or carer to take the photos on your behalf. We will also ask you to keep a personal diary of your thoughts and experiences over a period of up to 3 months.

At the workshop we will provide you with detailed information and instructions about what we expect.

3. Approximately 3 months after the workshop, we will ask you to take part in an individual interview in Stellenbosch/ Cape Town, at a place convenient to you. We will ask you to bring the camera and photographs you have taken, and also your personal diary. We will use these to help us talk about your experiences and thoughts in an individual interview which will last approximately 1 hour. Women will be interviewed by Ms Stine Hellum Braathen and men will be interviewed by Dr Poul Rohleder or Prof Leslie Swartz. The researchers will be assisted by an interpreter if relevant. With your permission interviews will be recorded so that a research assistant employed on this project can transcribe the interviews. Once interviews are transcribed, the recordings will be deleted.

After you have taken part in the above, we will then ask you if you would like to do the following extra things:

4. After the interview, we will ask you for permission to use some of your photographs, and some of what you shared in the interview to produce a book of people's stories, which will be freely available on the internet. This book will be used to educate people about the experiences of people with disabilities. We will not use your names in the book. We will discuss this book with you, and show you drafts of what we have written and ask you for your input. You do not have to agree to be part of this book if you do not want to.
5. One man and one woman will be invited to consider whether they would like to take part in a second interview, which will be video recorded, and will be used as a video clip for educational purposes. You do not need to do this if you do not want to. We will ask you about this at a later stage and you can decide then.

Note: If you agree to do points 1, 2 and 3 this does NOT mean that you have to do points 4 and 5 – we will ask you for permission later so that you can think about whether you want to participate in this or not.

3. POTENTIAL RISKS AND DISCOMFORTS

The study asks you to talk about personal and sensitive matters related to your sense of yourself as a sexual person, your experiences of sexual and intimate relationships, and experiences of sexual and reproductive health care. We will not ask you explicit questions about sex. We know that these are topics that some people find difficult to talk about, and you may feel embarrassed or shy, or even maybe upset talking about some of these things. You do not have to talk about anything that you do not want to share with us. You can also decide to end the interview at any time.

4. POTENTIAL BENEFITS TO SUBJECTS AND/OR TO SOCIETY

You will not receive any direct benefit from taking part in this study. What we have learnt from this study will be used to raise awareness among the general population about the experiences of people with disabilities and sexuality, sexual health and stigma.

5. PAYMENT FOR PARTICIPATION

For your participation in the workshop and the interview, you will receive payment of R400 to cover the cost of your time and travel. This will be paid in two instalments – R200 at the workshop and R200 on the day of the interview.

6. CONFIDENTIALITY

Any information that is obtained in connection with this study and that can be identified with you will remain confidential and will be disclosed only with your permission or as required by law. Confidentiality will be maintained by means of removing mention of any names in the interview transcripts and saving all recordings and transcripts on password-protected computers used by the researchers. We will ask that any photographs you take do not include the faces of people that can be identified.

We will use what we have learnt from all the interviews to write a report of the project to be presented to the funders (The International Federation of Applied Disability Research), for writing research articles in academic journals, present at academic conferences and produce educational material. We will not use your name in any reporting of results.

If you choose to agree that we can use your photographs and what you have shared with us during the interviews for the book, this may mean that people who know you, who read this book, may know it was you who said certain things. We will not use real names in this book, and you will get to see what we have written if we use your photographs and quotes from your interview. We will discuss this with you in detail later, if you choose to be part of this book.

7. PARTICIPATION AND WITHDRAWAL

You can choose whether to be in this study or not. If you volunteer to be in this study, you may withdraw at any time without consequences of any kind. You may also refuse to answer any questions you don't want to answer and still remain in the study. The investigator may withdraw you from this research if circumstances arise which warrant doing so.

You will get an opportunity to decide later if you want to take part in the book and/or an extra interview which will be used to create a short documentary video. Details will be provided after your interview, and you can decide then.

8. IDENTIFICATION OF INVESTIGATORS

If you have any questions or concerns about the research, please feel free to contact:

Dr Poul Rohleder, Department of Psychology, University of East London
Email: P.A.Rohleder@uel.ac.uk

Prof Leslie Swartz; Department of Psychology; Stellenbosch University, South Africa;
Email: lswartz@sun.ac.za

Mr Mussa Chiwaula, Director General of the Southern African Federation of the Disabled.
Email: mchiwaula@safod.net

Ms Stine Hellum Braathen; SINTEF Technology and Society, Department of Health Research; Oslo, Norway;
Email: stine.h.braathen@sintef.no

9. RIGHTS OF RESEARCH SUBJECTS

You may withdraw your consent at any time and discontinue participation without penalty. You are not waiving any legal claims, rights or remedies because of your participation in this research study. If you have questions regarding your rights as a research subject, contact Ms Maléne Fouché [mfouché@sun.ac.za; 021 808 4622] at the Division for Research Development.

SIGNATURE OF RESEARCH SUBJECT OR LEGAL REPRESENTATIVE

The information above was described to me by Poul Rohleder in English and I am in command of this language or it was satisfactorily translated to me. I was given the opportunity to ask questions and these questions were answered to my satisfaction.

I hereby consent voluntarily to participate in this study. I have been given a copy of this form.

Name of Subject/Participant

Name of Legal Representative (if applicable)

Signature of Subject/Participant or Legal Representative

Date

SIGNATURE OF INVESTIGATOR

I declare that I explained the information given in this document to _____ [*name of the subject/participant*] and/or [his/her] representative _____ [*name of the representative*]. [He/she] was encouraged and given ample time to ask me any questions. This conversation was conducted in [*Afrikaans/*English/*Xhosa/*Other*] and [*no translator was used/this conversation was translated into* _____ by _____].

Signature of Investigator

Date

APPENDIX 5: PHOTOGRAPHS FROM STAKEHOLDER'S CONFERENCE

Below are a selection of photographs of presenters, poster exhibition, and audience from the stakeholders' conference held in Cape Town in March 2017:

