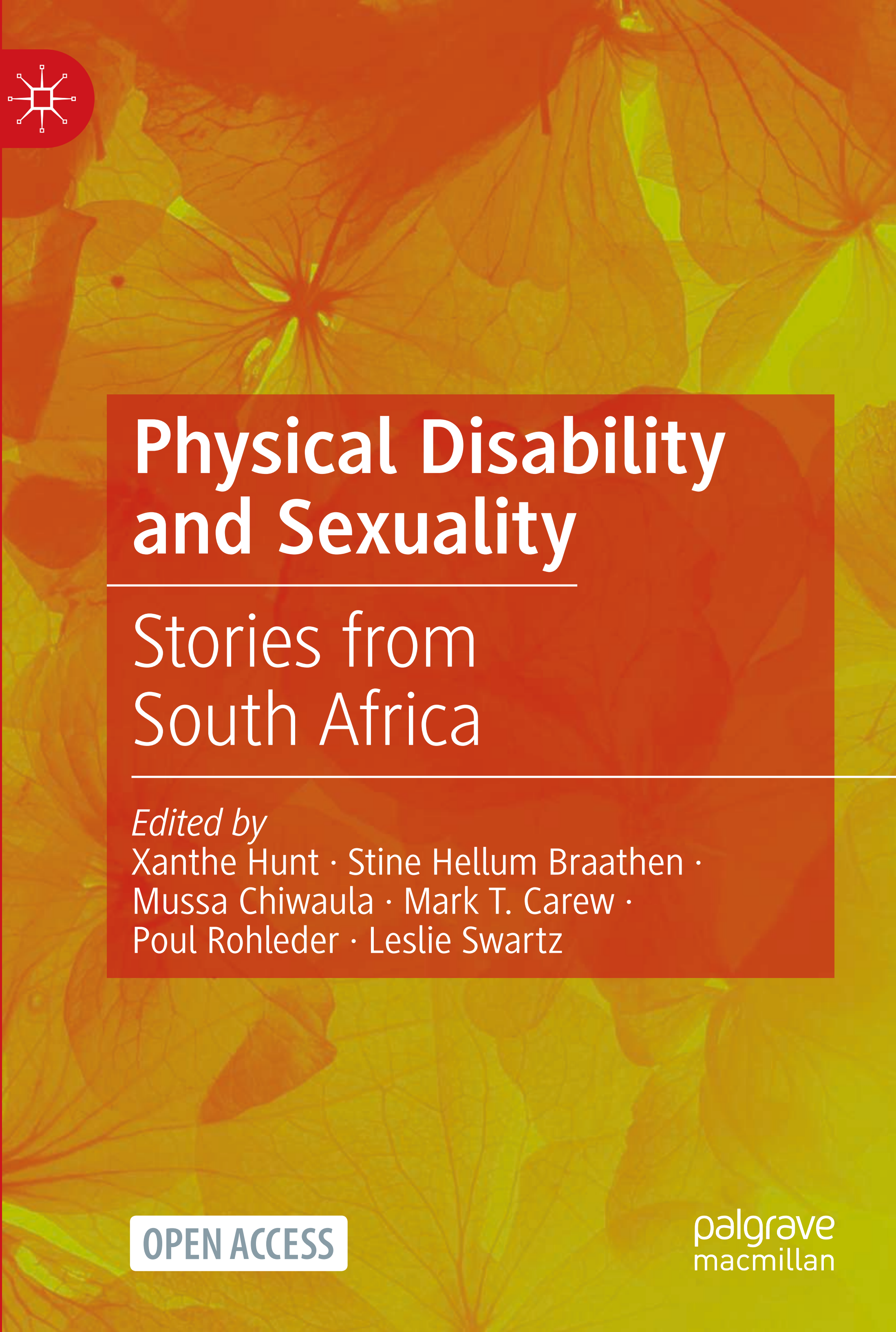

Physical Disability and Sexuality

Stories from South Africa

Edited by
Xanthe Hunt · Stine Hellum Braathen ·
Mussa Chiwaula · Mark T. Carew ·
Poul Rohleder · Leslie Swartz

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We were very fortunate that the project from which this book has been developed, was very fruitful. The editors of this book, together and with participants, published quite widely from the project. The project also formed the basis of the first editor's Ph.D. at Stellenbosch University in South Africa.

As such, we would like to note the following:

Parts of the material in this publication are based on Xanthe Dawn Hunt's published Ph.D. Dissertation (2017) "Through a different lens: Examining commonality and divergence in constructions and depictions of the sexuality of people with physical disabilities in South Africa". (online reference number 10019.1/104824).

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We would also like to note that this study was supported by the University of Essex, the University of Stellenbosch, and the University of East London, as well as the Southern African Federation of the Disabled, the South African National Research Foundation, and SINTEF in Norway.

Below, the reader will find an exhaustive list of the other publications drawn from this project, updated on the day upon which this manuscript was submitted to the publisher. We have been at pains not to repeat our past points in too much detail: the goal of this book is to provide a

knowledge synthesis and account of participant life experiences (previously unpublished) which is written simply and clearly, and in a form which is not too obviously academic.

As such, it is unlikely there will be much overlap in terms of our theoretical contributions to the literature below. However, in order to do justice to the participant narratives which form the backbone of this book, we do cover project content, some of which has been the subject of in-depth exploration elsewhere. Where relevant, reference is made to our other publications. We have also sought permissions to reuse certain content (including previously published quotes) from past publishers, and we are grateful to them for allowing us to share this work further.

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Carew, M. T., Braathen, S. H., Hunt, X., Swartz, L., & Rohleder, P. (2019). Predictors of negative beliefs toward the sexual rights and sexual healthcare of people with physical disabilities in South Africa. *Disability and Rehabilitation*.

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INTRODUCTION

All of the terms in the glossary, are contested. Debates about language are central to the politics of both sexuality and disability. In this very brief glossary, we define certain terms which we use in the book, according to how they are used in the book. However, almost all of the words below are the subject of disciplines and sub-disciplines, literatures, and disagreement, all beyond the scope of this brief section, and so the reader is encouraged to read further for a more comprehensive account of each term.

SEXUALITY

Sexuality refers, most broadly, to the quality of being sexual. It encompasses biological, erotic, emotional, and social feelings, and behaviours, and the manner in which people make sense of these. Sexuality, like many broad terms, is variously defined, its meaning depending greatly on the context in which it is used (Hunt, 2018). Trieschmann (1988) defines sexuality as "the expression of a sex drive, through sex acts, within the context of the personal identity of the individual: the maleness and femaleness of the individual that is so heavily influenced by past cultural learning, one's self-image, and the expectations that others have of the person" (p. 159). This definition is of utility, as it makes central the importance of the person–environment interaction in sexuality and acknowledges the role of culture, others, and self-image in determining an individual's sexuality (Hunt, 2018). However, Trieschmann's (1988) definition of sexuality does give primacy to sex acts, and so is usefully buttressed by the World Health Organisation's (2006) broader, and more inclusive, definition of sexuality as "a central aspect of being human throughout life [which] encompasses gender identities and roles, sexual orientation, eroticism, pleasure, intimacy and reproduction … influenced by the interaction of biological, psychological, social, economic, political, cultural, legal, historical, religious and spiritual factors" (World Health Organisation, 2006). This definition places less emphasis on heteronormative performances of gender and sexuality through sex acts, instead emphasising the numerous intersecting factors which influence an individual's conception of themselves as a sexual being and their behaviour in relation to sexual thinking and feeling.

Cisgender

The term cisgender refers to people who possess the reproductive organs and other biological sex characteristics associated with the gender (the social identity of man or woman) that they were assigned at birth (Aultman, 2014). The term cisgender came about due to a need to trouble the association between the identifiers man and woman, and the "natural" categories of sex. Cisgender people, as opposed to transgender people, have a gender identity which corresponds to their birth sex. By using the word cisgender as a prefix to man and woman, the term implicitly makes room to normalise the prefix transgender, for men and woman, severing the assumption that these identifiers can stand alone and denote a non-transgender identity (Aultman, 2014).

Transgender

Transgender people have a gender identity or gender expression that differs from the sex to which they were assigned at birth (Stryker & Whittle, 2006). This includes people whose gender identity is the opposite of their assigned sex (people who are referred to has trans men and trans women). However, transgender is also used as a term to reference people who do not identify as only feminine or masculine; including people who are non-binary (Richards et al., 2016).

HETEROSEXUAL

A simple definition of heterosexual will be used in this book, which is: people who are sexually attracted to people of the opposite gender. So, we mean, anyone who identifies as a man, who is attracted to people who identify as women, and anyone who identifies as a woman, who is attracted to people who identify as men (Association, 2008).

LGBTQ+

LGBTQ+ stands for lesbian, gay, bisexual, transgender, and queer/questioning (Griffith et al., 2017). There are various forms of this initialism, some of which entail more letters (denoting a broader array of sexual identities and orientations) or fewer letters (denoting an abbreviation of the full gender, sexual orientation and sexual identity spectrum). Commonly, LGBTQ+ is used to refer both to reference all topics pertaining to minority sexuality and gender identities, as well as to people who identify as any one of the identifications encompassed under the LGBTQ+ umbrella.

GENDER

Where the term sex is often used to denote the genital and biological differences between birth-assigned maleness or femaleness, gender denotes either of the two sexes (male and female), but with particular reference to the social. So, gender refers to the socially and culturally constructed differences between people of the category male and people of the category female, rather than biological differences (Oakley, 2016). There is a range of gender identities beyond man and woman, including non-binary people, Fa'afafine, Hijras, and Two-Spirit people. The term gender is also used more broadly to denote a range of identities that do not correspond to established ideas of male and female (Oakley, 2016).

FEMININITY

In this book, we use femininity to denote qualities or attributes regarded as characteristic of people who identify as women.

Masculinity

In this book, we use masculinity to refer to qualities or attributes regarded as characteristic of people who identify as men

Physical disability

In discussing physical disability, we adopt, most broadly, the operational definition of the United Kingdom's National Equality Act (Government of the United Kingdom, 2010); "a physical impairment that has a substantial and long term adverse effect on the person's ability to perform normal day to day activities e.g., walking, eating, going shopping" (p. 4). When we invited people to participate in the photovoice piece of the study upon which this book is based, we used this definition to help people self-identify as eligible. When we conducted a survey on attitudes to the sexuality of people with physical disabilities, we also used this definition. Despite the necessity of such an operational definition, there is also a need to think, briefly, about two broader ways of thinking about physical disability, both of which underlie this book. Firstly, consistent with the social model of disability, we align ourselves with the distinction between disability and impairment (Hahn, 1988; Shakespeare, 2006; Thomas, 2004). Impairment is a form of biological or physical difference, defined medically. Disability, on the other hand, is the social sequelae of inhabiting a world "designed" for people without impairments, when one has an impairment (the functional limitations one encounters when navigating a disabling social and physical environment) (Hahn, 1988). As Sherry (2007) notes, "the rationale for this heuristic distinction is to separate the experience of biological difference from the prejudice, discrimination and other negative social consequences that many disabled people experience" (p. 10). However, there is also a need to recognise disability as a social identity. To acknowledge that people with physical disabilities may identify as members of a heterogeneous group, who have certain experiences, both social and physical in common, is important in the present book. This draws attention to the social and personal dimensions of physical disability, which may be felt by people with physical disabilities, over and above experiences engendered by the interaction of their impairment with the broader social world.

PHOTOVOICE

Photovoice is a participatory action research method which uses photography as a means by which to gather data about a given topic with a group of research participants (hereafter, co-researchers) (Wang & Burris, 1997). During the course of a given research project, photovoice co-researchers use their cameras to record aspects of their daily lives relevant to the research question. During reflective sessions, led by the investigators, the co-researchers may use their photographs as a springboard from which to discuss and reflect on their daily lives and their experiences (Lal, Jarus, & Suto, 2012). This method of research allows not only for co-researchers to create, and share, their own visualised realities, but involves research "subjects" in the process of photography (Wang, 2003).

Photovoice puts co-researchers in charge of the representation of their own circumstances, and prompts them to "act as recorders and potential catalysts for change in their own communities" (Wang & Burris, 1997).

Photovoice allows for the generation of knowledge which is closely centred on the experiences of individuals and their interactions with the environment (Letts, 2003). Given the above-outlined importance of thinking about the environment when thinking about disability, this feature of the methodology was particularly appealing. Taking photographs is an activity which allows the creator to look both inward (thinking about what image they want to capture and what it will mean) and outward (being inspired by the environment to think about experience), and, in a project which is concerned with the interaction between inner and outer forces in determining lived experience, we selected photovoice as an appropriate methodology for exploring the experiences of sexuality of a group of people with physical disabilities.

A distinction must be drawn here between photovoice as defined and outlined by Caroline Wang and Burris (1997), and photovoice-type methods, such as those employed in the project upon which this book is based. Caroline Wang and Burris (1997) developed photovoice as a replicable, clearly defined, participatory action research tool. According to these authors, proper photovoice work entails several steps (for a clear summary, see Wang & Burris, 1997). However, prior to, and since, the work of these researchers, other photovoice-type research methodologies have been developed and employed across a number of contexts (Clark, 1999; Moletsane et al., 2007; Zecevic, Magalhaes, Madady, Halligan, & Reeves, 2010). These projects have in common the use of participant photography as a means of generating data. Yet, they vary greatly in their fidelity to the methodology outlined by Wang and Burris (1997). These deviations are often motivated either by constraints of the practical context (i.e. not having regular contact with the research team when transport costs are prohibitive), or ethical concerns in a given population (i.e. not using group work where there are privacy concerns).

The methods employed in the project upon which this book is based, will be outlined in due course.

Participants

We use the term participants in this book to describe people with physical disabilities who were recruited into the photovoice arm of the study on which this text is based. Although these individuals are also authors of chapters and narratives, when they are discussed in relation to the data which they generated during the project, we use the term participants. We use the term co-researchers when we discuss the academic contributions which some of the participants in the study in question, made to this book.

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CONTENTS

NOTES ON CONTRIBUTORS

Dr. Stine Hellum Braathen Research Manager, SINTEF Digital, Department of Health Research. Braathen has been doing research and published extensively in the field of disability studies in Norway and in southern Africa since 2004. She has been involved in several projects concerning sexual and reproductive health and disability/vulnerability.

Dr. Mark T. Carew is currently a Senior Researcher at Leonard Cheshire and an honorary Research Associate at University College London. Mark is a social psychologist by training, with eight years' experience researching disability, as well as other marginalised groups. His research interests within disability include sexual health care, stigma and discrimination, and the development of robust disability data mechanisms. Mark has published peer-reviewed journal articles, book chapters, and reports in these areas and has recently co-authored the book Disability and Sexual Health (Routledge, 2018).

Mussa Chiwaula is a disability activist with extensive experience in policy advocacy and analysis. He, with others, founded the Federation of Disability Organisations in Malawi (FEDOMA) where he served as Executive Director. He chaired the task force that spearheaded the development of the National Disability Policy, including lobbying and advocating for the enactment of the Disability Act. Mussa, who holds a B.Sc. degree in Community Development, now heads the Southern Africa Federation of the Disabled (SAFOD) based in Botswana. SAFOD is the leading

Southern African disability-focused network engaged in coordination of activities of organisations of disabled persons in Southern Africa. He is spearheading SAFOD in advocating for the mainstreaming of disability on the SADC development agenda. Mussa Chiwaula has been involved in many research studies on disability such as the SINTEF Living Conditions for Persons with Disabilities.

Dr. Xanthe Hunt is a Senior Researcher at the Institute for Life Course Health Research in the Department of Global Health at Stellenbosch University. In 2018, she received a Ph.D. from the Department of Psychology from the same university, for her work on the project on which this book is based, and for which she received the University's Chancellor's Medal. Her work spans public health, maternal and child health, and disability in Sub-Saharan Africa, and she is a consultant to the World Health Oranization for work related to disability in childhood.

Cleone Jordan is an alumna of the University of Cape Town. She is a researcher and activist whose mission is to work towards improving the lives of persons living with disability in South Africa. After sustaining a spinal injury in a road accident that resulted in quadriplegia, Cleone spent many years working in the disability sector at grassroots level. She has developed a nuanced understanding of the gravity of the isolation and many injustices faced by South Africans living with disabilities, such as exclusion from education, adequate housing, employment and community life. In July 2017, Cleone became the first person to be awarded a Master of Philosophy in Disability Studies with Distinction from the University of Cape Town. Cleone has been involved in the NGO sector since April 2011 and has recently teamed up with Afrique Rehabilitation and Research Consultants (ARRC). Cleone is also currently is engaged in studying for a Post-Graduate Diploma in Management Practice at the UCT Graduate School of Business.

Bongani Mapumulo is the Manager of the newly created Special Needs portfolio within the Stellenbosch University Student Representative Council. His most recent publication is in the book Transforming Transformation. His vision is to play a more instrumental role towards integration across gender and sexuality and most importantly making disability a transformation issue.

Dr. Vic McKinney is a disability activist, academic lecturer and researcher, and artist living in Cape Town. He became a quadriplegic paralysed from the shoulders down after being in an accident in 1987, aged 19. He lives in Cape Town with his wife, Emma, and two boys, Jamie and Benjamin.

Rosabelle Riese was born in 1955, and suffered from Polio as a child. She has been involved in Parasport since, 1977, an experience which she credits with helping her to come into her own. Rosabelle is a three-time Paralympian, and bronze medallist in air pistol. She has competed at numerous World Championships in table tennis, shooting and bowls. She still coaches and shares knowledge and skills with others, all of which stem from the wonderful experiences and satisfaction she has derived through Parasport. She is a proud mother and loves writing poetry.

Dr. Poul Rohleder is a Senior Lecturer at the Department of Psychosocial and Psychoanalytic Studies, University of Essex (UK). Prior to this, he was at the University of East London (UK). He is a clinical psychologist with research interests in sexuality and wellbeing. He is author (with Stine Hellum Braathen and Mark Carew) of Disability and Sexual Health: A Critical Exploration of Key Issues (Published by Routledge, 2018).

Professor Leslie Swartz is a clinical psychologist and distinguished professor of psychology at Stellenbosch University. He was the founding editor of African Journal of Disability and has published widely on disability rights and mental health issues with a focus on Sub-Saharan Africa.

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CHAPTER 1

Some Background, and a South African Study on Sexuality

Xanthe Hunt, Leslie Swartz, Stine Hellum Braathen, Mark T. Carew, Mussa Chiwaula, and Poul Rohleder

- 33 times lovestruck celebrities made us go "Aww" (msn.com/en-za)
- Can using weed affect my sexual performance? (timeslive.co.za)

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- Should local celebrities be encouraging people to find romantic partners on Linkedin and other professional networks? (news24.co.za)
- Is #MeToo casting a shadow on sexual pleasure? (iol.co.za).

These headlines were taken from home pages of major South African news sites on Wednesday 3 April 2019—the date on which we happened to be writing this introductory chapter.

Sex and sexuality seem to be everywhere—they are all over the media, a concern for everyone growing up, celebrated by some and condemned by others. It is not possible to open a newspaper or popular website without some discussion of sex. Though many people may say that sex is a taboo, the fact is that we cannot stop talking about it. According to Alexa.com (also accessed on 3 April 2019), which tracks website use, pornhub.com (a Youtube-like platform for pornographic videos) is the 27th most visited website globally, and 24th most visited website from South Africa. Many popular magazines aimed at men or women, or both, will regularly have tips for readers on how to be more sexy, or have more sex; many have columns devoted to people writing in with complaints about their sex lives (or lack thereof).

Sex and sexuality are not just matters of biology. When we use the term "sexuality", some might think of the physical acts of sex, or sexual orientation (e.g. being gay or lesbian), or about someone's gender or gender identity (e.g. being transgender or identifying as a man or woman or neither or both). In this book, we use the term "sexuality" to refer more

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broadly to the experience and quality of being sexual. The World Health Organisation (2006) provides a useful, broad definition of "sexuality" as:

> …a central aspect of being human throughout life and encompasses gender identities and roles, sexual orientation, eroticism, pleasure, intimacy and reproduction…influenced by the interaction of biological, psychological, social, economic, political, cultural, legal, historical, religious and spiritual factors. (WHO, 2006, p. 5)

As this definition suggests, the way in which we experience our sexuality, sexual urges, arousal and so on is very much shaped by what society and the cultural context that we are in understands about sexuality. Thus, society shapes the way in which our sexuality is expressed: we learn whether we are sexy, or not, in the eyes of others, and whether we are deemed fit to participate in sexual relationships. Very often, societal views involve expressions of power and control. We can see this, for example, in the many strongly held views that people in various societies may have about who should have sex with whom, how they should have sex, where and when they should have sex. We can see this when it comes to homosexuality, for example, where, in many parts of the world, homosexuality is regarded as an abnormality and abomination, punishable by law in some countries. At the time of writing this chapter, Brunei had recently brought in new laws bringing in death by stoning for having "gay sex". Meanwhile, in other societies, homosexuality is regarded as a normal expression of human sexuality, and—at the time of writing—Taiwan's parliament has recently legalised marriage between persons of the same gender. When it comes to sexuality, context, culture and social norms play a huge role, and as you will see, this role is not neutral, nor always rational or fair. In this book we also address gender and gender identity, but these are defined and discussed in depth elsewhere (see Chapters 4 and 6), as well as the more health-related aspects of sexuality, including sexual and reproductive health (see Chapter 8).

For people with disabilities, participation in sexual life is often complicated. This complication stems more from the attitudes of the world "out there" than the physical or psychological impairment of the individual. Social views about what is "normal" sexuality and what is not, what is acceptable and what is not, impact on how we view the sexual lives of people with disabilities. The sexuality of people with disabilities, including people with physical disabilities (with whom this book is concerned), has been a site of oppression and discrimination, based on many myths and misconceptions. Prevailing myths are, for instance, that people with physical disabilities are unable to have sex, experience less or no sexual desire, or lack the capacity for parenthood and should not baer children (Malacrida, 2009; Nguyen, Liamputtong, & Monfries, 2016). Additionally, societal understandings of masculinity and femininity, bodies and attractiveness, often lead to people with visible disabilities being seen as undesirable romantic or sexual partners (Hergenrather & Rhodes, 2007; Marini, Chan, Feist, & Flores-Torres, 2011). These sorts of attitudes represent social barriers excluding people with disabilities from full participation and enjoying fully sexual lives.

These attitudes also have implications for sexual and reproductive health (de Reus, Hanass-Hancock, Henken, & van Brake, 2015; Groce et al., 2013; O'Dea, Shuttleworth, & Wedgwood, 2012; Peta, 2017). Because of problematic prevailing attitudes, people with disabilities may be perceived as not in need of sexual and reproductive health care, or may not be able to access such care easily. Additionally, people with disabilities may be considered by some as vulnerable targets for abuse. These issues have negative implications for many people with disabilities in South Africa, a country with a high prevalence of human immunodeficiency virus (HIV), where the latest findings from the country's Human Sciences Research Council-published national household survey on HIV prevalence in South Africa (Leonardi, Bickenbach, Ustun, Kostanjsek, & Chatterji, 2006; WHO, 2001; WHO and The World Bank, 2011) indicate that people with disabilities (inclusive of all types of disabilities) may be at increased risk for acquiring HIV.

The adoption of the *Convention on the Rights of Persons with Disabilities (UNCRPD)* by the United Nations (United Nations, 2006), in 2006 formalised a new way of thinking about disability—the human rights approach to disability. Article 25 of the *UNCRPD* emphasises the need for government parties to recognise that people with disabilities have the right to the enjoyment of the highest attainable standard of health without discrimination on the basis of disability, including sexual and reproductive health. Governments are called upon to take all appropriate measures to ensure access for people with disabilities to health services that are gender-sensitive. The *UNCRPD* has been in place now for a little over a decade and some remarkable progress has been made in improving the rights of people with disabilities. Most countries in Southern Africa have ratified the *UNCRPD*. However, what remains to be achieved is the domestication of this human right instrument so that it becomes meaningful in terms of contributing to change in the lives of people with disabilities, including in respect to sexuality, and sexual and reproductive health.

In the spirit of the *UNCRPD*, awareness campaigns need to be developed and put in place in mitigating the falsehood that people with disabilities are, or should be non-sexual, and people with disabilities need to be enabled to access information regarding sexual reproductive health and HIV. This would give people with disabilities the ability to make informed personal decisions about all matters pertaining to their sexuality, as well as to their reproductive health rights, on an equal basis with people without disabilities.

Given the prevailing myths and misconceptions that exist, this book is intended to raise awareness of these issues, by drawing on materials produced from a research project exploring the experiences of some men and women with physical disabilities in South Africa, as well as on past research from around the world and on survey research conducted by the editors.

This book focuses on people with physical disabilities, because the research project which inspired us to write it focused exclusively on people with physical disabilities. The reason for this was that the project aimed to focus on exploring and challenging the myth that people with disabilities are less sexual than people without disabilities. Thus they are perceived by many people without disabilities to be asexual (even if they do not identify as such). In past research, this myth is more attributed to people with visible, physical disabilities, than other impairment types, and so our project, and this book, have concerned themselves only with physical disability.

The project also made use of visual materials (photographs and film) and so it made sense to focus on visible, physical disabilities, rather than other types of disabilities which may be less visible, or hidden.

This book, written co-operatively by academics, advocates, and people with physical disabilities who participated in our study, contains informative chapters about different topics related to physical disability and sexuality. The style and presentation of the book differs from a traditional research, theoretical or academic book in that it synthesises contemporary scholarship and theorising on disability and sexuality, with personal narratives and photographs. We have also tried to write it in language which is accessible to people who are not familiar with disability studies as a field.

Our intention, in doing this, is for the book to be of interest to both non-academic and academic audiences. The aim of the book is to provide you, the reader, not only with a research-based account of what impact disability has on the sexual lives of people with physical disabilities, or the impact of people without disability on the sexuality of people with disabilities, but also to provide this account from the personal, lived experiences of South Africans with physical disabilities themselves, so that you may know what these experiences are like from an "insider's" perspective. We hope that you will use this book to learn something new, and perhaps think about disability and sexuality, and indeed your own body and sexual self, in a different way.

Before we continue, we will pause to think about the various ways we can understand disability, and what it is. We will then tell you about the project that this book is based on, who the people involved are and what we did. Finally, we will provide an outline for the remainder of the chapters so that you have a sense of what you will be reading about in the rest of this book.

What Is Disability?

As sime as it may seem, the issue of defining disability is not a straightforward question, and it depends very much on where the experience of disability is located, from whose perspective and in which context. So, for example, would we say a person who makes use of a wheelchair is "disabled" because he or she uses a wheelchair? Or is he or she disabled because they cannot access a building because the way in is up a set of steps? A person who uses a wheelchair may be perfectly "able" to do many things, but may be "disabled" when they are excluded or prevented from doing other things. If that building had a ramp, the person using a wheelchair would then be "able" to enter and make use of the space, and so does the term "disabled" accurately describe them? Much of our understanding about disability often involves some sort of comparison to what is "normal". But what we regard as "normal" is not straightforward. "Normality" is shaped by contextual, cultural and individual experiences, beliefs and realities, and is a constantly changing concept. Thus, what is "normal" is not an absolute truth. So, for example, we have typically built buildings with steps leading up to the front door, because we have designed them around the needs of only those people who can walk up these steps, rather than use a ramp that is accessible to far more people. The steps do not have to be there; it is a choice to put in steps, rather than a ramp. This state of affairs is true for many things related to disability: disabling experiences are created by environments which are designed for people without disabilities. Disability is not inherently abnormal, but society is organised in such a way that makes it seem so.

You may still be confused. In fact, there is a lot of debate among theorists about how disability is to be understood. Two of the most frequently used models for understanding disability are the medical model and the social model. The medical model frames disability as being caused by some underlying biological or medical cause—a biological or psychological impairment caused by a disease or disorder. This can be represented in a diagram like this (Fig. 1.1).

In this model, disability is something that is located "inside" the individual, and can only be "fixed" by changing the underlying disease or disorder through medical intervention. Here, it is the body that needs to be "fixed".

In contrast, the social model of disability takes into account the role of the environment and sees the experience of "impairment" and "disability" as different. In this model, a person with an impairment experiences "disability" when he or she faces barriers to participation. This can be represented in a diagram like this (Fig. 1.2).

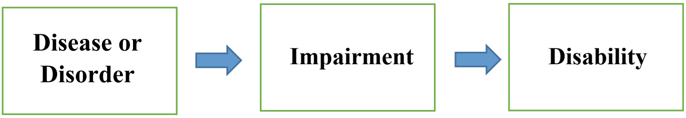

Fig. 1.1 A representation of the medical model of disability (Author's own)

Fig. 1.2 A representation of the social model of disability (Author's own)

In this model, disability is located in the environment, not the individual. Disability is diminished by making changes to the environment which allows people with impairments equal opportunities to participate. So, a person may have an impairment, but not necessarily experience a disability. So for example, let's take the experience of Mandla, below (we explain the use of names and pseudonyms later in this chapter). Here he talks about the changes that needed to be made to the physical environment at his work to make spaces accessible to him, so that he would not experience "disability".

Mandla's story

Mandla acquired a disability following a car accident in 2010. He became partially paraplegic. He can sometimes walk using crutches, and at other times makes use of a wheelchair. There had not been a person with disability employed at his place of work before, so the employers had to make adjustments to the physical environment to make the buildings and facilities accessible to him when he returned to work after his accident. Here he took a photograph of a ramp which was purposely built for him leading from the car park to the entrance of the building (see below section on "about the disability and sexuality project" for an explanation of where these photographs and personal stories come from). Mandla says:

> Ja, when I was doing these pictures…because I only took the ones for the parking, front and back…and some people asked me why are you taking pictures? Where are you going to take them? You know, they are scared you're going to take them to human rights and all those things. But I said, no, I'm taking these photos for my project. I'm trying to show what you have done for me. You've done a lot. You've made so many changes within a few months, which means you've accepted me from the first day I arrived at this point. And then when I came to you and said, listen here, I've got this plan, but I need to sit down and talk to you about it, then you said to the HR officer to come and talk to us about how must we make changes in this building for it to be accessible for you. I told them, firstly, there must be ramps. The first thing is the ramps. There must be ramps in this building. And then the toilets, there must be a disabled toilet as well in this building. And in terms of movement, there must be no place where I can't walk in because of the wheelchair. There must be no place whereby you say, no, this place is not accessible to wheelchairs. Because sometimes you're going to get visitors from outside coming here, wheelchair-bound people coming here, and then they will be stuck and what's going to happen then? How are you going to explain that? So I want you to make changes. The parking, there must be disabled parking because sometimes you get visitors driving cars. The other thing I must tell you, people who are physically disabled,

they can drive. You must know they can drive. Because cars can be made for people with disabilities. So if you've got a spinal cord injury and your legs can't work properly, you can still drive. There are automatic cars and everything. So they've made the parking. They just phoned maintenance and they came and just made the parking. And then the toilet, they had to revamp another toilet to be a disabled toilet. Ja, so many changes. And the gymnasium as well, they had to make a ramp there. So, so many changes in a few months. You see this ramp? If you look at it, it must look like this. You can see it was specially made as well, the ramp. There was no ramp. It was just the step. Now everyone is using this because it's next to the disabled parking. These two parkings are disabled parkings. So they had to revamp here again to make this thing accessible for me. You can see the wheelchairs can run smoothly here. Because you park here, and there's a disabled parking this side and that side. So if you park here, you don't have to push the wheelchair from the parking. You park here next to the entrance, then you just walk in there. You can see that it's me standing there.

More recently, theorists have stated that both the medical model and the social model are too simplistic, and pointed to the need to consider how these different aspects of a person's experience interact with one another. The biopsychosocial model, presented in the *International Classification of Functioning, Disability and Health (ICF)* developed by the World Health Organisation (2001), understands disability as both a social and medical construct, highlighting its interactive and dynamic nature. This model acknowledges both individual health status as well as personal and environmental (cultural and contextual) factors in the disability experience (Shisana et al., 2014). So, in this model, disability is not only seen as located in the individual (like the medical model) or the environment (like the social model), but as an interaction of both. Nico's photograph and story below can help us to understand this a little. Here Nico talks about the freedom that he sees people without disability have to move and do what they want. He talks about how some of his freedom is taken away by social attitudes (the environment), but he also talks about how his impairment makes it difficult for him to participate without help and assistance, and so he cannot be feel fully "free", regardless of how the environment is arranged. He captures here how it is both his body and the environment in interaction that makes him experience disability (Image 1.1).

Image 1.1 An accessible parking lot ramp built for Mandla by his employers, following his acquiring a physical disability (Photo by Mandla)

Nico's story

Nico is a 25-year old man who acquired a disability following an accident when he was 18. The accident left him semi-paraplegic, requiring him to use a wheelchair. Here he took a photo of a female friend in a pool, which to him represents his experience of (not having) freedom. Nico says:

> …this everybody desires. Besides the water, but look at the picture itself and the lady; that you call freedom, in the sense that people who are physically disabled, they also need the freedom to express themselves. They need to bind with non-disabled people for the understanding-wise. Sometimes people are always judging and criticising those who don't look in a perfect manner for them. The reason why I took this is also just to show the reflection of the water and this lady going into that water freely; jumping in that water. They can do what they want to do in the water. But now talking about myself again – I like to give an example of myself – standing at the edge of the water and telling myself I can go in that water, but how am I going to balance myself? Who is going to assist me? Who is going to guide me through this whole process where that non-disabled person can

Image 1.2 A photo of a woman in a white t-shirt swimming in the ocean, taken by Nico (Photo by Nico, previously published in the chapter by Hunt, X., Swartz, L., Braathen, S. H., Carew, M., Chiwaula, M., & Rohleder, P. (2019). Shooting back and (re) framing: Challenging dominant representations of people with physical disabilities in South Africa. In *Diverse voices of disabled sexualities in the global south* [pp. 33–53]. Cham: Palgrave Macmillan)

> contribute his or her help according to my need? That is what I'm working with here. (Image 1.2)

DISABILITY IN SOUTH AFRICA

This book highlights the experiences of people with physical disabilities in South Africa, because that is where we conducted our project. The stories depicted here are not reflective of the experiences of all people with physical disabilities, nor of all South Africans with disabilities, and only provide a small snapshot of life for some people with physical disabilities in a certain social, political, economic and cultural context. The stories of people with disabilities from the global South, however, are particularly important, and so that is why our study was not done in a high-income country. Across the world, the large majority of people with disabilities live in low- and middle-income countries, most of which are located in the global South (WHO & World Bank, 2011). However, much of the research on disability, sexuality, sexual and reproductive health is conducted in North America and Western Europe (Braathen, Rohleder, & Azalde, 2017; Carew, Braathen, Swartz, Hunt, & Rohleder, 2017). Thus, less is known about the sexual lives of people with disabilities from the countries and regions where they are most likely to live.

In a 2014 report based on the 2011 South African census data (Statistics South Africa, 2014), 7.5% of South Africa's population was reported to have a disability; an estimated 2.87 million people, 59% of whom were reported as female and 41% male. People with disabilities in South Africa have significantly lower levels of education and less access to education than people without disabilities. People with disabilities are also more likely to be unemployed and earn generally lower levels of income than people without disabilities. Thus, people with disabilities in South Africa are among the most marginalised groups, as is the case throughout the world.

This is attributable to social and economic structures being exclusionary of people with disabilities, and not to some limitation of people with disabilities themselves. If you only read one sentence in this book, read this one.

Now, while this book is based on the experiences of South Africans, it is worth noting that it has some limitations in relation to its origins; the people presented in this book are not representative of the majority of South Africans. Because the participants in our study volunteered themselves to write and take photographs and share their stories, we did not have control over the types of people who were included, nor did we try to take this control. As such, we have a group of men and women who all identify as heterosexual and cisgender, when we know that some South Africans with physical disabilities also identify as LGBTQ+ and transgender. Our participants also identify with a variety of ethnic, cultural, religious and socio-economic backgrounds, but as a small group they are not representative of the demographics of the country as a whole. Their stories are invaluable, and their value lies not in their representativeness of demography, but, rather, of emotional and social experience. Their stories may not always include insights with South African specificity, and as Southern researchers, the editors of this book are careful not to make any demands of participants to perform Southern-ness, when the stories they wanted to share were somewhat universal.

Still, as editors, we would like to highlight the necessity of future work on the topic of sexuality and disability in the country. This could usefully also create a platform for the voices of people from other ethnic, cultural, and socio-economic backgrounds, and other geographic areas, as well as other gender identities and sexual orientations. The value of research like this is in diversity and representation; so more work is always needed.

About the Disability and Sexuality Project

As noted, this volum has been produced from a research project that the editors of this book conducted between 2015 and 2017. The project was funded by the International Foundation of Applied Disability Research (www.firah.org), and one of the editors was supported by the National Research Foundation of South Africa (NRF). The project was developed from the existing work of the editors, who have previously done research or development work on disability, inclusion and health. The project was then run, in part, by the first editor of the book, whose Ph.D. concerned certain aspects of the research (see the Foreword for details).

The *Disability and Sexuality Project* explored prevailing myths and attitudes towards the sexuality of people with physical disabilities in South Africa. As mentioned above, a major social barrier for people with physical disabilities to live full sexual lives is the belief that people with disabilities (such as physical disabilities) are asexual (even if they do not identify as such), and are thus not perceived as sexual people. Asexuality is a valid sexual identity; but like any other, it should not be imposed on people from the outside, and it is the imposition with which we are concerned. The *Disability and Sexuality Project* was a collaborative, creative research project which aimed to:

- 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, as well as facilitators of, fulfilling sexual relationships, as well as other aspects of sexuality, among people with disabilities in South Africa; and
- raise public awareness about the intersection between disability stigma and sexuality.

As a research project we adopted the method of “participatory action research”, which is an attempt to do research not *on* the people being studied (in this case people with physical disabilities), but rather *with* them; with their active participation in designing the study and collecting data and reporting on findings. In doing so, we are trying to do research in a way that also takes *action* to promote inclusion and bring about change. It also foregrounds those who are experts in the topic (people with physical disabilities) in work concerning them. This book is one of the project’s products. So what is participatory action research?

Participatory Action Research

There are many ways in which to do participatory action research. Participatory action research does not refer to a specific method, but rather an approach to research. In such an approach, the aim is to generate knowledge and create actions on issues that affect people or communities, by means of a process of participation with the very people or communities it seeks to benefit (Kagan, Burton, & Siddiquee, 2008). In this approach, research is conducted as a team effort, not just by a team of researchers and academics, but with multiple partners, including stakeholders and research subjects. In this approach, research is done by researchers “working alongside the primary sources of knowing” (Goodley & Lawthom, 2005, p. 136). Furthermore, the aim is not just to conduct research for the sake of learning something (i.e. generate knowledge), but also to do something with that knowledge that brings about some social change (i.e. take action).

Participatory action research developed in various parts of the world, including South America, the United States of America (USA) and the United Kingdom (UK), as a way of addressing social problems and social inequalities. For example, in the 1940s in the USA, participatory action research was adopted as a way of investigating intergroup relations in real-life contexts, in order to generate understanding and bring about improvements in the lives of Indigenous Americans (Collier, 1945). In the UK, participatory action research developed as a means of responding to the social and mental health problems caused by the aftermath of the Second World War (Rapoport, 1970). In South America, the educationist Paulo Freire (1972) has been a very influential writer in participatory action research. He argued that learning can only take place when there is active dialogue between multiple parties, sharing ideas and points of view.

Lewin (1946), one of the early developers of participatory action research as an approach, described it as a cyclical process of inquiry and learning. In such a process, initial exploration of an issue will inform the planning of action steps to be further taken. The learning that takes place as a result of those first action steps then further informs the development of new action steps. Thus, through a process of learning, taking action, evaluating the results of that action, and taking further steps, change can start to occur. Important in this process is that multiple stakeholders have input at all these stages, rather than just the research team. Ideas, issues and action steps are explored collaboratively with all partners (both researchers and other stakeholders).

Participatory action research involves the active participation of stakeholders. However, "participation" can mean many things, and can include just sharing information, or consulting on issues of importance, to deciding and acting together on what should be done and how to do it. A useful way of thinking about degrees of participation is to think about it along two different axes (Kagan, Burton, Duckett, Lawthom, & Siddiquee, 2011):

passive participation <<< >>> proactive participation
low commitment <<< >>> high commitment.

So, with research related to issues of disability, people with disabilities may "participate" as members of an advisory board, which we could think of as a relatively low level of participation (passive participation) with minimal commitment. Where people with disabilities act as equal partners in the research process, this would be a high level of participation with maximum commitment.

Participation was a key feature of the *Disability and Sexuality Project* from the very start. The editors of the book comprised the core research team, which included academic researchers as well as stakeholders from civil society (from the Southern African Federation of the Disabled). The core research team consisted of members with disabilities and members without disabilities. As a core research team, we led on the design, planning and implementation of the research project, the collection and analysis of data, and the dissemination of findings. However, we also invited the active participation of the research "subjects", thirteen South African men and women with physical disabilities. In the book we use the term "participants" to refer to the people with disabilities we interviewed, but this does not imply that they were passive subjects being studied, and in this book, many are co-authors.

What We Did

The project adopted a mixed method design, using both survey and qualitative individual interview methods for collecting data. We got ethical approval to conduct the research from the University of East London (in the UK) and Stellenbosch University (in South Africa). The project involved two complimentary studies:

Study 1: A Survey of Societal Attitudes

An online survey was developed to explore the knowledge, attitudes and views of the "general" South African population about physical disability and sexuality. The survey included questions measuring prevailing myths about disability and sexuality, and attitudes about the sexual and reproductive health and rights of people with physical disabilities. In Chapter 2 we presented some results of this survey study.

There are many ways in which to design a survey questionnaire, but what was important in putting together a questionnaire about disability and sexuality was not only designing a questionnaire that had sound research principles, but that also reflected what persons with physical disabilities themselves identify as important areas to focus on. At the start of the project, we held a participants' workshop, where 18 people with physical disabilities who had expressed an initial interest in participating in the project took part. At this workshop, the *Disability and Sexuality Project* was presented, and the project aims and objectives were discussed. The workshop included a session on thinking about the survey to be conducted, generating ideas for what sorts of questions should be asked, and how. This had to be discussed in the form of a dialogue between academic researchers, who had particular sets of knowledge about how research surveys should be designed, and non-academics, who may have had strong ideas about what should be asked, but did not necessarily have the knowledge about how good survey questionnaires should be designed. What proved useful was for the core research team to give a presentation about designing surveys and the various forms of questions that could be included (e.g. questions that invited scored answers on a scale from 1 to 7, questions that invited an open reply, or questions that invited respondents to provide a "yes", "no" or "not sure" answer).

Participants could give ideas about what kind of topics to cover. One key decision made as a result of this dialogue was to make the survey open to responses from people with disabilities themselves. At first the core research team had thought of doing the survey only amongst respondents without disability. However, at the workshop, participants reflected on how people with disabilities themselves may hold prejudiced views about other people with disabilities or other types of disabilities.

The survey was made available as an online survey (using Qualtrics as the host site) and a paper questionnaire, and was translated into four of the most commonly spoken languages in South Africa: English, Afrikaans, isiXhosa and isiZulu. We ran the survey during 2016, and received a total of 1990 responses from South Africans from all walks of life. Of these, 125 respondents reported having a disability, while 1865 respondents reported being South Africans without disability. The demographic characteristics of the respondents are depicted in Table 1.1. It is worth noting that—while we included race as a category of optional identification for

Table 1.1 Demographics of survey respondents

	People with disability only (N = 125)	*People without disability only (N = 1865)*
Age range	18–76	18–59
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
Self-identified 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

respondents—we did not conduct any analyses by self-identified racial "group". We included racial identification to get a sense of whether our sample was at all representative of the demographics of the country, and the demographics of the country are based on a national Census which utilises racial categories (although the validity of doing so is debated). However, race was not relevant for, nor the proposed subject of, any of our subsequent analyses, and nor was language.

Survey studies are useful in that they collect specific data across a broad range of respondents. A survey provides numerical data which can be explored for statistical trends, as well as qualitative data that can be explored for themes across all responses. However, survey studies do have limitations. One key limitation is that although surveys enable the collection of data from a broad range of respondents, this is often at the expense of detailed, subjective responses about individual experiences. The survey was a useful way of investigating societal attitudes across a large number of respondents, but it would not have been a useful way of capturing the personal experiences of people with physical disabilities themselves. To do this latter work, a different method for collecting data was needed which would allow participants to make their own decisions about what personal stories to share.

Study 2: The Experiences of People with Physical Disabilities

After attending the participants' workshop, a total of 13 participants (six women and seven men) agreed to be interviewed about their personal experiences of sexuality and relationships as a person with a physical disability. This is an intensely private topic, so it was important that this was done in a sensitive way, respectful of what the participants felt comfortable sharing about themselves. As a core research team, we suggested using Photovoice as a method for inviting participants to tell their stories.

Photovoice (first developed by Wang & Burris, 1997) is a method of generating research data that is participatory, because it allows the person being researched to set their own agenda about what the topic of exploration is by facilitating the expression of their personal stories and meanings. Photovoice involves participants taking or using photographs as a way of recording aspects of their daily lives and experiences relevant to the issue being investigated. These photographs then act as material for eliciting personal narratives during a research interview. The participants become co-researchers in that they are invited to act like journalists to their own personal lives and experiences; creating and sharing their own recorded, visualised realities. Photovoice allows for the generation of research knowledge which is centred on the personal experiences of individuals and their interactions with their social and physical environment (Letts, 2003).

The six women and seven men who took part in this study were each given digital cameras. At the participants' workshop, a discussion session was dedicated to this Photovoice study and what each person was invited to do. The participants were invited to use other media, if preferred, such as drawing or writing. The participants were given three months to collect photographs or other material, after which they would then be interviewed individually. This activity invited participants to reflect upon their past and present experiences. With matters of sexuality, they were invited to take photographs that represented or were symbolic of their experiences and their feelings and thoughts about their sexual identity. They were not asked to take explicit photographs, but rather photographs that were symbolic of or represented their personal experiences (like the ones included earlier in this chapter). Thus, this process invited the photographer to look both inside themselves (by thinking about what photo they wanted to take and what it meant to them) as well as look outside for inspiration for what would capture that meaning or experience. Photovoice thus involves an interaction between the internal self and the outside world. This also echoes the very nature of social and intimate relationships—the self in relation to the other.

At the interview, participants were asked to bring a selection of up to five photographs (or drawings or other material), which then formed the basis for discussion during the interview. The topic was sexuality, relationships and sexual health. However, instead of the interview having a pre-determined set of questions that each participant was then asked, each interview was different, focusing as it did on the individual's unique personal experience and history.

The aim of the interviews was to generate research data which could then be analysed. However, as participatory action research aims to achieve, the purpose is not just to collect data for the sake of it, but to also take action: to do something with that data. The photovoice interviews elucidated a lot of rich material and images, which we could then use as a resource to do advocacy for change. We will include some of what we learned in these interviews in the remaining chapters of this book.

In addition to these two studies, we also produced a short, 16-minute documentary film about disability and sexuality in South Africa, featuring four of the participants who took part in this project. We have created a website on the project, which features some of the work that has been done, including the film and some of the photographs that were taken. The website is: www.disabilityandsexualityproject.com. Go and have a look!

Outline of the Book

We have included some of the personal stories, photographs, drawings and poems which arose from the project, in this book. We have also written the chapters with some of the participants as co-authors. In publishing the personal stories of the participants we worked with, we sometimes name individuals that speak or are being referred to. Typically, in research, pseudonyms tend to be used when reporting on results, in order to protect anonymity and confidentiality. However, in taking a participatory research approach, our participants are also co-researchers and co-authors and so they made their own choices as to whether they wanted to use a pseudonym (to protect their identity) or use their real names. In this book we use the names that participants have chosen and agreed to be used (whether actual name or pseudonym).

Chapter 2—Disability and sexuality: In Chapter 2 we will explore some of the myths and misconceptions that exist about the sexual lives of people with phsycial disabilities. We look particularly at the myth of asexuality, and we report on data from the survey study showing whether this myth exists in the views of South Africans without disability. We also look at the kinds of stereotypes about people with physical disabilities that survey respondents used. The chapter then looks at how this myth of asexuality means that many young people with physical disabilities are excluded from sexual health education, may be vulnerable to sexual abuse and exploitation, and generally feel excluded from the world of dating and relationships. We draw on existing research knowledge, as well as the pictures and personal stories of participants in our research project.

Chapter 3—Cleone's story: In this chapter, Cleone, a project participant, writes about how acquiring a disability in her early adulthood impacted on her sense of femininity and sexuality. Cleone was a model prior to acquiring a physical disability and she writes about attractiveness and the body, and her journey to reclaim her sense of femininity and sexuality.

Chapter 4—Disability and femininity: In Chapter 4 we will explore the intersections of disability and femininity. We will look at how disability influences the way women with physical disabilities are viewed and view themselves as sexual beings, using a combination of background literature and qualitative data from the photovoice study described above. We have also included pictures, written texts and stories produced by some of the female participants on the project.

Chapter 5—Rosabelle's story: In this short chapter, Rosabelle, one of the project participants, writes a personal story about how sport had a positive impact on her self-confidence, body image, and ultimately her sense of sexuality.

Chapter 6—Disability and masculinity: In Chapter 6 we will explore the intersections of physical disability and masculinity. We will look at how physical disability influences how men are viewed by others, and how men with physical disabilities view themselves as masculine and as sexual beings. We also look at the influence of culture on masculinity in the South African context. We draw on existing research knowledge, as well as the pictures and personal stories of some of the male participants in our research project.

Chapter 7—Bongani's story: In this chapter, Bongani writes about growing up with a physical disability in a Zulu family, as well as in the context of a "special school". He reflects on what disability has meant for his developing sense of himself as a young man, his sexuality and relationships, and his wishes for the future.

Chapter 8—Sexual and reproductive health: In Chapter 8, we will investigate some of the social (e.g. negative attitudes about sexuality and parenthood) and structural (e.g. inaccessible health care facilitates) barriers that people with physical disabilities face toward leading a pleasurable, safe and healthy sexual life. We do this by presenting an accessible review of the existing research literature, a summary of relevant survey evidence, and the use of the personal stories of our participants.

Chapter 9—Vic's story: In this chapter, Vic, a project participant, writes about getting married and becoming a father after having acquired a serious physical disability in an accident. He writes about how he and his wife underwent IVF to have two children. He also writes about the at times inappropriate reactions and questions from others about his wife's pregnancy and his sexuality.

Chapter 10—Reflections on the project: In this final chapter, we will reflect on the project and what has been learnt. The chapter also includes reflections from the participants themselves about what their experience has been in taking part in the project.

A Note on the Politics of Voice

The group of people who are editors of this book make up a diverse group. Some of us are men, some women, some identify as having a disability, some do not. Some identify as LGBT, some do not. We are also diverse in terms of where we live (half of us live in Africa, half do not), our heritage and countries of origin, and our "race" or skin colour. Most, but not all, of us are academics and researchers, and all of us are committed to disability inclusion globally, but with a special interest in African issues. However, we are not the same as our participants and we cannot speak for them. We cannot speak about "disability" as a whole—we all have our own limited experience. One of the key lessons of disability activism is that nobody can or should speak on behalf of anyone else. As far as possible, people should speak for themselves, and should not be spoken about—instead everyone should be part of the conversation. In putting this book together, we have tried to work according to this principle, and so, unusually for a research project, we have people who were being researched actually writing some of the material themselves. We are proud to work in this way. But it is also important that we are clear that we, as the editorial collective, made key choices about this book, and how to put it together—we have designed the book and edited it. We cannot avoid the fact that we have shaped the book, that we are often speaking about people, and that our perspectives are not the only ones. We hope that readers will think critically about this issue and will engage with us on it and all other issues.

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CHAPTER 2

Physical Disability and Sexuality, Some History and Some Findings

Stine Hellum Braathen, Mark T. Carew, Mussa Chiwaula, and Poul Rohleder

Introduction

How does a man or a woman who is paralysed and uses a wheelchair have sex? Do people who have physical disabilities have different sexual needs and desires than people without disabilities? Is sex and sexuality

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a different experience when your embodiment changes following an acquired disability? Why are there so few “sex symbols” in popular culture who are people with physical disabilities?

In this chapter we look at some of the myths and assumptions that many people without disabilities hold about the sexuality of people with physical disabilities. We look at what societal attitudes there may be concerning sexuality and disability, and what this means for people with physical disabilities and their sexual lives. We present some of the findings from the survey and interview study mentioned in Chapter 1, and some of the photos and personal stories of project participants.

DISABILITY AND SEXUALITY: MYTHS AND MISCONCEPTIONS

The Assumption of Asexuality

People in society, including health professionals, hold many shared views about the sexual lives of others. Many people hold ideas about what sorts of sexual beings other people are, whether they can or ought to have sexual relationships, and with whom. Research and anecdotal reports suggest that people without disability hold many incorrect assumptions about the sexual lives of people with disabilities (Hunt et al., 2017a, b, 2018). For example, people without disability may see a person who uses a wheelchair as incapable of having sex, and so they are assumed to be asexual. In disability studies, this has been written about as the “myth of asexuality” (Milligan & Neufeldt), and seems to be quite a prevalent assumption that people without disability have about people with physical disabilities (Carew, Braathen, Swartz, Hunt, & Rohleder, 2017; Rohleder, Braathen, & Carew, 2018). Asexuality itself is not a myth—some people identify as asexual—but for people with physical disabilities, they are merely assumed by others to be non-sexual, and even to have little interest in sex and intimacy, when for the vast majority of people with physical disabilities this is not true.

These assumptions by people without disability also include stigmatising and even oppressive attitudes and views about physical disability itself. As we saw in the first chapter, one can understand what is meant by “disability” not only in terms of bodily or psychological impairment, but more importantly to be a result of societal exclusion of people with various impairments (Goodley, 2016). One obvious example of how this happens is in terms of widely held misperceptions about the abilities of people with physical disabilities, for instance that being in a relationship with someone who has a physical disability means having to take care of them (Marini, Chan, Feist, & Flores-Torres, 2011).

People with physical disabilities are often subject to stigma and may be seen as possessing characteristics that are undesirable to others (Hunt et al., 2018). As such, people with physical disabilities are often on the receiving end of patronising behaviour and pity from others, especially where the cause of the disabling characteristic is perceived as uncontrollable (e.g. as the outcome of an accident rather than an addiction) (Goffman, 1997).

In the introduction, we spoke about impairments and disability, and the difference between the two. Impairments themselves are often seen as abnormalities and defects that need to be prevented and avoided. In the past this often resulted in the sterilisation of people with disabilities, particularly women. Men and women with physical disabilities were sterilised so as to prevent them from having children with physical disabilities, and in many cases in the past, this sterilisation was forced (Park & Radford, 1998; Tilley et al., 2012). Scholars refer to this as "sterilisation abuse" (Roy, 2010). Sterilisation of people with disabilities is not just a thing of the past; it is still practiced today, but more likely in cases where the person has an intellectual disability, rather than a physical disability.

However, even if sterilisation is not used today as a way of controlling the sexual and reproductive lives of people with physical disabilities, there are still strongly held views in society about whether people with physical disabilities can and should have children, and so they may be viewed as asexual, not just because they are assumed as incapable of having sex, but actually because some individuals without disabilities feel that they *should not* have sex, because they cannot or should not have children (Cuskelly & Gilmore, 2007; Gilmore & Chambers, 2010). The story of some of the participants who share narratives in this book describe experiences of being viewed as non-sexual, and Pride (see Chapter 4) and also notes that others doubted whether she should or could be in sexual relationships, marry, and have children. Vic, in Chapter 9, discusses others' attitudes to his wife's pregnancy, which also reflects this dynamic.

In recent decades, however, things *have* improved for people with physical disabilities in this area. Some research suggests that attitudes towards the sexuality of people with physical disabilities are nuanced and many may be positive, too (Hunt et al., 2018). As mentioned in Chapter 1, international policies and guidelines, like the *United Nations*

Convention on the Rights of People with Disabilities have ensured that the rights of people with disabilities are brought to attention (United Nations, 2006). Characters with disabilities, including physical disabilities, appear more in television programmes and movies in a broader array of roles, and are not only depicted narrowly as they were in the past (Milligan & Neufeldt, 2001). The improvement of attitudes towards physical disability will also be helped by continuing efforts from governments and businesses to make all aspects of society accessible to people with disabilities.

Evidence from our survey suggests that simply having the opportunity to interact with people who have physical disabilities is likely to combat negative attitudes towards them (Carew et al., 2019), including if this contact is virtual in nature (e.g. watching people with disabilities through media like the Paralympics; Carew et al., 2019). However, there is also evidence to suggest that this is primarily the case when the nature of the interaction is positive. If the nature of the interaction is negative, contact can, in fact, emphasise and increase stigmatising attitudes towards people with physical disabilities (Paluck et al., 2019). Despite the gradual positive societal change in past decades, many assumptions and stereotypes about disability still exist.

We have talked here about the myth of asexuality of people with physical disabilities, and of course we do not mean that *all* people without disability think this of people with physical disabilities. The question is: How prevalent is this myth?

In the research that was carried out in South Africa which informed the writing of this book (see description in Chapter 1), part of the work we did was a survey study, conducted in order to measure the views held by South Africans without disability about the sexuality of people with disabilities. Of the total 1990 respondents to the survey, 1865 people identified themselves as being without disability, and for analyses concerning people without disability's attitudes, we examined their responses. Concerning their views about the sexuality of people with physical disabilities, the survey revealed some clear differences between what views were held towards people with physical disabilities when compared to views held towards people without disability. The survey contained questions about respondents' beliefs about the sexuality and sexual rights of people with physical disabilities and the (general) population who are without disability. Respondents were asked to indicate what percentage of people with physical disabilities the following statements applied to:

Table 2.1 Percentage of (1) people with physical disabilities and (2) the general population to whom the following statements apply

	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
Benefit from sexual health care services	61.80	70.25
Benefit from reproductive health care services	59.04	69.60
Benefit from sexual education services	60.26	69.07

1. The percentage of 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 same questions applied to. The results are in Table 2.1, which is reproduced from an article which we published in the journal *Reproductive Health Matters*.[1]

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[1] The journal article in which this figure was published, Hunt, X., Carew, M. T., 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, is an open-access article, and so no permission was required for the reproduction of this figure.

Table 2.2 Percentage of (1) people with physical disabilities, (2) the general population, who identify as…

Percentage who identify as	*People with disabilities*	*General population*
Asexual	29.97	25.23
Bisexual	21.21	27.69
Gay or lesbian	23.12	32.12
Heterosexual	61.58	65.20

From this table we can see that respondents without disability, on average, felt that these statements about sexual rights and sexuality applied less to people with physical disabilities than to the general population without disability. So, for example, respondents, on average, felt that 61.47% of people with physical disabilities are capable of expressing sexuality compared to 72.49% of the general population without disability being seen as capable of expressing their sexuality. When we did a statistical analysis of these responses as a group measure, we found that these percentages were mostly significantly different (Hunt et al., 2017a). This means that in our sample, people with physical disabilities were viewed as less sexual and having fewer sexual health needs and rights than people without disability, though this does not mean that this pattern necessarily exists elsewhere (e.g. in the entire South African population).

We also asked respondents to indicate what percentage of people with and without physical disabilities identify as asexual, gay or lesbian, bisexual or heterosexual. The results are presented in Table 2.2.

The important thing to note in the table above is that respondents assume more people with physical disabilities to be asexual than people without disability. Furthermore, fewer people with physical disabilities are assumed to be gay or lesbian, heterosexual or bisexual than people without disability. These are assumptions that respondents without disability in our sample have; that does not mean that they are truths. What these findings show, however, is that people without disability tend to assume that physical disability somehow negates sexuality.

Stereotypes About Disability

Related to the assumptions about sexuality discussed above, many people without disability hold various stereotypes about people with physical disabilities. Stereotypes are sets of characteristics and personal qualities that are seen as shared by members of a social group and consequently attributed to individuals based on their perceived membership of that group (Brown, 2011). For example, a commonly held stereotype of British people is that they have what many refer to as "a stiff upper lip". This stereotype assumes this characteristic of British people, regardless of whether it is accurate.

People with physical disabilities have often been the subject of a number of problematic stereotypes, particularly by portrayals of disability in the media (e.g. films, books, TV shows; Rohleder et al., 2018). These portrayals include where a person with physical disability is portrayed as a kind of "freak" or as some kind of medical oddity (Condrau, 2007; Garland-Thomson, 2009). Popular disability stereotypes are not always negative at face value. Sometimes they can be well meaning, as in cases where people with disabilities are portrayed as inspirational people who have overcome hardships. These portrayals are sometimes referred to as the "supercrip" (Grue, 2016; Shakespeare, 1994)—the heroic, brave person with disability who has achieved greatness, or achieved something that is to be admired. However, the damage arises when stereotypes—even ones which could be seen in a positive light sometimes—are used at the expense of 'normal' representation. Over and over again, people with physical disabilities are portrayed in limited and limiting ways, rather than as real, complex characters. Common stereotypes are that people with physical disabilities are seen as weak, helpless and incompetent (Crawford & Ostrove, 2008), or that they are not "real" or "whole" men or women (Fine & Asch, 2018; Nario-Redmond, 2010), or as gendered as men and women without disability.

If you, reader, were asked to state three words or traits that come to mind when thinking about a man or woman with a physical disability, what would come to mind? Obviously, everyone is different and has had a different experience with people with physical disabilities.

Some of you may have a friend, partner or family member with a disability. You may even be a person with a disability yourself. So, the words or traits that come to mind may accurately portray the person that you know. But if you do not really know someone with a disability and you think in general terms, where do your ideas come from? What shaped them? In our survey study (see Chapter 1) we wanted to find out what some of the stereotypes are that people without disability have about people with disabilities in South Africa. We asked respondents to state three traits or words that came to mind when (a) thinking of a woman with a physical disability, and (b) a man with a physical disability.

Fig. 2.1 Stereotypes for men (Author's own)

What we found was striking, and similar to what has been found by another research study conducted in the United States of America (Crawford & Ostrove, 2008). In our survey, respondents without disability described men with physical disabilities most often in terms such as strong, funny, insecure, shy and determined. We have reported these findings extensively in an article in *Disability & Society.*[2] Similarly, women with physical disabilities were seen as strong, insecure, shy, kind, and friendly. Below are two word clouds depicting the most common words used for men and women with physical disabilities. What do you find interesting about what you see here? Were your words included in these word clouds? (Figs. 2.1 and 2.2).

There are many ways of interpreting what these words mean, but what we can see is some similarity in words used to describe both men and women (Hunt et al., 2018). We see stereotypes depicting both men and women with physical disabilities as withdrawn and dependent, Supercrips, nice guys/girls, angry/irritable and aloof, and asexual. These findings are

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[2] The findings from this work were first reported in a journal article: Hunt et al., (2018). Withdrawn, strong, kind, but de-gendered: non-disabled South Africans' stereotypes concerning persons with physical disabilities. *Disability & Society*, 1–22. We have requested permissions to recount our findings here. The request is Taylor & Francis order number 4604730263839.

Fig. 2.2 Stereotypes for women (Author's own)

interesting not only because they reveal the content of stereotypes about people with physical disabilities, but also because they are so similar across genders: usually, stereotypes for men and women differ along a gendered line, but for people with physical disabilities, many of the stereotypes were the same, regardless of whether the target of the stereotype was male or female. This seems to suggest that people with physical disabilities are seen as less gendered than people without disability, evidence also of the desexualisation of people with disabilities (Hunt et al., 2018). Overall, the stereotypes cited by our survey respondents seem to reflect gender-neutral disability stereotypes, rather than gender stereotypes. This seems to provide evidence that physical disability seems more salient than gender in terms seem to reflect gender-neutral disability stereotypes, rather than gender stereotypes. This seems to provide evidence that physical disability seems more salient than gender in terms of salience in stereotype activation: people without disability are likely to stereotype people with physical disabilities according to their disability status prior to their gender (for a similar conclusion see Vilchinsky, Werner, and Findler [2010]). Thus, people may see the disability first and foremost before seeing the man or woman. This is also a point made by many participants interviewed in our qualitative photovoice study, for example Bongani (see below).

What People with Physical Disabilities Experience

In our qualitative interviews with people with physical disabilities (see description of study in Chapter 1), many spoke about the various stereotypes and assumptions they faced from people without disability. For example, Mandla, a man who had acquired a physical disability as an adult in 2010, talked about how women tended to regard him as incapable of having sex, and thus not a "real" sexual partner:

> 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?" I said, "that's the problem with you people, when you look at people with spinal cord injuries, people with physical disabilities, you still have that mindset of saying that they can't have sex, they can't do this or they can't do that. That is your big mistake. We can have sex. We can live a normal life like everyone. So that thing must come out of your mind."

For some, these messages were received from childhood, with family members regarding the child with a physical disability as not suitable for future marriage and intimate relationships. In the next chapter, Martha's story speaks about this. Similarly, Khadija, a middle-aged, woman who was born with disability spoke about how her family always viewed her as asexual, and not able to get married and have intimate relationships, and expectations which she said that they, as a traditional Muslim family, had for other girls:

> For the family it's like, I'll never get married… 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.

Of course, having a physical disability does mean that there may be some difficulties with sexual functioning. Depending on the type of physical disability, a person may experience a lack of physical sensation that allows them to enjoy penetrative sex or be able to perform sexually in that way. For example, men with paralysis may not be able to get an erection, and may require medical aids to help with sexual performance. However, from our study it seemed a bigger barrier was the attitudes of many people without disability who assumed that sex is impossible for people with disabilities. For example, Sifiso, a 28-year-old man, who acquired a disability at the age of 23, says:

> …being disabled means that I can still do everything with the help of medicine, more especially when it comes to a sexual life. So, with the help of medicine I can be sexually active; with the help of medicine I can get babies. But other people, because they don't know, but only because they don't know, they think that, ah, he can't have sex. That's the first question in our society, they don't know what happens to a person who is using a wheelchair. They'll just assume that you have a waist problem and you can't be sexually active.

These assumptions, and being excluded in this way, can have a big impact on the psychological well-being of some people with physical disabilities. Furthermore, sexuality is often thought of as penetrative sex, but sexuality is much more than that. There are various ways of experiencing and expressing sexuality, including other forms of physical and emotional intimacy and touch, and companionship. For instance, the story of Pride and her photograph below tells about her experience of loneliness as a result of her sexuality being questioned by others.

Pride's Story

Pride is a 42-year-old woman who has lived for a long time with a physical disability as a result of polio. In her interview, she spoke about how her peers at school would dismiss her and tease her as being someone who could not have a boyfriend:

> I also wanted to be loved, to belong, to be appreciated. But people couldn't understand. I remember, the first time I was at high school now, and then the boys would follow me. And then I was with this boy and this boy heard that thing about me, and then the other one would pass and say, "oh, I don't think that disabled people can have boyfriends." But that would come to my heart also.

She went on to say how she experienced that men would want to try and have sex with her just to see whether indeed she could have sex. She said:

> …along the way some of the guys would just say, "no, I'm not interested in this one, I just want to test if she is sexually active or if she can do that."

As a result she felt that men would use her as a “test” just to see if she was capable of having sex or not. This left her feeling very vulnerable to abuse and exploitation, and she has decided to live a single life. However, this has meant that she is lonely. She explained:

> I’m still alone now. I don’t have a child. I don’t have a boyfriend. I’m just by myself. I don’t want to be hurt now. I had many disappointments, so now, no, it’s enough. I’ve had enough. That’s why I told myself, no, if God wants me to be like this, then it’s fine. I had dreams as a woman. I also wanted to get married and have children and have my own house. I wanted to be like that, but it never happened. I have my own car and my own house. I only have my house now and the car, that’s all. There’s no one next to me. There’s no shoulder to cry on. You need company at times. But now I don’t want someone who is going to come to take advantage of me at the same time.

What we see in Pride’s story is that sexuality to her is much more about love and companionship than it is about the act of sex alone. Yet, because for others sex acts are a point of entry into, or something which comes part and parcel with, reomantic relationships, and sex is something Pride has negative experiences of, she struggles to develop a real, meaningful intimate relationship and express her sexuality in a manner which works for her.

Excluded from Sex Education

We learn about sex and sexuality in our childhood and adolescent years. Typically, we are taught about sex and sexual health at school. Maybe our parents teach some of us about sex or give us a book to read about it. These days we also learn about sex and sexuality (positive and negative things) on the internet. For the most part, society understands that educating adolescents about sex, relationships and sexual health is important and necessary. When it comes to children and adolescents with disabilities, however, people’s views about this differ. A lot of research from all over the world has consistently shown that young people with disabilities receive less sexual health education than their peers without disability (Nario-Redmond, 2010).

There are various reasons for this. Research has shown that in countries throughout the world, people with disabilities receive less education overall than the general population. WHO & The World Bank (2011, p. 206) has stated that:

> In general, children with disabilities are less likely to start school and have lower rates of staying and being promoted in school.

This pattern has been found for both low-income and high-income countries, and females with disabilities are most disadvantaged in terms of their access to education. Reasons why children with disabilities receive lower levels of education has a lot to do with society's understandings about the capabilities and productivity of people with disabilities. People with disabilities, including physical disabilities, may be regarded as less capable of working and of being productive in employment, and so their education is not prioritised. Research has shown that in poorer countries, where the chances for employment are few, parents may choose to focus their resources on educating their children without disability, who will have a better chance of getting work, than their child with physical disability (WHO & The World Bank, 2011).

Another reason may be that educating a child with a physical disability requires more resources and is thus more expensive than educating a child who does not have a disability (Groce, 2003), and so families may not be able to meet these costs. Further, in some countries, such educational resources are not adequately provided by governments. Schools are also typically built with children without disability primarily in mind, and so many schools are inaccessible to children with physical disabilities. In mainstream schools and classes, children with disabilities may often be regarded as a disruption to the learning of other children.

Not receiving adequate levels of education consequently reduces the chances of children and adolescents with disabilities receiving sex education in schools. Nevertheless, even where children and adolescents with physical disabilities are at school, they are still less likely to receive sex education than children and adolescents without disability. This may often have to do with the assumption held by parents and teachers that young people with physical disabilities are asexual, or are unlikely to get married or have relationships, and thus do not need sex education (Wolfe, 1997). Some parents and teachers may acknowledge that young people with physical disabilities can be sexual, but are afraid of their child becoming sexual or having sex, and so the topic of sex education is best avoided. Two South African studies have found that educators lacked the knowledge and—particularly—confidence to successfully teach sexuality education to adolescents with disabilities (Chirawu et al., 2014; de Reus et al., 2015). This increased the students' vulnerability to HIV (de Reus et al., 2015).

Further, while poorly delivering sex education to youth with physical disabilities increases risk and robs young people sex education of knowledge about safe sexual practices, and sexual and reproductive health, it also limits opportunities for the development of sexual confidence and self-esteem. Sex education is also important in terms of providing young people with an understanding about their own bodies, and giving them the knowledge and skills needed to make their own informed choices about sex and relationships, what the social norms are about sexuality and relationships, and to recognise abusive or exploitative sexual behaviours. Young people with disabilities are thus often excluded from these educational needs. In South Africa, the failure of sex education to provide for children with disabilities has been cited as increasing these students' vulnerability to HIV and other negative sexual health outcomes (de Reus et al., 2015).

Not only are people with physical disabilities often excluded from sex education, but disability as a topic is typically not included in general sex education. The emphasis tends to be on the "normative" able body. Thus, young people with disabilities may not always receive sex education which is specifically relevant to their own needs (WHO & The World Bank (2011), and young people without disability do not typically get a chance to consider disability as an experience in relation to sexuality within the sex education they receive. This separation may play a role in how people without disability, and people with physical disabilities, consider the possibilities of having relationships with each other.

SEXUAL VIOLENCE AND ABUSE

In Pride's story above, she refers to her fear of being taken "advantage of", sexually. Sadly, there is reality to this for people with physical disabilities. Research from around the world has indicated that people with disabilities, particularly women and children with physical disabilities, are more likely to be victims of abuse. By abuse, we refer to a variety of forms of maltreatment, including sexual abuse, physical abuse, emotional abuse, coercion, neglect, deprivation and abandonment (Seidel et al., 2014). Sexual abuse most often refers to rape, but also includes other forms of coercive sexual acts, such as unwanted touching or kissing, forced penetration, sexual exploitation, sexual harassment and unwanted exposure to sexual acts or materials (Hassouneh-Phillips & McNeff, 2005).

People with physical disabilities are vulnerable to sexual abuse both at home and outside of home. We use the term “vulnerable” here, but it is important to state that this does not mean that the “fault” or the “problem” lies in the person with a physical disability. Many people with physical disabilities may not *feel* or regard themselves as vulnerable people. Perpetrators, however, may perceive people with disabilities as targets, because they may not be able to defend themselves, or perpetrators may think they might get away with their acts more easily. People with more severe disabilities may require assistance with dressing, toileting and personal care, and so may be vulnerable to the unwanted touch of carers they may be dependent on. Tas’s story below is not one of abuse, but he speaks here about how he is dependent on others for intimate care and assistance and this requires a great deal of trust in carers. For Tas, this largely a positive experience. However, for many women with physical disabilities, this same reliance on carers comes at th ecost of vulnerabilitiy to maltreatment.

Tas’s Story

Tas is a man in his early 30s who acquired a disability at the age of 18. He spoke about the importance for him of being well-groomed and well-dressed to feel good within himself and feel attractive to women. He provides here a photograph of himself being shaven by a carer (Image 2.1).

Commenting on the photograph, he says:

> They are busy shaving me here. I believe that we as men should also be in charge of how we look, grooming ourselves, cutting our nails and being neat at all times. So, the photograph was a photograph of while they were busy shaving me. I always like to be cleanly-shaven. I believe that hygiene is something very important for me. Because like I said, we have to go the extra mile because there’s such a lot of things that are already against us as people with disabilities. And I also need to shave a lot because when I kiss my girlfriend she always complains about my beard and stuff like that. So, I can’t do it myself. I usually have to ask people to shave me and to groom me and stuff like that. To do my facial hair is no problem, but I

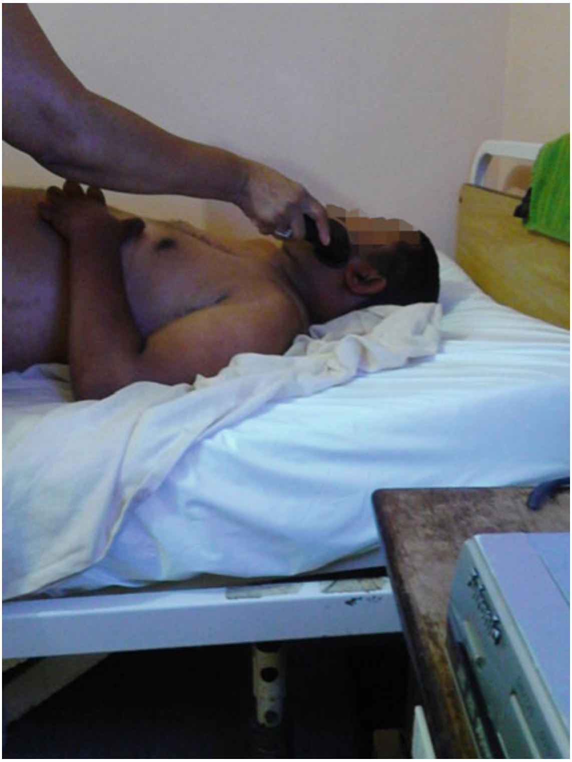

Image 2.1 Grooming (Photo by Tas)

> sometimes have difficulty asking people to shave my pubic hair. Okay, my armpit hair is still all right. It's mostly male nurses who work with us and it feels uncomfortable to actually ask a male nurse to shave your pubic hair or whatever. It's sometimes a tight situation because you don't know what position you put that male nurse in and what mindset he has or whatever. So, my facial hair and the hair under my armpits is okay. I like to be clean-shaven. Even with females at times, the boldness isn't always there. You need to have like a special relationship with the nurse to ask them to shave you there. Sometimes it is very difficult because you're letting people into a very personal space of yourself also. You know, sometimes what makes it really difficult is that you don't have any control over your body parts anymore. So, at times you will get an erection, which is quite unpleasant. I don't know why, but sometimes we still get an involuntary

> erection. That is also one of the things that we need to…you always need to have an open relationship with that person, so you need to talk about a lot of things that put you in tricky situations. People can think that you are a pervert or you're flirting with them. They wouldn't want to work with you or whatever. Or you think about things that they will go out and tell someone else about: I was shaving this guy now and he got an erection. So, we've got a lot of explaining to do and we've got a lot of things to do. Sometimes it's really difficult to get to a relationship where we can really trust people to talk all these things about themselves. It's really someone special that has walked a while with you and spent a lot of time with you.

Experiences of Dating and Relationships

Assumptions that people without disability may have about the sexuality of people with physical disabilities, and ideas about attractiveness and the body, make dating and relationships a potentially difficult experience for people with physical disabilities. Where a person with physical disability lives makes a difference. The issue of freedom of movement is key, and thus being within accessible environments with access to transportation helps the development of romantic relationships, as naturally it allows people with disabilities to engage in the full range of activities people without disability do (e.g. restaurants, cinema). In low- and middle-income countries, like South Africa, economic barriers and a dearth of free services to facilitate access, may make it all the more different for people with physical disabilities to freely engage in dating.

Another important factor in determining people with physical disability's capacity to date, is whether they may live in their own home or are residing in care. It may be the case that a young person with physical disability attends a "special school" or lives in residential care. People with physical disabilities who live in institutions typically do not have many opportunities to socialise with their peers without disability, to date and have relationships. The story of Bongani, a young man, in Chapter 7, includes his reflecting on what it meant for him to be an adolescent exploring his sexuality in a so-called special school.

Research from various parts of the world has shown that people without disability are sometimes reluctant to date or become romantically involved with someone with a physical disability, because they worry that it may be too awkward to socially interact, or the person with physical disability may require too much caregiving, or because they perceive people with physical disabilities as incompetent and dependent (Mueller-Johnson et al., 2014). Research has also shown that people without disability may have stereotypical views of people with physical disabilities as “weak” or “unattractive” (Fiske et al., 2002; Marini et al., 2011; Marini et al., 2013). Because of these assumptions and stereotypes, many people without disability report never having been on a date with someone who has a disability. For instance, a survey by a British disability charity found that just 5% of people without disability who responded to the survey had ever been on a date with a person who has a disability (Nario-Redmond, 2010).

In our survey study, discussed above, we also asked respondents to complete a story which involved a possible dating scenario between a person without disability and a person with a disability. The findings, report in the journal *Culture, Health and Sexuality*,[3] reveal largely negative attitudes of people without disability, to the idea of dating people with physical disabilities (Hunt et al., 2018). Respondents without disability perceived numerous barriers to dating a person with a physical disability, including that they thought the relationship would be socially stigmatised (Hunt et al., 2018). They also expressed anxiety and voiced concerns about the burden of care they believed such a relationship would place upon them; they thought that dating a person with a physical disability would be a lot of work. However, there was evidence to suggest that some people without disability held positive attitudes, and a few respondents were open to dating a person with physical disabilities (Hunt et al., 2018).

When it comes to meeting people, the participants that we interviewed in the part of our study with people with disabilities, often spoke about how they felt that others would see their disability first, and the rest of who they are as a person, second. Others would comment on the wheelchair or their disability, making them feel like they, as a whole person, were not fully seen. As a consequence, they felt that potential romantic partners often did not give them a fair chance to get to know

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[3] The paper which originally reported these findings is, Hunt, X., Swartz, L., Carew, M. T., Braathen, S. H., Chiwaula, M., & Rohleder, P. (2018). Dating persons with physical disabilities: The perceptions of South Africans without disabilities. *Culture, Health & Sexuality, 20*(2), 141–155. We asked for permission from the journal to refer to the findings contained in the paper, here. However, our analysis of dating beliefs uncovered in our study is detailed in that paper, and if you are interested about this topic, the paper will provide more detail. The request for permissions is Taylor & Francis order number 4594730091431.

them, and potentially develop feelings of attraction. For example, Bongani says:

> Someone who would greet me for instance, they would first mention my chair for some reason. Maybe they'll say: "that looks nice", or "is it expensive", or anything along those lines. Or, some sort of joke: "can I have a lift?" While maybe it's an innocent icebreaker, if you will, it does almost show that that is what they saw first and they decided to comment on that first, as opposed to saying, "hey", for instance. So to me that reflects that that is what they saw first, which, to me, it's almost like the disability comes before the person.

Similarly, Simon, a man in his 30s, talked about representing his disability in online dating:

> …once or twice that I [tried online dating], I'm not going to put a picture up there of my face or just face and shoulders – I put a picture up there of who I am. So I'll put a picture of my wheelchair on the beach or whatever. And I must say, from that I've had very little returns or replies. So I think the first thing people see is the chair, they don't see the person.

There may also be some beliefs, which our participants described as being part of the culture with which they identified, that discourage people without disability from dating or being in relationships with people who have physical disabilities. For example, Sifiso, a young man, spoke about how some people may believe him to be bewitched. He says:

> 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?

Naturally, there is not one single experience of being Xhosa, or of Xhosa culture; but Sifiso's experience of his own exclusion hinged on what he understood to be culturally determined ways of understanding physical disability.

Many of the participants spoke about how they felt unattractive and this was a barrier to meeting people, dating and having relationships, as they thought others saw them as unattractive. Typical statements from participants were:

> 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)

> Sometimes people are always judging and criticising those who don't look in a perfect manner for them. (Nico)

> My friends, long time before me, for them it was easy to have boyfriends. But for me it was not easy, because nobody wants to have a girlfriend who looks like this. (Pride)

For some participants, like Tas, reclaiming a sense of attractiveness was important, not only for self-esteem, but in an attempt to challenge the perception of unattractiveness from the public:

> 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. Because people generally have a mindset that people with disabilities are dirty, untidy and they don't really look good. So they have that kind of mindset that people with disabilities can't really dress up. When they see I've got a nice jacket on they will say, "ah, look at this jacket that you have on". So that also helps to change people's minds, that we still have a sense of style and we still want to look good and be accepted as normal people in society as well. (Tas; Image 2.2)

Concluding Notes and Take Home Points

So, let us return to the initial question posed in this chapter: “How does a man or a woman who is paralysed and uses a wheelchair have sex”? As we have seen in this chapter, and more broadly in this book, it is certainly possible, and for most people with physical disabilities, as with most people without disability, their sexual needs, wishes and desires are very much part of who they are. While sex is often thought of as penetrative, it is, in reality, practiced and experienced in a variety of ways. Thus,

Image 2.2 Looking good (Photo by Tas)

if penetrative expression is limited, there are still many ways of living out one's sexuality and to experience love and intimacy. However, as in many areas of the lives of people with physical disabilities, the attituedes of people without disabilities are influential, and can impact on the ability of people with physical disabilities to develop and express their sense of their sexuality.

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CHAPTER 3

Cleone's Story

Cleone Jordan

SKIN DEEP

When I was five years old I started to develop a skin disorder, vitiligo, which caused a lack of pigment in my skin. As I got older the vitiligo spread. I was teased relentlessly by an uncle who amused himself with the thought of my skin having different colours. He decided to call me chameleon. This had a huge impact on me and at a young age I realised I was different. In my pre-teens I became extremely self-conscious. The white patches on my face became more noticeable, especially in summer as my natural skin colour tanned. My knees and elbows were completely white and I received constant unwanted attention. I routinely covered up the marks with makeup. When I ran out of makeup I hid my skin by wearing thick stockings and long-sleeved tops even in the heat of summer. Over the years I saw numerous specialists and was treated with copious amounts of oral and topical medication which seemed to work as the pigment in my skin gradually returned. At the age of 13 most of the pigment in my skin had returned. For the first time, I didn't need to cover up and looked forward to having bare legs in summer like any other teenager. To make them look even better I decided to experiment with hair remover on my legs. I did not know any better. I did not know that

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the side effects of all the medication had led to a drastic thinning of my skin. I did not know that my skin was extremely delicate and sensitive to chemicals. I did not know that, as I removed the hair from my legs, I would be removing the skin as well. The ordeal caused third-degree burns which were excruciatingly painful. I was crushed. My legs were permanently scared. My self-confidence was non-existent and my self-esteem was at an all-time low.

As a Young Adult

Due in part to these early experiences and the resulting scars, I never thought of myself as beautiful in the traditional sense. I was too skinny, my breasts were too small, my hair too curly and my features unrefined. I was conditioned to think what a woman was supposed to look like, and I did not fit that mould. I was quiet, an introvert, extremely self-conscious and had low self-esteem. Even so, I understood that there was something about me that made me attractive to other people. I was well-liked, even popular and accepted in the "in crowd". I did modelling and was able to hide my insecurities with a mask of confidence that emerged through being a model, although the confidence was never truly there. This facade worked for many years. The make-up, hair, clothes and parties were wonderful - they hid the insecure parts of me and boosted my self-esteem even if only for a while. But I always questioned if there was more to life than the show, the fashion parade of life, the polished external that was required in order to fit in. As much as I needed this experience to feel accepted and validated as a person who was outwardly attractive, I recognised the superficiality of it all. There had to be more to life than what was seen at face value. It had to be more than just skin deep (Image 3.1).

Life Before Disability

My life before was very different. In the months and weeks before the accident, something changed in me that led me to see life in a new way, in a new light. I remember being so grateful for being alive and for having a healthy, beautiful body. I started really appreciating things that I had previously taken for granted, like being able to see the sky that was so blue and clouds and trees. I remember waking up in the morning and going outside to see the sky and being thankful for this. I remember taking deep breaths, filling up my lungs because it felt good. Trees and plants

Image 3.1 Skin (Photo by Amin Arnold Gray)

especially seemed to come alive to me and I realised how marvellous and splendid they were. To be able to hear music and birds and the rain, filled me with inexplicable gratitude. Everything seemed more beautiful than ever before, more alive. I paid attention to things more and more. I found a new appreciation for myself, for my body, that allowed me to see, hear, smell, taste and touch. I was falling in love with life, with myself and with humanity in ways I never thought possible. Life was different and I was different. I loved my long skinny legs that I once was so ashamed of, even with the scars. I remember sitting on the shower floor, wrapping my arms around my legs and kissing my thighs and knees, my heart bursting with appreciation for them; something I had never previously felt. I have never told anyone because it sounded stupid and ridiculous that I did that, but I did that. I kissed my legs because they were beautiful and I was thankful that they were mine. For the first time in my life I loved who I was and the body that housed me.

In the Early Years

I remember coming in and out of consciousness, and through my daze I heard them speaking. They said that if I survived I would be a vegetable. I couldn't understand what they meant and wondered what type of vegetable, and would I be tasty? I started thinking of my mother's cabbage stew, and then heard them say that my life wouldn't be worth living. It all came back to me; I was in a car crash and it was serious. That was 21 years ago. The journey since then has been a rollercoaster ride with heart-wrenching drops, exhilarating loops, ominous tunnels through dark mountainsides and everything in between.

I wondered, what was I meant to learn from all of this? It had to be terribly important because this experience that I was going through was life-altering, deep stuff, on so many levels. I had just started to embrace myself. I had finally come to terms with and appreciated the things about me that I thought were unlovable. I reached a place of spiritual awakening. And then everything changed. Did I really have to go through the test all over again? It felt like a test. How accepting of myself was I really, especially now, with a body that was unacceptable to many and perhaps even repulsive to some. In *Embodying the monster: Encounters with the vulnerable self*, Margrit Shildrick (2002) argues that bodies viewed as "disabled" are monstrous and that our reactions to them are ambivalent. I did not understand just how much the non-disabled norm informed my identity, and the vulnerabilities that would surface as a result of acquiring a physical disability.

Recovering from the physical injury was a long and tedious process. Recovering from the emotional and psychological trauma was in many instances more difficult and, in fact, masked, until symptoms of depression emerged. In the early years, my husband had been my only support. I felt lucky that I had someone who loved and cared for me the way he did and was often reminded by others how lucky I was. This reinforced the belief that people with physical disabilities do not have the luxury of being wanted, adored or loved, not only because of the burden they impose on others, but because of their bodily difference. Secretly, I was relieved that I was not single and did not have to go through the hassle of dating and hoping someone would find me worthy. I did not have to prove anything to anyone. When my husband left me, everything that I feared became my reality. For the first time since the accident I felt the full weight of my disability as there was no longer someone else to share the "burden" with. I had come face to face with my insecurities. I was not enough. I was not whole. I was a broken person. Only this time I could not hide the scars with make-up or clothes; they were there for the world to see.

Yet, going through the experience of awakening before the accident had in some way laid a healthy foundation for my emotional state. Even though I had reached the lowest point in my life, I understood that I had a lot of work to do and that rebuilding myself had to start with me. I had already started the journey of self-love and acceptance, so it was simply a matter of remembering and doing it again. But this proved extremely difficult, it was not like climbing back on a bike and riding. I recognised my own physical difference in terms of not having an able body and the set of limited physical abilities I had to work with. From that point on I only had myself to depend on, which was the real test. All the external stuff was gone; no more frills, nothing fake.

The internal dialogue was deep-rooted and relentless. Who was I—as a mother, as a partner, as a friend, and as a contributor to society? Who was I as a woman? My biggest fear after the breakup was that I would be alone, and that nobody would want to be with me, a divorced mother of two with a physical disability, let alone find me attractive. I knew that the non-disabled norm was what was valued and glorified socioculturally, because it is whole and is the standard which we aim to attain. My fears were very often validated by people closest to me. For example, a close family member was deciding what to wear to a wedding that we were both invited to. As we were talking, she stated without thinking, "at least you don't have to worry about what you would be wearing!" After realising what she had said, she then added, "Oh, you know what I mean!" It hit home because it was the truth. Why did I even bother? What was the use when, even though I understood that I would get everyone's attention because everyone notices the wheelchair, nobody would really *see* me. Was it only the external aspect of a person that held any value? Was it only the physical body and the clothes that adorned it? But why was that so important, and what about my essence as a person? Did that not count?

The body of an able-bodied person was what I had to strive to attain. If that was not achievable then I would try to live a life as close to what it was before disability. I started working again, which contributed to my financial independence. I became even more independent when I started to drive. I had a circle of friends, an active social life, had interesting hobbies and even dedicated time to charity. Yet, although my life had a semblance of normality, I was still reminded that my outward appearance wasn't what it should be. I was told to sit up straight; posture was indicative of confidence, as was the firm handshake—both of which I struggled to do as a quadriplegic. I had my own sense of style and felt most comfortable in jeans and t-shirts, never dresses, because I did not like to show off my legs. But I was often encouraged to wear sexier clothes and make-up, and to show my feminine side. When I did this, I was praised in a way that said, "See, if you do this you can be 'more' feminine, woman, sexy".

My hair was my crowning glory—thick, dark, long and lovely. It highlighted the feminine aspects of me which was perhaps lacking in other areas. I once again learned that my outward appearance, and how I was groomed, was important if I wanted to be accepted and acknowledged. It was also important to look my best if I wanted to attract a partner.

I experienced many difficulties in expressing my own uniqueness within a system designed for people without disability. I had to articulate a new way of imagining my body whilst at the same time blurring the boundaries. I did this by illustrating alternative representations of disability in a way that subtly defies the stereotypes of disability as asexual. By blurring the boundaries of what was generally accepted as feminine, I tried to create a notion of fluidity (Image 3.2).

A fluid notion of the body to me was one that questioned the dichotomy of perfect/imperfect or able-bodied/disabled.

This was also the time when I felt comfortable within myself to start dating again. From this point on, when I was in relationships, I never felt inadequate. I recognised my own physical difference in terms of not having an able body, and haing a certain set of physical limitations, and this did not seem to matter. I felt loved and adored, just as I was prior to my disability. My partners were all non-disabled and I never felt the lesser partner or that I was lacking in any way. When the relationships ended it was never as a result of my disability, unlike my marriage. Being in these new relationships has been a huge contributor towards my feelings of self-worth and validation as a woman. I was accepted by others in the most intimate way and felt that I was loved for who I was as a person as a whole. The relationships that I had built with family, friends, lovers, colleagues had in a sense validated me as a person of value. I had come to realise my own ability within my disability.

Over the years I had worked hard at achieving a relatively "normal" life. Who was I trying to be 'normal' for, I wondered? Was it for my friends so that I could fit into the mould of acceptability? Was it for my partners? Was it for myself? When something has value, it is because it is compared to something better or worse than itself. I realised that using others as a benchmark or mirror of how I should feel or look would only serve to make me feel inadequate and inferior. Why allow myself to be assessed by any norm which excludes me? The only way I could change this was to change the object of comparison, from someone else, to myself. In order to face myself and the essence of who I was as a person, I had to strip off all the frills and fluff. And so I did. One of the ways I did

Image 3.2 Reflection (Photo by Amin Arnold Gray)

this was to cut off all my hair. It was extremely liberating as my hair was part of the external which bound me to conform. In order to embrace myself completely, my value could no longer be dependent on others' opinions and acceptance of me. And for that to happen I had to come to the understanding that I was different, and it was okay to be different.

I can't always express my femininity in traditional ways, but that's okay. I no longer need to conform. I no longer need long hair. I can be myself and feel comfortable in my skin and in what I choose to cover my skin with. I am unique, my body is not perfect; but what is acceptable and what is a perfect body? So now, I wear dresses and shorts when I want to because I can. My quadriplegic legs are perfect. I have short, natural, unruly curls because that is how my hair is. It is perfect. I am a woman without having to be groomed in frills and bows and heels in pink, and I don't need to adapt to society's standards of femininity in order to show my femininity.

I now look at life with even more awe as I embrace the wonder of being able to see a perfect sunset, smell cinnamon, hear Satie, feel the sun against my skin and eat delicious food. But more than being humbled by my experiences, I love who I am and the body that houses me in all its imperfections.

CHAPTER 4

Physical Disability and Femininity: An Intersection of Identities

Xanthe Hunt, Stine Hellum Braathen, and Poul Rohleder

INTRODUCTION

Gender, femininity, and masculinity, and what we think about as gender, or womanliness or manliness, and how we feel gendered, or womanly or manly, are subject to substantial social mediation. What that means is that society, the way we are taught from a young age to think about our social world, the media, our schools, and many other social forces, shape how we think about gender, and the characteristics and traits we associate with women (femininity), and men (masculinity).

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At the time of writing this book, gender, femininity, and masculinity are highly visible and debated social topics. Not all people fall within the commonly used binary constructs of male/female, and not all people feel comfortable to, or should have to, identify as either man or woman, masculine or feminine; there is a lot in between. Current debates about gender, and the spectrum upon which people may situate themselves, is beyond the scope of this chapter—and (a limitation of this work) all of our participants identified as cisgender, and heterosexual (for definitions of these terms, see our glossary). But what is important to note is that gender, and associated social roles and attributes, are not only personal, and the subject of intense, individual, and diverse experience (as evidenced in current debates), but also subject to a lot of social *stuff*.

In this chapter we look at the intersection of disability and femininity particularly, and what it means for some of the participants we interviewed. In other sections, we discuss masculinity, but in this chapter, we focus on femininity because this was what our participants who identified as women spoke about. Our goal in this chapter is to examine the ways in which: (a) women with physical disabilities experience their own sense of gender, and femininity; and (b) to bring to light some of the ways in which societal thinking about womanliness and femininity (and here we focus on traditional and dominant ways of thinking about femininity) influence the participants' experiences of themselves.

We will first look at what we mean by gender, and then look at femininity in relation to people born with a physical disability and people who have acquired a physical disability. We discuss some of the stereotypes about disability and femininity—about women with physical disabilities—from previous research, and from our own work, and discuss what such stereotypes might mean for our participants, drawing on their photographs and stories.

Thinking About Gender and Disability

When we talk about gender, we talk about the state of being a boy/man or girl/woman or neither/both/somewhere in between. Unlike when we talk about a person's sex, gender implies a reference to the social and

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cultural differences between the categories "boy/man and girl/woman" rather than biological differences. Gender refers to our sense of self and not our anatomy. Our gender reflects the social and cultural *constructions* of sex with which we choose to identify: masculinity or femininity, or a bit of both or neither. Sex (what we might be defined as based on our anatomy) does not necessarily correspond to gender: people who are cisgender might have male sex organs, identify as men, and feel masculine; people who are transgender, though, may have female sex organs, identify as men, and feel masculine too.

Masculinity and femininity are not neutral concepts—they are ideologically, politically, culturally, and emotionally loaded, as evidenced in current debates around transgender people, and historical (and ongoing) challenges facing LGBTQ+ people. It is beyond the scope of this chapter to examine the myriad ways in which societies, regimes, and other social structures and groups may construct and contest these constructs.

In this chapter, though, we have to define femininity. Here we choose a simple one: qualities or attributes regarded as characteristic of people who identify as women. This is nice and broad, and it specifies the scope of the data we discuss here: any information concerning experiences of or opinions about, the qualities or attributes identified with woman-ness.

Now, a quick Google search brings up words such as "womanhood", "female gender role", "feminine traits" (understanding, empathetic, sensitive, submissive, gentle, modest, willowy, and pretty), "attributes and characteristics traditionally associated with girls and women", if you search femininity.

The first question we must consider, then, is what people have said and written in the past, about disability in relation to these characteristics: what does it mean for physical disability to be feminine, or feminineness to be embodied by someone with a physical disability?

Usually, gender is one of the primary markers of identity—for reasons social and political, we are most likely to identify people as male or female or identify them by ethnicity, age, occupation, class, or nationality (note, here, that we identify them, usually, as being cisgender, that is, assuming that what we see—physical sex—bears a direct relationship to the gender identity we assume them to have, although this is not necessarily the case) (Rich, 2014).

Unlike the case of the majority without disability, however, past research and theory suggest that, for people with a disability, it is their disability that is the primary hallmark of identity. That is, it is an identity which supersedes gender (Goffman, 1963; Rich, 2014). One is a person with a physical disability first, and a woman or man second. This is not necessarily how the person with disability identifies themselves, but, rather, the way in which society identifies them.

In the sections to follow, we will explore whether, and how, this ranking of identity might be the case, and what it means for women with physical disabilities. Turning our attention first to the meeting between physical disability and femininity, we discuss how authors have proposed femaleness to be variously accentuated or negated by physical impairments. We then take a look at some of the research which has tried to unpack the intersection of femininity and disability as it impacts on the lived experience of women with physical disabilities. First of all, however, it is necessary to examine the manner in which gender identity development (the process of coming to identify as female or feminine) as a woman with a physical disability differs depending on whether one's physical impairment is something with which one is born (congenital) or acquired.

Femininity and Sexuality in the Context of Acquired vs Congenital Physical Disability

When a woman's physical disability is acquired, particularly in mid- or late-life, then her gender and sexual identity development has already occurred: she may have already pursued sexual relationships, experienced intimacy, and developed a sense of herself as a woman (Higgins, 2010). The development of one's sexual self and sense of oneself as a gendered being for women with congenital disabilities, however, occurs in the context of disability. Relationships, sex, intimacy, and ideas about gender roles must all be explored in the context of a physical impairment, and a society which is not always kind in its reactions to it (MacDougall & Morin, 1979).

We heard the example in the chapter before, about the transitions which women go through when they acquire a physical disability later in life. Research suggests that some women with congenital physical disabilities are limited in their expression of their sexuality (not that they limit themselves, but that society might limit them) (Howland & Rintala, 2001; Vaughn, Silver, Murphy, Ashbaugh, & Hoffman, 2015). To nuance this statement: what has been found is that Howland and Rintala (2001) found that some women with physical disabilities delayed dating because they had been raised with the assumption that their disability somehow excluded them from sexual life. Other women in their study felt that they lacked the age-appropriate socialisation experience to date, because as young people, they had been sheltered by their parents, and social exclusions due to their impairment. This indicates that when sexual and gender identity development occurs in the context of disability (as opposed to before its onset), the result can be inhibitory on sexual development and trouble women's sense of themselves as feminine (Li & Yau, 2006; MacDougall & Morin, 1979). This makes sense if we consider how sexual and gender identity development takes place. As we grow up, we are slowly but surely given feedback from our social environment concerning appropriate behaviour for our gender, and how we are measuring up to societies' ideas about our fitness as members of our sex, and as people performing our gender. We are given gender models against which to measure ourselves (from Fairy tale characters to celebrities), and we are subject to social feedback which tells us whether we are appropriately performing desirability as is fitting of the gender with which we identify. When one is subject to an identity marker such as disability (an identity marker which may even trump the markings of gender), then this feedback loop is interrupted or perverted, and gender identity development is thrown into flux.

Firstly, there is an absence of visible prototypes of femininity for young girls with disabilities, and—as society tells these girls that they are not like people without disability—icons without disability may seem to have little relevance for them. Secondly, the kinds of social feedback which they may receive concerning their suitability as a feminine female sexual subject, may be negative. Taken together, these forces may mean that making sense of where one fits in terms of femaleness and femininity, is no mean feat for girls growing up with physical disabilities.

This can be exemplified by Pride's story. Pride suffered from polio as a small child, resulting in one of her legs being formed differently to the other, which causes her a lot of pain, and she walks with a limp. Throughout her life she had heard many myths and rumours spoken about her behind her back. The rumours included ones that she could not have sex, not have a child, and therefore she was not suitable as a girlfriend, and could not get married. As a young girl in primary school she recalls her friends telling her that because of her disability, "you can't have a boyfriend, you can't get a child, you can't get married". Today, as an adult, she believes that they were ignorant, and not aware of the realities of her disability:

> They don't know. They don't know. But I also wanted to be loved, to belong, to be appreciated. But people couldn't understand. I remember, the first time I was at high school now, and then the boys would follow me. And then I was with this boy, and this boy heard that thing about me, and then the other one would pass and say, oh, I don't think that disabled people can have boyfriends. But that would come to my heart also.

Most boys and men in her youth would not pay attention to her, but one particular boy liked her:

> With this one, I don't know what happened. He was just interested in me, and talking. And when you talk the person will realise, no, man, this person is normal, the way she talks and the way she does things. No, she's normal, there's nothing wrong… For me it was important because at least there was someone who could understand that I'm also human. I also have feelings like other people… My friends (had boyfriends) long time before me. So for them it was easy to have boyfriends, but for me it was not easy because nobody wants to have a girlfriend who looks like this.

She has been in a few relationships in her life, and has never felt that her partners have seen or treated her differently because of her disability. The problems, she explains, only ever arise from people without disability outside of the relationship:

> The people who are letting me down are the people outside the relationship who would say those things. Oh, you are in a relationship with a person like this? You know, people can talk and gossip about all those things. How can you have a relationship with someone like this? How are you going to do this and that? But in a relationship, no, I never experienced that because of my disability.

When disability is acquired, gender identity may be thrown into flux, but in different ways: women may measure themselves against past versions of themselves, and feel less feminine or less desirable; gender roles such as motherhood, which they previously felt attainable to them, they may suddenly question. However, research suggests that, for women with acquired physical disabilities, gender identity and sexual self-esteem is more established than for women with congenital disabilities (Howland & Rintala, 2001). Though by no means the final word on experiences of gender in the context of congenital or acquired disability, what this section is intended to do is provide a backdrop against which the following discussion can be considered. In some cases, we will see how acquired disability is negotiated in the context of an already flourishing sense of feminine self. In other sections, we will consider what it means to nurture ones' sense of self as feminine in the developmental context of physical disability. In answering these questions, it is important to think about what physical "difference"[1] means for femininity in the broadest sense, before refining its implications for the sexual and gender identity development of individual women.

Gender Ideologies and Physical Disability: More or Less a Woman?

Work on the relationship between disability and gender has historically been limited, partly due to the fact that people with disabilities are taken as being asexual, or sometimes even as a third gender (Shakespeare, 1994, 1999). Yet, for the past 20 years, a substantial body of work has used gender as a lens through which to explore disability (Lashley, 2016; Moodley & Graham, 2015; Rodarte & Muñoz, 2004), including important work in South Africa (Chappell, 2015, 2017; van der Heijden, Abrahams, & Harries, 2019). In the past it was argued that women with physical disabilities were doubly feminised (Rich, 2014). That is, women are traditionally stereotyped as weaker and more passive than men, and weakness and passivity are ascribed to people with physical disabilities, and so women with physical disabilities are simply twice as female. However, various authors (Cheng, 2009; Rich, 2014; Schlesinger, 1996; Tilley, Walmsley, Earle, & Atkinson, 2012) have argued against this "logic" that, actually, most evidence suggests that disability disrupts traditional ideologies and social norms regarding female gender identity and femininity just as much as male gender identity and masculinity. Consider the idea (be it right or wrong) that women should be able to cook and clean and look after their domestic space. For a woman with a severe spinal cord injury, this might not be possible. Because of this disruption, common myths relating to the gender, and associated traits and roles, of people with physical disabilities are constructed in opposition

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[1] Different, here, is in inverted commas because we do not mean that people with physical disabilities are different—different from what? What we want to show, however, is that, in a society which sees being without disability as the norm, people with physical disabilities are seen as different.

to the traditional gender characteristics of their respective group, should they identify with one (Schlesinger, 1996; Tilley et al., 2012). In the case of women with physical disabilities, myths concerning their sexuality and gender include that they are asexual, unmarriageable, infantile, cannot be mothers, are passive, and are a burden to carers and partners (Anderson & Kitchin, 2000; Galvin, 2005; Hassouneh-Phillips & McNeff, 2005; Hunt, Swartz, Rohleder, Carew, & Hellum Braathen, 2018). We saw, in Pride's story presented above, how others' attitudes in this area influenced her experience of herself.

Work concerning gender stereotypes and disability has supported the idea that disability negates femininity rather than boys it. In a large study on disability stereotypes (Nario-Redmond, 2010), the researchers asked students to describe men and women with disabilities. The idea was that the students' short descriptions would tell the researchers something about stereotypes regarding disability and gender. They did. The researchers then contrasted these stereotypes with stereotypes regarding men and women without disability. Only women and men without disability were stereotyped along traditional gender lines, whereas persons with disabilities were characterised as asexual and unattractive. Traditional female gender stereotypes were only found for targets without disability, and the stereotypes of female targets with disabilities were characterised as more similar to stereotypes for male people with disabilities. Overall, the stereotypes for women with disabilities were, well, less gendered. In a paper the editors of this book wrote concerning people without disability's stereotyping of people with physical disabilities, we found a similar disjuncture (Hunt et al., 2018): the findings suggested that stereotypes of people with physical disabilities were undifferentiated by gender. So, where people without disability would associate "traditional" characteristics with men and women without disability, and these characteristics would be very different for men and for women, when people without disability associated traits with people with physical disabilities, the traits for men with physical disabilities and women with physical disabilities were very similar, and foregrounded disability (Hunt et al., 2018).

The Effects on Women

An important theoretical note which must be made at this point is one concerning a way of thinking about social forces called symbolic interactionism (Rose, 1962). Symbolic interaction theory examines the ways in which “societal norms, stereotypes, and judgments affect stigmatized groups such as persons with physical disabilities” (Rich, 2014, p. 419). That is, it strives to allow us to think about how the way in which people “out there” in society think about us, influences the world “in here”, in our minds. This theory is particularly concerned with how stigmatised groups may come to internalise negative stereotypes about themselves: if everyone thinks we are like this, then maybe we are like this?

Femininity is as much shaped by how women who identify as feminine feel about and see themselves, as it is about how others see them. For any girl or woman, coming to terms with and embracing womanhood, femininity, and sexuality, or not, is a process that we live with and experience throughout our lives. For women whose bodies deviate from the norm this process is likely more complicated and challenging. Amongst the women that we interviewed, several explained that multiple events in their lives over long periods of time had changed the way they thought of themselves, both negatively and positively. This was also something one of the participants with a congenital physical disability in our study spoke about. Throughout her life she had been told that she was not a “proper woman”, that she was not suitable as a romantic partner, wife, and mother:

> …the world or others, this is what they see when they see me, and it’s not an option, but literally that I’m not an option.

Eventually she had also come to believe this herself, internalising the views of the “outside world”. As a result she did not recognise it if someone showed a romantic interest in her, believing it not to be possible:

> I didn’t see it. I can’t say it wasn’t there. I didn’t see it. I mean, now with the benefit of hindsight, I think maybe it was sometimes there but that I was trained to block it out and that I definitely didn’t encourage it, and that’s what I’m sorry about.

Gender is enacted through the performance of certain activities, activities which disability may make difficult or impossible (either in reality, or in the eyes of others). Symbolic interactionists have also suggested that marginalised groups of persons employ a variety of strategies to manage other people’s perceptions of them (Goffman, 1963; Rich, 2014). According to this perspective, compensation strategies are undertaken by individuals in order to hide, minimise, compensate for, or negate the socially stigmatised elements of their identities. When disability does meet gender, then, the former often works to negate the latter, in interactionist terms. In such a context—where women with physical disabilities are constantly butting up against others' preconceived ideas about their gender, femininity, and identity, their abilities, and capabilities—how do they enact or claim gender?

Both Khadija and Cleone indicated their long hair as an important symbol of their femininity, making them attractive to men and defining them as women in the way that they wanted to be womanly. The long hair was, for them, a way to compensate for their sense of otherwise lacking some socially defined aspects of femininity. Khadija had taken a picture of her long hair to illustrate her femininity. She explained the picture in the following way (Image 4.1).

> 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

Image 4.1 Khadija is pictured, back to the camera, with her long hair hanging down over her shoulders and the back of her wheelchair (Photo by supplied by Khadija, photographer not recalled)

> onto, it's my beautiful long hair. It still makes me feel that I'm a woman. My hair is part of my womanhood. (Khadija)

Similarly, Cleone said the following of the importance of her long her to shaping her femininity and attractiveness:

> So it was one of the most fascinating evenings for me because I had two guys come onto me in the same evening and it was such a boost to my ego. I really didn't feel like going. I didn't make any effort to make myself look good, but I had really beautiful, long hair. I must show you the picture, very nice, long hair. And I do think that that is the…what is the word…the appeal and attraction to men because of the hair.

Noluthando felt that her good looks were an important factor in determining her femininity and defining herself as a person, as a woman, and as a sexual being. Noluthando acquired a physical disability after a car accident in her twenties. She had worked as a model before the accident, and her good looks and keeping a neat and flawless appearance had always been important to her. When she was injured in the accident she needed to use a wheelchair, and, according to her account, her appearance changed. Noluthando explained why it is perhaps more important for her to look beautiful after acquiring a disability:

> I said I want to be even more (beautiful) than at the time when I was walking. I want to be a model on this wheelchair. So that's what I told myself. That's why I can't stop to be that model that I've been before. I'm telling myself even today that I'm still a model. And when people look at me they must see that, really, this lady is a model. And I must look beautiful always. It doesn't matter if I sit in a wheelchair, but I must look good. People must know that it's not only people who are able-bodied who can look good. Also us, we are differently-abled, but we need to look good. We need to take care of ourselves.

We know that gender roles and norms affect the embodied sexuality of women with physical disabilities. Specific activities are required of people in order to claim a gender role (Paludi, 2010). Many women with physical disabilities are excluded, or are perceived to be excluded, from such activities (remember the woman with the spinal cord injury who may not be able to cook and clean and run after children). This may mean that, for women with physical disabilities, womanhood—and a female gender identity—are achieved statuses: one must prove, more than women without disability, that one is capable of performing femaleness or femininity (Dotson, Stinson, & Christian, 2003). This is particularly difficult in light of societal ideas about what it means to be female or feminine. Take, for instance, appearance. Women in general are affected by societal expectations regarding their physical size, shape, and gracefulness (Wolf, 1991). As women with physical disabilities have bodies which differ from the prescribed ideal, they are vulnerable to negative appraisal; both their own, and others' (Paludi, 2010; Wendell, 2006).

Women with physical disabilities may experience their bodies as deficient in relation to conceptions of the ideal body, and thus flawed (Peuravaara, 2013). Researchers in England found that women with physical disabilities enacted exaggerated gender performances in order to affirm their gender identity (Batty, McGrath, & Reavey, 2014). Participants in these researchers' study gave accounts of performing hyper-feminine roles in order to compensate for the fact that others might see them as asexual, as well as their own sense of having their gender called into question. Thus, compensating for the "loss", or altering, of one's original sense of gender identity and femininity following an acquired impairment, or developing an exaggerated way of performing one's gender identity in the presence of a congenital disability, maybe common strategies employed by women with physical disabilities to combat the de-gendering that their disability may be the subject of by society (there is also evidence that this occurs amongst men with physical disabilities, as you will see in Chapter 6). Women with physical disabilities may, equally, try to hide their impairments in an attempt to cover up the visible signs of disability which could mark them as less feminine (Batty et al., 2014; Li & Yau, 2006). We also know that physical disability impacts on women's ideas about how able they are to perform desired gender roles. As the author Malacrida (2009) notes,

> Women are expected to aspire to norms of femininity that include ideal motherhood, where mothers are positioned as ever available, ever nurturing providers of active, involved and expert mothering – indeed, being a caregiver is a master status for adult women in modernity.

For instance, women with acquired physical disabilities in adulthood may feel that their motherhood role in the family is totally lost, and that they will never be able to have children (Li & Yau, 2006). Women with congenital physical disabilities may believe that this role will never be theirs. Unfortunately, research suggests that due to internalised doubts regarding their physicality and femininity, women with physical disabilities may feel that success in relationships or marriages bolsters their normalness and femaleness, whilst failed relationships reinforce perceptions of them as asexual (Galvin, 2005). This can put them at risk of staying in abusive or otherwise damaging relationships (Kvam & Braathen, 2008).

As is apparent, when femininity and disability meet, the interaction of identities is complex. Theory, and some research, suggests that disability works to trouble and at times negate not only society's views of women with physical disabilities as "adequately feminine", but also women with physical disabilities' sense of themselves as feminine beings. However, we must remember that masculinity and femininity are highly cultural, contextual, and even individual concepts, and are thus in constant flux, and so one must be careful not to make assumptions about the experiences of individual men and women.

In the chapter which follows, one of the participants in the study, who has gone on to co-author academic articles with the research team, provides some personal reflections on one experience of femininity in the context of a physical disability which is as moving as it is informative.

Concluding Notes and Take-Home Points

What is needed to change things? Some of the experiences outlined by the women who shared their stories in their chapter were difficult: they felt uncomfortable in their sense of themselves, and they felt that they did not "measure up" as women. Over time, happily, this shifted for some of them, and they shared experiences, too, of feeling womanly, beautiful, powerful, and of having loving relationships. Still, their accounts foreground some of the difficulties which face young women with disabilities, and women who acquire disabilities in the course of their lives: What can be done to make things better for these women? To make feeling feminine as a woman with a physical disability a non-issue? To make young people with disabilities who want to feel feminine, regardless of sex, able to do so without society telling them otherwise?

We would suggest it is a matter of representation and attitude change: central to most of the women's stories, here, was the sense that as people without disabilities themselves (prior to acquiring a disability), or from people without disabilities who they encountered (as people with disabilities), disability is framed as "less than" non-disability, and femininity is normatively embodied is "better than" femininity which is embodied in a person with a physical disability. For both of these things to change, social representations of femininity—in movies, magazines, the movies, textbooks, sexual education curricula, music videos, and elsewhere—need to include women with physical disabilities. Equally, social representations of physical disability—in movies, magazines, the movies, textbooks, sexual education curricula, music videos and elsewhere—need to be more, and include people with physical disabilities embodying a range of gender identifies, in a range of ways, with social value.

Attitude change is more complicated, because although it may happen inevitably as a result of more representational diversity, it also may not. Attitude change is complicated and poorly understood: if we as societies were any good at changing attitudes, racism, sexism, homophobia, transphobia, and other common forms of prejudice would not be as common as they are. However, awareness-raising and education around broader and inclusive conceptions of sexuality itself are needed. Contact between people without disability and people with disabilities, and inclusion of people with disabilities, in every sphere of life needs to be foregrounded. Research and writing such as this, and products from this project and those much bigger and diverse than this one, need to be shared and engaged with. If dialogue drives awareness, and awareness may lead to attitude change, then content to spark dialogue is needed.

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CHAPTER 5

Rosabelle's Story

Rosabelle Riese and Leslie Swartz

ROSABELLE'S STORY

I contracted polio at the age of one and a half. My early childhood mostly was spent in hospitals which meant that I didn't spend a lot of time with my family.

My earliest recollection of the opposite sex was in primary school and, thinking back, I was actually not conscious of my disability affecting any friendship with boys. Everything just seemed normal to me. I didn't feel different and I was very competitive academically. During High School and University I had a few friendships but no romances. It's probably at this stage that I started feeling self-conscious of my disability, and began lacking self-confidence. I had many sexual encounters in many cases with no emotional attachment nor commitment from partners. I suppose you could call this my explorative period. This ranged from one night stands to fairly long periods of being intimate with one person.

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When I started doing sports I started meeting a new breed of man. These were guys who actually were involved with, and doing a service to, those with disabilities, in order for them to enjoy their Sport (Image 5.1).

Besides my other social activities, sport created another avenue where I could be in touch with the opposite sex on a social level, and at times on a more intimate level. There were no barriers to overcome. I was seen as a woman and a human being.

As I've travelled quite a bit during my sporting career I met one of my partners in Finland after my divorce. He was a shooting coach for the Dutch team. Once again, I had no barriers to work through as he was involved for many years with people with physical disabilities. Unfortunately he passed away after we had been living together for 5 years.

My ex-husband also has a disability. (Of all my relationships, only two men were people with disabilities.) We became proud parents during our marriage. Being able to bear a child and become a mother also strengthened my ense of my womanhood. I yearned for another child, but it

Image 5.1 Rosabelle pictured with a bouquet of flowers and medal, following a Para-Sport event (Photo by Rosabelle Riese)

wasn't to be. My daughter, Marni, is now 26 years old and I am super proud of her.

At the start of some of my relationships I was always concerned about whether my partner would accept the shape of my body as I have scoliosis as well as deformities due to Polio, but it always got better as the relationship strengthened.

My self-confidence progressed and grew as I excelled in sport. Amongst my achievements are participation in three Paralympics (Bronze Medal in Shooting in Atlanta in 1996), three Gold medals in All Africa Games for Table Tennis and numerous Awards for Sportswoman with Disability, Flagbearer as well as Torchbearer, two Commonwealth Games, World Championships in Table Tennis, Shooting and Bowls. I also have South African titles in Powerlifting, Bowls, Table Tennis and Shooting. I am the only South African to have medalled in Air Pistol at Paralympics. My love for sport continues as I do coaching at times, and encourage others to participate in sport due to the fact that I had derived so much pleasure from it. Hard work in sport has its benefits, such as pride in one's own achievements, a healthy mind and body, meeting people, travelling the world and getting a taste of other cultures, to name a few.

Today I live in a self-help centre where 12 wheelchair users share and manage a house. Much has happened in my life and I am in the process of writing my autobiography. I am thankful for all the experiences in my life, some good and some not so good, but for now, I feel that life is great, and I know that being a sportswoman contributed to this.

I am, once again, in a relationship.

A Brief Commentary on Rosabelle's Story: Disability, Embodiment and the Power of Sport

Rosabelle tells her story to us as one of resilience—of facing difficulties and being able to overcome these, or to change her ideas of what life is and should be about. The very first sentences of Rosabelle's story tell us not only about a physical impairment ("I contracted polio"), but also about what happens to many children who are ill or have impairments—they spend time away from their families. This is something which can affect how people go on to relate to others in the world (Bowlby, 1983), but Rosabelle describes not being conscious of her disability in primary school, and not having difficulty relating to others.

For Rosabelle, as for many other people, the sense of feeling different and of losing self-confidence came with adolescence, a time when people become more interested in sex. Rosabelle describes a time of sexual exploration and experimentation, which is common at that time of life. As for many people who don't feel comfortable about their bodies, though, it may be that Rosabelle would have done things a bit differently if she had felt more confident in herself (Hassouneh-Phillips & McNeff, 2005; Liddiard & Slater, 2018). Just after telling us of her lack of self-confidence, she describes sexual encounters "with no emotional attachment nor commitment from partners". For some people, and this could be true to some extent for Rosabelle, sexual encounters without emotional attachment or commitment may be satisfying. But when we read her story as a whole, she seems more appreciative of relationships on "a more intimate level", as she puts it. And for Rosabelle, what has enabled this has been her involvement in sport.

Rosabelle describes her introduction to being a sportswoman in very positive terms. Things began to happen and to change in a number of ways, including the following:

1. **The people Rosabelle met.** As she began her participation as a sportswoman, Rosabelle met "a new breed of men"—men who were assisting sportspeople with physical disabilities in their sporting careers.
2. **Opportunities to socialise.** Rosabelle speaks about being in touch with members of the opposite sex on a social level, and sometimes on a more intimate level. The experience of being together in the world of sport seems to be an equaliser, and thus opens the door to more satisfying relationships.
3. **Opportunities to travel.** One of the things many people with disabilities face, especially in countries which are not rich, is being isolated and cut off from the larger world. The internet has helped many people feel more connected, but virtual contact cannot replace the experience of being in other places and meeting different people (Swartz & Marchetti-Mercer, 2019).
4. **Opportunities to be seen as an equal.** Rosabelle notes that when she got involved with sport, "there were no barriers to be overcome"—through sport, she has been able to be seen as someone who has something to offer, and something to offer through the abilities of her body. She has had the chance to see her body and

what it can do being valued by others, and this may result in a greater sense of confidence in her body, and in her sexuality, more generally.

5. **Opportunities to develop longer-term relationships.** These relationships have been key for Rosabelle in terms of building her sexual self-confidence as she notes that her worries about how her body looks tend to lessen as relationships develop.

When we undertook our study, we were not looking for participants with particular histories of physical disability, but we were very pleased that somebody from a disability sport background did choose to join the project. Participation in physical activity is well known to provide a range of benefits—physical, mental and social—to many people, and there is no public health plan in the world today which will not reasonably recommend physical activity. Historically, though, many people with physical disabilities have been excluded from sport for a range of reasons, some of which are rather similar to the ways in which people have assumed that people with physical disabilities do not or should not have sex. For example, just as in the case of the way that many people think about people with physical disabilities and sex (Hunt, Swartz, Rohleder, Carew, & Braathen, 2018), people may think about sport and physical activity as not really appropriate for people with physical disabilities (Howe, 2008). This may be partly due to a fear that participation in sport and physical activity may add to injuries and cause further disablement.

It is absolutely clear, though, that from the point of view of sportspeople with physical disabilities themselves, sport and physical activity is enjoyable and helpful in a range of ways. For many, sport is a way of gaining social acceptance and status, just as it has been for Rosabelle (Bantjes, Swartz, & Botha, 2019; Conchar, Bantjes, Swartz, & Derman, 2016). And social acceptance and status may well contribute, as is the case with Rosabelle, to greater sexual self-confidence. This is, of course, in addition to the confidence which may come from greater strength and prowess on the sports field.

Rosabelle's story is testimony to the potential and importance of sport and physical activity, but it is also important to remember that access to any kind of sport remains a challenge for many people with physical disabilities, especially in low- and middle-income countries (Swartz et al., 2016). The sexual rights and exclusions of people with physical disabilities are linked to other issues they face—and exclusion from sport and physical activity is one of these.

A final comment about the contribution of Rosabelle's story, and why it is placed so early in this book, is that it showcases the diversity of meaning of sexuality. When we asked people with physical disabilities to be part of the study, we noted that the topic was sexuality. However, when participants shared their stories, the links to what is traditionally considered sexuality (sexual acts, sexual health and maybe gender), were varied. Although Rosabelle's story mentions relationships and childbearing, sport is also a key theme and something central to Rosabelle's sense of her sexuality. This is something we would like the reader to bear in mind as you engage with this book; sexuality and sexual experience are as diverse as the people to whom they belong, and for people with physical disabilities, this diversity of experience makes an important contribution, as we will see, to our thinking about sexuality.

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CHAPTER 6

Physical Disability and Masculinity: Hegemony and Exclusion

Leslie Swartz, Bongani Mapumulo, and Poul Rohleder

This book is part of a groundswell of research and activism around disability and sexuality. If you Google "disability and sexuality" you get almost 400,000 hits, and over 3000 on Google Scholar. There are disability and sexuality books, manuals, websites, and podcasts. Many, if not most, of these writings and productions have a similar aim to our own—to dispel myths about disability and sexuality and to assert the right of people with disabilities to sexual pleasure and expression, in whatever form they may wish to participate in sex, or define for themselves what participation in sex may mean.

In relation to disability and gender, it is often said that disability makes women seem less feminine and men less masculine. In other chapters in

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this book, we discuss issues around women, disability and sexuality, but what does the idea that disability makes men seem less masculine mean, and does it apply, to how men who participated in this project and to how other men with physical disabilities see themselves? In this chapter, we will take a look at what the participants in our study said about this. In Chapter 7, Bongani Mapumulo describes some key issues that need to be taken into account when we think about physical disability and masculinity. He notes that all of us learn through processes of socialisation what it means to be a man or a woman, what the social roles are. These roles may change over time, but what is important for this chapter is the concept of hegemonic masculinity, which has a long history (Anderson & McCormack, 2018; Connell & Messerschmidt, 2005; Cornwall & Lindisfarne, 2016; Messerschmidt, 2019).

Though there are many debates about the idea of power, the key concepts for purposes of this chapter include the principle that in most contexts worldwide, there is a difference in power between men and women (for reasons of historical and ongoing, ingrained social, political, and economic inequalities), and that men are expected to be strong, unemotional, and powerful leaders. As Messerschmidt (2019) notes in a very recent article, it is also accepted today that hegemonic masculinity is not fixed but changes with contexts and across time. It is also true, though, that in many discussions of what masculinity is and does, disability is hardly mentioned. For example, in the recent book edited by Cornwall and Lindisfarne (2016), disability is mentioned few times but there is no full discussion of disability. Similarly, introducing a recent book on masculinities, Gough (2018) notes that masculinity studies need to know more and engage more with the lives of men with physical disabilities, but there is no focus on disability.

A relatively new concept in masculinity studies is what is termed "inclusive masculinity theory" (Anderson, 2010a, 2010b; Anderson & McGuire, 2010). The most recent article we could find stating the key outlines of the theory does not mention disability at all (Anderson & McCormack, 2018), nor does disability tend to be mentioned in debates on this supposedly "inclusive" theory (see, for example, De Boise, 2015; Magrath & Scoats, 2019; O'Neill, 2015; Scoats, 2017). For people who work in the field of disability studies, the word "inclusive" almost always implies including everybody, with people with disabilities being a key part of that inclusion (as in the term "inclusive education").

Inclusive masculinity theory, by contrast, distinguishes between what is termed “orthodox masculinity” which includes homophobic and misogynistic elements (in other words, elements of prejudice against gay people and against women), and “inclusive masculinity”, which does not (Anderson, 2005; Anderson & McGuire, 2010). Inclusive masculinity theory has usefully opened up space for debate, particularly on cultural changes around how gay men are seen, and on breaking the old stereotype that gay men are not really men.

It may be unfair to be pointing out how inclusive masculinity theory largely overlooks questions of disability[1] as this is not really the focus of the theory. It is, furthermore, certainly the case that there are texts dealing with discrimination in a range of areas which do consider both homophobia and disablism (Kilvington & Price, 2017). The key point we want to make here, however, is that even where the concept of “inclusion” is being thought about, many theorists are not thinking about disability as an inclusion issue. The feminist disability studies scholar Rosemarie Garland-Thomson (1996, 2009) often comments on how hidden disability is—that it is seen to be “nowhere”, or that when it is revealed, it is often as a form of freak show. Garland-Thomson and others are working hard to change how disability can and should be made more visible (Sandell, Dodd, & Garland-Thomson, 2013), but the general point remains: disability is often hidden and overlooked. This may be even more true in African, and especially rural, African contexts (Mji, Schneider, Vergunst, & Swartz, 2014), and Swartz et al. (2018) have gone so far as to argue that the act of making disability invisible may be seen as a form of violence against people with disabilities.

Regardless of whether Swartz et al. (2018) are correct in seeing the invisibility of disability as a form of violence, the question remains how men with physical disabilities engage with their own sexuality and their sense of themselves as men. Hegemonic masculinity emphasises conventions like physical strength, dominance, and power over others (especially women), and these attributes may not be available to men with physical disabilities, or—at least—not in the way in which traditional conceptions of masculinity demand them.

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[1] Anderson (2005) does briefly mention disability but only in the context of able-bodied athletes acquiring disabilities, permanently or temporarily, through sporting injuries.

Alternative and shifting views of masculinity, with the recognition that just as there may be "orthodox masculinity" there may also be "inclusive masculinity" (Anderson & McGuire, 2010), though critical of ideas about hegemonic masculinity, also tend to gloss over or ignore questions of disability and sexuality. Where, then, does this leave men with physical disabilities like the participants in the *Disability & sexuality* project? We would suggest that these are people who live with what we will term a *double erasure*—first, they tend to be excluded or side-lined from hegemonic masculinity, and even when theorists try to reformulate ideas about masculinity in more inclusive ways, they are again excluded. They are excluded from the work of societal repair that the idea of "inclusive masculinity" tries to undertake.[2] This not only further excludes them, but also, paradoxically, makes their exclusion more complete—if as we move to make ideas about manhood and masculinity more complete, we keep excluding some men, we may seem more inclusive and hence we will not look for the continuing exclusions.

With these issues in the background, let's look at what our male participants said about themselves and about being a man.

BEING A MAN: WHAT OUR PARTICIPANTS SAID

1. Hegemonic masculinity

It is clear from what our participants told us that they acutely feel the pressures consistent with the demands of hegemonic masculinity–men should be strong, powerful, and unemotional. Bongani, for example, speaks of the "alpha male" and of being "dominant", and Simon talks about the pressure to perform:

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[2] There are of course many men with disabilities who identify as gay, or who situate themselves across the LGBTIQA+ spectrum—so aspects of their masculinity and embodiment may well be covered to a degree by inclusive masculinity theory. As it happens, none of the participants in our study identified as LGBTIQA+, though we did try to include such participants in our study. For more discussion of the interface between disability and queer theory, please see McRuer (2006, 2018). Kunzel (2018) further notes that in the struggle to depathologise homosexuality, in the USA in particular, potential alignments between gay and disability politics may have been lost, as it was important for people who identify as LGBTIQA+, to declare themselves healthy and not deviant—and hence without disability.

> …whether I like it or not, there's almost a mainstream perception of what I mentioned: the alpha male, a breadwinner, a strong and unemotional person who is always rational, who is always one step ahead of everybody else and who is dominant within relationships within their immediate circle of friends. (Bongani)

> …because you are the guy who is going to be the one that needs to perform the whole time. (Simon)

None of the people we spoke to suggested that this pressure was unique to men with physical disabilities, but all in various ways indicated that their lives were deeply affected by their not easily and obviously matching up to the hegemonic masculine norms. The most obvious deviation our participants had from these norms was in terms of their physical impairments, but many of them, as Bongani mentioned above, quickly linked ideas of masculinity to questions of economic power, such as being "the breadwinner". This emphasis on financial strength as part of masculinity was echoed by other participants:

> …people would say that I can't contribute to society when it comes to employment. They would make statements like, You can't work. How can you work? (Tas)

> You know, if you're not financially strong to support your partner and yourself, then the challenges are big. And the first thing women look for is stability – most of them – and I found that a lot. I mean, it's like, are you able to support me or not? I don't support you. (Simon)

In South Africa, the pressure for men to perform the role of primary breadwinner may be greater than in higher-income countries; according to national reports, a smaller proportion of women than men are employed, and, a larger proportion of women than men are not economically active (StatsSA, 2011). This could be due to a host of reasons, but one of these may be culturally, socially, and pragmatically determined role expectations for women (to raise children, and bear the burden of domestic and care work), and for men (to earn in the formal and informal economies).

In his discussion with us, Simon has taken the issue further—voicing what he imagines women say, or what he has heard, he makes the flat statement, as if from a woman to a man, "I don't support you". What is interesting about this quote is that Simon is telling us here that he believes that women see certain roles as normal and natural—the statement "I don't support you" is absolutely emphatic, and Simon is not saying that women would prefer not to support men, but that women view it as a rule that women do not support men financially. Part of the talk around financial power as a feature of masculinity is the issue of perceptions of what men with physical disabilities can and cannot do. Tas articulates this very well here when he speaks in the voice of people in society, saying, "You can't work. How can you work?" These men have to live their lives operating against these incorrect perceptions of what men with physical disabilities can and cannot do.

When we look at how Simon and Tas discussed these issues with us, it's interesting to note that both of them did not just discuss how they are positioned as men, but they actually took on the voice of those they experience as positioning them in problematic ways. So we have:

> Simon (voicing what a woman would say): I don't support you.
>
> Tas (voicing what people without disability would say): You can't work. How can you work?

These injunctions about what gender roles are and should be, from the perspective of people Simon and Tas are talking about, are clear, straightforward and to the point. There is no ambiguity or shade of grey—the story is one of how men should be, how the world is, and how men with physical disabilities do not fit in. This is a form of what the disability studies scholar, Tom Shakespeare (2013), who has himself researched issues of disability and sexuality (Shakespeare, 1999, 2000; Shakespeare & Richardson, 2018), would call "disavowal"—and the disavowal is powerful as it is voiced by our participants as a law, not a social choice or preference. This is how things are, and men with physical disabilities do not measure up. In this regard, another comment by Shakespeare (1999) is also relevant here. He suggests that for a range of reasons people with disabilities may be seen not just as not measuring up to ideals of masculinity in the case of men, or femininity in the case of women, but actually as constituting a kind of "third gender" (Shakespeare, 1999, p. 55)—neither male, nor female, but "disabled". For Shakespeare, writing at the turn of the twentieth century, part of this perception was instantiated by there being three kinds of toilets in public buildings—“male”, “female”, and “disabled”. This may seem a bit far-fetched, but let’s think a bit about this. Twenty years ago, there was a strict division between sexes in terms of which public toilets they could use—men did not use women’s toilets and vice versa. But men and women with physical disabilities used the same spaces. There are obvious practical reasons for this, but the physical ordering of space tells a story about the world, about who qualifies fully as a man or a woman. It is certainly true that the social ordering of public toilet spaces has changed over the past few years, with many more gender-inclusive toilets than before, partly because of issues related to recognition of transgender rights. It is also true that the issue of toilets and access to them remains a core issue for disability activism (Liddiard, 2017; Liddiard & Slater, 2018). But for our thinking about what our participants said, the key issue here is the power of the social order which forces them to ask whether they qualify to be men at all.

An interesting feature of the talk of our participants, as we have quoted them above, is that some of the talk is about the body and the impairments themselves, but some is about a more symbolic form of power—the power of money. The men we spoke to all in various ways suggested that one way to qualify to enter the realm of being a man was through being financially strong, a provider, or, as Bongani put it, a “breadwinner”. In a world in which financial strength is greatly valued, this is not surprising, and it is not uncommon for conventionally unattractive (and often older) men in our society to be able to attract sexual partners who are very attractive, young, and desirable. But in terms of disability and being a man, there is something more going on here. The word “breadwinner” speaks not only to financial independence, but also to the ability of someone to take care of dependants—as Simon voices what women may say: “I don’t support you”. An aspect of what our participants and other men with physical disabilities have to deal with in their lives is the perception that they will be dependant—financially or otherwise—in a world in which independence is valued, and is seen as a key feature of what it means to be a real man. The fact is that all human beings are dependent on others in some way—we are interdependent as a species (Kittay, 2013; Tronto, 1993), but the social tolerance of expectations around dependence are highly gendered—socially we are more likely to think of women as dependent, but of successful men as being independent (Held, 2018). This, as we shall see in the next section, has implications for how our participants experience themselves as men in sexual relationships with women.

A further issue about how hegemonic masculinity may work is that of how men think about the status of women who become sexually involved with men with physical disabilities. Bongani puts it this way:

> 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? Is she going to be settling for something less than what she can achieve? (Bongani)

Here, Bongani speaks not only of men with physical disabilities as not fully being men ("diluted or minimised") but also of how the woman may be perceived. She could be seen to be "settling for less", whereas she might have been able to achieve better or more. The idea of a sexual partner as a prize or an achievement is of course not anything new or unusual, but it does link to ideas about what has been termed commodification. A lot has been written about the commodification of women's bodies, whereby a male sexual partner is seen to "own" a woman's body as he would own an item of monetary value (McCloskey, Boonzaier, Steinbrenner, & Hunter, 2016; Okeke-Ihejirika, Salami, & Amodu, in press). The issue of commodification of women is also discussed in research which explores, amongst other things, how men with physical disabilities feel about paying sex workers to have sex with them (Abbott et al., in press) and in relation to the commercialisation of unusual women's bodies for purposes of (often titillating) entertainment (Williams, 2017). But in what Bongani says here, it is also the man's body which can be commodified and a source of capital for the woman. In the case of disability, he says, the (disabled) goods may be less valuable than what the woman might be able to "achieve". The issue of commodification of men's bodies is a relatively new topic in how we understand gender. A Google Scholar search on the exact terms "commodification of men's bodies" yielded only two hits—one an unpublished thesis from 2006, and the other a very recent article (Shahvaroughi Farahani, Sohrabi, Mazaherinejadfard, & Hasan Larijani, 2018). A similar search on "commodification of women's bodies" yielded over 400 results. We believe that Bongani is on to something important here about ideas of masculinity in general, and this is an issue we return to in the section on recovering masculinity.

2. Men with disabilities doing sex

Not surprisingly, a lot of what our participants spoke about was the pressure to perform sexually. They discussed the need to satisfy their partners sexually. As Simon put it:

> What I have found, there's this thing of trying to prove yourself in trying to satisfy your partner. (Simon)

This emphasis on the need to satisfy women sexually is certainly not unique to men with physical disabilities (see, for example, Chadwick & van Anders, 2017; Porter, Douglas, & Collumbien, 2017), and some studies have even suggested that women's orgasms and pleasure in sexual experiences may be used by men as a way of measuring their own level of masculinity (Chadwick & van Anders, 2017; Porter et al., 2017). This is in contrast to many views of hegemonic masculinity as embodying an emphasis on men taking pleasure in sexual conquests, with relatively little concern with the women's experience (Alldred & Fox, 2015; Swartz, Colvin, & Harrison, 2018). The transition to disablement, for men who acquire a disability, may go along with an increased emphasis on pleasuring a partner rather than taking one's own pleasure. As Sifiso puts it:

> And now life is changing to be about someone else, but not yourself, but your partner. (Sifiso)

Here, Sifiso is talking about changes in sexuality after disablement, but as he goes on, he is talking about other issues which are not just about pleasing a female partner:

> Ja, and you know males, they have this problem of will I be able to satisfy Joy? That is the male mind in our society. They're thinking oh, that guy is satisfying his girlfriend because he is coming circumcised from the bushes. Now will I also satisfy Joy? So those were the things that I was thinking. (Sifiso)

In discussing what he calls "the male mind in our society", Sifiso is taking as given that there is a "male mind"—a way that men think of themselves and other men. But he is saying something more—he speaks here of competition amongst men ("that guy is satisfying his girlfriend"). Importantly, the issue of satisfying a sexual partner is for Sifiso linked to how he may or may not measure up, not just in terms of pleasuring a woman, but in terms of how he compares to other men. So for Sifiso, within the intimacy of the sexual encounter with a female partner, there is also the presence of his feeling of how he is watched and judged, not by this woman, or by women in general, but by other men.

It is interesting that Sifiso here refers to "coming circumcised from the bushes" as a path to providing sexual pleasure for women. Within Xhosa, and some other, traditions in southern Africa, young men undergo a coming of age process known in isiXhosa as *ulwaluko*, part of which involves circumcision (Magodyo, Andipatin, & Jackson, 2017; Mfecane, 2016). Colloquially, this secret process, to which women are not allowed access (Kiguwa & Siswana, 2018), is known as "going to the bush", as the process is generally undertaken in the forests away from where people live. Men "coming…from the bushes", as Sifiso puts it, are men returning from their rituals (including circumcision) to society—and to women. Traditionally, as men are ritually circumcised without anaesthetic, at the moment of the pain of the cutting of the foreskin, they cry out, "*Ndiyindoda*" (Mfecane, 2016). This literally means, "I am a man". In society, Xhosa men who have not been ritually circumcised, regardless of their age, are known as "boys". The social significance of the *ulwaluko* process is profound, as Nelson Mandela (1995) discusses in his autobiography, and it has been suggested that failure to perform the ritual may lead to considerable emotional distress, and possibly even psychosis, let alone the stressful consequences of the process itself for those who undergo it (Le Roux et al., 2007; Swartz, 1986, 1987; Yen & Wilbraham, 2003). Given the physical location of where the ceremonies are undertaken, and the physical privations for the process, not all men with physical disabilities can take part in the process. But as can be seen with the shout of "*Ndiyindoda*", this process is what turns a boy into a man—it is an absolute and clear marker of adult masculinity. The actual process by which urban South Africans find ways to declare themselves as socially fulfilling adult roles is more complicated than this and may relate centrally to issues of fertility and producing heirs (Swartz et al., 2018), which links to issues of reproductive rights discussed elsewhere in this book. Nevertheless, *ulwaluko* remains important, and the fact of the ritual process leads Sifiso to compare himself with men who have had the opportunity to shout out "*Ndiyindoda*" ("I am a man"). It is clear that this aspect of social comparison is very important, and penetrates into personal relationship spaces. Sifiso takes this issue of surveillance of sexual behaviour even further:

> Satisfying my partner is very important. But for her it's not an important thing. She keeps on telling me that I must not worry about that. But for me, it is important. Because I know for a fact that if it was me, I'd also love to be satisfied. It is a part of life that must be completely done. But for her, she doesn't mind about being satisfied, but I prefer to everything to see her satisfied. (Sifiso)

In this account, Sifiso presents the issue of satisfying a partner as a self-evident prescription—the way things should be ("Satisfying my partner is very important"). He experiences this as important even if the partner herself says she is not concerned with this issue, and it may be helpful for us to think about three ways in which Sifiso may be thinking about his partner repeatedly "telling me that I must not worry about that". Three possibilities are:

1. The woman may kindly be wishing to protect Sifiso from her need for sexual pleasure—in order to protect him she may be lying.
2. It is not possible for the woman not to be concerned about sexual pleasure, as if Sifiso were in her position he would "also love to be satisfied".
3. Sexually satisfying a woman is a requirement of being a man—"It is a part of lie that must be completely done".

One of the challenges faced by anyone who does not, or cannot, fulfil dominant social roles is that others may patronise them—they may make allowances for them out of pity and condescension. Much has been written about this in the disability literature, with activists wanting equality and rejecting pity or charity (Longmore, 2015; Swartz, 2018)

3. Recovering masculinity and sexuality

Given the difficulties our participants have discussed above, how do they renegotiate their own masculinity and sexuality? Some of this, according to them, is a question of what men with physical disabilities do as part of sexual intimacy. As Nico puts it:

> Positions, yes, I'm sorry, and much more flexibility. Why I'm saying flexi, you're flexible in doing things. (Nico)

Linked to this are broader ways of signalling to women that the men themselves are sexual beings and value their own bodies. Tas says:

> 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. (Tas)

It is important here that the issue is not just about how men look, but how they communicate through their dress their own attitudes towards themselves. The question of who may be considered an appropriate sexual partner links to broader questions about how society is organised, as Tas notes:

> One of the big things is, when I first became like an *extra* citizen in the community, after the whole reintegration process in society and become active again, and for me it was the first time I was part of something and I would get up in the morning and go to work. It was something very nice for me. It made me feel good. It made me feel like a man again. (Tas)

Here, Tas clearly articulates how in the process of disablement he moved from being a citizen in the community without having to claim his place, to being, as he puts it, an "extra", rather than a part of things. Tas's way out of this is through employment, an issue we have discussed above.

Regarding how to change things, it was Bongani, who, as we saw earlier, understood the male body with a physical disability possibly less of a prize or a commodity than is the normative male body without disability. For things to change, Bongani argues, it is not just men with physical disabilities who must change and adapt, but also their sexual partners:

> No, he is a man in this relationship just like any other man would have been, which means embracing me in my entirety as opposed to taking those bits that make sense for her. (Bongani)

Here, in his expressing his wish to be embraced "in his entirety", Bongani is making a complex argument. First, he wants to be seen not just as a body but as a full human being. He wants the woman to be curious enough to get to know him as a whole "as opposed to taking those bits that make sense for her", as he puts it. Finally, this is a story of men with physical disabilities resisting being placed in a hierarchy of commodification, with their bodies being seen as less than the ideal. It is for the women to learn and accept that there is more to Bongani (and to any man with a disability) than the failure to live up to the stereotype of how men and men's bodies should be.

What is fascinating here is that in enjoining women to be partners in the project of reclaiming and reinvigorating men with physical disabilities' masculinity, Bongani is echoing much of the feminist literature on how women's bodies are seen and commodified—that literature calls on men to see women (and here we deliberately paraphrase Bongani's words)—in their entirety as opposed to taking those bits that make sense for men (Fair, 2018; McCloskey, Boonzaier, Steinbrenner, & Hunter, 2016). We can see here that men with marginalised bodies argue, as do feminist scholars, that the job involves everyone—and not only those on the wrong end of power. Here, though, there is an inversion as Bongani's discussion is of women's power and women's role, instead of the usual discussions of male power.

Concluding Notes and Take-Home Points

We have seen in this chapter how the men who participated in our project really helped us understand some key issues about disability and masculinity. We heard about struggles with sex and sexuality and how these are dealt with both in intimate spaces, but also more broadly in terms of social roles. And we also saw how in being forced really to think about themselves and their masculinities, these men had interesting things to say about how to change the social and sexual order.

We would have liked to have talked more with these men, and to talk with a wider range of men, and especially with men who identified as LGBTIQA+. The small amount of information that we have is a limitation. But we have also seen that these small discussions can produce a richness of opinion and discussion, and we certainly have a lot to think about following this stage of our project.

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CHAPTER 7

Bongani's Story

Bongani Mapumulo

REFLECTIONS

When it comes to my masculinity as a Black South African Zulu man with a physical disability, who is also a student of disability studies, I need to talk about two things. I need to address my culture, how I was raised and how this shaped my non-academic experience of sexuality. But I also need to address how—as a student of social studies—I experience and engage with that literature which I have encountered on the subject of masculinity in the context of physical disability.

I wish I could say there is no fantasy, imagination or expectation which influences sex and sexual relations with ourselves and with others. But again, without these forces, how does sexuality become an enjoyable part of living and loving? The reason I raise the issue of expectations, fantasies and ideals is that, no matter how open-minded, unbiased and objective one tries to be, we all bring these unconscious elements with us when we are getting together with people, especially for the first time.

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Will I live up to the man she sees?
Will I give her everything she needs?
I just hope that when we're done she's pleased.
I hope it's everything you thought it'd be, oh!

Surprisingly, perhaps, these are lyrics by the famous R&B singer, Trey Songz, who is considered a sex symbol in many ways. You'll notice that there are elements of self-doubt and timidity in these lyrics. My aim in quoting them is to illustrate that if such negative thoughts can affect a famous musician with high status and the supposed ability to attract any woman he wants to, it is only natural that these feelings would be present in all man. In addition, I am deliberately making a musical reference because, in my younger and more impressionable years, music and movies provided a window into the intricacies of love and relationships. If I am going to be completely honest, I should add that, while life has left me with a more pragmatic outlook on love and sex, it would be a lie if I said all those images of perfect romance and fantasy which I encountered in the media I enjoyed, have completely disappeared from my mind.

Us Vs Them: A Small Piece of My Personal Story

Our upbringing has an enormous effect on the way we turn out as adults. Due to the injury that led to my paralysis at four years old, my parents made a decision to admit me into a so-called 'special school' for children with disabilities. Now, we can probably all agree that's rather an early age to be away from the comforts and amenities of one's home, especially when it happens in the context of a newly acquired paraplegic status. Don't get me wrong—I was extremely lucky to be in a school where I could access the best possible rehabilitation, given the traumatic event I had been through, losing the use of my lower limbs. But, in order to get this help, I now had to be away from home, staying with a bunch of strangers. The rehabilitation process was aided by having access to occupational therapists and physiotherapists, psychologists, teachers and caregivers that seemed to fully understand my needs for accomodation. In addition, the layout of the school was completely accessible. It was a very supportive environment.

And it was an environment marked by many of the normal naughtinesses of school years: just like any kid, my peers and I at the school also got up to no good. My friends and I once got into trouble for being found in a girls' hostel. There was no such thing as visiting hours; the school was designed for boys to live in their own space and girls to live in their own, so basically we had broken the rules. If truth be told, I was asking a girl out, but her friends decided to rat on me. Can you believe it? We were punished, and were told that we could not see each other. She had just read *Romeo and Juliet* or seen one of those "young person being rebellious against the world" type of movies, so we continued to see each other despite the housemothers saying we should separate. How's that for young love?

In our school, we participated in everything that mainstream schools did, like sports and music, and we also took excursions so that we could get to experience the "outside" world every now and again. That's where I think some of my insecurities first arose. By that I mean to say, it was clear to see that when I was out in the world in groups along with schoolmates, the way people would stare at us would make it absolutely clear that they had never seen such a large group of children with disabilities. I never really understood this, because from the point of view of me as a child who had been exposed to disability and kids with disabilities from a very early age, I assumed that an adult would have at some point been exposed to that as well. I think that is what led to a deeply rooted sense of inferiority that developed amongst most of us when it came to mainstream society and feeling left out. We were like fish out of water when we were not within the confines or gates of our school.

Our experience of the outside world came primarily through those school excursions, our time away on holidays, TV, and music. I think every school has that cool group that always seem to know everything that the larger group of kids don't know much about. I remember in our group of friends there was one boy who always had the coolest clothes, had more non-disabled friends that he hung out with during holidays, knew all the movies before most of us saw them, and, of course, had more experience with girls. I remember clearly this one time when we came back from holidays and this friend of ours, I don't want to say his real name, but let's call him Cyril, told us this story of the best New Year's Eve he had, where he went to this party, and he kissed this girl and apparently found his way a bit further south in terms of her anatomical region. He told this story in a very colourful manner and was so proud of himself. Between you and me, I think he added not just extra salt to that story but a few spices from very far away. But hey, we were just a bunch of teenagers who didn't know any better, so we just accepted that story. Now, the point of this story, is that Cyril had apparently hooked up with a non-disabled girl while the rest of us were still caught up dating within the scope of girls we found ourselves with at the school. To us, though it is hard to admit it, we saw non-disabled girls to be more of a prize than the girls with disabilities.

That is where my internalised prejudice regarding disability emerged. It was largely based on the issue of us, the children with disabilities, versus the kids of the bigger world that were without disabilities. To have any relationship with a non-disabled person was seen as an achievement, because we saw that as breaking the mould and out of the norm of your equal, your equal being another person with a disability, just like you. We viewed non-disabled people as superior to us, even on a friendly level, and being in a relationship with them was a bigger feat to achieve. I clearly remember that if a girl with a disability was dating a non-disabled boy from the outside world, she was immediately seen as being out of our league, despite her having a disability just like us. We knew just from that, that we stood no chance as boys with disabilities. Besides, which wheelchair user would stand a chance anyway, right?, I used to think. I will come back to discuss how such a view of the outside world informed my identity, disposition and attitude towards women when I eventually left school and integrated into mainstream society. However, it was with all of these experiences in mind, and my recollections of time at a 'special school' at the fore, that I took the following photo. In the picture below, is an area of my new university home, which is accessible to me. However, not all spaces in the world outside of a "special school" are accessible (Image 7.1). These physical spaces are a metaphor for my feelings regarding dating and relationships in the 'terrain' of a segregated school, and in the outside world, respectively: the outside world being fraught with inaccessibility.

There is another aspect that added to my feeling of being inferior as a man with a physical disability. Reflecting upon my own upbringing amongst men in my surroundings, gender roles are quite definitive of a place a person has in society. The culture I belong to is Zulu (I know there is no one definitive experience of a culture, but for the purposes of an understanding of my life, I will represent my experience of being Zulu). My family comes from an area called *Umbumbulu*, a rural area situated in the south of Durban in the KwaZulu Natal province of South Africa. In Zulu culture (as I experienced it), it is almost as if by virtue of being male, one is already perceived to have leadership qualities, and headship is something of a birthright. With such a birthright, one is expected to

Image 7.1 This is an area in a university residence which is flat and accessible. The image represents a symbol of accessibility aside from what I was exposed to back in my special school. Spaces communicate, they are able to tell you who is welcome and who is not (Photo by Bongani Mapumulo)

embrace and accept the responsibility of being a man and therefore a leader irrespective of whether on has physical prowess. Physical prowess, however, is something that I, as a man with a disability, often battled.

So, broadly, that is my position as I write this piece, personally, as it were. My upbringing and my culture both influenced how I came to experience having a disability, and how I saw this experience in relation to what I witnessed among non-disabled people and what I saw in broaer society. However, beyond my personal reflections on my experiences of physical disability, I am also coming into a phase of my life—as a student of social studies and disability scholarship—where I am beginning to engage with academic ideas and research about "disabled masculinity".

How I Think About Masculinity in the Context of Disability

Men's bodies have always had to submit to characteristics such as "strength, potency and physical activity" (Connell, 1995, p. 44). Morris (1991, p. 93) goes even further by asserting that:

> A social definition of masculinity is inextricably bound with a celebration of strength, of perfect bodies and to be masculine is not to be vulnerable. It is also linked to a celebration of youth and of taking bodily functions for granted.

Disability is often seen to be antithetical to this, a perception fuelled and strengthened by the portrayal of disability in movies as involving weakness, dependency and frailty. A typical portrayal is of a man who loses his masculinity due to some form of impairment. Such frailty can be in the form of impotency and the struggle to adjust to it. A movie most people would have watched is *Avatar*, where there is a lot of military activity. In this movie, disability is portrayed as incompatible with masculinity through the character Jake Sully, who is not only the physical but also the psychological inferior of his twin brother, who is a man without disability. And of course, in Me Before You, the character of Will Traynor, paralysed from the neck down, would rather die than face the reality of not being able to satisfy a woman sexually due to his disability. The movies' plots are a bit more complicated than that, to be fair, but the dominant narrative in the abovementioned movies is that disability and the main features of masculinity cannot coexist.

While I cannot personally relate to the way men who acquire a physical disability in their adult years struggle to adjust to their male sexuality, Murphy (1987) describes the issue of sexual dysfunction in men akin to being emasculated and effectively castrated. He says that the emphasis many people place on erectile failure is linked to the incorrect view that all sex is by definition penetrative, when in reality sexual and emotional relationships offer a much wider range of expression. According to Tiefer (1995), such an issue further strengthens the idea that normative sex, for men, is and has always been closely linked to the patriarchal and heterosexual ideology rather than to broader and less restrictive ideas about sex and sexuality. Sexual pleasure does not emanate solely from penetration and there are opportunities to look into more diverse experimentations and alternative techniques to encounter and experience pleasure and intimacy.

For me personally, learning about how much broader sex can be than just penetration, is important. For most of my life I, like many other people, was also fixated upon the idea of reaching sexual satisfaction by means of penetration and no other way. I attribute this to the information and influence I was exposed to from my earlier ages. This narrow view of sex led me to a state of utter confusion and internal conflict. To make matters worse, I thought of any possible non-disabled sexual partner as by definition superior to me. My role with such a partner would, I thought, have to be submissive (and hence in conflict with what I had learned about what it means to be a man). I had, in short, a view of myself as an outsider in the broader scope of sexual participation: someone who was meant to be dominant but would always—by virtue of social status—have to be submissive. I felt like an "Other", an other in the sense that people with disabilities are excluded from the male identity which relies on superiority and negation from vulnerability. An example of this othering process from a different area of society would be the way White heterosexual men view themselves in opposition to women, Black people and gay men. The way I came to understand society and these different identities and their "Others" was that White heterosexual men were at the top of the hierarchy. This left me with a single, horrible question: where could I find a place of pride for myself as a Black man with a disability? I don't like admitting to having had these views, and I don't believe in them anymore, but like all of us I was deeply affected by the world I grew up in and the values it imparted.

Well, now that we got that part—my current understanding of the theory—out of the way, I bet you are asking yourselves whether I have restricted myself to dating only other people with physical disabilities, just like how things were at boarding school? I would say that things have rather changed since then. Firstly, I can admit that after leaving school the dating pool has shrunk quite drastically, and predictably so. So, I had to spread my wings in other directions. Secondly, just like the famous singer I mentioned above, I have also become a bit of a sex symbol myself, just with less money and fame. With that, I am actually referring to a state of mind rather than a physical one. You might say that's rather arrogant and presumptuous of me, and I'd agree with you, except for the fact that as much as I had never seen myself as appealing, attractive and all that, the most unpredictable things have happened. I don't exactly know what to attribute this to, but being on the periphery or fringes of society has assisted me to understand and make sense of the world from a particular standpoint, and this has benefitted me romantically.

Now, I have no idea what it is like for non-disabled men experiencing confidence- and insecurity-related challenges as they grow up. In my case, though, I clearly remember my watershed moment. I want to refer to what a participant alluded to during a research project carried out by Gerschick and Miller (1995, p. 202). Eddie, one of the participants, made a comparison of himself, a man with a disability, with women's experiences. He said "…looking at himself in the mirror, in this context it is important to observe that people with disabilities often experience the unwanted attentions, intrusions, and stares with which women without disability are familiar". Eddie is a heterosexual, working-class man with spina bifida, who experiences a particular conflict in his way of navigating masculinity in the context of disability. Without getting into the intricate details of his utterances, the main idea from what he says is that he and men with disabilities in general "…do not automatically enjoy the power and privileges of men without disability and cannot be assumed to have access to the same physical resources" (1995, p. 202). Essentially, he suffers from a form of sexual oppression as a man with a disability and therefore sees himself first and foremost as a man a with disability rather than a heterosexual man. There is a rather complex issue of the hierarchy of identity politics here. He has something in common with women: a second class status in society's eyes, compared to heterosexual men.

I can completely relate to the above narrative by Eddie. Out of school and into mainstream society, I carried severe insecurities and deemed myself as inferior to my non-disabled peers. While I cannot deny that a majority of such perceptions and my self-image crisis were internal, many can also be attributed to the experience of the mainstream societal gaze, and the baggage that is attached to it. One is never really sure of the origin of such gazes, whether they are from a genuinely sincere and compassionate place, or simply from a person's need for satisfaction of their curiosity about the "other". Yet with all the baggage of the gaze, my watershed moment came at the end of a curious woman's gaze, albeit achieved at the cost of surprising honesty and vulnerability on her part. There was a coffee shop that I used to frequent during my lunch breaks. There was a woman who always used to take her break at the same time as me; there was nothing much to our relationship except the few and far between casual exchanges we'd make to each other. However, I remember one particular day when the coffee shop was full of patrons and all the tables were full, that I happened to be by myself at my table. She scanned the room for some open spaces, realised the only possible space would be at my table and headed straight to my table with her drink. I imagined she was going to wait for her meal to be delivered at my table. Now, you're probably thinking I saw this as my lucky day, but hell no, I got really anxious and started panicking. But at the back of my mind, I was thinking, "As soon as her food arrives, she'll leave me in peace to deal with my wimp-ish and meek tendencies". But she did nothing of the sort—she decided to have her meal at the table with me.

I honestly cannot remember the details of that conversation, but it lasted the entire duration of our lunch break. To cut the long story short, from that day we started to see more of each other and even took our conversations to other places besides the usual coffee shop. I would love to better describe how expressive and direct this woman was, but I think that would need its own chapter. Let me just say it was my first experience of an assertive, dominant and open-minded person, who definitely took note of my shy, inward disposition, but was still able to immerse herself into a world we both did not really understand. Somehow, she was able to extract and liberate the inner man concealed behind layers and layers of my so-called inferior masculinity in the context of disability. Now, retrospectively, I can admit that there was a whole degree of problematic objectification that took place in that experience. As such, I don't assume that—later in my life—I would have found the same relationship as fulfilling. However, for me, at that time of my life, given the number of confusing gazes and feedback I had been receiving up until that point, particularly from the opposite gender, this experience served a specific purpose. I grew to embrace the mirror reflections of myself a bit more, understood that societal projections are not always negative, but even when they are, one still can exercise one's own agency in how to deal with them. Lastly, I learnt that others, at times, will be able to see the positive in you, that which you are not able to admit to yourself because you are too caught up in the negative self-imposed perceptions. Most importantly, it normalised relationships for me: some will be good, some will be bad, some will just be normal, with both good and bad in them. But being a man with a physical disability doesn't make me feel more or less likely to have any of these experiences. It does not make me more or less of a partner, or more or less of a man.

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CHAPTER 8

Sexual and Reproductive Health: Layers of (in)Access

Xanthe Hunt, Leslie Swartz, Stine Hellum Braathen, and Poul Rohleder

INTRODUCTION

Access has three layers.
Here are the first two: (1) Is there something for me to 'get at'?, and (2) If this something exists—is it possible for me to 'get at' it?

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For instance, (1) Is there the right to vote? (yes), and (2) Am I as a woman allowed to vote? (yes) (1) Is there a dentist in my area? (yes), and (2) Does the dentist have enough capacity to serve a new client? (yes)

In these scenarios, I have access to the vote and access to dental care.

Now, the third layer: Is there some hard to define social, cultural, or otherwise not readily visible force which might stop me from 'getting at' the thing I can access (technically), according to layers one and two?

Will my dad let me leave the house for long enough to vote? Would the people at the voting booth turn me away, despite the legality of my desire to vote? Would the dentist turn me away because he does not serve tall people? Is his office in an area I cannot access because my car does not have four-wheel drive?

In these scenarios, I cannot cast my ballot, and my teeth remain uncared for. I do not, functionally, have access to voting rights or dental care.

For people with physical disabilities, any or all three of these layers of access might be compromised when it comes to a range of services and rights.

In this chapter, we are concerned with access to sexual and reproductive health (SRH) services, but the reader should bear in mind that what goes for SRH goes for just about everything else; access is a substantial issue for people with physical disabilities (and people with disabilities more generally).

And even though this chapter is about SRH broadly, it is focussed on issues of access because, as we will see, access cuts across most SRH issues, and this is particularly the case for people with physical disabilities in South Africa.

So back to the layers.

For the first layer, our question in this chapter is this: are there SRH services for people with physical disabilities generally, and in South Africa in particular?

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For the second layer, we want to know: is it possible for people with physical disabilities to access SRH services, and what did study participants say about this?

Finally, we want to know whether there are forces—social and cultural and otherwise not so visible stuff—which stop people with physical disabilities from accessing SRH services, and what does this look like in South Africa?

We are going to focus on SRH services here because they lie at the centre of SRH: it is hard to have sexual and reproductive health if we cannot access health services. The foregoing chapters in this book deal with the other facets of SRH and sexual life quite comprehensively, and so here we want to think about clinics and doctors and nurses, sex education classes, having or not having babies, and other health-related things.

We draw on data from interviews with participants from this project, as well as reviews of the literature. Because this project and the participants' narratives are situated in a South African and thus a southern perspective, we focus on the literature from low- and middle-income countries (LMICs).

Are there sexual and reproductive health services for people with physical disabilities?

In a 2009 guidance note for the World Health Organization, Groce et al. (UNFPA, 2009, p. 5) wrote,

> All too often, the SRH of persons with disabilities has been overlooked by both the disability community and those working on SRH. This leaves persons with disabilities among the most marginalised groups when it comes to SRH services. Yet persons with disabilities have the same needs for SRH services as everyone else. In fact, persons with disabilities may actually have greater needs for SRH education and care than persons without disabilities due to their increased vulnerability to abuse.

Ten years after that document was published, there is still solid evidence that SRH services for people with disabilities, including people with physical disabilities, are scant (Ahumuza, Matovu, Ddamulira, & Muhanguzi, 2014; DeBeaudrap et al., 2019; Iezzoni & Mitra, 2017; Mosher et al., 2017; Ride & Newton, 2018; Trani et al., 2011).

What we mean by 'SRH services for people with disabilities', is two things, and both are lacking. Firstly, there are few general health services in SRH which are accessible to people with disabilities. Secondly, there are few SRH services which are specifically targeted at serving people with disabilities. In both instances, this is particularly the case in LMICs like South Africa (Ahumuza et al., 2014; Smith, Murray, Yousafzai, & Kasonka, 2004; Trani et al., 2011).

Recent studies show that sexual health problems are more prevalent among people with disabilities than among people without disability, and sexual dysfunctions, problems in intimate relationships, and practical difficulties in sexual activities are more prevalent among people with physical disabilities (Pieters, Kedde, & Bender, 2018). Spinal cord injuries, for instance, can result in erectile dysfunctions, pain during sexual intercourse, reduced subjective arousal, and difficulties achieving orgasm (Pieters et al., 2018).

However, there is a substantial amount of evidence which shows that—when optimally supported by medical interventions, rehabilitation professionals, intimate partners, and others—people with physical disabilities can engage in meaningful and satisfying sexual lives (Ayaz et al., 2018; Hunt, Braathen, Swartz, Carew, & Rohleder, 2018). Much of what makes this possible are adequate supportive services and accommodations.

> There was very little support for people with disabilities; very little sexual health and reproductive support. I mean, there was little psychological support and very little support when it came to abilities to have sexual intercourse and all those things. So it was just like a…not a learning curve…but ja, whatever happens, happens.—Simon

As the above quote from a male participant highlights, for people with acquired physical disabilities, despite the importance of such assistance, there may be little support in the course of their rehabilitation, for SRH and sexual life. Upon acquiring a disability, and entering occupational therapy or other rehabilitative services, sexuality, and re-entry into sexual life as a person with a physical disability has historically been overlooked (Tepper, 1992). Recent research suggests that this is changing in high-income countries (HICs) to some degree (Pieters et al., 2018), but due to the general scarcity of services and overloading of those which do exist in LMICs, there are still failures in provision in South Africa (Rohleder et al., 2012; Wazakili, Mpofu, & Devlieger, 2009).

For people with congenital disabilities, and people with acquired disabilities after the period of acute rehabilitation, the difficulties of accessing SRH services endure.

For the general population of South Africans (regardless of disability status), SRH service delivery is patchy. Data suggest that sexual education in the country is not uniformly delivered (Africa, 2019), HIV testing services are underutilised (Africa, 2019), and social, cultural, and attitudinal barriers exist, particularly for women trying to access SRH services. Nurses, for instance, have been found to treat young women poorly when the latter attempt to access contraception or prenatal care (Holt et al., 2012; Wood & Jewkes, 2006).

There is very little data about whether or not people with physical disabilities are accessing general SRH services. In South Africa, for instance, the Department of Health keep no record of whether women giving birth at a government facility have a disability. This makes it hard to tell whether women with physical disabilities are having babies or not; if they are, whether they are having them at health facilities or not, and if they are not, why not?

One of the greatest learnings from the study on sexuality and disability has to do with the immense lack of epidemiological data about SRH for people with disabilities, and the SRH of people with disability.

There is also evidence that people with physical disabilities may require supports in SRH which make specialised services necessary (Pieters et al., 2018). As one of the participants noted:

> 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.—Vic

Given the overall lack of services in LMICs, there are almost no specialised SRH services for people with physical disabilities. Even in HICs, these are lacking. For instance, Mosher et al. (2017) found that American women with physical disabilities reported lower receipt of family planning services compared to women without disabilities. In their large survey in the United States, the authors found that discrepancies in access were larger among low-income women (Mosher et al., 2017). Similarly, in Canada, Tarasoff (2017) found that perinatal care systems are not set up to cater for women with physical disabilities. They noted that barriers to care might contribute to poor outcomes for women with disabilities and their infants.

In South Africa, task-shifting approaches, which utilise paraprofessional community health workers, have been successful in extending health services to hard to reach and underserved populations (Lewin et al., 2010). However, as we will see in the following sections, unless attitudinal barriers to service provision for people with physical disabilities are removed, disparities in access will likely endure, even if the number of service provision options increases.

A final note which should be made in this section, regarding the existence of SRH services, has to do with sex education at schools. Sex education—any content delivered routinely in schools which concerns sexuality, sexual health, gender identity, and related thematic areas—is largely overlooked at schools for people with physical disabilities. Although South Africa as a country has a standard sex education (so-called 'sex ed') curriculum, delivered as part of the subject Life Orientation, there is evidence that in schools for children with disabilities, this curriculum is poorly and inconsistently implemented (Chirawu, Hanass-Hancock, Aderemi, de Reus, & Henken, 2014). Moreover, it does not address disability-specific sex education, and as such may not be sufficient to meet the education needs of children with disabilities, including children with physical disabilities.

Given that the study participants were all already adults at the time that we conducted their interviews, there were few retrospective accounts of sex education. Further, given that these would have referred to a time often decades before the start of the study, it may not have been relevant here. However, one participant discussed her sexual development, and the disinclination of the adults in her world to engage in dialogue about sexuality. She noted:

> When I became a young woman and I started getting my periods, my mum looked at me with big eyes, but she never told me what's happening here. I had to fend for myself. I had to learn this from school. Even at school they wouldn't say much: be careful of the boys, but nobody made it clear to me… I was never educated. Nobody spoke to me about sex. Nobody gave me the facts of life. I had to hear and pick it up as people spoke or from my surroundings or whatever. So whatever I gathered as I grew up, I had certain beliefs, although I wasn't even sure if it was factual.

Despite the fact that she was referring to an experience that happened in the 1980s, recent evidence from South African adolescents and young adults suggests that not much has changed since the participant's time (Chappell, 2016; Chirawu et al., 2014; de Reus, Hanass-Hancock, Henken, & van Brakel, 2015).

One of the concluding points concerning the existence of services, before we turn to a discussion of access, is that the lack of service provision for people with physical disabilities creates vulnerability and risk, over and above that already experienced by people with disabilities as a marginalised group. For instance, it has been suggested that women with physical disabilities' lack of social experience (due to parental or teacher attitudes) and lack of exposure to sexual education, creates additional vulnerability to sexual violence, and may lead women with physical disabilities to be less likely to disclose violence experiences (Crawford & Ostrove, 2003; Kvam & Braathen, 2008).

Lack of sexual health education has also been cited as a risk for unwanted pregnancy, the contraction of sexually transmitted diseases, and limited sexual expression among adolescents with disabilities (Bremer, Cockburn, & Ruth, 2010; Nguyen, Liamputtong, & Monfries, 2016; Seidel, Wienholz, Michel, Luppa, & Riedel-Heller, 2014).

Is it possible for people with physical disabilities to access SRH services, and what did study participants say about this?

The next question, pertinent to our discussion of access, has to do with structural barriers people with physical disabilities encounter in going to clinics and hospitals and obtaining SRH services. If services which could serve the SRH needs of people with physical disabilities do exist, what practical things get in the way of this happening?

The first barrier worth noting is that buildings may be inaccessible and clinics and other SRH services unwelcoming to people with physical disabilities.

Studies examining access to health care for people with disabilities in South Africa have found a multitude of barriers to access, including inaccessibility of health facilities (lack of accessible toilets, ramps, etc.), problems getting to/from health facilities (lack of accessible transport, lack of support, etc.), lack of staff and equipment at facilities, geographical barriers (terrain, distance, crime, etc.), and attitudinal barriers (see for instance, Mji et al., 2017; Vergunst et al., 2017; Vergunst, Swartz, Mji, MacLachlan, & Mannan, 2015). In the image below, one of our participants, Simon, illustrated what physical barriers could look like, and 'feel like', both practically, but also metaphorically.

As one of the participants explained:

> It's quite a tricky situation seeing a person with a disability still going to ask for condoms. Some people don't feel comfortable in doing it. Most

> people with disabilities won't go to the hospital and ask for condoms. On the other hand, they won't have the financial capabilities of buying condoms as well, so they end up not using condoms.—Tas

Although Tas does not explicitly note why it is that people with [physical] disabilities do not go the clinic, he suggests that discomfort arises from providers' or members of the public's assumptions that people with physical disabilities do not need condoms (and as such should not be sexual in the first place).

Furthermore, service providers' lack of knowledge about disability produces a negative effect on accessibility. Vic explains that 'these health facilities, they know very little about people with disabilities and sex and sexual reproduction'.

Now, the right of people with disabilities to enjoy the highest attainable standard of health without discrimination is clearly stated in Article 25 of the United Nations Convention on the Rights of Persons with Disabilities (UNCRPD). This treaty was ratified by 175 countries in 2017, including South Africa.

Yet, people with disabilities are up to four times more likely than people without disability to find health care providers' skills and facilities inadequate to meet their health needs (not to mention to be denied health care and to be treated poorly in contacts with the health care system) (Aresu, 2018). The information available on barriers and facilitators to health care for people with disabilities remain limited with little data disaggregated by region, gender, age, or disability (Aresu, 2018).

Furthermore, prior to the UNCRPD, at the United Nations General Assembly in 2015, the adoption of the Sustainable Development Goals (SDGs) included disability in the post-Millennium Development Goals definition, which set the ambitious goal of leaving 'no one behind'. SDG 3 seeks to ensure healthy lives and promote well-being for all at all ages.

Yet, WHO estimates that 50% of people with disabilities cannot afford health care, which brings into focus perhaps one of the most pervasive barriers to health care access for people with physical disabilities: lack of economic means.

People with disabilities are, on average, poorer than people without disabilities (Braithwaite & Mont, 2009; Eide & Ingstad, 2011; Groce, Kett, Lang, & Trani, 2011). This is because employment opportunities which are accommodating of people with disabilities are fewer than for people without disability, and because the requirements for functional supports engendered by impairments (like needing a wheelchair, or accessible transport), can be substantial: so, a person with a physical disability may be less able to earn, and yet have expenses greater than, a person without disability.

As Nico explains, this has significant implications for sexuality and life quality:

> 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.

He continued:

> I used to get the same treatment at the rehabilitation centre where you do physio here, but due to finance-wise they don't give it anymore. But now they will give you a prescription to a specific place, but in that case you have to pay more but you have to pay for your pleasure, plus-minus R500, just for that specific thing that you want. And if that specific thing is finished you just have to repeat again. It's a lot of money. That is the case we are busy with now. And in my instance also I had to order these things. You have to pay for the product and you have to pay for the delivery as well. So it's a kind of tricky situation there that I'm going through now. And at the end of the day, but that is what you want or that is what you need, not just for yourself but for your partner as well. Can you see what physically-challenged people have to go through on a daily basis.

Another participant, Simon, similarly noted:

> I don't have support for assistive devices, all those things. Everything that I have and that I have to use, I pay out of my pocket. So, a lot of my finances go into just being able to operate affectively. I mean, my wheelchair costs R100 000. Where does that come from? It's my savings that went in there. The adaptations to my car, you know, proper cushions, looking after your health, all those things, it's a huge cost. I actually just work to provide for my disability at the moment, and that's tough.

What these participants' narratives point to is the impact of disability on an individual's economic situation, and the consequences of not being able to afford accommodations, on people's lives, and—in this study—their sexual well-being.

What else gets in the way?

It should be clear, from the above discussion, that even when there are services, and even when progress is made in provision, specifically for people with physical disabilities, when it comes to SRH information and services, the rights of this population continue to be violated.

It is clear, from a substantial body of research evidence, that much of this continued difficulty is due to deep-rooted discriminatory attitudes and practices from service providers and the public. What is more, even when attitudes are not explicitly discriminatory, the depth of societal assumptions about people with physical disabilities means that prejudicial behaviour is acted out by people without disability, even without the intention of doing so (Hunt et al., 2018).

Assumptions are part of the problem, here: as people with physical disabilities are taken to be asexual, the need for sex education for youth with physical disabilities is overlooked or improperly provided (Cheausuwantavee, 2002; East & Orchard, 2014; Seidel et al., 2014). We noted above that provision of sex education for young people with physical disabilities is limited, but what is also clear is that the reason for this is often teachers' knowledge and attitudes. The misconception that people with physical disabilities are asexual and so sexually inactive means that education systems and educators may overlook the need for sex education for students with disabilities (Pebdani, Johnson, & Amtmann, 2014).

As noted above, people with physical disabilities face additional risk of negative SRH outcomes, and sexual violence. Yet, despite this risk, two South African studies have produced evidence that educators tasked with delivering sex education content to students with disabilities lacked the knowledge and confidence to successfully teach this student population (Chirawu et al., 2014; de Reus et al., 2015). This again increased the students' vulnerability to HIV (de Reus et al., 2015; Wazakili et al., 2006).

Exacerbating the vulnerabilities created by the dearth of sexual health education, is the fact that almost nothing is known about how or if HIV prevention is being rolled out in South Africa for youth with disabilities (Chappell, 2016). This is despite the fact that researchers have noted an urgent need to provide sexuality education for youth with disabilities, and that HIV prevention is one of the primary public health foci of the country in relation to youth without disability (de Reus et al., 2015; Hunt et al., 2017).

The participants in the study discussed attitudinal barriers to access extensively.

One participant, who was living with a congenital disability, recounted the horrific encounter which she had with a health care provider:

> I went to a professor of genetics, and he was very cold. He said, well, if we had already found out the genes that cause [your condition], 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 [my condition] is a reason for abortion. So the whole motivation why I went to ask him about this so that I could be better informed, was just like blanketed by that.—Anne

Meanwhile, Pride explained:

> Oh, the nurses [at the clinic] 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.
> Interviewer: Because of your disability?
> Participant: Yes, how can you have a boyfriend? You can't have a boyfriend if you have a disability.

Pride, and other participants, explained that service providers found their requests—as people with physical disabilities—for HIV tests, contraception, or pregnancy services, strange or surprising, evidencing an underlying assumption that physical disability rendered people unfit for, or not in need of, SRH services.

Concluding notes and take-home points

Clearly, people with physical disabilities are excluded from sexual health education (Cheausuwantavee, 2002; Seidel et al., 2014), and sexual and reproductive health care (Hunt et al., 2017; Peta, 2017). They also experience challenges to their sexual development and assaults on their sexual self-esteem by people without disability who assume that they are less sexual because of their disability (Hunt, 2018). People with physical disabilities are also, often, lacking in access to sexual education (de Reus et al., 2015), and this might lead to additional SRH vulnerabilities, particularly in South Africa.

When a phenomenon, like access to SRH for people with physical disabilities, is determined by so many things it may seem hard to propose solutions. What thinking about access in terms of layers, as laid out here, might help us to do is find targeted solutions for every determinant.

Let's revisit our framework:

> For the first layer: how can we increase the number of SRH services for people with physical disabilities in South Africa?
> For the second layer: how can we make SRH services more accessible to people with physical disabilities?
> Finally: how can we shift the societal norms, assumptions, and prejudices which get in the way of people with physical disabilities accessing of SRH services?

Coverage and knowledge of what is needed—Clearly, SRH service coverage in South Africa needs to be widened and in a more equitable way, for all people. However, it is also apparent that specialised services for people with physical disabilities are needed. Specialist service provision needs to be grounded in the evidence base, and so what is required, first and foremost, is service-user research into the kinds of accessible services which might be most useful for people with physical disabilities in accessing SRH services. Epidemiological data, too, are needed if we are to have a better position from which to lobby for specialised services: as long as the scope of the need goes undefined, it will be hard to motivate for service delivery in an already over-burdened system.

Accessibility—Those environments, products, or services which cater for SRH in South Africa must be able to meet the needs of all persons, including people with physical disabilities (Aresu, 2018).

Participation—Efforts to improve SRH services must include the meaningful engagement of women and men, boys and girls living with physical disabilities in the design, implementation, monitoring, evaluation of all programmes, and policies affecting their lives (Aresu, 2018).

Equality and non-discrimination—Finally there needs to be widespread, systematic actions to challenge all of the attitudes, behaviours, and policies which discriminate against people on the grounds of disability (Aresu, 2018). Particular efforts need to be focussed on shifting public and service provider attitudes to the sexuality of people with physical disabilities, as these have a clear, deleterious impact on the SRH of people with physical disabilities.

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CHAPTER 9

Vic's Story

Vic McKinney

REFLECTIONS ON FATHERHOOD

As a boy growing up in Cape Town, South Africa, I always imagined that I would be a father one day. It was something that I took for granted. I had a very comfortable childhood growing up in a middle-class suburb in South Africa. I did not focus on fatherhood too much, I just imagined that I would go to university after completing school and then travel as much as I could until settling down in my early 30s with a family. That was my vague idea. I just always assumed that I would be a dad.

I was also very fortunate in that my father and I were very close—I was an only child and as a young boy he was my idol. By my late teens we were like best friends. This was a privilege not lost on me, especially when I saw how some of my close friends battled in their relationships with their fathers. Furthermore, it was heartening to know how proud he was of me, especially when I was accepted to, and enrolled at, the University of Cape Town as a fine art student.

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So when we had an accident on the road a month after my 19th birthday and towards the end of my first year at university, my life was turned upside down. My father died in the accident, and I was rendered paralysed from the shoulders down.

The early years following the accident were hard to get through. This was Primarily because, when I came out of rehabilitation (after an extended period of about nine months in hospital), I discovered that I had two disabilities—the one was my paralysis, and the other was how I was now regarded by other people.

During my confinement in hospital I was given an application form to live in a special residential home for people in wheelchairs. The message appeared quite clear to me: if you could not be healed, if you could not be fixed, then you did not belong in mainstream society. This was very difficult for me to handle. In an instant I had gone from being an active student who enjoyed the outdoors, photography and playing sport on a weekly basis, to being a social outcast that most people did not know how to talk to.

I did not go into the residential home. My mom and I felt that I would never get the level of care that I needed and would not survive very long in such a place. So I came home.

It was extremely challenging, to say the least. I was 20 years old and my mom had to look after me like I was a baby. I relied on her for everything: to get washed and dressed, and even to eat and drink. I became a boy again. A terrified little boy who needed his mommy. This had a profound effect on me. To exacerbate things, my mother had to give up her new job and her life to look after me. I felt like a burden, and this feeling had a substantial impact on me.

For many years after the accident, I thought that I could not be in a relationship—that I would be a burden, and that I would not be able to contribute to any relationship as an equal partner. This sense of myself as being inferior halted my maturity in many ways. At the time of my accident I was establishing my place in the world as a young man in terms of my masculinity and sexuality—but all that went out the window when I acquired a disability. It was extremely difficult, especially in the early years of my paralysis, to deal with the attitudes of people without disability in public.

When people looked at me, I felt as if they only focused on my wheelchair and did not see me as a person. Often, people would look away straightaway, pretending as if they did not see me. Sometimes people would just stare at me without saying anything. I have never been able to just blend into the crowd, since being a wheelchair user there is always some kind of reaction to my disability. As a young university student, when I met people, the first questions they would ask me were, 'What do you do?', and 'Do you have a girlfriend?' We are all social beings. These two questions link you to your fundamental value in society: the ability to work and to have children one day.

However, when people met me when I was in a wheelchair, the first question on their mind was 'What happened to you?' I found that to be the most common reaction people without disability had to me, and, while it was an okay question in and of itself, the problem was that people's interest in me did not go any further than that. That is what was—and sometimes still is—really difficult. It makes me sad. Generally, people do not expect me to be able to do anything or to be in a relationship because I'm in a wheelchair.

In the early days of my disability, I was not seen as a sexual being anymore—or so I thought. Six years after my accident, I did get into a relationship that was quite intense and physical. It was short-lived, but had a profound effect on me. It awoke feelings within me that I had suppressed and gave me the belief that I could be attractive to someone. The new sense of confidence it bestowed on me saw me enter into a few subsequent relationships over the next 10 years.

My next relationship was with a friend I had known before my accident, and we had a summer romance. We had a good connection and I felt relaxed around her, which helped me not to stress about things. For example, I did not know how well my body would perform sexually, but I decided not to worry about it. After all, I had been through so much, what else could go wrong? It was great just to be close to somebody and I discovered that intimacy goes far beyond intercourse alone. From a physical point of view, over the years, the sensation in my body had gradually increased and I also discovered I could wiggle my toes and fingers slightly. During this relationship I was discovering what my body could and could not do in bed and it was quite exciting. I found out, to my pleasant surprise, that I could get an erection naturally while kissing. I did not ejaculate during sex, but afterwards my urine would be cloudy and so I realised that I was producing sperm. I gained a great deal from this relationship and it gave me a lot of confidence to be with the opposite sex again.

I grew a lot more confident and comfortable with my sexuality and I was out to have fun. A while after that, I got into a long-term relationship. It was a very physical relationship and that was quite important to me at the time. However, looking back at it, it was not a very mature relationship and after we had moved in together it did not last very long. The topic of children came up and I quickly realised that we were in no way ready for that. I refused to have children at that stage and the relationship ended soon after.

On a positive note, however, it did get me out of the house that I had shared with my mom for so many years. I was now living in my own place and did a lot of necessary growing up. Another positive factor was that during this relationship I discovered that I could ejaculate naturally. When it happened it was a very pleasant surprise and was the first time that I'd done so in 17 years. I realised I could probably have done it earlier but I just hadn't focused on it. It can take quite a while but then again, that is also the fun part!

However, with that comes a word of warning for somebody else in my position. A few times after I had ejaculated I immediately got a pounding headache, so I spoke to my doctor about it. He said that this is in fact extremely dangerous as it is hyperreflexia—this is an over-reactive response from the nervous system which can occur in people with spinal cord injuries. So he gave me a tablet to take 10 min beforehand which would regulate and decrease my blood pressure and so minimise the chances of having a stroke. It is also interesting to reflect upon the fact that during my rehabilitation from my accident, which occurred in 1987, no health professional ever discussed with me the possibility of being in a future sexual relationship, let alone having children. It simply was not thought of and no one took into account how it might affect my view of myself or my well-being overall. In the eyes of the medical fraternity, and society in general, once I became paralysed I was not considered as having a sexual identity anymore. My feeling is that this is still very much a problem for people with disabilities today, particularly in South Africa. Current Western culture may have a more open attitude about being sexually active, however, I think it is still very difficult for most people with disabilities to be seen as having a sexual identity, let alone being regarded as equal members within their communities.

Sometime after the break-up, a close friend of mine came over one day and he recalls how I had decided not to have any long-term relationships anymore—I had decided that they were too complicated and too painful. So he was surprised when he called me about a month later and I told him that I had met the love of my life, Emma. We had met at the University of Cape Town, where I was studying, and it was that special occurrence when we both just knew that we were meant to be together. We started dating and were discussing our future together very soon after that. We talked about having children within two weeks of beginning our relationship. We were married a year later in 2009, 22 years after I became paralysed, and started trying to have children about six months later.

One of the first things we did was have my semen tested and analysed. We discovered that the chances of falling pregnant naturally were very slim. My sperm count was on the low side, only about 20 million—the required amount is usually between 25 million and 500 million. Furthermore, besides the count, a semen analysis looks at the motility (the ability to swim forward) as well as the morphology (shape) of the sperm. The shape of my sperm was fine but they were a bit sluggish in movement.

To fall pregnant, we initially tried artificial insemination (AI) a number of times. It is much cheaper than the in vitro fertilisation (IVF) process and also slightly less invasive for the woman concerned. Basically, on the selected day of ovulation, I produced a sperm sample in the morning which was taken to the clinic to be 'washed' and processed and a small extract taken to be inserted in Emma. Emma took medication to facilitate conception. Also, I would produce a sample at home—it is far more comfortable and research has shown that producing samples at home as opposed to the clinic is more successful. After the sperm was inserted via a specialised syringe by the doctor, it was basically a waiting game to see if we had fallen pregnant. We did not expect much at the beginning but were still hopeful, and consequently disappointed when it did not work for three months in a row. After the third disappointment we were due to go overseas for a conference and decided to do IVF once we had returned the following month. I discovered from our doctor that falling pregnant is basically a numbers game. We had a minimal chance of falling pregnant naturally; the artificial insemination increased the odds somewhat but not a great deal, whereas the IVF process presented a 35% chance of success. It is, however, quite expensive and an uncomfortable process, for the woman in particular—my dear wife had to inject herself with medication daily to increase her egg production which made her feel bloated and uncomfortable. Again, on a set day of the ovulation process, I produced a sample in the morning which was taken to the clinic to be prepared—the important thing is to keep it warm, and my wife recalls keeping the sample cup with my fresh sperm in her bra while driving 10 min down the road to the clinic! The whole process was very clinical, and yet so deeply personal. What a story to share with our children when they're old enough to understand!

At the clinic they extracted eggs from Emma and injected my sperm directly into a few of the promising looking ones in the hope that they would fertilise. This part of IVF is known as Intracytoplasmic sperm injection (ICSI) and only requires one sperm per egg, which greatly reduces the chances of having twins. The fertilisation takes about five days after which we had one really good embryo (fertilised egg) and Emma and I went back to the clinic to have this transferred into her womb. Thereafter the waiting began for us, along with attending many checkups (especially during the first three months) to see whether the embryo had taken and the pregnancy was going smoothly.

We were very fortunate that it took first time and we had a beautiful healthy boy. Having my first son was an incredible experience. He spent a lot of his first six months asleep on my chest. We soon bonded and have the same connection that I had with my father—and in a way it is like having my dad back, which is amazing (Image 9.1). Having grown up as an only child, that was my mindset—and when Emma said that she wanted another child it kind of threw me. I was not averse to the idea, I had just not thought about it and felt that I had everything I wanted in our first boy. However, I was happy to try for another child and we went through the IVF process again three and a half years later. Fortunately, it was successful the first time once again and today we have two sons. It was wonderful to go through the same, yet different, experience with a second child. It is amazing how different the boys are in personality. I am fortunate that as an academic researcher I work a lot from home and so have time to spend with my boys and watch them grow up. These are valuable years and you cannot get them back once they have passed. During her pregnancy, Emma recalls that while being out in public with me (and having a very pregnant tummy) she received lots of quizzical and confused stares from onlookers, wondering whether I could possibly be the father. Sadly, these kinds of attitudes are quite common. But you never quite get used to them. One time, in a shopping centre, a woman came up to my wife and asked how we had sex.

This presents a challenge to my wife and I—both of us are academics with PhD's. We lecture on disability awareness and consider ourselves educators regarding disability issues. In that sense, we appreciate that

Image 9.1 *Two of Vic's favourite images include Emma when she was pregnant and getting a kiss from his young son Jamie. These photographs are on his mirror in his room* (Photo by Vic McKinney)

society in general is ignorant about disability and we need to change these views. However, there's a time, place and way to address personal topics properly and a shopping centre is not one of them. Emma admits that she was conflicted regarding her response to this rude woman—tempted to say that she has a great time and swings from the chandeliers, and equally tempted to tell the woman to get lost! In the end she chose to ignore her and we carried on shopping. These days I sometimes get the same quizzical looks when I'm driving around in my wheelchair with my two sons on board—one sitting on my lap tray and one sitting on my footrest between my feet.

For me, having my family has changed my identity—I am a father and a husband, first and foremost. My disability is secondary. However, I know that that is not how other people necessarily see me, and that is where change needs to happen in society.

Looking back, I sometimes regretted how much time I wasted after my accident, going through those relationships and getting my act together before I started studying and working properly. However, I realise now that it was necessary—I simply needed that amount of time to grieve and readjust to my new life of non-movement in a wheelchair. Furthermore, those relationships I had were stepping stones in my maturation, and it makes me appreciate even more what I have today.

I am also acutely aware of the privilege I have as a White wheelchair user in South Africa, and I jumped at the chance of being part of research into disability and sexuality, of which this book is a product. Most of the work and research Emma and I are involved in is dedicated to improving the lives of people with disabilities. People are genuinely surprised when I explain that we estimate there are over 30,000 wheelchair users in the greater Cape Town area, because we hardly see them. They have a fundamental human right to participate in society—to be educated and find employment and be in a relationship. And to have children, as most of us take for granted.

And to have children, as most of us take for granted.

We, as a society, have a long way to go to change negative attitudes towards disability. As humans, our sexuality is a fundamental part of who we are, and when you acquire a disability, sadly, it is often taken away from you. My wish is for people to realise that anybody can acquire a disability at any time. It may change you physically, and perhaps intellectually, but it does not change who you are, your value in society or your sexuality and sexual needs, including the desire to experience love and start a family.

CHAPTER 10

The Meaning of Participation: Reflections on Our Study

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‘Nothing About Us Without Us’

Article 23 of the United Nations Convention for the Rights of Persons with Disability (UNCRPD) emphasises the importance of the equal participation of people with disabilities in all areas of life, and the need

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for the elimination of 'discrimination against persons with disabilities in all matters relating to marriage, family, parenthood and relationships' (United Nations, 2006). This includes in respect of sexuality and sexual and reproductive health rights. Yet, there is a long way to go for such equality in participation to be realised. As is evident in the earlier chapters of this book, one of the greatest barriers is the negative attitudes and misconceptions of people without disabilities about the sexual needs and experiences of people with physical disabilities.

For equality to be achieved, the voices of people with physical disabilities themselves need to be included, as full participants, in the design, implementation, monitoring and evaluation of national programmes and policies related to sexuality and sexual and reproductive health. However, across the world, many people with disabilities lack knowledge and awareness about, or access to, their sexual and reproductive health and rights. This is even more pronounced in low- and middle-income countries, and accross much of Sub-Saharan Africa. While a lot of work is being done in HIV and sexual and reproductive health generally, there is little representation of disability in mainstream sexual health initiatives. When decisions are made about people with disabilities, they may be made by people without disabilities, and lack input from the people that they effect: people with disabilities themselves.

One of the mottos of the disability rights movement is 'Nothing about us without us' (Charlton, 1998). What this motto means is that it is necessary to bring people with disabilities to the table when it comes to making disability-relevant decisions. Furthermore, mainstream services need to be

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made inclusive, and this can be achieved by including the voices of people with disabilities, and by opening up discussion and advocacy for sexuality and sexual and reproductive health issues. This is not only at programme planning and health policy level, but in research and public education initiatives too.

This book is based on a research project that explored the experiences of people with physical disabilities. The earlier chapters have explored aspects of sexuality, relationships, femininity, and masculinity, and sexual and reproductive health, not just from an academic/research perspective, but through the personal experiences and voices of people with disabilities themselves.

Working Together to Tell Stories

Research typically involves the collection of data, after which researchers analyse it, and then report the findings in academic journals for other academics and researchers to read and learn from. This is important, and necessary to develop a critical mass of knowledge that can then be drawn on by interested parties to develop further action. But often, the benefits that such research has for the people on the ground, so to speak, takes a long time to develop, and the participants of the particular studies are not typically involved in what happens to the results; what further actions it may inform.

We wanted to do something different with the project upon which this book is based—and with this book. It was important to research what the societal attitudes were towards people with physical disabilities in South Africa, and what the personal experiences of people with physical disabilities were. Our survey of societal attitudes emphasised the need for more information and awareness about the sexuality and sexual experiences of people with disabilities.

However, this study also involved the work, stories, and photographs of people with physical disabilities. This part of the project generated a lot of useful, personal, and emotive data, in addition to powerful images. We wanted to put these to use to inform people—including non-academic readers—generally about what the issues are for people with physical disabilities when it comes to matters of sexuality, relationships, and sexual and reproductive health. A large part of the *Disability and Sexuality Project* included activities for getting these stories told and ‘out there’. This book is one such activity.

The process of doing something collaborative, like this book, is not a straightforward one. Important questions need to be reflected on—what will the book say? Who is the book for? And perhaps more importantly, who will publish it? This is no ordinary book. We wanted a book that was educational, that was academic in its content, but that also incorporated the personal, everyday stories of the participants we worked for. It is not a typical book for academic publishers. A publisher we initially approached rejected our proposal for the book, stating that to their mind it was not academic enough. We believe that this view, though understandable, is problematic. In-keeping with much contemporary work on disability studies, we believe that it is important to bridge the divides between the 'academic' and the 'popular'—to bring more people into the conversation (Garland-Thomson, 2005; Swartz, van der Merwe, Buckland, & McDougall, 2012). In our experience (and most members of our team are experienced academic authors) it has in fact been more challenging to us academically to attempt to bridge divides than to write in the traditional academic way. Although it has meant that we omit certain scholarly topics and forego certain theoretical discussion, we have tried to make concepts accessible to a wide audience. You as a reader will be the best judge of the extent to which we have succeeded.

The process of writing the book needed to be thought about. What will the content be? Who will write it and how? It is a collaborative effort between academics and researchers, experienced in writing for academic purposes, and men and women with physical disabilities who have varying experiences of writing, whether for academic or personal purposes. Some had no experience in writing at all. Some chapters are personal stories, while others draw on more academic content. The writers needed time to work at their differing paces and levels of confidence. There are different voices and different styles of writing. To our mind, this is what makes the book interesting, and we hope you, the reader, will agree.

One of the products that we worked on together, academics and participants with physical disabilities, was the production of a short documentary film. The film included personal stories of four individuals, with an overall narration by a fifth individual. More than the book, this required careful consideration of what key messages to tell in this film. The film script was co-created by all involved, telling both stories of exclusion as well as inclusion. The film is available to view for free on our project website: www.disabilityandsexualityproject.com. The film is also available with subtitles for those who use them.

The Experience of Participating

What has it been like to participate in a project like this, and work together on this book? For the core research team, it has been a journey of exploration. It has been fascinating, emotional, humbling, exciting, and hard work. For the thirteen people we worked with, this was also a new and exciting experience. At a final workshop marking the end of the formal research study, we invited participants to write their personal reflections and feedback on taking part in the project. This is some of what was written:

> "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 participant 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 really 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."

> "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 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."

> "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."

As these quotes reflect, the positive experience was not just about taking part in the study, but rather participating in a project, and sharing an experience together. For most, participation was not about helping the research team, or helping to take part in research generally, but rather, the hope of using their experience for advocacy, with the hope of bringing about social change. As one person reminded us all:

> "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 – not just as people who need care, but as whole people with needs as all other people have."

A Note on the Work Which Needs to Be Done

The lessons about participation are perhaps the most valuable from this study and this book. But the content of the findings also bears revisiting here. And, the chapters of this book provide a useful framework on which to hang some of our ideas about what needs to be done in research, practice, and participatory work concerning physical disability and sexuality. These ideas are the result of the academic and disability organisation research teams' reflections, as well as anecdotes shared by participants. Chapter 1 was about this project—so the question to be raised is, what kind of research needs to be done in the future? In the realm of sexuality and disability research in the country, it would be extremely interesting and valuable, going forward, for there to be more work with people with disabilities from other ethnic, cultural, and socioeconomic backgrounds, and other geographic areas, as well as other gender identities, and sexual orientations, to those included in this project and book. The value of research like that upon which this project is based is in diversity and representation. So, the short answer to what kind of research is needed, is: more research.

Chapter 2 shared some more background about this study, but also reflected on our findings regarding people without disability's attitudes towards the sexuality of people with disabilities. Changing attitudes is complicated, and some of the work which must be done to achieve inclusive, equitable attitudes towards people with physical disabilities will rely on shifting conceptions of the sexuality of people with physical disabilities. The automatic assumption that people with physical disabilities are somehow not sexual, could be shifted through representation (popular culture showing more people with disabilities in normative romantic and social roles), as well as through more projects such as this one, which seeks to share stories as a way to raise awareness. However, to really promote intimate citizenship for people with physical disabilities, it will also be important to shift how people without disability—and society as a whole—represents sexuality. As long as sexuality is represented and thought about as something which only fit, young, attractive, people without disability can optimally 'achieve', attitudes towards the sexuality of people with physical disabilities will unlikely change (Hunt, 2018).

Chapter 3, Rosabelle's story, showcases the fundamental importance of inclusion in all areas of life, for people with physical disabilities' sense of themselves, including in seemingly unrelated areas. In countries like South Africa where inequalities in access to citizenship and participation are rampant, the project of inclusion and accessibility is a fundamentally important one. Opportunities for people with physical disabilities to achieve as great a degree of independence and participation as possible will be central to their capacity to achieve inclusion.

In Chapters 4 and 6, we spoke about femininity and masculinity, respectively. What each of these chapters, and the stories shared by Cleone, Bongani, and Vic, in their respective chapters, showcase, is the imperative of shifting attitudes to people with disabilities, and thinking about gender and expectations for gender roles, when people are young. All of these co-author participants spoke about the role which their socialisation had played in making difficult their experience of physical disability. Primarily this was due to their expectations for what 'normal' (without disability) men and women were expected to be and do, and their feelings of not measuring up to this in some way. As Chapter 6 illustrates, much of what needs to be done to shift these narrow and constraining conceptions of gender, will entail social movements around gender and sexuality which include people with disabilities (including physical disabilities), and movements around disability which include people with a broad array of gender identifications. As noted, a limitation of our work in this project is the absence of transgender and LGBTQ+ voices. Future research work could usefully examine how LGBTQ+ experiences of people with physical disabilities in South Africa. Exclusion is often a multilayered phenomenon, and so the voices of people who are minorities in more than one area (as people with disabilities and as sexual minorities) are vitally important to the project of inclusion.

In Chapter 8, we reflect on the state of SRH access for people with physical disabilities, with a focus on South Africa. One of the greatest learnings from the *Disability & sexuality* project had to do with the immense lack of epidemiological data about SRH for people with physical disabilities, and the SRH of people with physical disabilities. This kind of data could include information such as:

1. How many of the women who give birth in South Africa every year are women with physical disabilities?
2. How many of the women who file a sexual assault complaint in South Africa every year are women with physical disabilities?
3. How many of the people who access contraceptive services in South Africa every year are people with physical disabilities?
4. Of all of the children and adolescents with physical disabilities in South Africa, how many have received comprehensive sexual education?

The fact that we cannot really answer any of these questions is a considerable problem for those of us who want to provide services for people with physical disabilities. Until the scope of the need is established, it is hard to pitch services. While studies such as the one upon which this book is based are important for reasons of inclusion and voicing, large-scale epidemiological studies are very important too, and public health as a field could contribute a lot to understanding the needs of people with disabilities in South Africa, and other low- and middle-income countries.

The research results from this study, the stories shared, and the conclusions of this work all point to the need to think about recent theorisations of intimate citizenship by Ignagni, Shromans, Liddiard, and Runswick-Cole (2016). 'Intimate citizenship' concerns our rights, responsibilities, and agency to make personal and private decisions about with whom and how we are intimate, when we share intimacy, and why (Plummer, 2001).

As Hunt (2018) noted, the right to intimate citizenship, for people with physical disabilities, is impinged upon by the thoughts, feelings, and actions of non-disabled people (and internalisations of disablist attitudes). Ignagni et al. (2016) wrote, about intellectual disability, that 'intimate citizenship is fragile in the lives of labelled people' (p. 132). This seems to be true in the lives of South African people with physical disabilities. If people with physical disabilities continue to be excluded from dominant conceptions of sexuality and excluded from services and relationships, and as a consequence to feel 'less than' people without disability, their intimate citizenship will continue to be precarious.

This matters because, as Hunt (2018) notes, intimate, equitable relationships play a dominant role in securing the social support and capital which support activity in numerous other facets of existence, including safety and security, and accessing important resources (Ignagni et al., 2016). Equitable intimate relationships and partnerships are also a source of support against violence and discrimination, experiences to which people with physical disabilities in South Africa are all too vulnerable (Astbury & Walji, 2014; Hunt, 2018). As such, the attitudinal barriers described by the participants in this study, and revealed in the survey, may have very real social and economic costs for people with physical disabilities (Hunt, 2018).

Concluding Notes and Take-Home Points

What this project highlights is that these issues of sexual recognition and exclusion are issues of citizenship and justice, and part of the solution to injustices involves collaboration and creativity. The process of doing work that is participatory, *requires* creativity. Much of the process of working together on this project, and writing this book, evolved over time. It required us to be surprised and discover new ideas along the way. It required us to be challenged and to learn along the way. Above all it required us to enjoy working together and learning from one another. We hope that this has been reflected in this book, and that, in turn, you the reader have been surprised, challenged, and inspired to learn something new.

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