



Disability and Sexuality: Stories from South Africa

4:00pm: Welcome
 4:30pm: Presentation
 5:15pm: Break and refreshments
 5:45pm: Film and discussion
 6:30pm: Performance by Unmute

Outline

- Welcome and background – Mussa Chiwaula
- What we did – Poul Rohleder
- Survey results – Mark Carew and Xanthe Hunt
- Interviews and next steps – Stine Hellum Braathen
- (break)
- Film and discussion – Leslie Swartz

Background

The World Health Organisation (WHO, 2006) has developed a broad definition of **sexual health** which emphasises the importance of human rights and wellbeing:

“...a state of physical, emotional, mental and social well-being in relation to sexuality; it is not merely the absence of disease, dysfunction or infirmity. Sexual health requires a positive and respectful approach to sexuality and sexual relationships, as well as the possibility of having pleasurable and safe sexual experiences, free of coercion, discrimination and violence” (WHO, 2006; pg. 5).

Background

- UNCRPD Article 25 - Health

Persons with disabilities have the right to the enjoyment of the highest attainable standard of health without discrimination on the basis of disability. States Parties shall take all appropriate measures to ensure access for persons with disabilities to health services that are gender-sensitive, including health-related rehabilitation. In particular, States Parties shall:

a.) Provide persons with disabilities with the same range, quality and standard of free or affordable health care and programmes as provided to other persons, **including in the area of sexual and reproductive health** and population-based public health programmes;

Why the research/project?

- There is an increased recognition that sexual health is a human right, yet, research evidence suggests that persons with disabilities may be generally excluded from living fully sexual and sexually healthy lives.
- One social barrier previously identified is the myth of asexuality; that is that persons with disabilities are assumed to be asexual, and thus not perceived as sexual persons.
- This is a topic for which there is a paucity of research, and which is of immediate relevance to broader health concerns, particularly HIV.

Project Aims:

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

Key issues the project seeks to address



- Sexuality as a sight of oppression and discrimination
- Myth of asexuality
- Barriers to accessing sexual and reproductive health care
- Increased risk for HIV

Partners

- **Dr Poul Rohleder**, School of Psychology, University of East London (UK)
- **Mr Mussa Chiwaula**, Director General of the Southern African Federation of the Disabled (Botswana)
- **Prof Leslie Swartz**, Department of Psychology; Stellenbosch University (South Africa)
- **Dr Stine Hellum Braathen**, SINTEF Technology and Society, Department of Health Research (Norway)
- **Ms Xanthe Hunt**, Department of Psychology, Stellenbosch University (South Africa)
- **Dr Mark Carew**, Research Assistant, University of East London (UK)



Funding

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Method:

Study 1: Societal attitudes survey

- Measuring dating beliefs; social distance; perceived sexual rights; perceived access needs to sexual and reproductive health
- Qualitative questions: Story completion; and word association

Study 2: Qualitative study

- Used Photovoice
- Individual interviews with 6 women and 8 men

Planned Outputs:

- Book
- Documentary film
- Website
- Journal articles and book chapters
- Conference presentations



Study 1: Survey

- Online survey advertised through newspaper websites; social media; student email lists at 2 universities
- Field workers collecting pen and paper responses
- Total 1990 respondents
 - Ages 18-76 (average age 26)
 - Approximately equal males and females
 - 45% Black; 40% White; 8.6% Coloured; 4.5% Asian; 1.8% other
 - 51.5% had a school leaving certificate

Survey results: Sexual rights

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

	People with disabilities	General population
capable of expressing sexuality	61.47%	72.49%
sexuality is a basic human need	66.21%	73.03%
should be allowed to have children	74.22%	74.38%

Survey results: Access to sexual health

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

	People with disabilities	General population
benefit from sexual healthcare services	61.80%	70.25%
benefit from reproductive healthcare services	59.04%	69.60%
benefit from sexual education services	60.26%	69.07%

Survey Results: Dating beliefs

QUESTION:

“Jane, who is non-disabled, meets John, 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, John tells Jane that he really likes her, and invites her to go out on a date the following weekend. How does Jane react to this? How might she respond to John?”, and “Why might Jane react in this way? What are her thoughts and feelings about the situation?”

Results: Dating beliefs – response dynamics



Inclusive attitudes

“[the non-disabled woman] feels excited to go out with him, as with any other boy” and “[the PWPd] is a possible romantic companion, and if they've gotten on well so far, why not pursue the relationship to see if he might be a compatible partner”.

Results: Dating beliefs – response dynamics



Pity and condescension

“[the non-disabled person] goes out with [the PWPD] for one date out of sympathy for him but unfortunately does not return his calls afterwards”.

Results: Dating beliefs – response dynamics



Need to overcompensate for disability

“If the conversation and [the PWPD’s] company were exceptional then [the non-disabled person] will certainly react positively and respond with the affirmative. If not, she can reserve her right to refuse [the PWPD’s] invitation”.

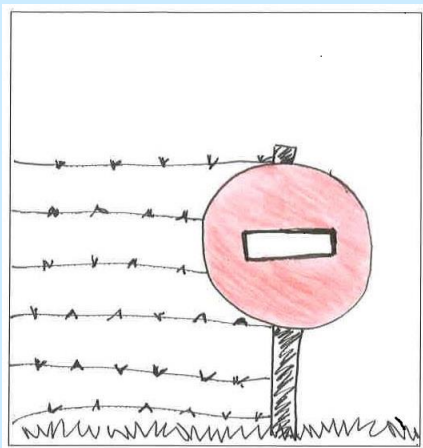
Results: Dating beliefs - reactions



Disgust

“[the non-disabled woman] might respond with disgust due to his disability and tell John it’s her reason not to pursue anything with him.”

Results: Dating beliefs - reactions



Disability an insurmountable obstacle

“[the non-disabled person] might have a problem with John's disability, perhaps the prospect of being intimate with [the PWPD] given his physical condition makes her feel uncomfortable. In this case, she may pretend not to like him although she does, because she is uncertain about the situation.”

Results: Dating beliefs - reactions



Sex concerns and desexualisation

“There might be a deal breaker in terms of disabilities, as in if she is paralysed from the waist down and does want someone sexually active then he wouldn’t want to date her, but at the least they would be friends”

Study 2: Photovoice Study

- Individual interviews with 8 men and 6 women during March/April 2016
- Use of Photovoice as an aid to generate personal stories about disability and sexuality
- Photovoice is a research method where participants are invited to take photos of things that represent their experience, and then talk about them.
- Photos, drawings, poems

Results: Themes from interviews with women



- Sexuality is seen as strongly connected to romantic love, relationships, building a family and being a mother;
- Many women feel that many men do not see them as sexual beings, because they think that they will not be able to have children and be good wives due to their disability;
- The women who had children had experienced that many people, including health workers, were surprised that a disabled woman could be pregnant.
- Some of the women had been told from when they were small children that they could not expect to ever be girlfriends, wives or mothers because of their disability.

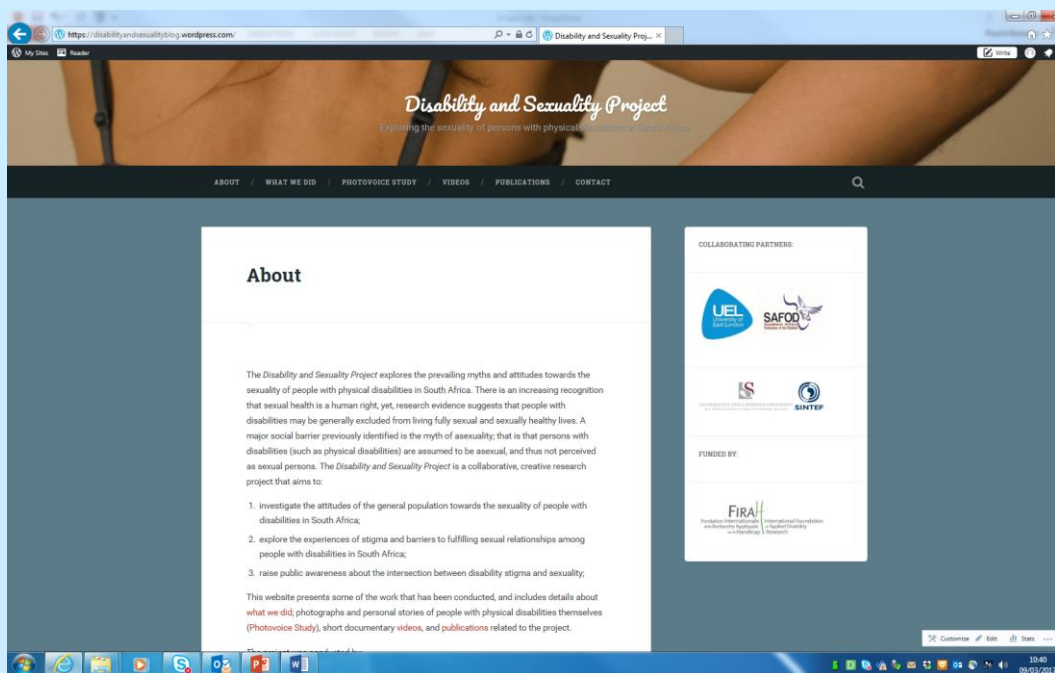
Results: Themes from interviews with men

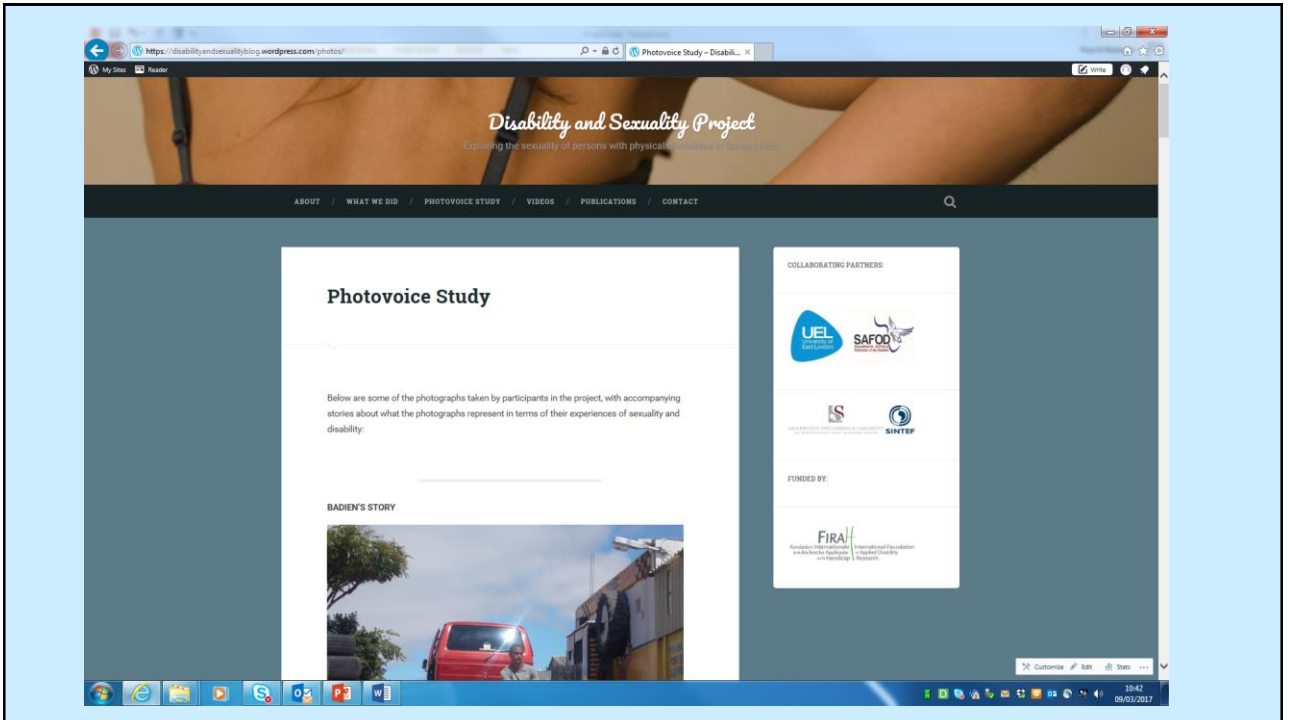


- Sexuality is seen as strongly connected to notions of masculinity, and being an “adequate” lover able to “pleasure” their female partner.
- Some men spoke about their struggles with being dependent and “passive” in a relationship and how this challenges their traditional, cultural beliefs about masculinity;
- Some men, and one young man in particular, spoke about how when meeting women for the first time, they felt like they tended to see their disability first rather than who they were as a person.

Next steps

- Website – photos, videos, papers
- Book
- Academic dissemination
- Future project – intervention study?





After the break...

16-minute film:

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