

We need to talk about Ballen: Towards a working protocol for representing people with intellectual disabilities and the photographic practice.

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Declaration

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Abstract

Representations of people with intellectual and developmental disabilities (PWIDD) in the media are rare, and when they do exist, portrayals tend to reflect and perpetuate their marginalization by relying on harmful stereotypes and tropes. Knowing that the media can be a powerful influence on public discourse, this study argues that it is the ethical responsibility of media-makers to interrogate our own practice and to carefully consider how our representations affect PWIDD. Additionally, if we consider it our ethical imperative to uphold the dignity and humanity of PWIDD and to advocate for their civil rights, it stands that they be given the opportunity to have a say in their own representations, and to participate in research which concerns them. So, how do we make media representations of PWIDD more inclusive, ethical and humanizing? The aim of this study is to formulate working ethical guidelines for media-makers to aid the production of compelling, diverse and destigmatising representations which foregrounds PWIDD's humanity and dignity. Media-makers are members of the mass media (e.g. photographers, journalists, illustrators, editors, producers, stylists etc.) who create and influence the creation and dissemination of media. This study was grounded in feminist disability studies and drew on literature about disability rights, cultural studies, journalism and media studies. Through participatory action research's reoccurring process of fact-finding, action, reflection and championing for social justice and change, I explored how PWIDD wanted to be represented, or how they wanted to be described and portrayed in various forms of media. Using multimethodology, I collected a wide array of data from various sources. Firstly, through continuously investigating the literature and interrogating past and contemporary representations of PWIDD in the media. Then, by embarking on a collaborative photographic project with several participants, using Photovoice, interviews and photographic portraiture. By using Thematic Analysis (Braun and Clarke, 2012) to code, compare and categorise the data (transcriptions and photographs) eight themes emerged. These themes centred around what was important to the participants which could inform media-makers planning to represent PWIDD. By integrating the findings and themes with the literature, I was able to develop working guidelines which aim to subvert the ableist gaze. These included centering disabled voices, avoiding cliches, stereotypes and tropes and making the process inclusive and accessible. The results of this study suggested that active, accessible and meaningful collaboration between media-makers and PWIDD is

not only possible, but desirable to create compelling, diverse and destigmatising representations which foregrounds their humanity and dignity.

Keywords: representation, portraiture, photography, disability, intellectual disability, participatory action research, inclusivity, photovoice, feminist disability

Opsomming

Representasies van mense met intellektuele en ontwikkelingsgestremdhede (MMIOG) vind weinig in die media plaas. Indien dit wel plaasvind, is uitbeeldings dikwels geneig om marginalisering te reflekteer en te vererger deur staat te maak op skadelike stereotipes en afmakende verteenwoordigings. Wetende dat die media 'n magtige invloed op openbare gesprek het, argumenteer hierdie studie dat mediamakers 'n etiese verantwoordelikheid het om ons eie praktyke voortdurend te bevraagteken en versigtige oorweging te skenk oor hoe ons representasies MMIOG affekteer. Bykomend hiertoe, as ons oorweging skenk aan die etiese verantwoordelikheid om die waardigheid en menswees van MMIOG te handhaaf en hulle siviele regte te bevorder, beteken dit dat hulle die geleentheid gegee word om 'n sê te hê in hul eie representasie en om deel te neem in die navorsing wat hulle raak. So, hoe maak ons media respresentasies van mense met verstandelike en ontwikkelingsversteurings meer inklusief, eties en humanisties? The doel van hierdie studie is om werkbare etiese riglyne vir media makers te formuleer om te help met die produksie van oortuigende, diverse en destigmatiserende representasies wat die menslikheid en waardigheid van MMIOG op die voorgrond plaas. Mediamakers is lede van die massa media (bv. fotografe, joernaliste, illustreerders, redakteurs, regisseurs, styliste ens.) wat die skepping en verspreiding van die media skep en beïnvloed. Die studie was gegrond op Feministiese Gestremdhedsstudies (Feminist Disability Studies) en is ontgin uit literatuur wat handel oor gestremdheidsregte, kulturele studies, joernalistiek en media studies. Deur Deelnemende Aksienavorsing (Participatory Action Research) se herhalende proses van feitevinding, aksie, refleksie en kampvegting vir sosiale geregtigheid en verandering, ondersoek ek hoe MMIOG gerepresenteer wil word in die media, asook hoe hulle in die verskillende vorme van media beskryf en uitgebeeld wil word. Met die gebruik van multi-metodologie het ek 'n groot verskeidenheid data uit verskillende bronne versamel. Eerstens, deur die aaneenlopende ondersoek van die literatuur en die indringende ondersoek van vorige en hedendaagse verteenwoordigings van MMIOG in die media. Daarna, om 'n samewerkende fotografiese projek met verskeie deelnemers te begin deur gebruik te maak van Photovoice, onderhoude en fotografiese portrette. Met die gebruik van Tematiese Analise (Braun en Clarke, 2012) om die data te kodeer, vergelyk en te kategoriseer (transkripsies en foto's), het agt temas na vore gekom. Hierdie was gesentreerd rondom dit wat belangrik was vir die deelnemers en waaroor

mediamakers hulself moet vergewis wanneer hulle beplan om MMIOG te verteenwoordig. Deur die bevindinge en temas van die literatuur te integreer, was ek in staat om werkende riglyne op te stel wat ten doel het om 'n validistiese blik (ableist gaze) te ondermyn. Dit het die sentrerings van gestremde stemme, vermyding van clichés, stereotipes en afmakende uitbeeldings ingesluit en die proses is meer inklusief en toeganklik gemaak. Die resultate van die studie suggereer dat aktiewe, toeganklike en betekenisvolle samewerking tussen mediamakers en MMVOV nie alleenlik moontlik is nie, maar verkieslik ten einde oortuigende, uiteenlopende en destigmatiserende representasies van hulle menslikheid en waardigheid op die voorgrond te plaas.

Sleutelwoorde. representasie, portrette, fotografie, gestremdheid, intellektuele gestremdheid, deelnemende aksienavorsing, inklusiwiteit, photovoice, feminisitiese gestremdheid.

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Preface

Sometime in 1993, while travelling through the Western Transvaal of South Africa, the American geologist Roger Ballen made a photographic portrait of two men living in one of the impoverished small towns through which he travelled (Greenberg, 2015). They were brothers, twins. Their names were Dresie and Casie.

Upon their meeting, Ballen must have understood that they had some form of disability, as he later recounts being unsure if Casie could understand his greeting and he noted that he had difficulty speaking (Verwey, 2012). We can assume that Ballen found the twins aesthetically intriguing- according to him, the sight of Casie working in the garden made him stop his car and venture out to meet him. And being a practiced and skillful photographer, Ballen must have known that an intriguing subject often makes for an intriguing picture. But, what he couldn't have known in that moment was that he had just taken the one photograph for which he would be most remembered (Coslovich, 2009; Pilcher, 2010; Taylor, 2018).

In the image, Figure 1, Dresie and Casie stand close beside each other, shoulder to shoulder against a plain white background. Each wears a plain, light-toned shirt, one clean, one stained. The brother on the left-most side of the frame is wearing the clean shirt which is partly tucked in at his waist. His arms are folded. From his mouth hangs a short strand of drool. His brother stands to the right of the frame, one visible arm hangs at his side, the other has been cropped out. Both brothers wear frowned, quizzical looks. The image is presented in black and white.

Figure 1

Dresie and Casie, Western Transvaal (Ballen, 1993)



This image of the twins has become one of the most famous photographs by Ballen, who would become one of the most renowned documentary art photographers of our time (Mufson, 2017, Roger Ballen Photography, 2021). And eventually, I argue, this portrait (Figure 1) would also arguably become one of the most culturally significant contemporary, global representations of people with intellectual disabilities. I will unpack this image's cultural significance, ethical contention, and possible lessons to be learnt for visual storytellers later in this thesis. The image's relevance for the reader now is due to its

significance for how I, as a photojournalist and principal investigator of this study came to the field of intellectual and developmental disabilities (IDD) and first became interested in the pursuit of ethical representations of people with intellectual and developmental disabilities (PWIDD).

As a photojournalist, I came to the field of disability studies and the intellectual disability services through a clinical practitioner who would later become my wife. As we courted, my future-wife (whom I refer to as 'Wife' in this thesis) shared ideas of disability which I had never before heard. Like many neurotypical people, I had limited experience of intellectual and developmental disability. I had met very few people with such disabilities and had meaningful conversations with even fewer. And while Wife [they/them] spoke about their work and passion for the field of IDD, I struggled to marry the complex, dignified image of PWIDD as portrayed by their words with the one image that was burned into my brain. This portrait of Dresie and Casie (Figure 1). The incongruence planted the seed for what would later become this study, and left me with a question I hoped would be answered through this research: Why had I never encountered media about PWIDD which reflected the rich and valuable lives of PWIDD as communicated by this clinical practitioner?

For me, the twins were there from the start. Dresie and Casie's image (Figure 1), which in the context of this thesis has come to symbolise the need for a discussion about media ethics, is one poignant example of how much media representations really matter.

The legacy of the image (Figure 1), which will be unpacked in the literature review of this study, reminds us that representations do not exist in a vacuum. As I argue, each image or piece of media are but one puzzle piece which fit into a larger image made up of decades of representations, stereotypes and prejudices of PWIDD. As I study this image and its cultural significance, it becomes clear to me that we need to do more than just 'talk about Ballen'. We need to talk about the mechanics of representation (how we as photographers create and present our images), their effects and the responsibility of media makers to create ethical portrayals of PWIDD.

In this study, the portrait (Figure 1) and 'the need to talk about Ballen' is not really about Ballen, the photographer. It's about what we do right, what we do wrong and how we hope to do better.

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Chapter I: Introduction

In contemporary South African society and in most cases globally, there exists a pervasive culture of marginalisation and oppression for people with disabilities (Shaboodien, 2016). This is especially true when it comes to people with intellectual and developmental disabilities (PWIDD), who are often denied the right to meaningfully participate in society and make decisions about their own lives. Although South Africa signed the United Nations Convention on the Rights of Persons with Disabilities (UNCRPD), thereby requiring our country to adhere to guidelines and commitments for fighting stigma in various sectors of society, amongst other commitments, little has changed in how our society treats adults with intellectual impairments (Capri & Swartz, 2018; United Nations, 2006).

There has also been little progress made to improve the South African public's perceptions of people with intellectual and developmental disability (PWIDD) (Capri & Swartz, 2018). Instead, "individuals with impairments are disabled by assumptions of helplessness and powerlessness in South Africa" (Bantjes, Swartz, Conchar, & Derman, 2015, as cited by Capri & Swartz, 2018, p. 286).

Because stories shape our world, the media and cultural representations play a pivotal role in this disabling process, and they are integral parts of the system which excludes and marginalises people with disabilities (Barnes, 1992; Garland-Thomson, 2005b; Gold & Auslander, 1999; Stadler, J, 2006). As Barnes notes, "disabling stereotypes which medicalise, patronise, criminalise and demonise disabled people abound in books, films, on television, and in the press" (1992, p. 39). This has very real implications for their lived experiences and standing in society as well as their sense of self. In the words of the American and disabled actress, Jillian Mercado as quoted in an online feature article, "it's important to know how deeply rooted the underrepresentation and ableism can be" in contemporary media. She adds, "the way that representation has been for people with disabilities isn't in the best light, sometimes quite literally" (in Lu, 2020, para 5).

In South Africa, people with intellectual and developmental disabilities have historically been

kept separate from mainstream society (Foskett, 2014; Department of Social Development, 2016). While this isolation, often a result of state institutionalization, has not been experienced in the same way by South Africans of different races due to racialised policies by the apartheid government, it has still meant that, historically, few people experience everyday contact with PWIDD (Charlton, 1998). So, the portrayal of PWIDD in art and the mainstream media in South Africa is crucial – as for some, it may constitute the only thing which makes up their understanding of intellectual and developmental disability and those living with it (Burns & Haller, 2015).

In fact, the global disability rights movement and its scholars have long acknowledged how important cultural representations are, and they have emphasised how these affect the day to day lives of people with disabilities (Bolt, 2012; Sandell & Dodd, 2010). Essentially, the stories we tell and images we show of people with disabilities shapes the way society sees and treats them, as is the case with all other groups in society (Barnes, 1992, Garland-Thomson, 2005). In advocating for the rights of people with intellectual disability in South Africa, then, it is imperative to address their portrayal in our cultural representations. Doing so and supporting the creation of dignified and respectful portrayals can promote inclusion and tolerance in our society.

It is important to note that there have been pushes toward reform in the way PWIDD are portrayed in media globally and in South Africa. There is a way to go, and change may be slow, but several local and global media professionals (and the organisations they work at) are becoming more reflective about the links between stigma and representation and are making efforts to reform the way they represent people with disabilities. One only has to turn to photographers like Justine Tjalinks (2016), projects like The Radical Beauty Project (2021) and Netflix shows like *Atypical* (2021) to see examples of a push for destigmatising media practice, although like the latter, they are often imperfect. There may also be more cause for optimism in recent years as the world (particularly in the west) grapples with social and cultural movements like #metoo and #blacklivesmatter, which are also, in part,

concerned with interrogating the link between marginality, oppression and representation. For example, as Carter (2015) argues, with the onset of the #blacklivesmatter movement, in the United States of America there has been public outcry over how the unequal treatment of black Americans and white Americans in news media. Carter argues that one such example is the way in which black (or POC, people of colour) victims and perpetrators are represented in news media in comparison to white victims and perpetrators. Comparatively, it is argued, white people are memorialised in news media with images which emphasise their humanity and value to society, whereas black people have tended to be portrayed in far less glowing terms. Carter speaks of this, claiming that “the narrative seems to soften when White Americans commit an act, while African Americans are usually vilified by media” (Carter, 2015, p. ii).

While there are conversations occurring globally about the link between media representations and marginality regarding identity categories like race, gender and sexuality, the drive to change the media’s approach to covering people with disabilities (PWDs) has been slower. Zoe Proctor, who started an international modelling and acting agency for people with disabilities says, “historically people who have a disability have been left out of the diversity debate” and that they “are still the largest and most underrepresented minority group in the media and fashion industries” (Proctor in Huber, 2020, para 12).

In my thesis, I set out to understand the global and South African history of representations of people with intellectual and developmental disabilities (PWIDD), outline the way in which representations either reflect and perpetuate stigma, or subvert it and promote inclusivity and dignity. To do this, I explored academic fields of enquiry set out by leading global and South African academics in the fields of Disability Studies, Media Studies and Cultural Studies. I wondered what could be learned by applying this knowledge when pursuing a photographic portraiture project which set out to create ethical and dignified representations of PWIDD, particularly for South African photojournalists.

In the study of the literature, and later by looking at contemporary examples of media which

includes (and oftentimes excludes) PWIDD globally and in the South African context, I have hoped to answer three questions:

1. Which tropes abound in media about PWIDD and how do they contribute to stigma?
2. How can media makers approach representing PWIDD to fight stigma?
3. And what are the practical realities and challenges behind this endeavour?

I asked these questions of the literature in the aforementioned fields of enquiry, but I also applied what I was learning to engage critically with contemporary media which I encountered during my time researching and being a media consumer.

This final question was applied especially to my own experiences of creating studio portraits of PWIDD in Cape Town which I set out to make using the ideals of inclusive participatory action research design (PAR), incorporating Photovoice as well as interviews with my participants. Using these methods, I hoped to create dignified portraits which would imbue the sitter (person being photographed) with dignity.

It must be noted that this study was impacted greatly by the COVID19 pandemic. Unfortunately, the portrait-making, interviewing and recruiting processes were disrupted and ultimately halted in early 2020. Because PWIDD are considered a vulnerable population to the effects of the virus and resulting lockdowns (Courtenay & Perera, 2020), I did not resume in-person data collection even when lockdown regulations in South Africa were relaxed. Additionally, the academic institution through which this study was conducted, Stellenbosch University instituted a ban on data collection when the pandemic took hold of our country.

As such, the results of the following study were based on engagement with existing academic literature and contemporary case studies, as well as with the three participants and my own reflections of the data as a practicing photojournalist in South Africa. I hope that this research encourages more aspiring and practicing journalists to consult the insights of media studies and disability studies to

critically engage with how we can better represent PWIDD in the South African media. And save for that rather ambitious goal, my humbler hope was that with care, time and knowledge, I was able to make the people I photographed feel valuable and seen.

Chapter II: Literature Review

Through my initial engagement with the literature around the topics of ‘intellectual disability’, ‘media representation’ and its effects on stigma, I identified various topics and theories to explore. Firstly, I sought to understand and present a definition of intellectual disability and establish its prevalence in South Africa and globally. I then tried to position people with intellectual and developmental disabilities (PWIDD) in our global and South African social-historical context and briefly outline their marginality by describing some relevant touchstones of their oppression. I then turned to several theoretical frameworks to

1. Understand conceptions of intellectual and developmental disorders (IDD) in society and academia. For this, I became acquainted with the most prevalent models of disability, namely the medical model and social model, followed by a few emerging models which I will present in later in this chapter.
2. Present a useful lens through which to situate the social and cultural significance of representation, I briefly explored the field of cultural studies as a framework to introduce representations as they relate to power and culture. From there my investigation of the literature narrowed its focus to the particularities of photographic representation, the study of semiotics and ethical standards across various forms of media like fine art and journalism.
3. Orient myself to media of people with disabilities and PWIDD, I mapped out trends and tropes evident in media about PWIDD historically and in contemporary life. I finally applied these two examples of contemporary media I came across during my study.

Intellectual and Developmental Disabilities

The term ‘intellectual disability’ (ID) or ‘intellectual and developmental disabilities’(IDD) is an umbrella term which refers to a broad range of conditions which vary in severity (Adnams, 2016;

McConkey, 2019). Generally, people with IDD struggle with intellectual and adaptive functioning. This means that they have difficulties with adapting to the demands of everyday life (Adnams & Johns, 2016; Shaboodien, 2016; Vehmas, 2012).

Difficulties in three general areas of everyday functioning are associated with intellectual disabilities, namely: “conceptual – thinking and reasoning skills, social – communication and interpretive skills,” and lastly, practical – a person’s ability to take care of their personal hygiene or finances” (Adnams & Johns, 2016, p. 8).

According to the World Health Organisation (WHO), people with intellectual disabilities might have “a significantly reduced ability to understand new and complex information and to learn and apply new skills” and due to this, PWIDD’s ability to live independently can be impaired (World Health Organisation, 2019).

People with intellectual and developmental disabilities may also present with other conditions which disable them, such as visual impairment or mental health conditions (McConkey, 2019).

Intellectual disabilities are generally understood and diagnosed as one of four severities, mild, moderate, severe and profound (Tassé, Luckasson, Schalock, 2016). While people with IDD have higher support needs generally than people who are neurotypical, their intellectual impairment does not take away from the fact that they have the capacity to inhabit rich inner worlds and the ability to enjoy and contribute meaningfully to society and culture (Vehmas, 2012).

The term “Intellectual and Developmental Disability.”

The phrase “intellectual and developmental disability” has come to be a more acceptable term for people who were previously defined as “mentally handicapped” in South Africa. The change in language was partly an attempt to shed some of the stigma associated with the term (Adnams & Johns, 2016, p. 8).

There is some debate among the disability community about the terms ‘people with disabilities’

vs. 'disabled people', or people-first vs. identity-first language (Heumann, Salinas & Hess, 2019). In this thesis, the abbreviation 'PWD' will be used when referring to 'people with disabilities', which encompasses physical, mental, intellectual and developmental disabilities broadly. Furthermore, the abbreviation 'PWIDD' is used in this thesis to refer to 'people with intellectual and developmental disabilities' and the abbreviation 'IDD' is used to abbreviate 'intellectual and developmental disabilities.'

Diagnosis and Aetiology

Clinically speaking, the diagnosis of an intellectual or developmental disorder requires that deficits in "intellectual functioning and adaptive behaviour" (Carr & O'Reilly, 2010, p. 9) be present before the age of 18. Such "disorders usually have a childhood onset but tend to persist into adulthood...They generally follow a steady course rather than the periods of remissions and relapses that characterize many mental disorders" (World Health Organisation, 2019, para 15).

Prevalence. It is difficult to make accurate claims about the prevalence of IDD in South Africa partly because there are varying terms and methods used to define IDD in national surveys and studies. For example, intellectual disability has not been effectively categorised and therefore counted in our South African census (Adnams, 2016; Foskett, 2014; Lehohla, 2014). There was one such error made while trying to ascertain the prevalence of IDD in the 2001 national census survey. The census claimed that 0,5% of the South African population had some form of intellectual disability, but the count did not include people in institutional care, "therefore excluding a large population of persons with disabilities" (Adnams, 2010, p.437).

We do, however, know from global studies that we can make a conservative estimation that 1% of the world's population has some form of an intellectual disability (Adnams, 2016). But since IDD is more prevalent in low-and middle-income countries, we could also potentially place that estimation at 2% of our population (Adnams, 2016).

Social Context: Stigma and Marginalization

People with disabilities are among the most marginalised people in most countries in the world (Amponsah-Bediako, 2013). For many, living with a disability means to live with more struggle, pain and trauma than their non-disabled peers (Watermeyer, 2013).

PWDs are more often placed on the margins of economic, social and civic life and experience significant barriers to the pursuit of happiness, equality and safety. They are more likely to live in poverty (Emmet, 2006; McConkey, 2019), less likely to enjoy gainful employment (United Nations Department of Public Information, 2007) and to have access to quality education (Schneider, 2006). People with intellectual and developmental disabilities (as well as mental disabilities) are more likely to suffer police brutality (Wright, 2018), be victims of abuse (Wilczynski, Connolly, Dubard, Henderson, McIntosh, 2014) and are more likely to struggle to find romantic and sexual fulfilment (Hunt, Braathen, Chiwaula, Carew, Rohleder & Swartz, 2021; Wiegerink, Stam, Gorter, Cohen-Kettenis, Roebroek, 2010).

At the 2020 United Nations General Assembly, the Special Rapporteur on the Rights of Persons with Disabilities, Devandas-Aguilar (2020), presented a report which stated that despite global advances in disability rights over the past 50 years, “the deeply rooted negative perceptions about the value of [PWDs] lives continue to be a prevalent obstacle in all societies” (Devandas-Aguilar, 2020, p. 3). She noted that in many ways, this was rooted in the value system of ableism.

Ableism is a “value system” (Devandas-Aguilar, 2020, p. 3) which holds true certain expectations of physical appearance, ability, intelligence and behaviour which individuals must meet to be considered ‘normal’ or valuable in society. In ableist thinking, impairment and subsequent disability is seen as misfortune and “it is generally assumed that the quality of life of persons with disabilities is very low” (Devandas-Aguilar, 2020, p. 3). Stigma and oppression experienced by people with disabilities is often rooted in ableist thinking “as it informs legislation, policies and practices” (Devandas-Aguilar, 2020, p. 3).

The severity and effects of ableism vary throughout society, over differing temporal and

geographic contexts. Ableism changes over time and place, but it also appears differently in relation to different types of disability, like between physical and intellectual disabilities. Ableist ideas of visual impairment will, for example, understandably be different to ableist ideas of a developmental disability like that experienced by people on the autism spectrum. It is true also that like many other marginalized identities, there is an intersection between race, gender, sexuality, socioeconomic status and more.

In many cases, harmful perceptions (or stereotypes) about PWDs which are rooted in ableism, have been passed through society for generations have very real implications for PWDs, including for those with intellectual and developmental disabilities. In various parts of the globe like the United States and Germany, for example, this harmful ableist ideology led to the creation of the eugenics movement, which was considered a “widely accepted approach” during the late 1800s and early 1900s (Devandas-Aguilar, 2020, p. 3). Eugenic ideology deemed certain people ‘desirable’ or ‘undesirable’ to society based on their genetic makeup or on how closely they matched the ideals of the perceived ‘perfect citizen’ (Soudien & Baxten, 2006). This ideology gave way to eugenic practices like the atrocities perpetrated by the Nazi regime in Germany, which resulted in the murder of more than 300 000 PWDs who were deemed ‘useless eaters’ (Soudien & Baxter, 2006). A further 400 000 were forcibly sterilised by the Nazi regime (Devandas-Aguilar, 2020; Ley, Robertson & Light, 2019). Despite the clear link between great moral atrocities justified by eugenics, and the disenfranchisement of PWDs in modern society, “the significance of the eugenics movement and its impact on how societies continue to dismiss the value of the lives of persons with disabilities has long remained confined to disability circles” (Devandas-Aguilar, 2020, p. 3-4).

The marginalisation of PWDs and PWIDDs around the globe is an ongoing human rights concern. As could be imagined, the situation for PWIDD is often exacerbated by living in the global south and in low or middle-income countries like South Africa.

The South African Context

South Africa is among the most unequal societies in the world (StatsSA, 2020). In environments like these which are strained by socioeconomic turmoil, the marginalisation of PWDs is often worse than in wealthier and more equal nations. For example, when it comes to poverty, Emmett explains that “in South Africa, with its history of colonial subjugation and racial oppression, racial inequalities, poverty and disability are intertwined in complex configurations” (2006, p. 207). Simply put, “disability is both a cause and consequence of poverty” (Emmett, 2006, p. 208), reiterating the disempowered position of many South Africans with disabilities. As Swartz and Watermeyer note, “the idea of ‘oppression’ is firmly attached within South African colloquial culture to the idea of race; however, the marker of disability has yet to achieve this status...in short, the story of disability- in our country as well as any other- is a story of social oppression” (2006, p.1)

Pre-democracy under the apartheid system, policy regarding people with disabilities focused on interventions guided by “social welfare and medical concern” (Department of Social Development, 2016, p.31) in line with the “medical model” of disability which will be discussed later in this literature review. As such, it saw to the “provision of social grants and some very basic and rudimentary social services such as rehabilitation and habilitation services” (Department of Social Development, 2016, p. 31). With the apartheid government’s racist policies which prioritised the social and economic wellbeing of white South Africans over the majority black population, South Africans with disabilities who were black, mixed, Asian or comprised of other non-Caucasian ethnicities were also side-lined in receiving services from the state (Department of Social Development, 2016). As such, white South Africans with disabilities received “far more, as well as better services than their black (African, Coloured and Indian) counterparts” (Department of Social Development, 2016, p.32). Women, and especially women of colour, also received limited services in relation to men (Department of Social Development, 2016, p.32). South Africa’s history of systematised racial and gender inequality has resulted in people with

disabilities being one of the most marginalised groups in our country (Department of Social Development, 2016).

South Africans with disabilities commonly experience “mobility impairment, and difficulty in using public transport” (Behrens & Görgens, 2019, p.189). And PWDs also experience challenges to accessing quality education in South Africa (Howell, 2006). They also are more likely to lack employment (Trani, Moodley, Anand, Graham & Thu Maw, 2020). In their study of South Africans with and without disabilities in Johannesburg, Trani et al. (2020) found that “having a disability was directly and significantly predictive of depression ...and low self-esteem” (p.6). This suggests that social stigma against South Africans with disabilities is an “effect of stigma on respectively depression and self-esteem” (p.6) in South African society.

Overall, Trani et al (2020) found that “in a deprived urban area of South Africa, populated by Black South Africans, disability more than relative poverty, age or gender is the most powerful driver of discrimination, depression and reduced self-esteem” (Trani et al. 2020, p.8). This highlights the complex racial, class and gendered aspects of ableism and the marginalisation of PWDs in South Africa. In their study, Trani et al. (2020) also mention the particularity of intellectual and developmental disabilities, which is associated with “structural stigma” which is only “aggravated by ethnicity (being Black South African compared to White) as well as socioeconomic status” (p.2).

South Africa boasts one of the most progressive constitutional systems in the world and the rights of PWDs and PWIDD are enshrined by its assertions (Department of Social Development, 2009; Department of Social Development, 2016). But, “despite the existence of policies and services for the population with intellectual disabilities in South Africa, recognition of and provision for their needs carries low priority” (Adnams, 2010, p. 346). In its policy on disability, the Department of Social Development (2009) acknowledges that there is a long road to equity and inclusion for South Africans with disability:

Government has made remarkable progress in developing enabling legislation, transforming the state machinery and putting structures in place to be representative and responsive to the developmental needs of the People with Disabilities. However, People with Disabilities still face extreme social, economic and political levels of inequality and discrimination, contributing to their underdevelopment, marginalization, unequal access to resources and lack of service provision (p. 2).

As Adnams (2010) explains, “within this context, people with intellectual disabilities (PWID) in South Africa mirror [social] inequity and are to be found amongst the poorest, most vulnerable and marginalized” (p.346). For example, “PWID are vulnerable and South Africa suffers from persistently high rates of rape and sexual abuse” (Foskett, 2014, p.10).

For many reasons, which I have tried to summarise in this chapter but which actually warrants tomes of explanation, PWDs and especially PWIDD are marginalised from many aspects of South African society. The Department of Social Development (2009) summarises that “it is a known fact that different social, economic and political factors interact and create underdevelopment, marginalization, unequal access to resources and lack of service provision to People with Disabilities” in South Africa (p.12).

One of the most recent and egregious contraventions to the human rights of PWIDD in South Africa was the so-called ‘Esidimeni tragedy’ in which an estimated 143 people with disabilities died after being transferred from Life Esidimeni psychiatric facilities in Gauteng province to unprepared and under resourced non-governmental institutions (Capri, Watermeyer, McKenzie & Coetzee, 2017; Hodal & Hammond, 2018). The advocate, Dirk Groenewald summarised the scandal as one of “the greatest cause of human rights violation since the dawn of our democracy” (in Bornman, 2018, para. 1).

On the direction of Gauteng Department of Health, approximately 1 700 patients, were transferred from the privately-owned Life Esidimeni care facility to save costs in the pursuit of deinstitutionalisation and were victims of gross violations of their dignity and human rights (Bornman,

2018; Hodal & Hammond, 2018; Section27, 2021). It's also important to note that "at least half of the Esidimeni deceased lived with severe to profound intellectual disability" although this fact was not widely known by the public (Capri et al., 2017, para 4).

Following the public exposure of the scandal, the South African government embarked on an historic arbitration process, comprised of 44 days of hearings which resulted in R1-million in constitutional damages being paid out to each of the families of victims (Msomi & de Villiers, 2018).

As noted by Capri, Watermeyer, McKenzie and Coetzee (2017), the Esidimeni tragedy is not simply an example of "medical maladministration" but "a story about the socio-political abuse of people who only matter once they die" (para 2). They go on to argue that the scandal brought to light this gross abuse of human rights, but the "tragedy is an outcome of structurally embedded social injustices" remain in our country and its healthcare system (Capri et al., 2017, para 13). Further on in this thesis, I will unpack the Esidimeni tragedy in terms of what can be learned by the way that it was covered by the media. I will go into more detail about how the coverage, as well as comments made by officials who were implicated in the scandal reveal many of society's prejudices about PWIDD later in this chapter.

Disability Models

There are several "different perspectives" or "belief systems" about disability, known as 'models' (Amponsah-Bediako, 2013, p. 122). These models are a useful way to categorise, track and explain society's core beliefs about the phenomenon of disability. By exploring and critiquing the models, one hopes to understand the ways in which society views disability. Essentially, the models can be the lenses through which we view society's relationship to disability and those who live with it.

There are many divergent and intertwining models of disability in the realm of disability studies, but it's useful to begin with the two most prominent models in the literature which have driven discourse on disability for decades. These are the 'medical model' and the 'social model'. They are by no means the only prominent models, but their central ideological conflict makes them a good place to

start in an introduction to disability studies as they are a good illustration of some of the core ideological divides in disability services and studies. They are both most defined by their position on the concept of 'disability' vs 'impairment'.

Mike Oliver (2004), a founding thinker of the social model, summarised the conflict: "Models are ways of translating ideas into practice and the idea underpinning the individual [medical] model was that of personal tragedy, while the idea underpinning the social model was that of externally imposed restriction" (p.19).

Broadly, the medical model places the pathology within the individual (person with disability), focusing on the physical impairment within a person, whereas the social model places the pathology within the society which disables a PWD because of social attitudes and arrangements in response to the impairment (Dodd, Jones, Jolly & Sandell, 2010). These models (social, medical and later developments) are continually being renegotiated and developed by those in the disability rights field. In one such instance, the medical model forms the basis for the 'expert model of disability' which ascribes the labels of 'fixer' and 'fixee' to clinicians and PWDs respectively (Amponsah-Bediako, 2013). Similarly, the 'cultural model of disability' which "focuses on a range of cultural factors...[which] include medical and social factors [and] focuses on how different notions of disability and non-disability operate in the context of a specific culture" (Retief & Letšosa, 2018, p. 6) was thought in many ways to be the spiritual successor to the social model which proposed that disability could be found not in the body (or brain) of a person, but rather in society in the form of disabling stigma and social structures. Later theorists have built upon the social and medical models and presented alternatives like the 'ethical model of disability' (Kittay, 2011) and the 'feminist model of disability' (Garland-Thomson, 1997, 2002, 2005a) which approaches disability through a feminist lens.

These core models, the social and medical models, are oftentimes seen as at odds with each other, but it can be argued that it is necessary to have perspectives and schools of thought which are as

complex and varied as disability itself, “considering the heterogeneity of disability and ability” (Devlieger, Brown, Miranda-Galarza & Strickfaden, 2016, p.19).

In this chapter, I will briefly outline the medical and social models, as well look at later developments, namely the ‘cultural model of disability’ and an African perspective, the ‘ubuntu model’. Concepts laid out in these models will be referred to throughout this thesis.

The Medical Model

The medical model, which dominated western societies’ working conceptions of disability for most of the twentieth century, is “an epistemological hierarchy [which] positions biological realities as the most important mode of attribution in making sense of human experience” (Watermeyer, 2013, p. 29). The philosophy of the model is rooted in the biomedical approach to care and focuses on the detection and treatment of impairments. It supposes that it is the job of doctors and clinicians more broadly to correct impairments and thus the eliminate the root of human struggle (Watermeyer, 2013). The medical model sees disability as one and the same as impairment. It works on the assumption that disability is located in the body (McDougall, 2006) and it is something which ideally must be eradicated or alleviated by medical intervention (Brosco, 2010; Shaboodien, 2016; Watermeyer, 2013).

As Jackson notes, “other, similar descriptors [for the medical model] such as: personal tragedy model, individual model, and rehabilitation model, are often used interchangeably” (2018, p. 4). The medical model regards disability as a personal, private reality and is concerned with treating the individual (Amponsah-Bediako, 2013). The model is constructed around the belief that disability is “largely unconnected to the social or geographical environments” (Amponsah-Bediako, 2013, p. 122).

The medical model has been an influential model over much of the globe and especially in South Africa. In their Policy on Disability, the Department of Social Development (DSD) reflects that in pre-democracy “disability was addressed as a social welfare and medical concern within a framework known as the “medical model” (2009, p. 10). They go on to claim that the post 1994, new democratic

government adopted the social model of disability as its mandated approach to policy (Department of Social Development, 2009). But, K and Duncan (2006) claim that at their time of writing “psychiatry as a discipline in South Africa remain[ed] steeped in biomedical approaches to psychiatric impairment” (p.203).

Even though its widely held among scholars and activists that “the medical model...has dominated the formulation of disability policy for many years” (Amponsah-Bediako, 2013, p. 123) as well as shaped medical treatment, the model has also been heavily criticized. Garland-Thomson (1997) summarises the core critique which activists have levelled at the medical model, saying that its “interpretation of disability assumes that any somatic trait that falls short of the idealized norm must be corrected or eliminated” (p. 79). According to critics, this school of thought works under the assumption that “disability is dysfunctional” (Barnes & Mercer, 2003, p. 2). As a result, disability scholars have long bemoaned the harmful effects of the medical model on the disabled community, all the while “its attitudinal limitations are not yet fully appreciated by lay and professional role players alike” (K & Duncan, 2006, p. 307).

The medical model also affects the care and experiences of PWIDD, globally and in South Africa. For example, in her 2013 study, McKenzie found that participants with IDD “are not expected to take responsibility... so it falls to the parents and doctors to ...and plan for them This is particularly important as there is a high likelihood of ill-treatment” (p. 375). Additionally, Bertelli, Bianco, Merli and Salvador-Carulla (2015) claims that the “medical approach to therapeutic interventions with people who have IDD/ID ... have tended not to consider the uniqueness of people with IDD/ID fully and have been more likely to use the general population norm as their point of reference”(p.245). This highlights a possible medical conceptualisation which could limit the individualised care of each PWIDD. Especially as “it is not a reasonable therapeutic goal to have people with IDD/ID live their lives as close as possible to people without IDD/ID, because ultimately they have to find satisfaction in those aspects of life that are

important to them and that they can understand and experience” (Bertelli et al, 2015, p. 245).

Bertelli et al add that this has “resulted in interventions that have dealt primarily with containing troublesome behaviours and helping to alleviate symptoms, rather than to address the root causes of the problems” (Bertelli et al, 2015, p.245). While there is significant criticism of this model’s assumptions about disability from scholars and activists, the medical model also “has a significant role to play in the diagnosis and alleviation of biopsychosocial distress” (K & Duncan, 2006; p. 307). Because of “[the medical model’s] therapeutic aspects which may cure or alleviate the physical and mental condition of disabled people [it] cannot be rejected outright” (Amponsah-Bediako, 2013, p.123).

The benefits of the medical model lie in its acknowledgement of how impairments can negatively impact on PWDs lives, and that medical and clinical interventions can alleviate suffering. Impairments are not just disabilities but biological realities and resulting suffering can impede PWDs ability to live fulfilling lives and be included in society.

The medical model is longstanding and ubiquitous, it does not simply influence biomedical spheres of PWD’s lives. It also it enacts its conceptions of disability in the crafting of public policy, the educational system, charity institutions (Dodd et al., 2010) and, of course, in other levels of medical care.

Ultimately, the medical model is most criticised for reducing disability to the physical impairment of the individual, and negating the social, political and economic marginality that people with disabilities face because of their impairments (Watermeyer, 2013). But there are also many ways in which the biomedical understandings of impairment are necessary for acknowledging the impairing aspect of disability, which can significantly hamper a person’s activities of daily living. And to then assist PWDs with the healthcare and support needed to access civic life.

The key takeaways from the medical model are:

- Impairment is disability,
- Disability lies in the body of the disabled, not society,
- And must be treated by medical clinicians as such.

The Social Model

In the late 1970s as disability rights activists and academics sought to challenge the overmedicalization and individualization of disability rooted in the medical model (Waldschmidt, 2017), a new conception of disability was being formed in various countries across the globe. It is widely believed that the social model originated in Britain and then spread to parts of America, Africa and Asia (Gallagher, Connor & Ferri, 2014). The renowned British sociologist and disability rights activist, Tom Shakespeare (2010) defines the movement as social models borne out of the emergence of the Disability Rights Movement, a “family of social explanations of disability” (p. 266).

Shakespeare (2010) traces various early iterations of the social model to North America, Nordic countries and Britain (p. 266). The model is seen as an effective political tool, which was helped progress the British disability movement (Shakespeare, 2010; Hasler, 1993). The first organisation to officially pioneer the social model’s conception of disability and popularise the term were the Union of Physically Impaired Against Segregation (UPIAS) in the United Kingdom (Shakespeare, 2010; Berghs, Atkin, Hatton & Thomas, 2019). The UPIAS advocated for a society which was inclusive and accessible, so as to allow PWDs participation in civil life, and they used the philosophy of the social model to advocate for social change which would promote social inclusion and access to civic life for PWDs (Berghs et al, 2019, p. 1034).

This included campaigning for access to “medical care, transport, employment, education and welfare sectors or ending societal discrimination through rights legislation” (Berghs et al., 2019, p. 1034). In short, this model views disability as a social construct (Stalker, 2012), it understands disability

as a form of social inequality, and asserts that people with disabilities are an oppressed social minority (Waldschmidt, 2017).

The social model critiques the medical model as oppressive and stands in theoretical opposition to it. The social model's conceptualisation of disability is not individualised. Where the medical model places the disabling within the impairment and individual, the social model supposes that it is society's inability to fully account for the needs of disabled individuals and resulting failure to provide appropriate services that is truly disabling (Oliver, 1996; Dodd et al., 2010; Shaboodien, 2016). Or as Colin Barnes eloquently puts it, "that people with any form of accredited impairment are disabled by an unjust and uncaring society" (2012, p.12). The UPIAS and social model of disability critiqued the over-medicalisation of disability, but did not completely disregard the need for medical treatment related to impairment (Berghs et al., 2019) acknowledging the role medical interventions could have on the quality of life and civil rights of PWDs. Shakespeare (2010) understands the core beliefs of the social model as a series of dichotomies between: Impairment and disability. Impairment is "individual and private" while disability is "structural and public" according to social model thinking (Shakespeare, 2010, p.197).

The social model and medical or individual model. The social model understands disability as socially constructed and the medical model places the disability within the individual and the 'broken' body. The medical model sees the body as broken and in need of repair where the social model sees a broken society which disables its citizens with impairments. Disabled people and non-disabled people. This dichotomy recognizes people with disabilities as an oppressed group which require civil rights to be liberated, fully included members of society as opposed to charity. The liberation of PWD is rooted in civil rights, not charity. To this end, people with disabilities must be central in the movement toward attaining full civil liberty.

The social model has been an effective theory for advancing the civil rights of PWDs, in Shakespeare's opinion because of its simplicity. For this reason, it is memorable and effective as a

political tool (Shakespeare, 2010). The social model presents a “clear agenda for social change” (Shakespeare, 2010, p.198), identifying barriers to civil liberty for PWDs and advocating for changes which increase the inclusion of PWDs to the economic, cultural, academic and domestic opportunities central to civic life. It “places the moral responsibility on society to remove the burdens which have been imposed” on PWDs (Shakespeare, 2010, p.198).

On a recent podcast called *You're Wrong About*, the journalist and author, Eric Garcia echoed the sentiments of the social model, “I say this as an autistic person... we are human beings, we are fine just as we are. What really needs to happen is changing the world to adapt so that autistic people can live in it” (Garcia, 2021, 35:44). The social model has been a successful theory which has affected activism in the disability rights movement, academia and the public’s understandings of disability (Waldschmidt, 2017) and continues to do so today. It has also furthered efforts to make society more accessible and inclusive for PWDs.

Over the past two decades, the social model's school of thought has been widely debated by disability studies scholars, but there has been wide understanding that it is a “key conceptual tool” for furthering the rights disabled people (Dodd et al., 2010; Shakespeare, 2010). Amponsah-Bediako (2013) claims that since its inception, the social model’s influence can be seen in “thinking and policies in countries as diverse as Britain, Japan, South Africa and the USA” (p. 131).

The adoption and growth of the social model’s influence has brought about some tangible change in the advancement of the disability rights movement. One such example is how British activists used the assumptions of the model to expose various forms of discrimination and ableism in their society and this discrimination was used to argue for the resulting 1995 Disability Discrimination Act (Barnes, 2012). And because of this act, “services, buildings and public transport have been required to be accessible to disabled people, and most statutory and voluntary organisations have adopted the social model approach” (Shakespeare, 2006, p.199).

Beyond the practical changes brought about by the growth of the social model, Shakespeare argues that the model has psychological benefits for the individual person with disabilities, as well as the collective, for its role in “improving the self-esteem of disabled people and building a positive sense of collective identity” (2006, p.199).

In accounts of disability such as the medical and individual model, which assumes that impairment (and therefore disability) is a fault to be corrected, language such as the term ‘invalid’ can harm PWD’s self-esteem and be a barrier to inclusion in society. It is the social model’s reframing of disability as a social imperative to change, which Shakespeare argues empowers PWDs (2006). He surmises, “it is not the disabled person who is to blame, but society. She does not have to change, society does. Rather than feeling self-pity, she can feel anger and pride” (Shakespeare, 2006, p.200).

The social model’s principles and effects have extended to South Africa’s disability rights movement in both advocacy and the crafting of government policy related to the well-being of South Africans with disabilities. As du Plessis (2013) writes, “the human rights and development approach that was adopted by the South African disability movement is, at the macro-level, consistent with the social model of disability, because the central claim of the latter is that disability is caused wholly or substantially by social and environmental barriers that prevent disabled people from living independently and from participating in their communities” (p. 208).

In South Africa, disability studies academics have contributed significant theoretical frameworks built on the ideological and practical legacy of the social model. Most notably, these include Judith McKenzie, who suggests “a neologism of poss(ability)” to contend with the medical and social model’s perception of disability as static and instead suggests a “fluid conception of impairment” (2013, p.377) and Brian Watermeyer (2013) with his proposal of a contextual psychology of disablism which “explores individual psychological experience, whilst retaining a rigorous critique of social forces of oppression” (p.i).

A study conducted in Johannesburg which included 3915 households and sought to investigate the link between disability and depression and low self-esteem, Trani et al (2020) noted that their “findings substantiate the social model of disability which holds the view that, through stigma and discrimination, society is responsible for the systematic exclusion of persons with disabilities from all spheres of life” (Trani et al. 2020, p.7). They also noted the particularity of stigmatization on people with “psychosocial or intellectual disabilities”, finding that it “results in distress, withdrawal and experience of low self-esteem” (Trani et al. 2020, p.7).

While the simplicity of the philosophy of the social model is partly key to its effectiveness, it also poses a problem. Critics have called its ideology and political agenda far too narrow (Shakespeare, 2006; Gallagher et al., 2014). Berghs et al. (2019) also note a key criticism, that the social model has become a far too ‘rights-based approach’ which focuses too heavily on legislation and needed a more active approach to change.

Berghs et al. (2019) propose that disability rights activists desire the adoption of a social model of human rights which furthers civil liberty of PWDs but is not seen as “the end in itself” (para 4). In other words, the adoption of the social model must be a practical means of attaining quality of life for PWDs. The ratification of such a model in legislation and policy should not be seen as the ultimate goal, but the means to the end- which is the opportunity for PWDs to enjoy full civil liberties.

Other critics of the model believe that it attempts to homogenise disabilities and those who live with them, negating the many different forms which disability takes and the ways in which PWDs experience their disabilities (Gallagher et al., 2014). Some have also claimed that the model is based on “a romantic concept of social inclusion” (Anastasiou & Kauffman, 2011, p. 367) which may be unattainable.

Furthermore, critics have worried that the social model’s focus on social realities and not biological/biomedical ones could be an obstacle to helpful medical intervention for PWDs (Anastasiou &

Kauffman, 2011). As to the model's conception of disability vs. impairment, Anastasiou and Kauffman (2011), critics of the model, claim that it is discredited by the lack of consensus among disability scholars (Gallagher et al., 2014).

Critics of the social model have also argued that its promulgation by a small group of majority heterosexual men with physical impairments has "produced... a narrow understanding of disability" (Shakespeare, 2006, p. 200) which has not included the diverse voices of a very diverse population. This could be a particularly pertinent point when considering the South African context in which there exists an incredibly diverse population spreading over multiple cultural, economic, ethnic and political realities. In light of calls to decolonise or re-indigenise systems of power and ideologies adds further incentive for the model's growth and expansion in the South African context.

Those who level this criticism argue that the aim of the social model could be better realised by the inclusion of diverse voices, a more integrated concept of disability and impairment (as social and biological in nature), a recommitment to realising inclusion and civil liberty in tangible ways and a focus on what PWDs need to thrive, not simply survive in society.

Additionally, when it comes to intellectual and developmental disabilities, the social model "is often overlooked in research and writing about learning difficulty. While there are notable exceptions, the majority of research has not attempted to explicitly use the social model as a tool for analysing the views and experiences of people with learning difficulties, nor invite people so labelled to inform a social model" (Chappell, Goodley & Lawthom, 2001, p.45). Chappell et al. (2001) conclude in their paper on the links between the social model of disability and people with learning difficulties, that failing to acknowledge the pertinence of the social model of disability as a starting point for the advancement of the rights of PWDs broadly, "would not only ignore the emancipatory roads that the social model lays out for us to follow, but would also fail to heed the voices and actions of dissent from people who have been given a label of 'learning difficulties'" (p.49)

The Cultural Model

The conflict between the social and medical models of disability is by no means open and shut. Instead, scholars and activists have proposed numerous models building on these, influencing and branching off into models such as the cultural model, which is “presented as a logical continuation of the social model but encompasses the moral and medical models” (Devlieger et al., 2016, p.19).

It’s difficult to convey one unified idea of what a cultural model of disability is, definitions of the model differ, just as understandings of the term ‘culture’ differs depending on the speaker and their field of interest (Waldshmidt, 2018). Some academics have pointed to cultural representations as theatre, film, advertising and art, for example, and have looked at the way in which they represent PWDs, as well as the implications of such on PWDs (Waldshmidt, 2018). Others point to ‘cultural locations of disability’, namely in the work of Snyder and Mitchell (2006) who define these as “nineteenth-century charity systems, institutions for the feebleminded during the eugenics period; the international disability research industry” and so on (p. 3).

The concept is evolving still, as Devlieger et al. notes, the “cultural model approach, as it stands, remains an unfinished project that requires continued updates” (2016, p. 19). While academics spanning across academic institutions around the world have been engaged in enquiries based in the cultural model of disability, such as Shakespeare (1994), Rosemarie Garland-Thomson (2002) and Devlieger (2005), “the literature is frequently content with only presenting short definitions” (Waldshmidt, 2018, para. 32)

For the purposes of this thesis, the most relevant conception of the cultural model of disability is one presented by Devlieger et al. (2016) which also brings to disability studies the field of semiotics. Devlieger et al. effectively summarised the cultural model as “built on the semiotics of disability as found in words and images spread throughout postmodern societies where individuals’ identities are not given but made, and where individuals are predisposed to participate in social movements” (2016,

p. 19).

According to Devlieger et al., the cultural model takes a more postmodern approach to disability and highlights the role of language in how society makes meaning of disability, “trusting that since disability was constructed, it could also be deconstructed...and had the potential to be a resource for creativity and empowerment” (Devlieger et al., 2016, p.19). The study applies critical tools from various social sciences such as anthropology and media studies to do this deconstruction (Waldshmidt, 2018).

In conclusion, the cultural model of disability is an evolving approach to the field, one which can help us understand disability and society through critically engaging with our cultural actions, our creation, dissemination and consumption of cultural products and how they reflect and perpetuate societies ideas of disability. The model takes a multi-faceted view of disability, involving “inclusive modes of thought that confirm the complexity of disability as both an existential, technical, and social phenomenon, in other words defined and reflected by culture” (Devlieger, 2005, p. 8).

The Ubuntu Model

It’s no secret that for much of its short history, global disability studies have been dominated by thinkers and theories from the global north, sometimes referred to as the developed world (Grech, 2011; Berghs, 2017) a particularly ironic fact when considering that “majority of the world’s disabled people live in developing countries” (Shakespeare, 2016, p. 1153). Calls for decolonisation of knowledge systems has burst from the limited confines of the academy and into mainstream media, popularised by movements such as RhodesMustFall, which became a global movement with significant influence (Ahmed, 2020; Bhabra, Gebrial & Nişancioğlu, 2018; Chaudhuri, 2016; Rodrigues, 2020). In light of this it is easy to see how important it is to add African perspectives on disability to the field, something provided by the emerging African approach to disability, the ubuntu model.

The African humanist philosophy of Ubuntu has its origins in the Nguni phrase ‘Umuntu ngumuntu ngabantu’ (‘a person is a person through other people’) (Ngubane-Mokiwa, 2018; Shutte,

1993). Central to the ideology of Ubuntu is the value of community, as such it prioritises collective well-being, kindness and compassion (Ngubane-Mokiwa, 2018).

Ubuntu champions diversity and inclusion, it celebrates difference and teaches acceptance of all people regardless of their differences (Ngubane-Mokiwa, 2018; Eze, 2008). Since impairment is a part of the human condition, the ubuntu model sees disability as a part of what it means to be human (Berghs, 2017). As Waldschmidt wonders, why are “certain differences subsumed under the label ‘disabled’ and others considered as ‘normal’ manifestations of diversity?” (2017, p.19-20), a question which would seem to echo ubuntu. An African ubuntu perspective on disability would likely embrace disability as yet another variant in the human experience, like race, gender and age and subsume it with the others as valuable aspects of human diversity, a welcome addition to human collective experience.

The ubuntu model of disability uses the theoretical underpinnings of ubuntu as a lens through which to consider the treatment of those with disabilities in our community. Berghs (2017) notes, in ubuntu, oppression is caused by “inhuman actions...such as forms of exploitation, degradation or violence” (p. 2), and these threaten our common humanity. It follows on then that “social ethics of ubuntu has its roots in collective social action” (Berghs, 2017, p.2) and that activism and the pursuit of social justice and equality for PWDs must be central to the ubuntu model of disability. As Berghs (2017) summarises, “if I am, because we are, then ensuring your well-being, dignity and rights as citizen, will also ensure mine” (p. 4).

Berghs (2017) argues that ubuntu, Mandela and the struggle against apartheid were direct influences on the development of the social model of disability through Finkelstein, who was a founding member of UPIAS and grew up in South Africa. Some scholars have noted the need to integrate ubuntu and other indigenous knowledge systems into clinical fields such as psychiatry, at the same time it could play a significant role in “advancing the disability agenda in South Africa” (K & Duncan, 2006, p. 307).

It is important to note that while the ubuntu model of disability presents an African perspective

on disability rights, there is significant stigma of people with disabilities linked to various traditional African beliefs. For example, the experiences of people with albinism. Albinism is a group of genetic conditions “that cause a deficiency in melanin production” (Baker, Lund, Nythati & Taylor, 2010, p. 169) and is commonly associated with other physical disabilities such as visual impairment and extreme sensitivity to the sun (Baker et al., 2010). People with albinism in Southern Africa experience stigma and marginalisation which is a “result from the web of beliefs surrounding the condition” (Baker et al. 2010, p.178). As Bayat (2015) notes, murder and abuse of children with disabilities is a worrying phenomenon in regions of Africa like the “ritual killing of spirit children in Ghana”. In her 2015 paper based on a study of ritual killing and abuse of children with IDD in West Africa, Bayat concludes that “killing and abuse of children with ID are explained within the context of indigenous African religions, animism and folk culture” (p.1). While she found no trustworthy data which suggested that these ritualistic killings still occur during her fieldwork, she concludes that “children with disabilities are not treated with any noticeable degree of human dignity or respect,” (p.8) certainly in part due to these traditional beliefs.

Representation, Culture and The Media

“The media affect us in many ways: a major socialising influence, a carrier of culture, a source of information, education and entertainment, an important factor in political communication and participation in a democracy, and a communicator of ideological values and norms, attitudes and beliefs” (Stadler, 2006, p. 373). What we see in the media shapes what we think of as possible, as the quote sometimes attributed to Marian Wright Edelman goes, “you can’t be what you can’t see” (Maclellan, 2017). The media can be seen as a vital part of creating our cultural understandings of the world. But what exactly is culture?

The definition of the term 'culture' has been long been deliberated by academics from various disciplines (Charlton, 1998). The anthropologist, Clifford Geertz explains culture as “a historically transmitted pattern of meanings embodied in symbols,” and he adds that these symbols are integral to

building and communicating our “knowledge and attitudes toward life” (Geertz, 1973, p. 89). It is most relevant to this study to consider culture in this way, as made up of various representations. These signs and symbols convey meaning about the world through language (including visual language used in images and film) and both reflect and partake in creating our cultural understandings of the world.

Through the field of cultural studies, theorists such as the famed cultural theorist Stuart Hall have drawn the connection between these cultural symbols and power. Hall says that “this interest in combining the study of symbolic forms and meanings with the study of power has always been at the center” of cultural studies (Hall, Osborne & Segal, 1997, p. 24).

As the hands which create (media-makers) and the means by which cultural representations are disseminated to the public (media industry), the media is inextricably linked to representation and culture. For the purposes of this study, I am concerned with understanding the way that the media and the representations it creates affect culture, specifically as it relates to the marginalisation of PWDs and PWIDDs. I considered ‘the media’ as the seat of this cultural power, in that the media has the power to choose who they represent, and how to represent them and therefore can mold or challenge cultural stereotypes which affects PWIDD’s lives. As conventional wisdom goes, great power must be wielded with great responsibly.

Photography and Representation.

Photography is one of the most powerful and ubiquitous mediums of representation available to us. Photography chronicles the personal and the political, from family albums to global news publications (Sontag, 1977). Photography often gives the illusion of being a slice of reality, rather than subjective representations of it (Sontag, 1977). Part of photography’s curious power lies in its apparent objectivity because it is partly a mechanical process. Although photographs are taken by people and therefore have a “high level of subjective involvement” (Williams, 2017, p. 3), the ‘hand’ (so to say) is a mechanical tool which gives the “aura of machine objectivity” (Sturken & Cartwright, P.16).

And in the context of photojournalism, understanding that “journalism by nature is reactive and practical rather than philosophical and introspective,” (Kovak, 2020) there is a trend toward more self-reflexive journalists. For example, documentary photojournalist, Druscovich recently penned an essay called ‘we are not innocent’ in which she “questions the ethical and moral responsibility of the photographer to create humanising work. She calls for the era of photography which lacks context, point of view, and consent to come to an end” (Druscovich, 2021, para 1). In the essay, Druscovich (2021) makes the case that:

Photography is not innocent and it is not just a mere extension of sight. Each photograph is the result of the decisions we took and the knowledge we carry. The photograph may try to document reality, but it’s not reality; it’s a construction. To this builders’ task, we, as documentary photographers, dedicate our lives. (para 2)

Lister and Wells elaborate on the process of making imagery, noting that “convention and meaning enter into the business of making photographs at the most basic technical level” (Lister & Wells, 2011, p. 73). When we make photographs, we are not engaging in the simple act of composing, metering for exposure and pressing the shutter release button. Margret Duane acknowledges the many levels of control and power at play when making and publishing images and focusses our attention on ethical considerations which must be held throughout the photographic process from conceptualisation and planning (sometimes called pre-production) to the physical act of making images (production) and through all the post-production processes of selection, retouching and writing after which the project becomes a product to be sold and distributed (Duane, 2015).

Lister and Wells also make a point of the fact that “the use of [photographic or representational] conventions by photographers is a matter of assimilated ‘know-how’, a trained sense of ‘this is how to do it’ gained ‘on the job’ and by observing” (Lister & Wells, 2011, p. 74). In this sense it is especially important that we underscore the responsibility we as photographers must represent our world

ethically, and to see this undertaking as a process in which we will constantly be learning.

Semiotics and the Mechanics of Representation

The 'mechanics of representation' are the technical and/or stylistic choices made by media-makers which helps them to convey the meaning in their representation. These choices shape how symbols are interpreted by the audience. Depending on the context, these choices could be influenced by many things such as the principles of art and design, their personal taste, their perceived or real audience or client, or their personal or organisational ethics, for example, a style guide or ethical code established by a publication (Paul Getty Trust, 2011; Thurston, 1945).

In trying to understand what exactly makes 'good' art, or beautiful art, those interested in the realm of the aesthetic have attempted to categorise the employment of certain 'principles of art' and design (Thurston, 1945). This contested list of elements has been known to include symmetry, harmony, contrast, balance and so on (Thurston, 1945; Paul Getty Trust, 2011) and while they are not 'laws' of art and are open to interpretation and rejection, they are a good place to start in quantifying which technical decisions are considered when creating media. Each medium has its own principles and ideas about best-practice, which changes throughout history and as technology and society changes.

How these principles are used are often also influenced by their intention, as in what the media-maker intends to say (Knight, 2017). For example, when portraying a subject, a photographer may choose to employ bright light (referred to as 'high-key') or low light (referred to as 'low-key'). Each of these decisions could affect the overall mood of the image and therefore how the subject is portrayed. Bright light may signify a certain authenticity and jovial spirit in the subject. Conversely, a darker portrait may portray a more dramatic, mysterious or ominous feeling over the subject. Similarly, a writer has the same control over the portrayal of their subjects with their choice of language. A filmmaker can use sound to either arouse suspicion or endear the subject to the audience. Each medium of representation has many techniques which can be employed by the media-makers to create meaning about a certain

topic or person.

The study of semiotic analysis is helpful in giving a framework to make the connections between these mechanics of representation and the meaning they create in media. Very simply put, semiotics is 'the study of signs' (Chandler, 2017; Lister & Wells, 2011). And 'signs' are anything which stands for something and which conveys meaning, for example words and images. The study of semiotics is useful for this research as it "helps us to take apart what is taken for granted, making our interpretive systems more explicit" (Chandler, 2017, p. 8). It can give us the language to understand and critically engage with how representations convey meaning by breaking it up into signs. Finally, as Chandler asserts, "to decline the study of signs is to leave to others the control of the world of meanings that we inhabit" (2017, p. 9). On the flip side, with semiotics we can gain some understanding and control over the media we make. According to the Saussurean Model of linguistics, developed by Ferdinand de Saussure, who is considered the "founder of modern linguistics" (Chandler, 2017, p. 13), signs comprise of two basic, distinguishable elements, the 'signifier' and the 'signified' (Chandler, 2017). The signifier is the symbol which stands for the sign (Chandler, 2017), as in a word such as 'chair'. The signified is the actual thing which the symbol refers to (Chandler, 2017), in that case, the structural object created for sitting, the physical object.

One of the ways in which semiotics tries to uncover meaning is to identify the denotative and connotative meanings in an attempt to understand the relationship between the signifier and the signified (Chandler, 2017). The denotation of a sign is a literal meaning or definition, for example, a wooden chair stands on a white floor, it has no cushioning and is empty. Denotative meanings are largely ahistorical, in that the denotation of a sign does not change even as the world does, the chair will exist on a white floor, empty and with no cushioning throughout history and have the same denotative meaning. Denotation is something which viewers from any culture and at any time in history would agree on (Chandler, 2017).

The connotation, on the other hand, is the underlying, implied meaning of a sign as in, the associations made by viewers. In the example of the empty chair, a connotation for one person might be the association of 'comfort' and the potential for 'rest', for another it could be 'emptiness' and 'unease'. The study of semiotics is a complex one, with several contested schools of thought such as the 'Saussian,' 'triadic' and 'Structuralist' models, but for the purposes of this study, I will use only the basics as outlined here (Chandler, 2017).

The simplified understanding of this method of analysis from semiotics will guide my visual analysis of the media I explore in this research to help understand how representational techniques employed by media makers such as use of quotes and sources in articles or lighting techniques (in other words, denotative definitions) informs the likely connotations which viewers might make. I will try to place this in the socio-political and historical context and try to understand how these signs (media) are both a symptom and cause of the marginalisation of people with IDD in society.

In one example of how semiotics makes apparent the relationship between the mechanics of representation and meaning, we turn to Sontag speaking of the German photographer and social documentarian, August Sander. Sander sought to document a wide sample of German society by way of portraiture. Sontag (1977) points out that,

Unselfconsciously, Sander adjusted his style to the social rank of the person he was photographing. Professionals and the rich tend to be photographed indoors, without props. They speak for themselves. Laborers and derelicts are usually photographed in a setting (often outdoors) which locates them, which speaks for them- as if they could not be assumed to have the kinds of separate identities normally achieved in the middle and upper classes (p. 60-61).

The denotative description of his images which she points out, is the subject's setting. The connotation she reads from the signs and symbols (denotative) is the meaning communicated to the viewer by these technical decisions on behalf of the photographer, that those of the upper and middle

classes have self-contained identities while those from lower classes are tied to their environments. Sontag notes that he claims to never have had the intention of criticizing his subjects, but as she adds, it does not mean that he has not described them (Sontag, 1977). Describing our world is something which no media maker can escape and understanding how we create judgements and assumptions in our work is vital if we are to use our medium and power ethically.

Media and Journalistic Ethics

The founding editors of *Art Practical*, Smith & Maloney speak of creative ethics in their piece ‘Is it possible to create a code of ethics for the arts?’. In the piece, they define an ethical decision as one which “prioritises collective obligation over individual circumstances” in pursuit of “the greatest good” for society (Art Practical, 2015). They note that ethical decisions are often complex and that the contemporary art world has no unified code of ethics (2015). But, when Smith & Maloney (2015) speak of ‘the arts’, it must be noted that they are not speaking about the creative arts as a whole, but more specifically the contemporary, commercial art industry- as in visual art as it stands in galleries, owned, maintained, bought and sold through art professionals and created by professional artists. As opposed to visual artists who create artwork with the intention of communicating information (artful communication) to the public, like graphic designers, journalists or advertising industry professionals. But, if we stretch the definition of ‘the arts’ to encompass all who create art, or media, we see that ‘the arts’ is made up of many different industries with numerous types of media-makers, and each of these industries and its workers must grapple with their own ethical standards and responsibilities.

Once it became clear to me that one of the biggest themes emerging in this research was media ethics, I set out to discover what the various fields within ‘the arts’, that is all those who create media in some form, had to say about ideal ethical practice.

What do ‘the arts’ have to say about ethical practices regarding representation? When it comes to the commercial art industry (as referred to earlier), writing about ethics often addresses standards for

financial dealings and best practice regarding labour rights (Smith & Maloney, 2015). As evidenced in the College Art Association's (CAA) 'Professional practices for artists' which was adopted in 1977 and revised in 2011. This is unsurprising based on the fact that most commercial artists in this field are independent practitioners who must be equipped to establish and maintain various business relationships with clients, galleries and agents (Atkinson, 2017).

The CAA's guidelines also include best practice regarding "safe use of materials and equipment", and copyright concerns (2011). There is little to say about the best practice ethics towards society and those being represented in art, when applicable.

But, there is Atkinson's essay on ethics for artists, in which she flags privacy as an ethical consideration for artists. She asserts that "any work that affects the privacy of an individual should be cleared with that person before being shown" (2017, para 33). She elaborates that artists must also make sure that anyone included in their work fully understands what their inclusion entails and their consent should be attained with release forms (Atkinson, 2017).

Consent is often the first layer of responsibility which media makers have to encounter when including people in their media as subjects. Documentary photographer, Malik explains her take on the importance of gaining consent from potential subjects, "I have chosen to actively ask my subjects to be photographed. I do not want them to be stolen moments. I want them to be given, to be honest, for a person to be seen as they wish to be seen" (Malik, 2015, para 1). Asking for informed consent from someone being portrayed in media can make some attempt to alleviate the power imbalance inherent in the production process and give the subject some control over their representation.

Nowhere is the need for informed, legal consent more crucial than in the genre of documentary media. This genre requires a nuanced discourse regarding ethics, especially as it relates to privacy and consent. Documentary photographers and filmmakers have debated the need for informed, ongoing consent in their side of the media industry despite the significant challenges associated with gaining true

consent in their craft (Palumbo, 2019; Dodd, 2019; Désormiers, 2018). This is especially true in the age of digital imagery and the internet when photographers have far more freedom to publish their work and far less control over what happens to their images once they're in the public domain. This adds a layer of responsibility to the practice of creating media, the responsibility to preserve the rights and dignity of the people directly represented in the work.

Practice in the genre of documentary media adds more to the discussion of media ethics partly because it is a form of journalism, in that it attempts to convey factual accounts of real-world phenomena it is therefore closely aligned with journalistic practice (Plantinga, 2005). And so, we turn to journalism and wonder which ethical codes govern journalistic practice.

“Let us today drudge on about our inescapably impossible task of providing every week a first rough draft of a history that will never be completed about a world we can never really understand.”

(Remarks ascribed to Graham, 1963 in Shafer, 2010, para 7)

Media-makers working in the field of journalism have quite a different landscape to contend with regarding ethical standards. Of course, journalism being ‘the first draft of history’, ethical practices are far more consequential and much more widely discussed and codified.

The journalistic industry, or some forms of informational media, has existed in some form for many centuries, going back to ancient civilizations who disseminated information by early technology like clay tablets (Harrower, 2007). But as media and understandings of its effect on society grew, so did ideas of ethical standards for media-makers working in the field.

While the first printed newspaper was created in 1605 (Anderson, Downie Jr, & Schudson, 2016) the first significant push to codify ethical standards for the industry only emerged over two centuries later in the late 1800's (Harrower, 2007). These codes of ethics vary across time, geographic location and organisations with many newsrooms creating their own sets of standards for their staff to follow (Harrower, 2007). The Society of Professional Journalism's code, which was created in 1996, categorises

ethical considerations into 4 ideals (summarized from Harrower, 2007, p. 149):

1. Seek truth and report it: using fairness, honesty and courage in gathering, reporting and interpreting information,
2. Minimize harm: by treating sources, subjects and colleagues as human beings deserving of respect,
3. Act independently: to be free of obligation to any interest other than the public's right to know and,
4. Be accountable: to our readers, listeners, viewers and peers.

And what can ethical discussions in the field of journalism teach us about ethical practice regarding representations, especially of marginalised groups? Ideal number 2 is a good place to start as it puts the inherent dignity and the right to be treated with respect at the core of our media-making practice. Could we assume that stigmatising representations amount to a contravention of this ideal in that they are harmful to those being represented, can a representation (and the practice which created it) be regarded as respectful, and therefore ethical, if the subject has been shown in a stigmatising light?

Media-makers are human beings, we are socialised by the culture we represent. Our beliefs are very much like the public's, subject to our context, ever changing and influenced by a cacophony of influencing agents. It is no wonder then that the media not only molds public perceptions about social phenomena like disability, but as importantly, reflects it. We bring to our media all of our past experiences. Some photographers have even presented the idea that a portrait made of someone is as much a portrait of the photographer as it is of the sitter. As renowned photographer Ansel Adams once said, "you don't make a photograph just with a camera. You bring to the act of photography all the pictures you have seen, the books you have read, the music you have heard, the people you have loved." (PhotoFocus, 2021, para 1)

Strong ethical literacy and self-reflexivity is crucial for media-makers to make intentional media which upholds the dignity of the subject, as well as does the critical work of deconstructing stereotypes which marginalise some members of society.

Representations of People with Intellectual Disabilities

Throughout history, cultural products (and particularly, visual media) have represented disabled people as “less or more than merely human” (Gartner & Joe, 1987, p. 2). These harmful representations are vast and varied and both reflect and perpetuate society’s harmful views of PWD and impairment. In fact, there have been calls for disability studies to turn its attention more to cultural representations (Garland-Thomson, 2009; Stadler, 2006). Carlson and Kittay note that “as early as Plato’s Republic (460c) we find references to the abandonment of “defective infants”” (2010, p.3). Garland-Thomson notes that “until the civil rights understanding of disability opened the door to political action and consumer culture, the only public images of people with disabilities were medical photographs and public charity campaigns” (Garland-Thomson, 2005b. p. 525). People with disabilities, it can be argued, have been objectified, infantilised, side-lined and erased in the history of our media (Shakespeare, 1994).

While my research is primarily interested in contemporary photographic practice and destigmatisation, the historical legacy of media representations beyond just the visual kind must still be acknowledged. For this reason, I will do a sweeping look at the history of disability and representation. I will touch on key moments of representation and trends which can be identified to understand how disability has been portrayed and treated by society. These trends include, (a) pathologizing or the medicalization of disability, (b) ‘enfreakment’, and (c) erasure.

The medical gaze finds its origins in the medical model of disability, which most often focuses on the body as the site for disability/ impairment, as mentioned in the medical model. The medicalisation of disability and those with disabilities is reflected in the media. Burns & Haller called this a form of media coverage, the Traditional Medical Model, the one which presents disability “as an illness or

malfunction” (Burns & Haller, 2015, p. 269). It sees disability as something to be rehabilitated or cured (Moore, & Slee, 2012). When translated into media representations, this model uses several techniques to medicalise disability and PWDs. Through this lens people with disabilities are most often represented in relation to medical phenomena, like “the history of surgery, cure, prosthetic aids and rehabilitation” (Carden-Coyne, 2010, p.70).

Medicalised imagery of PWDs can be harmful to society’s perceptions of disabilities, especially when overproliferated in our media landscape. One only needs to remember the role of Nazi propaganda and eugenic ideology in the murder and sterilisation of people with disabilities to underscore this point (Bachrach, 2007, Garland-Thomson, 1997). The emergence of pseudoscientific schools of thought such as “eugenics and social Darwinism – all contributed to and compounded ancient fears and prejudices” (Barnes, 2012, p. 13) about PWDs which had been present in society since before industrialisation and urbanisation (Barnes, 2012).

I would argue that the medical gaze sets the scene for the tropes which follow in this section. The danger of the medical gaze is that it can fail to acknowledge and foreground the humanity of PWDs. It can serve to reduce them to an impairment, something to be cured, a medical oddity. I will unpack one such form, the so-called ‘the freak show’ phenomenon below. A denial of the complexity and humanity of PWDs creates the environment in which tropes like those I have collated later in this chapter.

The legacy of the freak show is arguably the first stop on any journey through the history of disability representations. Sandell and Dodd (2010) define the freak show as “individuals perceived to possess unusual or inexplicable bodies performed for and were stared at by the paying public” (p. 6). These photographic and live displays are early and harmful representations of people with intellectual and physical disabilities. They were at their height of popularity circa the nineteenth and early twentieth century (McDougall, Swartz & van der Merwe, 2006a) where difference and disabilities were

emphasised and exoticised for commercial entertainment (Mji, Schneider, Vergunst, Swartz, 2013).

Williams outlines the freak show blueprint as having “an exaggerated title to sell the show, an overdramatic hype-man/narrator to keep viewers enthralled, the freak who we can simultaneously pity, blame, relate to and reject” (2017, p.87).

Besides the physical, staged representations of disability, show promoters also circulated ‘enfreaking’ images with ‘freaky-text’ to attract visitors (Hevey, 2010). It is, however, interesting to note that even in this oppressive system, performers crafted their own portrayals. ‘Freak show’ performers sold their own images which showed self-determination and control over their portrayals. These representations seemed to subvert or deny the ‘freak’ label usually applied to the performers (Hevey, 2010, Solomon, 2012).

While the height of the traditional freak show’s popularity has passed, it must be said that the form is not dead, as Williams (2017) notes. It lives on in television shows such as *Freakshow*, a reality show which premiered in February 2013 and which follows a modern day *Freakshow* (Williams, 2017). Netflix’s *The Undateables* is another reflection of this phenomenon which chronicles people with disabilities or ‘challenging conditions’ (Channel4, 2019) as they search for love in a world which deems them “undateable”. While this show may appear to position itself as inclusive, helping partakers find connection and intimacy, its name solidifies the subjects as undesirable or as Frances Ryan says, “you do wonder why Channel 4 didn’t go the whole hog and just use the title “You’re weird and no one wants to have sex with you”” (Ryan, 2014, para 1).

The legacy of the freak show or what Hevey calls ‘enfreakment’ (2010) can be “found in literature, popular culture, and in Hevey’s own study, in charity advertising” (Sandell & Dodd, 2010, p. 6). ‘Enfreakment’ is achieved through several representational techniques or choices (mechanics of representation) which serves to dehumanise by foregrounding negative stereotypes showing “the disabled person as pitiable, pathetic, dependent and vulnerable; as evil, criminal or otherwise villainous,

as sexless or sexually deviant” (Sandell & Dodd, 2010, p. 6).

While problematic representations have been very harmful for the public's view of disability, it is also the lack of representation and exclusion from mainstream society which serves as one of the greatest stigmatisers (Mji, et al, 2013). In a media climate that excludes PWDs and PWIDDs, narrow perspectives of disability are allowed to dominate the public understanding (Delin, 2002). Through this erasure, people with physical and intellectual disabilities are silenced, and their issues are not taken up by the media (Mji, et al, 2013). It can be argued that the failure to include people with intellectual disabilities in the public domain (including in cultural representations) is a form of symbolic violence (Hunt et al, 2017). It should also be noted that writers like Burns & Haller (2015), Barnes (1992) have identified and published about common tropes of disability in the media and that there is an expansive list compiled by TVtropes.com (2021).

Media Tropes of People with Disabilities

Historically people with learning difficulties have been ascribed many different identities – often opposing, contradictory identities, not of their making or choosing. They have been portrayed as asexual and as sexually promiscuous; as dangerous/innocent; in league with the devil/a gift from the angels. (Stalker, 2012, p.127)

When we critically engage with media, literature and art which includes PWIDD, the framing of their narratives can often be grouped into several main tropes, similar to these mentioned by Stalker. I have attempted to identify these tropes from the literature and contemporary media in order to understand how certain signs and symbols suggest connotations which contribute to or subvert stigma. These cultural narratives are often dehumanising, stigmatising and oppressive (Garland-Thomson, 2005, p. 1567). David Bolt (2012) says that leaving these tropes unexamined has ensured their longevity in our cultural sphere thereby allowing people with disabilities to be painted as either less or more than human (Gartner, A. & Joe, T., 1987).

It is important to understand tropes of disability because “when we see the same kinds of images and views represented in the media over and over, without having access to alternative discourses, it is easy to accept them as natural and legitimate” (Stadler, 2006, p. 375). I identified five common tropes of PWIDD in the media: (a) the heroes, (b) the freaks and demons, (c) metaphors, (d) the pitied and (e) the children.

The heroes. The heroes are a common trope we see throughout various representations of people with disabilities, and PWIDD is one of the disabled as bravely striving towards “a quality of life that is less disabled, more normal” (Riley, 2007, p. x). In these cases, the subjects are lauded for attaining some form of “normality”, for overcoming massive adversity (Garland-Thomson, 2005). In these representations, the disabled subject is often framed by notions of humility, bravery, determination and the triumph of human will. They are exceptions which are meant to inspire others faced by adversity, as well as inspire gratitude in the non-disabled viewer for their able body and neurotypical mind.

It is important to note here that the “disabled hero” is not the same as the non-disabled or neurotypical hero, who may use their willpower and talents to save others. The trope of the heroes is most notably seen in what is sometimes termed “inspiration porn”, which is the “representation of disability as a form of disadvantage that can be overcome for the titillation of other people/observers” (Grue, 2016, p. 388). In this trope, the disabled subject is objectified, devalued and mystified (Grue, 2016). “It is not just the heroic super-human who disabled young people are judged against, as problematic is the ‘normal’ young person they are asked to aspire to be” (McLaughlin, J & Coleman-Fountain, E, 2014, p. 83)

“We’ve all read headlines like this before: “This Student With Cerebral Palsy Went To Prom With Her Best Friend And It Was Magical,” says Lu. “For decades, the media has tended to portray people with disabilities (or those around them) as inspirations or heroes—a genre of reporting known as

“inspiration porn,” (Lu, 2017, para 1).

When it comes to covering stories like this, we look to how certain stories are highlighted in media over others. Journalists look for news values, including universal experiences which we can all relate to. As an example, journalist Keith Sharon explains that a story about a disabled university graduate might be best centered on his mother who helped him complete his degree because “not everyone understands what a quadriplegic has to deal with, but everyone understands what a relationship is like with their mother.” (Sharon in Lu, 2017, para 7). Wu (2017) notes that “emotion-driven journalism is the hallmark of inspiration porn, which often focuses on the altruism of those who help people with disabilities” (para 9).

Wu thinks that journalists’ reliance on emotion to drive interest in consumers is causing bad journalism about disabilities. “Of the eight news values (proximity, timeliness, prominence, magnitude, conflict, oddity, impact, and emotion), emotion too often rises to the top when telling stories about disability communities,” (2017, para 10) and these stories don’t really get to the heart of disability issues because of this focus, “inspiration porn rarely goes beyond that to address major disability issues like workplace discrimination, stigma and bullying, and accessibility in schools” (para. 10)

Enfreakment and demonization. This leads us well into the next common trope found in representations of PWID: enfreakment and demonisation. Like the hero trope, it also objectifies and mystifies its subjects, but not to inspire and put them on a pedestal, rather to tantalise, thrill and fetishise.

One of the most famous photographers whose work stigmatised people with disabilities in this way is Diane Arbus; her photojournalism often presented people with disabilities as frightful symbols of a new world “(dis) order” (Hevey, 2013, p. 434). What is most harmful in the reception of photographic bodies of work like hers even by her critics, is that her “factual” portrayals of “freaks” is not questioned (Hevey, 2013, p. 435).

In contemporary South African photography, Roger Ballen (as mentioned in the Preface) the lauded is often compared to Arbus for his subject matter (“outsiders” and notably, often people with disabilities) and for his style which is dark and nightmarish (Huston, 2012). The dark and unsettling effect of his images makes use of very specific techniques, namely “making his figures assume unnatural, forced positions, hiding them, turning them into actors, transferring them onto a level different from that of the portrait tradition” (Guadagnini, 2010). While Ballen himself has denied that his work is exploitative and stigmatising, but rather his expression of the absurdity of life (O'Hagan, 2015), the stigmatising effects of his image of Dresie and Casie as introduced in the preface of this thesis cannot be denied. The work “prompted questions about their...genetic make-up and whether the images were exploitative” (Taylor, 2018, para 15). The series in which the image was published, called *Platteland*, sparked controversy and many have since questioned whether Ballen exploited his subjects.

Metaphors. It sometimes happens that when PWDs are represented in media, what is focused on is not exactly the person themselves (their particular experience or characteristics etc.) but rather what the aspect of the person being presented actually means about us, the viewer, or about society. In this way they are used as metaphors. Often, the inclusion of PWDs in media can serve as triggers for existential or moralistic concerns of the assumed neurotypical audience, again like with Dresie and Casie. Sean O'Hagan (2012), an art critic who specialises in photography recalls how Roger Ballen interpreted the success of his most renowned image, the portrait of Dresie and Casie to viewers at an opening night tour of his 2012 retrospective at Manchester Gallery:

He [Ballen] also insisted that our fascination with the mentally and physically handicapped twins, Dresie and Casie, was to do not with their almost outlandish appearance, but because “they're your cousins. You're related to them. You are seeing a picture of your insides” (para 4).

This trope of ‘disability as metaphor’ or ‘symbols for society’s greater existential concerns’ can be traced through society’s long history of literature and art. Shakespeare argues that, disability is the

“most active and prominent metaphor of all,” and that disabled people become the ciphers for the aspects of life which non-disabled people cannot deal with or process (1994, p. 287). Essentially disability becomes a shorthand for a non-disabled society's fears of frailty and mortality (Watermeyer, 2003).

In literature, an impairment is often a metaphor for a deeper character flaw, or a greater social truth – a missing limb could be a symbol of loss (Hevey, 2013). In *How to Read Literature Like a Professor*, Foster claims that if a blind character is introduced into a story, the writer must include certain accommodations for the character, for example each other character must notice the disability and so behave differently (Foster, 2003). These accommodations or “a minor constellation of difficulties”, he goes on to say, means that “something important must be at stake” (Foster, 2003, p.201). In other words, a disabled character cannot be in a story unless it's for a reason, and that reason is not simply because they are worthy and interesting characters, they must be a symbol of that drives the stories of other characters.

Christopher Shinn summarises disabled playwright John Belluso's theory that the trope of “disability as metaphor” is partly to blame for the lack of disabled actors playing disabled roles in Hollywood and on stage (Shinn, 2014). Shinn and Belluso believe that this saves audiences the discomfort of seeing disability as something real which affects real people. They can comfort themselves in the knowledge that the actor is in fact neurotypical or without physical disability (Shinn, 2014). As Shinn says, “it is reassuring for the audience to see an actor like Daniel Day Lewis, after so convincingly portraying disability in *My Left Foot*, get up from his seat in the auditorium and walk to the stage to accept his award. There is a collective “Phew” as people see it was all an illusion. (Shin, 2014).

Shinn also argues that the fact that most disabled characters in Hollywood are not played by actors with disabilities is one mechanism that enforces this trope. It allows the character's disability to serve as something the non-disabled viewer can relate to their own lives, their own “otherness”,

struggles or isolation (2014).

The pitied. Rosemary Garland-Thomson refers to the trope of the pitied as “the sentimental narrative” of disability, where people with disabilities are “occasions for narcissistic pity” or catalysts for life lessons for the non-disabled viewers (2005, p. 1568). A great example of the trope of people with disabilities as pitiful is the media produced to drum up support for charities. These demeaning images are another form of fetishism and objectification (Shakespeare, 1994). Here, pity from the viewers is encouraged and commodified. As Shakespeare puts it, “pity is an expression of superiority: it can also be the obverse of hatred and aggression” (Shakespeare, 1994, p. 187).

Imagery related to this conception of PWDs can be compared to racially inappropriate imagery of people in the Global South used for charity campaigns and it could be argued that colonisation and imperialism are evident for both examples (Shakespeare, 1994). A pitied person with disabilities is seen as passive, dependent, incapable of making decisions or taking actions for their own (Shakespeare, 1994).

When PWIDD become objects of pity, the narrative emphasis is on the hardships of disability. The writer and PWD, Sturm (2019) recounts an anecdote in which her personal story was reframed by editors to reflect the trope of the pitied:

To me it seemed that the new passage mainly consisted of the word, “suffering.” “She suffers from Ehlers-Danlos syndrome. She suffers from chronic pain.” My life was reduced to misery, as often happens when non-disabled journalists cover disability. Most people living with disabilities don’t spend their lives in agony; they merely have a certain condition or disability. And in this case nobody had asked me whether I felt like I was suffering. It was just assumed I did.” (para 2-3)

In this example, Sturm is drawing our attention to the choice of language used by the editor, words as symbols and signs, the choices of how to use these are the mechanics of representation which are used to change the meaning of the piece.

In one study of news coverage of the National Disability Insurance Scheme in Australia, content analysis revealed of the 455 relevant articles, 306 (or 67 %) of them were considered forms of the 'social pathology' model. The social pathology model is, according to Burns and Haller, when the media presents people with disabilities as dependent and disadvantaged, the state as benevolent and the benefits or extra support given to PWDs by the government is a "gift, not a right" (Burns & Haller, 2015, p. 269).

The children. The prevalence of children with disabilities as subjects in media about disability has its legacy partly in Telethons. This has been widely covered in disability studies by various academics who have explored how these charity spectacles were carefully crafted to tug on the heart strings of viewers. Children were selected and presented to fulfil the image of innocent angels (Longmore, 2013). "Telethons also displayed children as the representative type of disabled person and often treated the disabled adults who appeared on the broadcasts as though they were children (Longmore, 2005, p. 505). One way in which this trope is perpetuated by the media is in how stories about PWIDD are often told through or by their family and/or particularly their parents (Stuart, 2020;).

Capri & Swartz note that infantilisation of PWIDD in society is pervasive in higher income countries and that because South African society has limited general awareness of disability rights issues, infantilisation may be more pervasive for PWIDD (2018). They also note that in the infantilisation of PWIDD, "the bestowal of childlike properties on disabled individuals is perpetuated by compromised cultural competence, ignorance, and stigmatisation" (Capri & Swartz, 2018, p. 286).

The set of assumptions which lead to infantilisation of PWIDD can be changed by cultural projects which raise awareness and fight stigmatisation. The Department of Social Development also highlights "paternalistic attitudes" which "continue to hamper their integration into society both at a social and economic level" (Department of Social Development, 2009, p.12).

Tropes of People with Intellectual Disability in Action

Dresie and Casie. The introductory example of a culturally significant representation of PWIDD in photographic media, Dresie and Casie will be further unpacked here. The portrait has been described as “almost outlandish” (O’Hagan, 2012, para. 4), “distressing” (Coslovich, 2009, para 1) as “appear[ing] to invite responses concerned with race and degeneration (Johnson, 2009, para 24). The twins have been described as looking “scary and dangerous” (outlaststrager, 2014). Senior arts writer for The Age, Gabriella Coslovich is critical of the way Ballen has portrayed the twins. Coslovich (2009) describes the appearance of Dresie and Casie in Figure 1 as follows:

The twins have misshapen faces, necks as thick as bullocks', ears that protrude like chimps', bluntly cut spiky hair and prominent lower lips. Ballen has photographed them with a long thread of drool dangling from their blubbery mouths, their shirts wet and stained with dribble. (para 2)

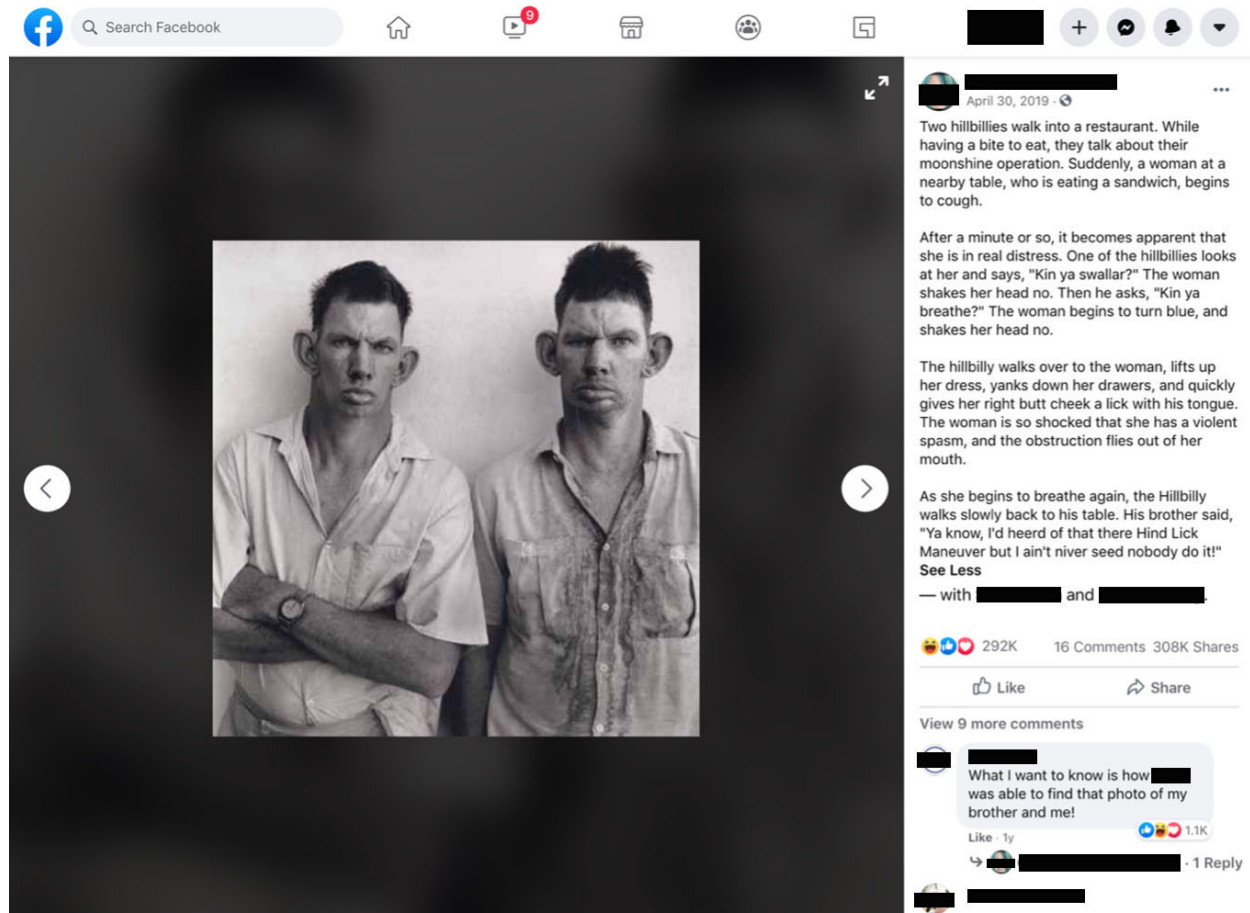
Despite (or arguably because) of the twins’ less-than-flattering presentation in the image, the portrait (Figure 1) has become a sought-after piece of art. Prints of the work have fetched incredible prices on auction ever since its publication in 1994. For example, in 2015, a print fetched over R227 000 at auction (Christie’s, 2021), another sold for over R 167 000 in 2016 (Phillips, 2021) and another for just over R 141 000 in 2020 (Sotheby’s, 2020). These prints were just three in the long sold-out edition of 35 prints.

The image of Dresie and Casie (Figure 1) has become a significant portrait in not only the art world, but in popular culture where they have become symbols of negative stereotypes that society holds about people with intellectual and developmental disabilities (PWIDD) and the object of ridicule. Today, this iconic image (Figure 1) of the twins sporadically features in memes (jokes circulating via social media and the internet, often accompanied by an image and created anonymously) mocking ‘inbred ‘or hillbilly people’. In one example, a Facebook user circulated the image (Figure 2) on Facebook

alongside a 'hillbilly joke', presuming the twins to be the 'butt' of the joke (Redacted, 2019).

Figure 2

'Two hillbillies' Facebook post of Dresie and Casie

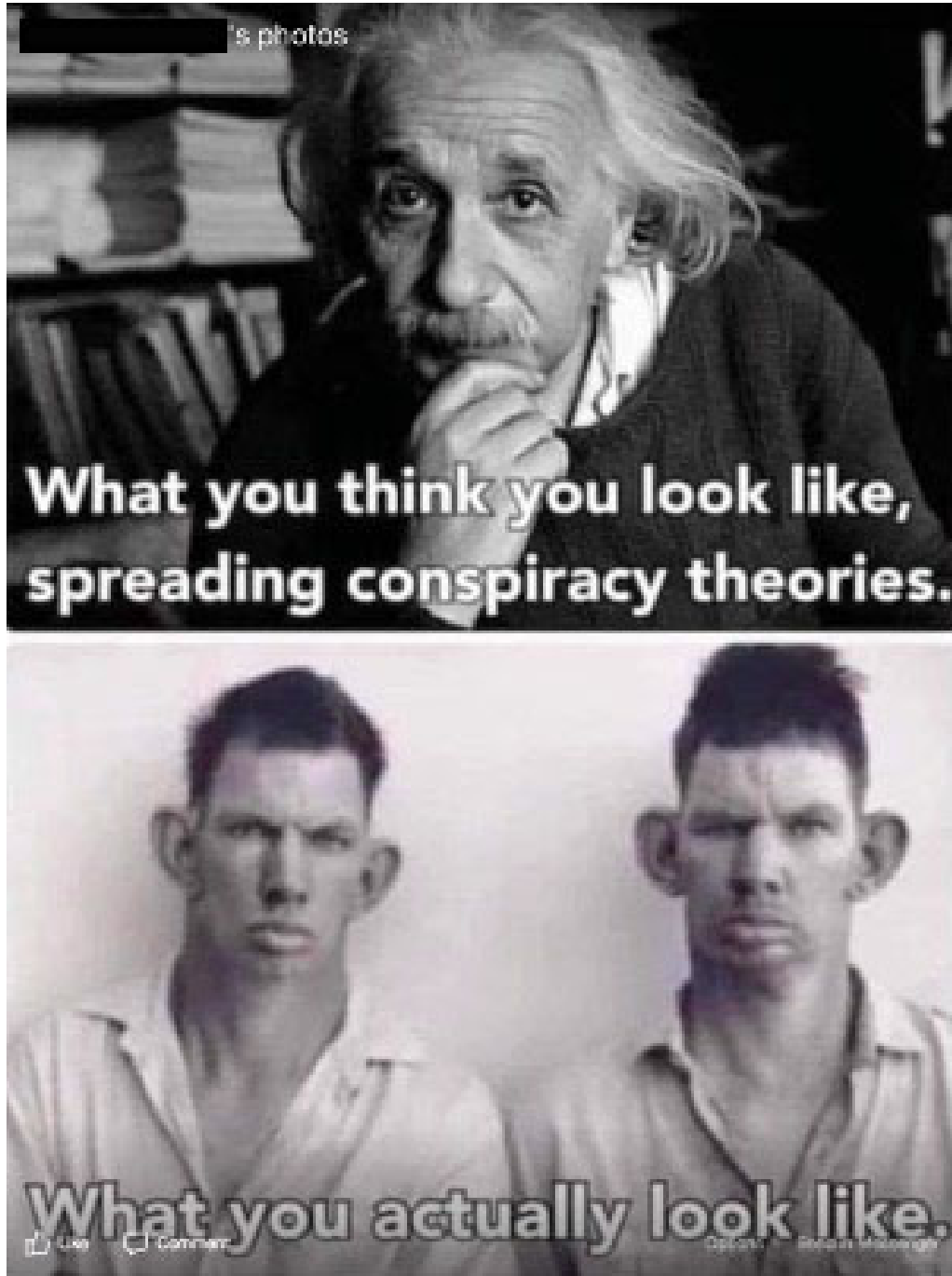


Note. Screenshot of a Facebook post with the image of Dresie and Casie accompanied by comment implying that they are 'hillbillies' (Redacted, 2019)

And another image (Figure 3) circulated on the social media messaging application, Whatsapp and other online platforms, to poke fun at people who spread conspiracy theories in 2020 (ponder, 2020; Cold Lake Dad (he/him), 2020; 9GAG, 2020; Jon, 2020).

Figure 3.

Conspiracy theory meme of Einstein and Dresie and Casie



Note. Top panel: Picture of Einstein with the text, “What you think you look, spreading conspiracy theories.” Bottom panel: Dresie and Casie captioned, “What you actually look like.”

Researching the image online, one quickly finds links between the portrait of Dresie and Casie and the characters of the murderous twins (Figure 4) in the thriller video game franchise, *Outlast* (Gold_Jeffblum, 2015, Red Barrels, 2015). Below is an excerpt from a fan-made blog which speaks about the link between the characters and real-life twins, “everyone who knows *Outlast* also knows the mysterious cannibal twins...perhaps some of you read the *Outlast* wiki so you might know that they are based on these two men...” (outlaststrager, 2014, para 1). The author then included the image of Dresie and Casie (Figure 1).

Figure 4.

Image of the "mysterious cannibal twins"



Note. Image from the video game, *Outlast*, of the "mysterious cannibal twins" which were inspired by the portrait of Dresie and Casie.

The link between the portrait (Figure 1) and the video game characters (Figure 4) was confirmed by the production company, Red Barrel in a Facebook post. Ballen's image is shared in the post, the accompanying text reads, "those two seem familiar...We've seen them in Outlast. Do you think there's a resemblance?" (Red Barrels, 2015). One Facebook user named Marsh asked the company "So, I know this picture of old. Was it an inspiration or merely a coincidence? Because I have often wondered" (Red Barrels, 2015). To which they responded, "inspiration" (Red Barrels, 2015). Another user named Alharbi asked, "are they really killers?" (Red Barrels, 2015). But, as outlaststrager's blog notes, this scary representation of the twins is not who they really are. They say: "I wanted to know more about them so I did a little research. If you look at the photo they appear scary and dangerous. But this is FAR from the truth. This is how they look today..." (outlaststrager, 2014, para 3). The author then included another image of Dresie and Casie (Figure 5).

Figure 5

A photograph of Dresie and Casie (Verwey, 2012)



Note. photograph of Dresie and Casie portrayed in a similar style to Ballen's portrait (Figure 1), but they are smiling and neatly dressed (Verwey, 2012).

This image (Figure 5) is originally sourced from an article by Herman Verwey, which appears to destigmatise and demystify the twins. Verwey offers a representation of the twins which is humanising and dignified. It is, unfortunately, a rare reframing of Dresie and Casie as more than subjects in a famous photograph, but as three-dimensional humans. And so, we see that this deceptively simple portrait (Figure 1) is actually layered in complexity and given its clear significance as a famous representation of PWIDD, what could the image (Figure 1) teach us in discussions about how we represent PWIDD in the media?

Before the lauded portrait (Figure 1) became a placeholder for demeaning stereotypes of PWIDD on the internet, it featured in a body of work by Ballen called *Platteland*, a series which at first publication in 1994 was controversial for portraying “poor white” communities in small town South Africa (Greenberg, 2015; Taylor, 2018;) at the end of the Apartheid regime (Rogerballen.com, 2021) - a portrayal which undermined the Apartheid regime’s claims of racial superiority of whites over black South Africans (Etherton, 2020). The work was powerful and controversial at the time because it seemed to challenge the myth of white superiority.

Discussing the nature of iconic images, accomplished photojournalist Stuart Franklin says that “iconic photographs are accelerated into prominence due less to their formal excellence as photographs than to their fit with political expedience” (2019, para 6). The famous image (Figure 1) of the twins became iconic not only because of its striking aesthetic, but also because it fit into a poignant political narrative of the time, one which questioned the myth of white supremacy. Perhaps now it is time to reframe the image’s political importance in terms of disability rights and representation.

Fred Won Gold. When one of my participants, Fred, mentioned to me in an interview that he had been an accomplished swimmer in the past, he asserted that he was incredibly proud of this and wanted it included in his representation. He sent me an article (Appendix A: Fred Won Gold [newspaper clipping]) from a newspaper which detailed his accomplishments.

He had won six gold medals and one silver at the Down’s Syndrome Swimming Championships in 2002, held in England (Ajam, 2002). I found the article such an interesting example of the complexities and ambiguities of media representation of disabilities in South Africa, and possibly globally. Immediately, I was struck by the accompanying photograph of Fred in a swimming pool, triumphantly holding his fist in the air, unsmiling (befitting the seriousness of his achievement). The photograph was assumedly taken right after one of his wins. The caption below the photograph reads, “Talented... “I felt so happy and very proud when I stood on the podium and they handed me my

medals,” said Fred Gamble.” (Ajam, 2002, para 11).

He was the only person in the photograph. The champion. The message communicated by this image and caption implied that Fred had accomplished something worth being proud of, on his own, by the merits of his own talents and efforts. The photograph portrayed Fred as a winner, and this is especially meaningful given the tendency to portray PWIDD as ‘inspiration porn’ for achieving something close to ‘normality’ (Barnes, 1992). He is displayed here as a hero, a national pride for his talent and achievements as a sportsperson on an international level, while still acknowledging his identity as a person with Down’s syndrome.

The article which accompanied the photograph in some ways echoed this centering of Fred as an accomplished sportsman. It made mention of his disability only as a fact about him and the reason he had competed in this particular event, therefore avoiding the common mistake of medicalising him. The article also mentioned one of his parents but only in relation to how his father had fundraised to make his participation possible. Unlike many other media examples which prioritise the voices of parents over PWIDD. Notably, the journalist also chose to include Fred’s own voice in the article, portraying him as competent, and able to comment on his wins. The result is an article that keeps Fred at the center of his own story. And does not, at its core condescend him.

That said, there are two ways in which the story fails to represent Fred in a dignified way. Firstly, the headline reads “Down’s boy scoops heap of medals in British pool” (Ajam, 2002). The word “boy” infantilises him and contravenes established journalistic norms and ethics (Harrower, 2007). As Harrower notes in his journalism textbook, “you are a boy or girl until your 18th birthday. Then you become a man or woman” (Harrower, 2007, p. 54). As the article itself notes, Fred is 20 years old at the time the article was published (Ajam, 2002).

Further along in the article, the journalist chose to include a quote by Fred’s teacher on how smart he is. The article reads, “he is not only good at swimming, he reads well and excels at

mathematics” (Ajam, 2002, para 7). These facts are ones which play into the trope in which mundane accomplishments by PWD are highlighted, as in the trope of ‘the heroes’. While this quote could be seen as an inclusion which seeks to dispel that myth that PWIDD are incompetent in all intellectual pursuits, it also has nothing to do with his swimming achievements and highlights instead his role as a student. These two choices could be seen to infantilise Fred. I’m yet to read an article at the top of the weekly sports section in which an Olympic athlete like Chad le Clos is praised for being good at math...

The Case of Esidimeni. The human rights scandal now known as the ‘Esidimeni tragedy’ provides a robust case study of contemporary media coverage relating to PWIDD. The coverage of the scandal was vast on all national media channels and even internationally (Bornman, 2018; Capri, Watermeyer, McKenzie & Coetzee, 2017; Child, 2017; Dasoo, 2016; eNCA, 2019; Hodal & Hammond, 2018; Mitchley, 2018).

In researching the media coverage of the tragedy, I noticed that the majority of the coverage focused on holding the responsible officials to task for the tragedy, and otherwise centered on the suffering and grief of the families. It may seem appropriate that media focused on holding public officials responsible in this way, with headlines like ‘Bleak situation for families hit by Esidimeni tragedy’ in the *Saturday Star* (Molelekwa & Green, 2017), ‘Gauteng and Life Esidimeni families fight over payments’ (Nyathi, 2020), ‘How does she sleep at night?- sister of one of Life Esidimeni 94 on MEC’ (Raborife, 2017).

However, the coverage had a glaring hole: where are the voices of the victims who survived? In any other tragedy of this scale, one assumes that the media would clamour for comment from the survivors. Yet, they did not from the survivors of the Esidimeni tragedy. Instead, the story of Life Esidimeni was told mostly through the voices of families who lost loved ones and through the officials and care workers who were involved. One such example of this can be seen in an extensive piece by the British newspaper, *The Guardian*.

The journalists “interviewed more than 20 family members whose loved ones were transferred out of Life Esidimeni, nearly all of whom later died” (Hodal & Hammond, 2018, para. 44). The entire article includes 29 named “characters”, 9 of whom were family members of victims, of which 7 speak directly, 8 are healthcare workers of which 6 speak, and 3 are from government officials, of which 2 speak. 9 victims are named of which 7 are deceased, 2 were survivors and only one of those speaks. Of 29 people named in this extensive article, only 1 is a victim who speaks. There may be very good reasons why the names and voices of living victims were excluded from the coverage of Life Esidimeni, for example to protect the identity of the victim. But what this omission can do is fail to remind readers that although 144 people lost their lives in the tragedy, over 1 700 PWIDD and mental health illnesses were victims of the scandal. In light of this, it’s pertinent to remember the poignant words by Dr Capri, Watermeyer, McKenzie and Coetzee, “Esidimeni is not only a scandal of medical maladministration. It is a story about the sociopolitical abuse of people who only matter once they die” (2017, para 2).

Summary

Through frequently repeated stories, or tropes, the media can shape and reflect stigma about PWIDD which have very real consequences for their lives. Media-maker’s overreliance on these tropes drives damaging narratives which continue to uphold ideological barriers to PWIDD’s inclusion and empowerment in society, as well as presents superficial understandings of them and their lives. Understanding how these tropes work to stigmatise PWIDD in society can give us a vital view into the media production process and how stigma influences it. To this end, I leave you with Sturm to sum up the media’s problem with tropes:

I often feel that my stories don’t find their way into newspapers, because they are not inspirational enough. That people with disabilities must be seen as either superheroes or victims with no joy in their lives. Neither reflects the whole truth, of course, and both skew the perception of one of the largest minorities in the world. (2019, para 6).

We know that media representations are powerful socialising forces in society, and that various sectors of the media have attempted to grapple with their ethical responsibilities. However, without an understanding of powerful models of disability and their effects on the lives of PWDs, the media may be destined to repeat their mistakes and perpetuate medicalisation, erasure, infantilisation, demonisation and so on. It follows on then that there is a media imperative (at all levels) to understand the stigmatisation of PWDs to correct public perceptions of disability and promote inclusion.

Chapter III: Research Aims and Questions

Research Problem

Representations of people with intellectual and developmental disabilities (PWIDD) in the media are few and far between, and when they do exist, portrayals tend to perpetuate stigma and marginalization of PWIDD by relying on common tropes and the social stereotypes which they reflect and perpetuate (Wool, 2021). It is widely understood that media representation of marginalized groups in our society is important and meaningful to civic life. Among disability rights activists and disability studies scholars, the belief that media representation further marginalizes PWIDD is also widely held (Gartner & Joe, 1987; Garland-Thomson, 2005b; Shakespeare, 1994). And yet, discussions about ethical practice in media with relation to disability are yet to become commonplace in our educational institutions, newsrooms, galleries and writers' rooms. Lively dialogue among media makers is critical to creating a media landscape which promotes inclusion and fosters understanding about those living with disabilities. Additionally, PWIDDs have the right to be included in our media, and for inclusion to be affected with dignity, humanity and complexity.

Research Aims

The idea for this study was sparked by the perceived lack of dignifying and visible representations of PWIDD in mainstream media. Knowing that PWIDD experience marginality and disempowerment in South Africa, I aimed to understand how we, as media-makers, can create destigmatising and humanising portrayals.

The overall aim for this study was to develop working provisional protocol for media-makers on how to produce dignifying representations of PWIDD. Central to this was the inclusion of PWIDD as collaborators in the development of these guidelines. I suspected that, given the chance to participate in their representation, my participants could have a meaningful and empowering experience. On my part, I was curious about the kinds of media we could make together if the process was collaborative,

accessible and guided by what I had learned from my literature review about media representations and disability studies. To achieve this aim, the following objectives needed to be met:

1. To understand the media's representations of PWIDD through a thorough investigation of the scholarly empirical and theoretical literature and mainstream media (including news media, opinion and feature journalism, social media, interviews with journalists and photographers etc.). The results of this were detailed in the literature review presented earlier in this study.
2. Secondly, to collaborate with PWIDD to produce professional studio portraits of them using interviews and Photovoice
3. To apply what I had learnt from my investigation of the scholarly empirical and theoretical literature, mainstream media and collaboration with PWIDD in my own photographic and journalistic practice
4. To identify themes by analyzing textual data, interview transcriptions, Photovoice images and field notes to inform the development of ethical guidelines for better representations of PWIDD.

Research Questions

I formulated research questions based on each goal to further focus what could otherwise be a very broad range of inquiry. The main question was, what should be included in the working ethical guidelines for media-makers to create better representations of PWIDD? To answer this question, I first needed answers to the following:

- What can an investigation of the scholarly empirical and theoretical literature as well as historical and contemporary media tell me about the representation of PWIDD?

- What is the history of representation of PWIDD? Which key issues and historical representations of PWIDD are relevant to understanding the way PWIDD are, and/or should be portrayed in the media today?
- How do media representations perpetuate and reflect social stigma and marginalization of PWIDD? Which visual or narrative patterns are common in media portrayals of PWIDD and how do they affect stigma?
- To what extent do these tropes still exist in contemporary media?
- How do PWIDD want to be represented?
- How can the photographic process be accessible, collaborative and ethical when working with PWIDD?
- What accommodations may PWIDD need to participate in media-making?
- How can I apply what I have learnt from the literature, media and PWIDD in my own photographic and journalistic practice?
- How can I balance rigorous journalism with a disability rights-centered practice and with the demands of the media industry?
- Using Thematic Analysis, what are the themes and sub-themes (from data collected by answering the questions above) which can inform the development of ethical guidelines?
- Which ideas, topics and insights are repeated across all the areas of exploration as answered by the questions above?
- What do they tell media-makers about how to approach PWIDD?

Chapter IV: Methodology

In the Methodology chapter I will give a detailed account of how I ensured that this research is rigorous, valid and credible. I have chosen feminist disability studies as this framework for the study and so will start with how the theories and principles guided the research. I then position myself as the researcher who is also a photographer and media-maker, and knowing this will provide context as to why I specifically included photovoice within the participatory action research (PAR). I will then go on to explain aspects pertaining to the research design, research setting, participants and inclusion criteria, data collection and analysis. In the end I will provide a thorough account of the ethical considerations of this study as it pertains to people with intellectual and developmental disabilities (PWIDD).

Theoretical Framework: Feminist Disability Studies

My research is grounded in feminist disability theory. Feminist disability scholars were among the first to highlight the importance of representation in shaping society's attitudes and understanding of disability and ableism following on from feminist theory's concerns with representations of femininity (Shakespeare, 1994). Drawing on theories created by feminist scholars on gender and power, feminist disability scholars have uncovered the relationships between ableism, power and marginalisation.

Shakespeare (1994) notes that the focus on cultural representations of disability were more likely to be led by feminist scholars and feminist theory because the relationship between representation and marginalisation are a natural progression of feminist concerns with how women is represented in society, the creation and entrenchment of cultural stereotypes, and enforcement of societal norms of beauty. Many of the concerns of disability studies are concerns that feminist studies have been grappling with for decades (Garland-Thomson, 2002).

Feminism breaks down and confronts stereotypes of inferiority related to women and their bodies. In the same vein, feminist disability studies are an academic field of enquiry which challenges the assumptions of impairments as "flaws" or defects (Garland-Thomson, 2005a, 2002). The theory

understands disability not as contained in the body, but instead in the enactment of a cultural system which disables based on physical impairments (Garland-Thomson, 2002). To feminist disability scholars, disability is a cultural system applied to bodies and minds of the disabled which stigmatises the individual (Garland-Thomson, 2002).

In many ways, the feminist disability study model continues the work of the social model. As Rosemarie Garland-Thomson succinctly says, “feminist disability studies questions the dominant premises that cast disability as a bodily problem to be addressed by normalization procedures rather than as a socially constructed identity and a representational system similar to gender.” (2005a, p. 1559).

The idea that disability theory is relevant only to people with disabilities is what Eve Sedgwick (1990) refers to as a “minoritizing view” (p.1); in contrast, feminist disability studies proposes a ‘universalising view’. Feminist disability studies speaks of the ‘universalising view’ of disability which, in comparison to a “minoritizing view”, asserts that in the ‘universalising view’, disability issues are relevant to all people, even those who do not live with a disability (Garland-Thomson, 2002). A ‘universalising view’ is a concept which places disability alongside other identity and cultural categories and which expands universal understandings of what it means to be human (Garland-Thomson, 2005a). This view acknowledges that disability affects us all, is relevant to us all and that further down the intersectional feminist journey, the plight of PWD is the plight of us all.

Garland-Thomson also claims that integrating disability studies into feminist studies does not narrow the focus to only women with disabilities, just as feminism is not only concerned with the world as it relates to women, but instead it strengthens and expands the theoretical framework to consider how intersecting identities and systems intertwine and affect each other, making it more intersectional.

Feminist disability theory does not assume that disability is a natural marker of inferiority, just like feminism rejects the notion of femaleness as a state of inadequacy (Garland-Thomson, 2002).

Rather, disability is a cultural construct based on the peculiarities of the body, much like the social categories of race and gender which are more ideological than biological realities that still translates to unequal power dynamics, to being marginalised from mainstream culture, the economy and access to the social and architectural environment (Garland-Thomson, 2002). In this way, the feminist approach helps to place disability as an identity category and cultural concept which expands our understanding of what it means to be human, to relate to one another and to our embodied experience of the world (Garland-Thomson, 2002).

The theory challenges our otherwise limited understandings of human diversity, seeing disability instead as a form of bodily variation (Garland-Thomson, 2002) which I argue, calls for a change in the way we represent people with disabilities, not as oddities or receptacles for our pity, but instead as a humans, complex and varied. Feminist disability theory rejects the notion of disability as a biological reality which must be eradicated or fixed, prioritises the value of disabled people's lives and emphasises the need to reform society to accommodate people with disabilities (Garland-Thomson, 2005a).

Garland-Thomson (2013) claims that a failure to combine feminist studies and disability studies has done a disservice to both fields of enquiry, saying:

I must wearily conclude that much of current disability studies does a great deal of wheel reinventing. This is largely due to the fact that many disability studies scholars simply don't know either feminist theory or the institutional history of women's studies (p. 333)

Concluding that a more integrated approach by both would strengthen each and progress our understandings or the relationship between marginality, identity and cultural representations. Of all the models I have explored in my preliminary literature review, feminist disability theory seems to suit the underlying aims of my research the best because feminist disability theory challenges dominant, disempowering tropes and narratives of disability by reimagining it. The academic field of inquiry draws on feminism's concerns with "the status of the lived body, the politics of appearance, the medicalisation

of the body, the privilege of normalcy, multiculturalism, sexuality, the social construction of identity and the commitment to integration” (Garland-Thomson, 2002, p. 4) all of which are concerns which can be reflected in representations of PWIDD.

Feminist thought aligns with my desire to deconstruct representations of PWID and understand how it contributes to systemic oppression, isolation and erasure of people with disabilities in society (Garland-Thomson, 2005b). Furthermore, the part of my research which involves creating media about PWIDD aims to reimagine and redefine the cultural narratives associated with intellectual disability. The photographic interventions made in this research could also be seen as what feminist disability studies calls 'narrative retrieval'. In feminism, there is an emphasis on the multitude of experiences and identities which exist in womxnkind and so emerge anthologies and cultural projects which amplify womxn's (and intersectionally, people of other identities, such as LGBT, racially oppressed) perspectives, to “challenge normative voices” (Garland-Thomson, 2005, p. 1561).

As Rosemarie Garland-Thomson (2005) says, “Feminist disability studies wants to unsettle tired stereotypes about people with disabilities” (p. 1557), which is one of the great objectives of my research. Feminist disability theory informs critical engagement with the mechanics of representation and stigma and provides the baseline assertion that PWIDD’s inherent value to society requires representations which reflect them in a humanising and dignified manner, as well as the ethical imperative of the media to actively work to dispel harmful perceptions about PWDs.

The Researcher and Reflexivity

For the research methodology, particularly the data collection, to be appreciated, I need to provide some context as to how this research came about and background information about myself. In doing so, I will also outline the importance of reflexivity in my research, especially because I played a critical role in generating and co-constructing the data.

I am a photographer and photojournalist from Cape Town, South Africa. I completed a Bachelor

of Journalism in 2012 at (the university currently known as) Rhodes University in Makhanda, the Eastern Cape. During my third and fourth years I specialised in photojournalism, a course which comprised both of theoretical and practical components. After my studies, I worked in the corporate and marketing industry for three years, prior to becoming a freelance photojournalist focusing on feature writing, portraiture and documentary photography.

As a photojournalist, freelancing has allowed me to foster my desire to advocate for social justice for queer communities, womxn and people with disabilities. My academic journey through this study has allowed me to discover my keen interest in the mechanics of representation and its influence on society. Over the past few years, I have become aware of the need for restorative representations of marginalised communities in the media and especially for PWIDD. My identity and intellectual growth as a queer feminist have informed my belief that social justice must be intersectional and that the members of marginalised communities must be an integral part of the fight for inclusion.

As I mentioned in the Preface, I came to the field of disability studies by meeting my wife ('Wife'). They are a clinical psychologist in the field of intellectual and developmental disability and their perspective of the field has had a profound impact on my own interest. Their experiences of working with PWIDD, especially as it relates to trauma, have inevitably influenced my understanding of the marginality and oppression that PWIDD are at high risk of experiencing.

It is evident then, that reflexivity needs to be considered throughout the research process and even more so because I was required to draw on my professional skills as a photojournalist. Within a participatory action research (PAR) framework, I collaborated with my participants, thus critical self-awareness was imperative on my behalf. I needed to be continuously aware of how I projected my own subjective views onto the research and how I was constructed and experienced by the participants.

Reflexivity generally refers to the examination of one's own beliefs, judgments and practices during the research process and how these may have influenced the research. If positionality refers to

what we know and believe then reflexivity is about what we do with this knowledge. (Finlay, 1998 in University of Warwick, 2021).

Throughout the study, I was aware of my positionality as a photojournalist and the power that comes with being responsible for the representation of the people who I photograph and write about. But also interrogating my own ableism and inexperience with working with PWIDD. For example, I was unsure of where to set my expectations of my participants in this collaboration. My unfamiliarity with PWIDD left me feeling apprehensive and unsure of my abilities to engage with them on topics like 'representation', 'identity,' 'media' and 'ableism'- topics so complex that it spans many academic disciplines. At times, I experienced this uncertainty as something akin to disabling. Then, there was my wife (who worked in the field of intellectual disability services at the time), who in various conversations affirmed my feelings of uncertainty, as they sometimes say "if you want to run with PWIDD, you have to foster a tolerance for feeling incompetent." My role in the research and how I took care in working with the participants, collecting and interpreting the data will be detailed in this chapter, as well as in the Discussion.

Research Design

The research was qualitative and exploratory in nature. It was guided by the principles of feminist disability studies and participatory action research. Using multimethodology, data was collected using interviews, Photovoice and field notes of my photographic practice. Data was analysed using Thematic Analysis (Braun and Clarke, 2006) and recommendations based on these themes were collated into working ethical guidelines for media-makers regarding disability.

A qualitative and explorative approach was adopted because it allowed me to delve into the richness and complexity of media ethics, the photographic practice and PWIDD's lived experiences. Multiple sources of data were drawn on, including interviews with participants, Photovoice and field notes on the photographic practice, all in the context of the literature (Creswell and Creswell,

2018). PAR also gave participants the opportunity to reflect on themselves and how they'd like to be represented to the world (Babbie, 2016).

Qualitative research methodologies are appropriate when small populations are targeted as was the case in this study (Babbie, 2016). It is not to say that PWIDD are a small population, but rather accessibility and their opportunity to participate in research is unfortunately limited, for all the reasons described in the literature review.

In summary, qualitative methods allowed for an in-depth understanding of the perceptions of PWIDD, my observations and interpretations and the textual data from the literature about the representation of PWIDD in the media (Babbie, 2016; Creswell and Creswell, 2018).

Participatory Action Research

With inclusion and participation at the heart of this research, participatory action research (PAR) was chosen to guide the methodology. It aligns with the feminist disability framework, and is underscored by an ethos that can be considered as akin to the disability rights movement's mantra 'nothing about us without us'. The guiding principles of PAR dictate meaningful and active collaboration with those involved in the study throughout the process. Participants must be involved in decision making which guides the research (MacDonald, 2012). In this study, multiple interviews were held with each participant, allowing them to reflect on emerging ideas and to make suggestions of their own about the image we planned to make of them. In the two instances where I made portraits of participants, care was taken to make the space accessible and give the best opportunity for meaningful collaboration.

The values of PAR were reflected in several methodological steps which elicited from participants active participation in the process of creating a representation of them. In the work done with the participants, there was always an underlying goal to find out how they would like to be represented. The participants were also given the opportunity to document their own lives through

Photovoice, a method which equips participants with their own compact, easy to use camera. They were then instructed on how to use the camera to document their lives, what they care about and what makes them 'them'.

PAR is a qualitative research methodology which aims to understand aspects of the subjective human experience and enact social change (MacDonald, 2012). A common framework associated with PAR is a "cyclical process of fact finding, action, reflection, leading to further inquiry and action for change" (Minker, 2000, p. 191). This cyclical process suited the study well as I endeavoured to learn how to make ethical representations of PWIDD as well as reflect on the process to suggest how media makers could improve media for PWIDD.

The ultimate goal of PAR is to enact some form of social change or intervention (MacDonald, 2012). The initial action which was planned for this study was an exhibition to showcase the work to the public with the hopes of adding ethical and complex portrayals of PWIDD. But due to several crucial challenges posed by the COVID-19 pandemic, this exhibition could not be created as planned.

PAR is concerned with building individual's capacity to reflect on their social realities and empowering them to play a part in changing it (MacDonald, 2012). In this way, the researcher also assumes the role of facilitator, as I did for my participants, guiding them to conceptualise and create representations of themselves and their lives. This is especially significant and important for the intellectually disabled community as their verbal and cognitive impairments make it challenging to intervene and subvert the status quo alone.

I was committed to taking on the challenges associated with PAR, its time intensity, requirement of in-depth knowledge of the group being studied, and flexibility and sensitivity to consider the multitude of values and agendas of the various participants (MacDonald, 2012).

Photovoice

Photovoice is a data collection method and research strategy usually associated with participatory action research (Dassah, Aldersey and Norman, 2017). This photography-based research method actively includes participants in the recording of their lives and experiences by putting stills cameras in their hands and asking them to photograph their day-to-day experiences.

The method is particularly useful and often used in research with marginalised communities who have limited political and social power (Dassah et al, 2017). In documenting the personal lives of marginalised groups from an insider's perspective, the method allows the opportunity for researchers and participants to make the personal political. Photovoice was thought to be an especially apt tool for inclusion in this research as it may transcend verbal communication, which can sometimes be challenging for PWIDD.

The inclusion of this method allowed the participants to document their lives and communicate what is important to them in a unique way, which helped in the crafting of complex, unique and dignified portrayals. The use of photovoice also offered them a glimpse of what goes into the creation of a photograph, which was useful during the production of the final portrait. The resulting photographs were a catalyst for ideas and discussion between myself and the participants and allowed me to get a glimpse into the participant's lives in a very unique, visually-driven way (Dassah et al, 2017).

Research Setting

The study took place in Cape Town and its surrounds, with participants living in residences for PWIDD - commonly called 'group homes'. Interviews and meetings with participants were carried out in their place of residence, with the exception of the photographic studio space used to create their formal portraits, and one case where I met a participant at their place of work. The formal portraits were taken at Sunshine Co.'s studios in Cape Town, Bokaap. Sunshine was chosen because they are a leading and fully equipped studio space and photographic gear rental service with whom I already had a

good working relationship. The layout of the studio was private, convenient and comfortable. It had private bathrooms, private changing rooms, a makeup and wardrobe section and a kitchen and resting area. Furthermore, the staff and management were willing to make any accommodations needed for the participants.

Participants: Photovoice and Studio Portraits

The participants of this study were people with intellectual and developmental disabilities recruited from residential facilities and organisations in Cape Town, South Africa. To recruit participants, I approached the management of these residences to gain access and find potential candidates. Initially, I aimed to include around 10 participants reflecting a diverse range of demographics such as age, gender, race. But due to the COVID-19 pandemic, recruitment and data collection had to be halted and thus, only three participants were included. The inclusion criteria were as follows:

Participants must -

- Be people with intellectual disabilities known to be in the mild range. The individual's likely IDD range was assessed by my co-researcher, Dr Capri, who is a clinical psychologist in the field of intellectual disability - my wife's work-wife. When potential participants were identified as being outside the range of mild intellectual disability, they were no longer considered eligible to take part in the study.
- Be no younger than 18 years old and no older than 65. Participants younger than 18 were not included in the study because we wanted to ensure that participants had the best chance to consent to the process. An age cut-off of 18 also meant that we would have a better chance to avoid perpetuating infantilization of PWIDD through the over proliferation of children with disabilities. Individuals over the age of 65 were excluded to diminish chances of age-related complications impacting them during the study, especially when off-site at Sunshine Co.'s photographic studios. It does, however, deserve saying that people

falling outside of this age range do still have the same right to be included in media and future projects should take note of this.

- Have the capacity to give informed consent. It was vital, not only in ethical research practice, but also in pursuit of ethical media practice, that all participants had the ability to give informed consent. Their capacity to consent was assessed by my co-researcher, Dr Charlotte Capri, who is a clinical psychologist in the field of intellectual disability, and who has a track record of research on intellectual disability rights and participation. Dr Capri and I felt confident that 3 of our participants had the ability to give informed consent. There were some questions in this regard with one participant who's compromised verbal expressive language made it impossible for him to provide emphatic consent. We decided to not include him in this research, but still arranged for him to partake in the activities as it did appear he was excited about the project. This is unfortunate, but it is of utmost importance that all the participants can express clear consent to all aspects of the study, especially because their photographs may be available to the public.
- Have the ability to use a camera for Photovoice. People with physical disabilities which would make it impossible for them to use a camera would need to be excluded from the study on the basis that they would have trouble taking part in Photovoice. That said, accessibility was a consideration, cameras with touch screens, which were lightweight and easy to use were sourced to increase possible accessibility.
- Be English or Afrikaans speaking. For convenience and budget constraints, participants needed to be fluent in either English or Afrikaans. This presented a limitation to the study and considerable efforts should be taken to include those who speak other African languages, especially South African sign language.

- Be sampled from a diverse range of socio-economic statuses, race, gender and sexualities. We felt it was important to include a sample which reflects our country (and province). To this end, considerable efforts were made to find diverse individuals in terms of race, age, gender, sexuality and socio-economic groupings. This is also in line with the disability rights slogan ‘nothing about us without us’ (Charlton, 1998) and principles of inclusion and intersectionality held by feminist disability studies. This endeavour was severely limited by the halting of the study during the COVID19 pandemic and unfortunately the three participants who were finally included did not reflect the diversity I set out for in the onset of the study.

Data Collection

Multiple sets of data were collected through the course of the study. Data included interview transcriptions, participant’s Photovoice photographs and notes on my observations and reflections from the studio days. The data was collated and analysed according to Thematic Analysis.

Seven potential participants were identified to take part in the study, of which 3 were eligible. In the interview with the second potential participant, they declined to participate once they had heard about the study and were informed of their right to give or withhold consent. Myself and Dr Capri agreed that this was a good sign about the efficacy of our informed, ongoing consent process and that the potential participant felt comfortable rejecting the opportunity to participate.

The fourth potential participant took part in the interview and photovoice processes, but unfortunately due to their physical disability and speech impediment, we were unable to fully ascertain if they could give informed consent. In the interest of participation and based on their enthusiasm for the process, the photovoice section of the data collection was completed with them, but along with the interview data, would not be used in the study.

The sixth and seventh potential participants were also excluded from the study as they did not

meet with participation criteria. They would or could not show that they understood the study, which is necessary for informed consent. In addition, Dr Capri's clinical observations and screening of these participants suggested that they were in the moderate intellectual disability level.

In the end, three participants took part in the study. Two of these participants completed the data collection process which ended in two conceptualised photographic portraits shot in a studio. The third participant could not complete this section of the study due to the COVID-19 pandemic which halted the data collection process (more details to follow). Interestingly, though, a studio portrait of this participant was made by me during the recruitment process as his place of residence. The management were enthusiastic about the study and requested that I make simple portraits of each of their residents. This portrait could be considered as similar to the former two participants' portraits in style.

Interviews

Once participants had been identified, I set up dates with each of them to introduce myself and the project. This interview had three basic aims, firstly to outline the project, including what will be required of them, how the data will be used and the basics of consent. It was also explained and emphasised to participants from the beginning that they may withdraw their consent at any point in the process without fear of negative consequences. This was done partly to combat any agreeableness which may prevent participants from speaking up about what they really want. My co-researcher, Dr Capri, assisted throughout this process.

Once consent was given, I did an intake interview to find out more about the participant. The interviews were semi-structured and questions were used to guide the conversation to ascertain how the participants felt about photographic representation, as well as uncover some ideas on how they would like to be represented. For ideas on how to represent them, I guided the participants to talk about their interests, personalities, what they believed made them unique. I asked how they would like to be seen, what they want other people to think of them and what they thought were their best

qualities. We then discussed how these could be used in their portraits, i.e. one of the participants said that she enjoys making jokes, and so we thought having her smile or laughing could be a good option. We were looking for aspects that could be translated into visual language in a way that was aesthetically pleasing, thematically meaningful and appropriate for their final portrait.

At the end of the interviews, I instructed the participants on the basics of photovoice, how to use the camera. This was done in simple English, in a manner that they understood, and I was able to build rapport with the participants. These interviews were all recorded and transcribed. The participants were given the option of being accompanied by a carer; only two chose to be interviewed on their own. While the participants carried out the Photovoice project (on average two weeks), I transcribed the interviews and extracted some key elements that came up several times or that I felt had particular meaning which we could explore further in the follow-up interviews.

Photovoice and follow-up interviews

For Photovoice, the participants were provided with a camera to document aspects of their lives. The cameras were specially selected to account for the possible physical disabilities participants may have. The Canon M6 (which were the selected models) are light, compact and easy to use. They have a flip up touchscreen which were thought to be assistive and meant that the participants could choose whether or not to use a small viewfinder and to hold the camera up to their face. It also meant that participants would not potentially struggle with little dials. Knowing that the participants would not be experienced photographers and so may make exposure errors (i.e. not account for dark shadows or overblown highlights in skies), it was important to have cameras with good sensors which would allow considerable detail to be saved in post-production. The good megapixel amount (24.2 megapixels) also meant that images could be cropped and blown up for exhibition purposes. The Canon M6 is also beginner-friendly while providing professional quality. All the participants reported feeling competent in using the cameras and the cameras gave them the freedom to learn and experiment.

During the follow-up interviews, the participants and I went through the photographs they had taken. These interviews were less structured but centered on the participant's photographs. The meetings were generally filled with excitement and enthusiasm and all the participants indicated how much they had enjoyed Photovoice. The photographs complimented the data I had collected from the transcriptions of the initial interviews and prompted further discussion. For example, we spoke about how often they photographed certain things, their reflections on the photographs and the photographic experience as a whole. I also had the opportunity to ask for more detail where necessary.

At the end, we revisited possible concepts for the studio portraits, how they wanted to be photographed and what we could include. We also finalised logistics around the studio days. I again checked in whether the participant still wanted to continue with the project as per ongoing informed consent.

The second interview was recorded and transcribed. Each participant's photographs were stored on an external hard drive, backed up on a second hard drive and password protected. Each hard drive was stored safely at two separate, secure venues.

The photographs could be considered as 'visual communication' which added to, or complimented the participant's insights, stories and contributions to the study. The photographs, in and of themselves, are not data. It is the participants' discussion around their experience of Photovoice that is the data. For example, their reflections on why they had taken certain photographs, what they think those photographs tell people about themselves, and how they felt working with the camera and taking the photographs. Where applicable, photographs were incorporated as visual aids in the results.

Studio Portraits: Preproduction, Production and Postproduction

The studio portraits entailed three parts, (a) preproduction, (b) production and, (c) postproduction. I have provided the following detailed account of the studio portrait production process to illustrate the complexities and intricacies of the behind-the-scenes of media making. This is a 'sample'

of the cultural context in which media is made, or rather, in which I made media. Throughout the preproduction, production and postproduction stages I kept field notes comprising of descriptive and reflective information on the photographic practice as it related to the participants, the intention, the photographic quality, logistical considerations, ethical principles, level of collaboration and participation.

Preproduction: The Planning Phase. During this phase I continued with conceptualising which I had started with the participants when we discussed ideas for their portraits. I mulled over our conversations and the Photovoice contributions, sought references from both my personal and other photographers' portfolios, and applied my photographic skills and experience to guide stylistic choices like lighting, backdrop, pose, composition, props, wardrobe etc. for the portraits. With these in mind, I recruited and consulted with a makeup artist, stylist, lighting assistant and studio manager to finalise the production, i.e. artistic direction, equipment requirements, set layout and design and stylistic requirements. The studio was booked and logistical arrangements were made with Sunshine Co., the crew, the participants and their carers. I was in regular communication with the stylist, Jelena Jablanovic in this planning phase as I fleshed out the concepts and she guided me as to the possibilities regarding availability and budget for costume, props and hair and makeup.

Production: The Creation Phase. The participants were brought to Sunshine Co. studios for a studio photoshoot. Before they arrived, I had already briefed the team and we prepared the studio for the shoot. The set was dressed and the lighting set up and tested, all in preparation for the shoot. When the participant arrived, they were introduced to the crew and shown around the studio. They started with makeup. I initiated the collaborative process between the hair and makeup artist and participant through which they established the desired 'look.' Next, the participant changed into their first wardrobe option and took their place in front of the camera.

I proceeded to take photographs, talking to the participants while making adjustments, often explaining what I was doing as well as giving direction and making suggestions for poses, facial

expressions, movement etc. This can be a foreign experience for most people, so it is common for photographers to tell jokes and anecdotes to make the participants feel comfortable and yield better results.

The camera was tethered (connected via cable) to a laptop which allowed the participants to see the raw images throughout the shoot. We frequently convened around the laptop to discuss the images. I asked questions to encourage feedback and for them to participate in the creation of the image.

I retrospectively wrote about my observations and reflections on each day in the studio. Much of my attention was focused on the technical aspects of photographing the participants; were the images of high quality? Were they well lit, aesthetically pleasing and did I have enough high-quality options to choose from in the later selection and postproduction process?

In addition, I tried to remain mindful of what was happening in the studio, particularly with the participants. Did they feel comfortable enough in the space to collaborate, raise concerns, ask questions and make suggestions? What could I do to make the process more accessible? Was the set professional? Did the crew feel that they could do their jobs timeously and to their best abilities? What were the interactions between the crew and participants like? I also made note to often check in with the participants, asking them what they thought of the images we were making, were they enjoying the experience, how did they feel about their wardrobe and hair for example.

Postproduction: Editing and Retouching. Once the images were downloaded and backed up, I selected the best images based on their artistic merits and the feedback received from the participants during the shoot. I edited and retouched the photographs through photo editing software (CaptureOne and Adobe Photoshop Creative Cloud). This included simple tweaks of exposure, contrast, colour grading and light skin retouching.

A Small Note on a Big Pandemic. I gained ethical clearance in early 2019 and by the end of the year had collected data from interviews and Photovoice with only three participants (as outlined previously). But then the outbreak of the deadly Corona Virus pandemic, to which PWIDD are particularly vulnerable (Morris in de Beer-Procter, 2020a), changed the course of the study dramatically. This meant that in person data collection was during the severe lockdowns impossible. The University of Stellenbosch ethics department issued a halt to all in-person data collection as a result of the pandemic.

I was faced with a big decision in the study, I had to either postpone the data collection and extend the study indefinitely while the world awaited vaccine rollouts and some semblance of ‘normality,’ or I had to collate what I had learned thus far. In the interim, I continued with a thorough investigation of the literature, and this, combined with the data collected through the interviews lead to the beginnings of a fairly meaningful list of guidelines and talking points for media-makers on the representation of PWIDD.

Data Analysis

It is in the nature of PAR that data analysis and data collection occur simultaneously and recursively. For this reason, the distinction between data collection and analysis in this proposal is somewhat arbitrary. I will make use of thematic analysis of my collected data, in line with the approach of Braun and Clarke (2012) and informed by feminist disability studies. The purpose is to develop themes that will provide insight into what media-makers need to know when working with PWIDD. My field notes, reflections and investigation of the literature will further the conversation on these themes in the Discussion chapter.

Furthermore, the Discussion will explore the links between theory and practice and tell a broader story of the themes which will be contextualised in the literature under investigation. By investigation, I am referring not only to the literature initially reviewed, but rather the literature and the media I have continued to study as a journalist. Media here referring to industry related articles and

discussion relating to ethics, consent, education, representation and disability. When I say, ‘as a journalist,’ it means that I am using my practice of journalism, or the process of finding, interpreting and communicating information that is in the public interest. It is about digesting the very broad and complex field that I am studying; media and disability studies, which includes cultural studies, feminist disability studies, semiotics and media ethics to not only communicate ‘truth’ about the relationship between stigma and media representation of PWIDD, but also to ascertain what practical changes are necessary.

Thematic Analysis.

The qualitative data collected from the transcripts of the intake interviews and follow-up interviews of the reflections on Photovoice were analysed according to Thematic Analysis. It is a method of analysing qualitative data, such as transcriptions, field notes and textual data to identify patterns, ideas and subjects which come up repeatedly in the data. These are coded, categorized and compared to develop meaningful themes which translated into working ethical guidelines for media-makers regarding disability.

This was completed through a step-by-step process outlined by Braun and Clarke (2012).

- Firstly, I transcribed the recordings of the interviews and noted my observations and reflections of the studio portrait production process. My observations and reflections on the photographic and interview practice were noted. I was then able to familiarise myself to the patterns and experiences emerging from the data.
- Secondly, I started generating codes from the data collected. This was quite the feat as I had collected a wide array of data from interviews, personal notes and reflections, photographs and textual data from the literature. I continuously revisited this data in what has been described as “a theorizing activity” (Nowell, Norris, White, Moules; 2017, p. 5).

- The codes generated, when viewed separately, did not have sufficient meaning to the study. I had to further sort and collate different codes identified across all of my data in order to identify themes. Through searching for themes, the data came together to capture the most salient concepts that are relevant to the overall aim of the study (Aronson, 1994; Nowell et al. 2017)
- The next step, reviewing the themes, involved elaboration, which is the process of focusing on the finer nuances of the themes. Through this process I was able to demonstrate how the themes could be traced back to the data, “how they fit together, and the overall story they tell about the data” (Nowell et al. 2017, p.10).
- In the fifth phase, defining and naming the themes, I identified what aspect of each theme was important and why. I interpreted the data according to the thematic categories from analysis, including additional data from the literature on media ethics and practice which applied to PWIDD. I wrote a detailed analysis of each theme (the Results and Discussion chapters) and was satisfied with how, collectively, the themes told a story about media-makers’ responsibilities in representing PWIDD.
- The last step in Thematic Analysis, naturally, is the write-up of the study. In the Results and Discussion chapters I outline and evaluate the themes. I start with describing the themes, including quotes, original texts and specific points of interpretation to demonstrate the validity and merit of my analysis (Braun & Clarke, 2006; Nowell et al. 2017).

There is the possibility that more in-depth visual analysis of the photovoice images, for example using a semiotic approach, which could present fascinating and meaningful results. But this opportunity was not pursued because of the aims of this study, which lead us to collect data which could reveal patterns related to photographic practice (participant experiences of the photovoice exercise), to what it showed about their unique personalities and to what could be learned about what they found

important (for suggestions about how to represent them). As such, the Photovoice images are analysed and interpreted according to what they add to the themes identified from the interview data. As such, the photovoice images are analysed and interpreted according to what they add to the themes identified from the interview data and were used to facilitate discussion between myself and the participants (Dassah et al, 2017).

Trustworthiness of the Data

Trustworthiness of the data was ensured through member-checking, triangulation, reflexivity and by using multiple forms and sources of data (interview transcripts, Photovoice, field notes, literature and textual data). Member-checking occurred throughout the study to increase the rigor and trustworthiness of the data (Krueger & Casey, 2000). I had a number of meetings with each participant which provided us with an opportunity to verify the correctness of the data and findings. Further details how this was done is explained in Ethical Considerations. Triangulation was done with my supervisor and co-researcher at regular intervals to provide space for feedback and ideas for further inquiry. And as explained previously (The Researcher and Reflexivity) I practiced reflexivity throughout the research.

Ethical Considerations

PWIDD are considered a vulnerable population, but their vulnerability does not negate their right to visibility and inclusion in our media and the opportunities it affords citizens to participate in society and culture. Similarly, it can be considered unethical and disabling to exclude PWIDD from participating in studies, even more so when the research is about them (Capri and Coetzee, 2012).

In both academia and the media industry, those of us working with PWIDD must carefully consider and commit ourselves to a set of values and ethical practices which uphold their dignity. As Capri and Coetzee (2012, p. 3) wrote, "...if one takes a position that it is unethical to exclude intellectually impaired individuals from participating in research, the formulation of solutions to difficulties regarding inclusion remains the researcher's responsibility."

I was committed to adhere to and amplify the values and commitments set out in the United Nations Convention on the Rights of Persons with Disabilities and Optional Protocol, signed by South Africa, particularly article 12 (equal recognition before the law), article 17 (protecting the integrity of the person) and article 21 (freedom of expression and opinion, and access to information) and article 30 (participation in cultural life, recreation, leisure and sport) which emphasises the need to allow people with disabilities the equal participation and representation in society.

Ethical approval was obtained from the Research Ethics Committee of Stellenbosch University in March 2019 to collect data. The study was registered as a sanctioned project in fulfilment of the requirements of the master's degree. The following details the considerations and process of obtaining ethical consent. In line with the ethics committee's approval, several methodological considerations and protocol were followed.

- Accessibility was key to ensuring ethical, informed consent could be obtained. If we weren't sure that participants meaningfully understood the study, how could we be sure that they would meaningfully engage with it and could give proper informed consent? To do this we considered the following,
- Time. We felt it important to ensure that time pressure would not affect the participants, that they wouldn't feel rushed and that they felt comfortable enough to spend more time on something if they needed to. This meant that we blocked off what would usually be considered 'more than enough time' to interview and to photograph the participants. Half of a day (3-4 hours) was set aside for meetings and interviews, including travel to and from venues. A full day was set aside for producing each studio portrait.
- Language. Taking into account time considerations as mentioned above, care was taken to speak at a slower pace and to repeat what I was saying in different words, as an extra way of explaining if they didn't get it the first time.

- Support from an 'ally'. We also made sure that each participant was made aware that they had the option to be accompanied by a trusted carer or family member etc.
- Careful explanation. The reasons for the study and the process were explained to the subjects upon the first meeting and was often reiterated throughout. It was important for ethical rigor to make sure that the participant understood the information being given to them. To ensure this, my co-researcher accompanied me to each initial interview and an illustrated information sheet (Appendix D: Consent Forms - Illustrated) was used as an aid for participants with higher support needs. We also double checked that participants (especially when unsure about their level of IDD) could explain what we had said back to us some form to ensure that they truly understood what the study entailed.
- Voluntary participation. Participants were assured that they could withdraw from the study at any time without fear of consequences or loss of benefits, and that images and media would not be used in the thesis or publicly in any way. They were reminded of this at every stage of the study to ensure that there is open communication and ongoing understanding and informed consent.
- Consent. Informed and ongoing consent of participants were a priority in this study. Consent was discussed with each participant at the beginning of the study and throughout. I went through information about the study (Appendix B: Information Sheet), as well as the final publication of images carefully with each participant, in language that they understood and allowed them enough time to answer questions and ensure understanding. This was done with the help of my co-researcher and was part of ensuring informed consent. All of the final participants provided consent. Their legal guardians were also contacted and asked for additional consent.

- Participants were also instructed on consent in relation to others, when and how cameras should and should not be used to photograph other people before they embarked on the photovoice section. Where consent was not obtained for subjects in participant's pictures to be published, the images were not used or faces were blurred out when included in this thesis.
- It was also explained to participants that information about them will be used in my thesis. All of the participants agreed to their first names being used in the thesis and possible photographic publications. Other identifying information was not included, i.e. residence, place of work, last name etc. All of the participants said that they understood and gave consent.
- All explanations and acquisition of consent and assent were done with the assistance of my co-researcher, Dr Charlotte Capri.
- Release forms. The participants were informed that once the production process is complete, the images may be used in exhibitions, in magazines, on the internet and that people will see the pictures. This was done with the help of illustrations, based on consent forms used by Dr Charlotte Capri (Appendix C: Consent Form - Written; Appendix D: Consent Forms - Illustrated; Appendix E: Model Release Form).
- The consequences of publication were explained to all of the participants (i.e. that consent cannot be withdrawn once images are published as they become public). Each participant was asked to sign a release form to allow the publication of their images, if they so choose. They were given the option of denying certain uses for their images in the release form (Appendix E: Model Release Form).
- The release form which participants signed offered several options for what the participant allowed their images to be used for. The release form included a list with tick boxes, giving

or withholding permission for their images to be used in certain ways. The participants gave expressed permission for their first names to be used in the thesis and in publications.

- Secure storage of data. Individual interview data was kept private, on two password protected hard drives. Images which were not used were deleted and those which were released by participants will be kept by myself on digital hard drives for future use or reference. I also printed the photovoice images taken by the participants to give to them.
- Provisions for adverse incidents. Provisions were made for any unforeseen, negative impact that may have resulted from their participation in the study. For example, a clinical psychologist experienced in the field of intellectual disability agreed to be available should a participant require psychological support. There were no adverse events or any negative experiences that required external support.

Limitations of the Study

The limitations of this study include a lack of generalizability about people with intellectual and developmental disabilities. Due to the COVID19 pandemic, the sample size was smaller than intended and a more diverse demographic reflective of the South African population could not be recruited. All participants were of similar age, race and socioeconomic background.

Sample criteria required participants who were identified as falling within the mild range of intellectual disability which excluded those with moderate to profound IDD. While this decision was made under careful consideration for ethical and practical reasons, PWIDD in moderate and profound ranges provide an opportunity for further inquiry.

All participants were based in Cape Town and surrounds and live-in residences for PWIDD. As such, the experiences of participants living in informal settlements, state institutions or family homes were not gathered. All participants were first language English speakers, and all interviews were conducted in English.

In terms of the results and guidelines as they relate to media practice, the absence of feedback from industry stakeholders is noted. This leaves much scope for further study. Additionally, media disciplines such as radio and filmmaking have not been explored as thoroughly as writing and photography.

Summary

This chapter addressed the full particulars of how the research was conducted. As a qualitative, multimethodology it required clear and detailed information on how the data was collected from a wide array of sources. It explained how PAR and Photovoice was informed by feminist disability studies as well as how I am positioned within this theoretical framework. The importance and use of member-checking, triangulation and reflexivity was defined, and special attention was given to the ethical considerations required in a study about - and with - PWIDD. It described how themes were generated through Thematic Analysis, and how these will be described and elaborate in the following chapters.

Chapter V: Results

Introduction

Through a process of coding, categorizing and comparing, as required for thematic analysis (Braun & Clarke, 2012), eight themes were identified and sometimes further broken down into sub-themes. These themes can be read as distinct but also interconnected ways of understanding the data.

The following is by no means an exhaustive list of themes due to the limited sample size necessitated by the onset of the COVID-19 pandemic. These themes could be expanded, corroborated or challenged if they are investigated with a more diverse and expansive sample group. Although the sample group was limited, the themes were repeated throughout all six interviews and due to this consistency, can be considered comparable and meaningful.

Themes and Sub-Themes

In this chapter I will present these findings, as well as evidence and interpretations in the form of direct quotes taken from interviews, reflections from my field notes and personal communication with experts in relevant fields. These will be accompanied by several selected photovoice images which relate to the themes. The following table outlines each theme and sub-themes.

Table 1*Themes and Sub-Themes Identified in the Analysis of the Data*

Theme	Sub-Themes
1. It is important to me that you get to know me	1.1 I know who I am and my preferences 1.2 I know my strengths and weaknesses 1.3 My gender matters 1.4 I want to show you
2. It is important to me that you know that I am valuable	2.1 I do meaningful work 2.2 My contribution takes sacrifice 2.3 I contribute to society
3. It is important to me that you appreciate my dreams and aspirations	
4. It is important to me that I am seen in a positive light	4.1 I know how I want to be seen, and not 4.2 I have opinions on the media
5. It is important to me that I am treated like an equal	5.1 I know stigma 5.2 I know respect
6. It is important to me that you know that I love and am loved	6.1 I am loved 6.2 I love
7. It is important to me that I participate	7.1 I can make media, too 7.2 There are things I need to participate
8. It is important to me that the 'D-word' be handled with care	

Theme 1 - It's important to me that you get to know me.

The data collected from interviews with participants, which constituted the most expansive data set for analysis in the study, had a central aim of finding out 'who the participants are'. As in, finding out what makes them unique which can be translated into visual language in their photographic

representation. The interviews therefore included several questions designed to illicit what participants could communicate about themselves, relating to their personalities, interests and concerns. This was guided by the feminist disability studies concern with “narrative retrieval” (Garland-Thomson, 2005a) which acknowledges that disability is only one facet to a PWIDD’s experience and by portraying PWIDD’s full range of humanity, media-makers can challenge normative stereotypes which stigmatise PWIDD.

Across the interviews with all three participants in the study, each showed a confident understanding of what made them unique, of who they are and what their interests are, as well as an ability and willingness to share this with the researchers. Each documented their lives through Photovoice with enthusiasm, evidencing their grasp of the documentary nature of the exercise. Additionally, they showed keen interest in sharing the images with the researchers. This theme was further categorized into subthemes. Table of theme 1 with sub-themes and illustrative quotes can be found under Appendix F. See Table 2 .

Theme 1.1 - I know who I am, my likes and dislikes. All participants showed a nuanced understanding of what makes them unique. Each could confidently define their personality and knew what they wanted others to know about them. Participants each gave concrete examples of their interests, including their taste in music, favourite pastimes and their fashion preferences. They also explained what they didn’t like, including how they liked to be treated and what they found difficult in daily life. The confidence with which the participants could communicate who they are suggests that ‘narrative retrieval’ to portray a PWIDD is an endeavor which can be undertaken by media-makers with PWIDD.

Participants captured images which portrayed their interests. In the first interview with Fred, he mentioned a few musicians that he was fond of. Natalie expressed her love for animals and made several images (Figure 6) of domestic cats. In Figure 7, Fred is documenting the radio and CDs that he owns, indicating his desire to portray his love of music.

Figure 6

Natalie is an "animal lover"

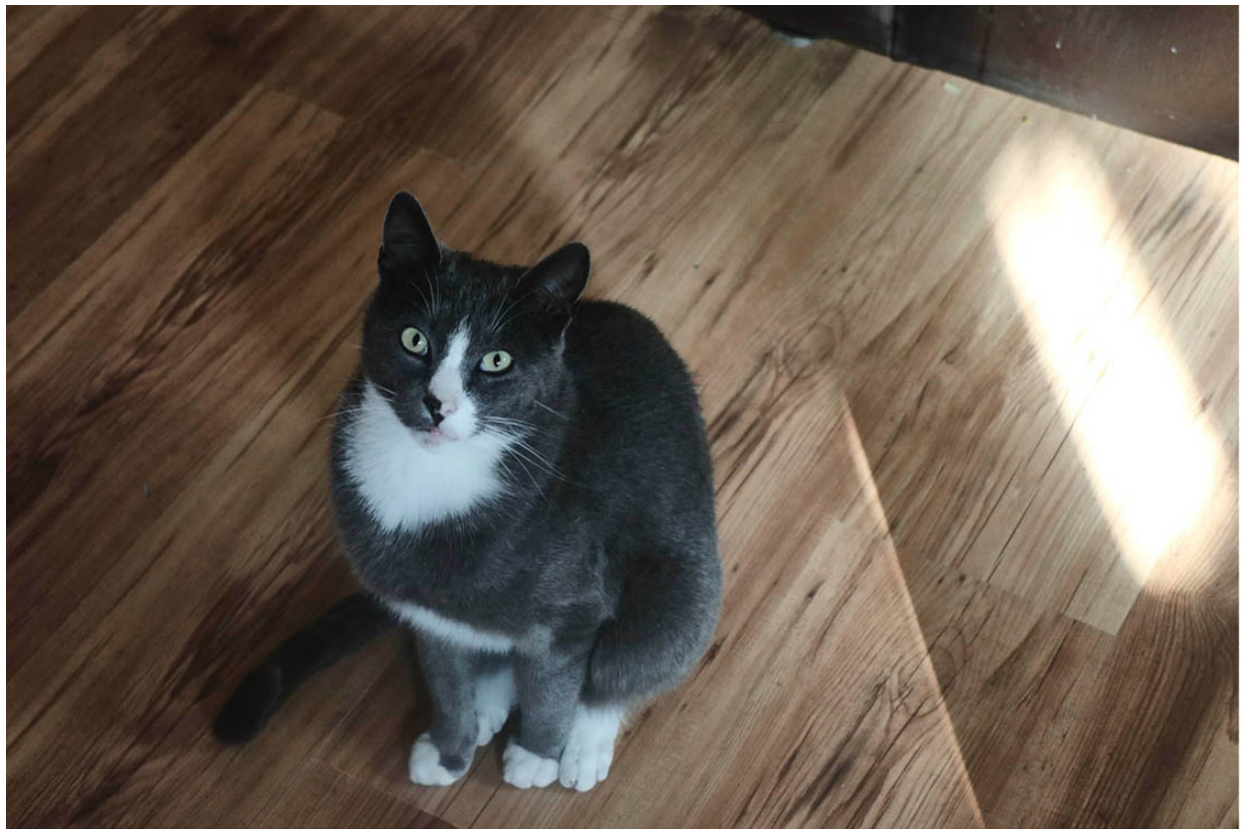


Figure 7

Fred has "quite a lot of CDs"



Theme 1.2 - I know my strengths and weaknesses. All of the participants could define what they felt their strengths and weaknesses were, how they felt about them and what it meant for their personal growth. For example, weaknesses (or challenges) were often related to difficulties regulating their anger, but two of the participants also spoke about the efforts they were making to improve and noted their successes in this regard. It could be noted that several of the good characteristics named by participants were the antithesis to aggression, anger and 'bad behaviour,' using words like "calm," "sweet," "kind" and "gentle" to describe themselves (Table 2). This may suggest their intention to show their personal growth and/or an understanding of their complex, multi-layered personalities.

All participants shared what they were good at, emphasizing their talents and abilities, which may be interpreted as a reaction to their awareness of stigma around their disabilities, that emphasizing ability may have been an effort to subvert this stigma.

Theme 1.3 - My gender matters. All the participants expressed some form of their own gender identity, their preferred performance of gender and in one participant's case, how her gender influenced her life and how others treated her. Further interrogation into participant's gendered experiences could yield additional, potentially fascinating insights, but would exceed the scope and focus of this study. However, this theme is seen as significant to the study's theoretical framework of feminist disability studies which asserts that gender, like other identity groupings, is relevant to understanding a person's multilayered experience of themselves and their place in the world.

Fred captured an image depicting woodcutting (Figure 8), which he says that he is good at, as in Figure 8. This particular image also depicts an activity which can be interpreted as indicative of his feeling that he needs to "be that man" (Table 2), as he reflected while speaking about his beard (another stereotypically 'male' attribute).

Figure 8

Fred "keep[s] [his] biceps"



In addition, I wondered how my gender influenced what the participants felt comfortable sharing. For example, Natalie reflected on being the only woman in the house and how she trusted her house mothers with 'girl's stuff,' like relating to menstruation (Table 2). It is interesting to note that she shared intimate details relating to sexual and reproductive health with me and Dr Capri, and we were all women. I reflected on the inter-subjective dynamic which might have made her trust me with intimate, 'feminine' details.

As noted in the limitations, the sample did not include a broad demographic reflective of our country's people. If the sample was more diverse for example in terms of race, we could have expected additional themes related to identity categories. For example, race, sexual orientation, gender diversity and class.

Theme 1.4 - I want to show you. The willingness with which participants shared details about themselves and their lives suggests their desire to connect, and to be seen and heard. It also suggests that they may know that they are valuable and worth knowing. Participants also documented their lives enthusiastically through Photovoice, showing intimate spaces like their bedrooms (Figure 9; Figure 10; Figure 11; Figure 12), everyday activities they partake in and the people, places and things they love.

It could be argued that this theme was present in all the images that the participants chose to share. Every image was made for many reasons, but it could also be interpreted that all images were made to share an aspect of the participant's life. This intention was particularly present in each participant's documentation of their most intimate spaces, their bedrooms. It could be interpreted that the act of showing such a typically private space could indicate a level of openness and trust for the researcher and the viewer.

Figure 9

Fred's home away from away from home



Figure 10

Loren's room

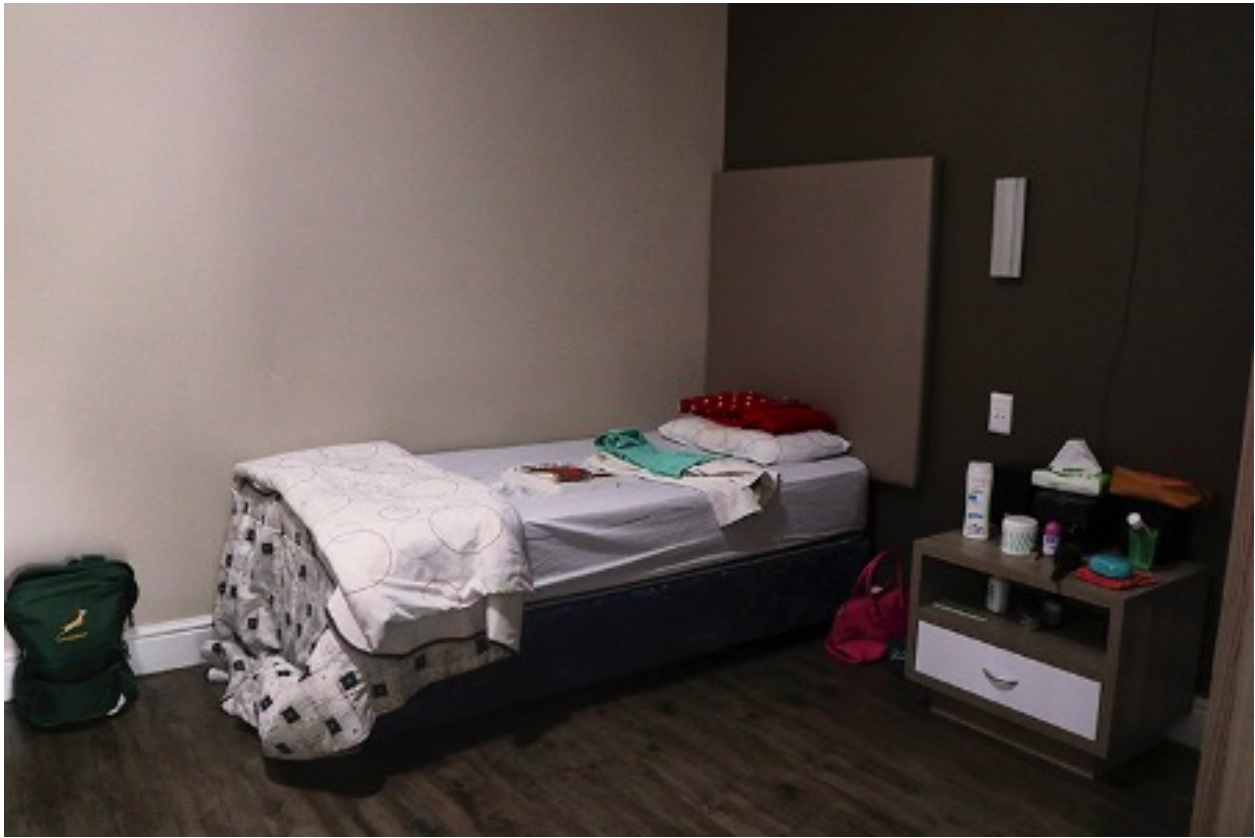


Figure 11

Fred's room



Figure 12*Natalie's room*

The participants seemed to show a keen interest in sharing what was important to them. This theme was echoed in my photojournalistic practice with subjects and sources displaying willingness to be included in media. This further supports the PAR's principle of inclusion and may be encouragement for media-makers to give PWIDD the opportunity to share their lives.

As we've seen in the literature, society often plays a role in disabling PWIDD resulting in their exclusion, from many things, and in this case, the media. In light of this, the fact that they liked taking photos and being photographed is politically poignant. It could be seen as them taking their story back, or as feminist disability studies calls it, 'narrative retrieval' as a means to "challenge normative voices"

(Garland-Thomson, 2005a, p. 1561).

Theme 2. It's important that you know I'm valuable.

All three participants spoke about their value to society, especially displaying pride in their work and expressing their work as an aspect of who they are. They also highlighted their achievements and active participation in civic and social life. See Table 3 for illustrative quotes.

Theme 2.1 - I do meaningful work. When asked to share with the researchers 'who they are', all participants made reference to their work reasonably early on in the first interviews. This was backed up by their desire to share aspects of their work through photovoice.

Figure 13. Fred on "another workday...by the dairy" portrays Fred's work in the dairy, the choice of location and inclusion of the cows recalls the theme of 'I do meaningful work' and 'my contribution takes sacrifice' as he made several references like, "I'm just a bit sleepy... [waking up early] for the cows".

Figure 13

Fred on "another workday...by the dairy"



Theme 2.2 My contribution takes sacrifice. It was evident that the three participants wanted to underscore that they made sacrifices to contribute. One participant shared challenges she experienced travelling to work, expressing her frustration at aspects of her commute . They all seemed to appreciate that their contribution to society is valuable and wanted to portray this. Personal experience with a PWIDD who spoke about crunch time at work.

Figure 14. Natalie's "back to work the next day" depicts Natalie lying on the couch, harking back to her reflection of an image of her on the couch portraying that she's "always depressed on a Sunday" because she has to go back to work the next day. This could be interpreted as her expressing that her work comes with certain sacrifices.

Figure 14

Natalie's "back to work the next day"



Theme 2.3. I contribute to society. Participants shared ways in which they contributed to their communities, underscoring social value as well as civic value. Early on in our first interview, Fred asked, "can I tell you about the swimming...I had a big gala in England". Later on in the interview, he mentioned that he had a won gold medal at this international competition, something he indicated several times

that he was proud of.

In Figure 15. Loren's thumb which "voted...for the right party", the viewer is shown the ink stain on Loren's thumb which indicates that she voted in a South African election, showing her active, political contribution to society and underscoring her ability to partake in a fundamental democratic process.

Figure 15

Loren's thumb which "voted...for the right party"



Theme 3. It's important that you appreciate my dreams and aspirations.

The participants each had answers about where they'd like to travel to if given the chance. One participant spoke about how she wishes she could learn to read and write, but acknowledged that there were obstacles to this dream. Another spoke about wanting to have a home of her own one day.

Upon reflecting on Figure 16. Natalie's 'one day', Natalie spoke about how this scene of a carer who works at the residence she lives in made her think about what her life would be like if she had her own home, possibly indicating that she dreams of living independently, saying, “like one day if I ever have a house of my own, then I’ll do this sort of thing” (Table 4). In the first interview, Natalie spoke about how people sometimes asked her if she’d ever live alone and she responded “not at the moment. Not capable of doing that at the moment.” The addition of “at the moment” implies that she thinks, or wants others to think, that living independently may be possible in the future.

Figure 16

Natalie's "one day"



Theme 4. It's important that I'm seen in a positive light

Each participant said that they liked having their photograph taken, but also gave examples of how they didn't like to be represented. Two participants also spoke about their experiences of media representations of PWDs and how it made them feel, each used the term "sad" (Table 5).

This recalls a contentious debate in media-making in which each media producer must weigh up the rights and dignity of the subject versus what is in the public interest (Ethical Journalism Network, 2021). Since there are so few examples of media about PWIDD and considering the stereotyping which often occurs when they are included in media, one could argue that there is far less space to include images which could be seen as critical of PWIDD. There is still a far way to go to subvert the 'ableist gaze'.

Theme 4.1 I know how I want to be seen, and not. Participants could define how they'd like to be seen by others and what they'd like viewers to think about them when they viewed images of them. Participants could also express what they didn't like in representations of themselves, with the exception of one participant who said that she never had never seen an image of herself which she did not like. Aspects of representations which they didn't like seemed to underscore that consent and dignity is important to them when it comes to images. One participant spoke about not wanting to be pictured looking disheveled, which echoed taunts made by bullies at her work.

Of portrayal of themselves, two participants spoke about which images they didn't like of themselves which seemed to underscore consent and dignity, Natalie doesn't like being photographed when her hair is a mess or her clothes are dirty, and Fred spoke about an image of him that he didn't like because he was in the bathtub. One could wonder if this image is similar to a reasonably common tendency for parents to photograph their small children in the bath.

Theme 4.2 I have opinions on media. Two participants could recall media representations of people with disabilities and describe what they felt about it and why. One participant even described

what was stigmatizing about the representations and said what she would like to see more of. As per feminist disability studies, which asserts that disability be viewed as an identity category that expands on our understanding of what it means to be human. Disability is yet another embodied experience of life. Taking this into account, media-makers should take care not to ignore the disability but also to not reduce PWIDD to their disability, acknowledge their full humanity and range of experiences. Loren captures this perfectly, “they could be also normal people...like you and Charlotte and my family. Just that they can be able to do things for themselves, but then they can’t...they can’t.” (Table 5)

Theme 5. It’s important that I’m treated like an equal

Each participant spoke about times when they felt like they were disrespected, that people didn’t recognize their ability, their value and their dignity. This sometimes had to do with bullying, people underestimating their abilities or not showing them respect.

Theme 5.1 I know stigma. Participants could define how they felt stigmatized in their lives, particularly related to bullying and being underestimated. Natalie felt particularly bullied at work where “they say sometimes that I’m a very stupid person...I mean, I’ve got this, this what’s it, this cerebral palsy... like I’m very handicapped in a way...” (Table 6). Here Natalie is making a clear link between her disability and the stigma she experiences from bullies. This is backed up by much of the literature addressed earlier in this thesis, which conveys that PWDs and PWIDD experience significant marginality in various aspects of their lives.

Theme 5.2 I know respect. Participants could also express how they liked to be treated with the respect and acknowledgment of their value that they felt they deserved. Loren also recognized that consent was an important aspect in representations, reflecting on an image she took of someone who didn’t want their photograph taken. The participant recognized that she had to apologise to the person. Loren also speaks about how mad she gets when people disrespect her, ignore her or don’t greet her.

Theme 6. It's important that you know that I love and am loved

Speaking about their lives and what was important to them, the theme of family, friends and community came up for all participants. They emphasized how their family and social lives were important to them, that they loved those around them and were loved in return. Each participant spoke about parents they had lost and shared about their aspects of their grief. See Table 7.

Theme 6.1 I am loved. Participants spoke of and shared images of family and friends, emphasizing their role in their lives. In some cases, they noted that their families adored and cared for them. The notion of 'being cared for' is also different in the case of most PWIDD who require a level of care to support their daily living. If the sample size had been bigger, there may very well have been contrary insights, as family situations differ. Figure 17. Fred loves his poodle is a particularly good illustration of this.

Figure 17

Fred loves his poodle



Theme 6.2 - I love. Two participants spoke about the people they love and how they make their lives better. This could be interpreted as expressing a sense of belonging, asserting that they have strong connections with people. They each also included images of their families, friends and in two cases, their pets, indicating their value to them.

Natalie also included an image of her brother, Figure 18, which she said conveyed that “he’s part of me”. Loren captured an image (Figure 19) of a large, purple teddy bear which she was given to remember her late mother. She recalls that when her mother was alive, she loved teddy bears.

Figure 18

Natalie's "he's a part of me"



Figure 19

Loren, "my mom loved teddies"



Theme 7 - It's important to me that I participate.

Each of the participants were enthusiastic about taking part in the study and especially expressed their enjoyment of the Photovoice section. They expressed that they liked being photographed, one participant noted that it made her feel special, as well as that they enjoyed the act of photographing and sharing their lives. Each participant also actively participated in the conceptualization of their final portraits in different ways, some with more support and prompting than others. The enthusiasm for participating in the photographic process was evident in all participant's reflections upon the completion of the photovoice process. Each showed an interest in experimenting with the technical aspects of photography, like Natalie's series of self-portraits in Figure 19. When asked

about her self-portraits, she said, “[I could] see a different part of me through the glass... A pretty part”. See Table 8 .

Figure 20

A different part of me through the glass



Theme 7.1 - I can make media, too. Each participant was keen to know if their photographs were “good” and showed pride in their images. In their own way, each also embraced experimenting with photography and showed that they enjoyed learning to take nice photographs.

During the interview process, participants were asked questions which could direct conceptualisation of each’s professional portrait. Eliciting ideas from participants was not always

straightforward and so questions were framed in accessible terms and rephrased again at various points in the process. Each could say what they preferred in terms of clothing and what they wanted the image to say about them. Through some discussion, conceptualization was accomplished collaboratively, something I think was made possible by the amount of time set aside for interactions with the participants.

Theme 7.2 There are things I need to participate. True participation required that the process be accessible and that the participants felt comfortable, supported and empowered to ask questions, voice any anxiety or displeasure, or revoke consent without fear of negative consequences. As such, throughout the two interviews and throughout the studio day, I repeatedly asked questions related to the project, to ascertain if any adjustments needed to be made or to give an opportunity to answer concerns participants had.

All three participants were generally excited about their participation in the project, but did raise concerns and voice preferences for certain aspects of the process. For example, one participant asked about the studio shoot, wanting to know which the area in which the studio is located and whether the area was safe. Another participant spoke about how she was worried that makeup applied to her face for the shoot may irritate her skin. Concerns about sensory needs, physical accessibility, and allowing for ample time to allow for meaningful collaboration were addressed with relevant stakeholders, for example with staff at the studio.

The use and awareness of IDD-friendly communication techniques also emerged as crucial for accessibility and participation. I found several techniques or guidelines for accessible communication throughout the research process. This information was shared with crew and studio staff before the scheduled studio shoots and was an ongoing area of inquiry throughout the research.

Theme 8. It's important that the 'D-word' be handled with care

Throughout phase one and two of this study, a recurring theme of how to approach disability with PWDs came up in a few significant ways. Each participant understood their disability differently and used various ways of describing it. In some instances, there was confusion about the term 'intellectual disability'. In some cases, an alternative definition (suggested by clinicians in the field) cleared confusion. In two instances, the participant and one source did not agree with these descriptions of disability in terms of themselves.

From the beginning of phase one, I noted my own anxiety about how to speak about disability with PWIDD. I noted that it may be unethical to represent a PWIDD, described as such publicly, if I could not establish that they knew they had a disability. In consultation with my co-researcher, Dr Capri, as well as several other experts in the field of IDD, various alternative descriptions for 'intellectual and developmental disability' which could aid communication with PWIDD emerged. These included euphemisms such as 'learning disability' or descriptive accounts of impairment like "So, um, like sometimes, people find it difficult to maybe think really fast" or "maybe they need to hear something two times before they can understand it" or "maybe you struggle to learn things quickly" or "it takes you a bit longer to do things" (Table 9). In my notes, I emphasised that when a PWIDD was recommended as a source or subject for media, I should establish with the recommender whether the person knew they had a disability and which language they used to describe it.

Sometimes participants and sources preferred to speak about their disability in terms of what it meant for them in their daily lives, in other words they expressed their identity as a PWIDD in terms of struggles they have to overcome. Sometimes, a physical disability like cerebral palsy or epilepsy was a better term to encapsulate how they were impaired.

Figure 21

Fred "can be very able"

**Summary**

Some of the key takeaways from these themes includes the evidence that the participants have a sense of themselves, they know who they are and that they deserve respect, love and recognition for their abilities. They also know, to some extent know that they do not always get the respect they deserve. Knowing that the media is a reflection and often perpetration of social stigma that PWIDD face, it's relevant to know that the participants did not see themselves as objects of pity. They illustrated that know that they are normal human beings who can do things and sometimes can't, and when they can't...they can't. The PWIDD in my study knew that there were compelling things about them and their lives. They shared so much of themselves so enthusiastically and expressed that they enjoyed the act of media-making. It stands then that the media, as well as society, not only has some damage to mend in their treatment of PWIDD, but an incredible opportunity to tell better stories.

Chapter VI: Discussion

Introduction

As the themes outlined in the result section were beginning to emerge through the various stages of data collection and analysis, they were compared to my own reflections and information found upon further investigation into the literature and media. In this way, I was able to situate the themes not only in their context but also explore what they meant for media practice. The following discussion will explore the relationships between stigma, representation, media practice, societal context, participant findings and possible changes needed to reform the media and obstacles which may impede progress.

How do PWIDD want to be portrayed?

“Yes, I have seen it on the tv,” Loren answers, her voice is husky, her tone assured. It’s a brisk, early winter’s afternoon in Cape Town, and we’re talking about media portrayals of people with intellectual and developmental disabilities. People like Loren. “Sometimes I get sad and walk away...” she continues, every now and then her voice softens. “It is very sad because I am not like that, why are they like that?”

“Like what?” I ask.

She continues, “...like a complete vegetable.” She does not mince her words. Loren, like my other two participants, knows that in some ways, the world doesn’t always see her the way she sees herself. She wants people to see her as “happy, calm and collected”. She tells me that if she could, she’d tell media makers that they don’t need to portray their characters with disabilities in this way, as unable, dependent or mere objects of pity. Instead, she would tell them that they could show PWDs as ‘normal’, like me and my co-researcher, Dr Capri.

Just like the rest of us, PWIDD can be portrayed as average people who can do things, and then sometimes... they can’t. No big deal. “If they can’t, they can’t,” Loren says, matter-of-factly. She said

she'd tell the media if she could, but she did. She told me, a media-maker. A lens-based journalist who could do exactly that.

When I started this study, I wasn't sure if I would be able to answer one of my key questions, "how do people with IDD want to be represented in the media?" I worried about obstacles to eliciting their thoughts on abstract concepts like 'media', 'representation' and 'stigma'. As a newcomer to the field of IDD, and a neurotypical journalist with little experience of PWIDD, I was acutely aware of my own inexperience. But what I was not yet aware of, was how my assumptions were just another example of how PWIDD are often underestimated by neurotypicals. Just ask Fred, who said "I don't know why but, some people say that I can't do certain things, but I think I can, do a lot actually... I can be very able". I guess you could call it "the soft bigotry of low expectations" (Washington Post, 2000).

In fact, it wasn't until I properly engaged in the processes of participatory action research: fact-finding, action, followed by reflection and further inquiry, and finally, action for change (Minker, 2000) that I realised how rich and insightful my participant's opinions were, if you took the time to ask. But we don't always ask. We don't always know how. But more on that later...

The other two participants may not have expressed their criticism of the media in as concrete terms as Loren, but they could tell me how they didn't want to be portrayed. Natalie doesn't want to be photographed when she's disheveled, particularly when her hair (which she takes great joy in styling) is messy or her clothes look dirty. It's hard to hear this and not recall Dresie and Casie and how Ballen's lens immortalised their disheveled appearance on that day. Instead, when you see an image of her, Natalie wants you know that she's "pretty" and "nice", "a very sweet person, very gentle". Fred wants you to know that he's an accomplished swimmer who has represented his country in international competition (for which he won gold!). It's something he's proud of, and when you see an image of him, he wants you to be proud, too. It is my interpretation that my participants showed me, in various ways throughout our collaborations that they know that they are valuable members of society, with qualities

worth recognising, and with dignity worth upholding.

The Media and Stigma

Even though significant strides have been made in their pursuit of disability rights in recent decades, PWDs and PWIDDs still experience significant barriers to inclusion in society (Heumann, 2019). Among these barriers are social stigma and ableism which is reflected and perpetuated, in no small part, by the media. Social awareness about the relationship between stigma and representation in the media has grown, particularly driven by feminist and racial justice movements like BlackLivesMatter and intersectional feminism (Jiménez-Martínez, 2020;). But, even though diversity in the media “is in the zeitgeist”, as Heumann notes, “disability is being left out of the conversation” (2019, p. 3). For example, in the recently published UCLA Hollywood Diversity Report, which aimed to “to generate comprehensive research analyses of the inclusion of diverse groups in film and television” (Hunt & Ramón, p. 5), no specific mention of the inclusion of PWDs was made, let alone people with intellectual and developmental disabilities.

We know that PWDs are often excluded from the job market (Emmet, 2006; McConkey, 2019) and the media industry is no different. Hollywood, for example has been accused of ‘cripping up’ (Vallera, 2019; Novic, 2018) by hiring talent without disabilities, but with name recognition, to play disabled roles. For example, Sally Hawkins received an Academy Award nomination for best actress for her role as Elisa, who has a speech disability, in Guillermo del Toro's *The Shape of Water* (Novic, 2018). In 2015 Eddie Redmayne won a Golden Globe for his roles as Stephen Hawking (GoldenGlobes.com).

Activists have pointed out that the harmful trend of “blacking up”, in which characters of colour are played by white actors, has become increasingly taboo (Vallera, 2019) but “cripping up” is yet receive the same social disapproval (Ryan, 2015; Vallera, 2019). Television show *Orange is the New Black*, *Mad Max: Fury Road* and *The Fault in Our Stars* even went so far as to employ CGI technology (which is famously time-intensive and expensive) to allow non-disabled actors to play non-amputees

(Shinn, 2014; Failes, 2015; Lee, 2017). *The Fault in Our Stars* even employed a stunt double who was an amputee to make character, Gus' leg more realistic (Lee, 2014).

While the inclusion of disabled characters, with increasingly destigmatising and complex roles is a huge step in the right direction, the exclusion of disabled artists and actors from the production process is meaningful. It also impacts the art, for example the earlier mentioned *The Shape of Water* which featured a disabled protagonist was hailed by critics as positive representation. Elisa, the character, had meaningful employment, deep connections and friendships, independence and sexual desire which could be fulfilled (Novic, 2018). But, because the lead actress was not hearing or verbally impaired and a therefore was not a long-time sign language speaker, her delivery of the lines was "halting, stilted and not at all like someone who'd been signing since she was a child" (Novic, 2018). The exclusion of PWDs from working 'behind the camera' in the media industry is not limited to Hollywood, "very few people with disabilities work in the media industry which is clearly the best way to mainstream disability in the media" (Fundación, 2007, p.7). Further study into the barriers to inclusion for PWDs in the media industry warrants further study.

Ethical Practice

So, where do media-makers go to learn about ethical practice regarding disability? Interestingly, my investigation into disability studies literature yielded many nuanced and poignant criticisms of the media's role in the stigmatisation of disability. For example, the tropes I collected and detailed in my literature review drew on prolific writing by scholars such as Garland-Thomson (2002, 2005b), Shakespeare (1994), etc. I found a wealth of perspectives on disability which I felt could influence a change in media representations of PWDs, if media-makers engaged with them and integrated their findings into their practice. So, why is progress towards disability rights-centered media practice still so slow?

If we are to assume that most media-makers, like me, are inexperienced with covering the topic of disability and interacting with PWIDD, but recognise that media should be produced ethically and uphold their dignity, what are some of the barriers to progress?

We may find answers when we consider why and how media makers create their representations in the way that they do, as well as the context in which they create, the media industry. Burns & Haller note that a core consideration for media-makers in the field of journalism, for example is finding a strong 'angle', and so "they choose what to put in and leave out of a story, what story elements deserve more or less attention and how those elements are to be framed" (2015, p. 263). These angles are often chosen with the intent of appealing to a wide audience, often guided by the eight news values. As Wu (2017) notes, "of the eight news values (proximity, timeliness, prominence, magnitude, conflict, oddity, impact, and emotion), emotion too often rises to the top when telling stories about disability communities" (para 10).

This phenomenon is not limited to the field of journalism. One could argue that visual artists, for example, also need to find an angle from which to present their work. They too make decisions about what they feel is important and how to frame the topic they're interested in. In the same vein, advertising media-makers make similar choices about which stories to tell on behalf of their client, with the goal of promoting a product. As storytellers, all media-makers make similar decisions about how to present a compelling narrative which suits their purposes and in doing so, shape public discourse on communities like PWDs.

Media-makers do not, however, create in a vacuum. There are significant pressures placed on them as they navigate an increasingly competitive, financially strained industry which demands larger quantities of media content in shorter periods of time (Satchwell, Bikitsha, & Mkhondo, 2021). For a contemporary look at the industry's context and the challenges faced by media-makers in South Africa, I turn to the recently released, independent report, 'Inquiry into Media Ethics and Credibility' (Satchwell

et al, 2021), by the South African National Editors Forum. The report listed a summary of the systemic problems which affect the practice of ethical journalism in South Africa. These included, revenue challenges impacting on sustainability; the related diminution of resources for professional development and training and for the effective exercise of editorial and sub-editing checks and balances; the social media-fuelled pressure to break stories ever faster amidst competing mis- and disinformation narratives. (Satchwell et al, 2021, p.1)

In this context, it is easy to see how media-makers who cannot afford to dedicate the required time to each story, and/or who do not have access to the same level of expert support and academic knowledge which this study afforded me, could struggle to employ the same inclusionary and accessible media practices relating to PWIDD. I was aware that as a postgraduate student, as well as media-maker, I occupied a privileged position while conducting this research. Pursuing this study afforded me the time, space and expert guidance to grapple with some of the challenges faced by media when trying to represent PWIDD ethically, a luxury not afforded to most media-makers.

Accessibility and Inclusion

Using accessible language when speaking to PWIDD, for example, presented a host of challenges which I explored. Speaking in plain language, as I was guided by experts, is sometimes easier said than done, especially when engaging in abstract and complex ideas. In this area I had to grapple with my incompetence at times. It was (and is) an ongoing learning process for me. In fact, you can find suggestions and questions about accessible communication littered throughout my notes over the course of this study. I noted what worked, and what didn't. I sought advice, consulted the literature (also including media industry publications) and tried to imagine practical directions for integrating this knowledge in my journalistic practice.

I could conduct longer interviews, host the Photovoice exercise and book full shoot days in a well-resourced studio run by a team who was enthusiastic about making the space accessible. I also had

ample time for transcribing and analysing interview notes, as well as for pre and post-production of photoshoots. I was supported by many experts who guided me with advice on ways of working with PWIDD, including how to overcome some of its challenges.

Challenges like approaching the 'D-word', as in, broaching the topic of a participant's disability. I felt that ethically, I could not include a PWIDD in media which identified them as having IDD if I was unable to explain that they would be identified publicly as such. In the course of the study I encountered several PWIDD who did not know that they had a disability, or used different terms to describe their experience. Sometimes, they used words like 'learning disability' or 'handicap'. McConkey echoes this experience in working with PWIDD, reflecting that sometimes, "they are unable to make sense of why they are different to their brothers and sisters" (2019, p. 329).

In some cases, I sensed that the PWIDD may have been defended against being labelled as 'disabled'. In my thematic analysis, I found participants often emphasising their abilities over their disabilities, perhaps being aware that disability carries social stigma. In some cases, I sensed that they were unaware of their disability and felt that it was not ethical to disclose or impose on them my idea of their disability. "In my experience, parents and professionals are reluctant to openly discuss such issues," reflects McConkey (2019, p. 329). Which may explain why some PWIDD do not understand or define their disability in the ways in which we expect. I concluded that when speaking to someone who referred a PWIDD for inclusion in media, it would be good practice to ask them if that person knew they had a disability, and then to ask which words or terms they used to understand it.

This time and access to experts are privileges which most working journalists do not enjoy, on account of industry pressures. Additionally, research on disability rights and representation through academic journals and books is not typically accessible for many working journalists due to paywalls.

I believe that it is due to these privileges that I found such success while developing inclusive and collaborative working relationships with the participants in my study. Noting the successes and

challenges I encountered during this study, I collected advice and guidelines on representing PWIDD for myself. While I knew that these guidelines were ‘working’ guidelines which should be added to and changed as I gained more experience, I also wondered if they may be helpful to media educators.

I had short personal conversations with three media educators, including one who lectures at a South African university and two independent media professionals who engage in media education for publications and corporate clients. Each conveyed that they had not personally come across a set of standards or guidelines on how to cover disability and include PWIDD in media. They also shared their feelings that education for media-makers regarding disability was important and expressed interest in finding ways to disseminate my working guidelines.

Media-makers hold significant power. And this study is by no means the only attempt to understand this power and wield it responsibly when it comes to disability. It must be noted that there are many media-makers like photographers, writers and filmmakers who have made their own contributions towards including destigmatising portrayals of PWDs in our collective media archive. Photographers like Snezhana von Büdingen and her piece “Meeting Sophie” (Lerman, 2020); Justine Tjallinks (2016). Writers like Karina Sterm (2019); Aimee Christian (2020). Actors like Jillian Mercado (Fabian, 2019a), Domonique Brown, Spencer Harte, Nikki Gutman, Naomi Rubin and Layla Weiner (Fabian, 2019). Filmmakers like Jim LeBrecht (Luterman, 2020). Significant work has also been done by South African academics and media makers to include PWIDD in media and academia, notably *Zip My Brain Harts*, an interdisciplinary book which features the work of photographer Angela Buckland as she delves into her son’s disability (McDougall, Swartz & van der Merwe, 2006a). The piece is accompanied and contextualised by contributions from Kathleen McDougall, Professor Leslie Swartz (who supervised this thesis) and Amelia van der Merwe, with a powerful foreword by Justice Albie Sachs who is also a person with a disability.

When I first met my wife, they told me about the rich inner worlds of the PWIDD they had worked with. It seemed both completely obvious and totally unfamiliar to me. And my experience as a journalist led me to wonder why I had not seen media which reflected PWIDD in this way. When I embarked on this study, I knew that there was much to learn for a neurotypical, non-disabled photojournalist and student researcher. I found myself unsure, but curious. And what I encountered was incredible generosity, patience and trust from the participants who embarked on this journey with me. I felt like, in their own ways, each participant shared a part of their rich inner worlds with me. And given the knowledge, media-makers can experience and portray the complexity of PWIDD in a way that could make a difference.

Subverting the Ableist Gaze: Working Protocol

The following suggestions constitute a working protocol for representing PWIDD in the media. They have been informed by the feminist disability studies concept of a “universalising view” which asserts that disability is relevant to us all and affects us whether we are disabled or not. This translates to the notion that the plight of PWIDD is the plight of us all. And in agreement with the ubuntu model of disability’s, “if I am, because we are, then ensuring your well-being, dignity and rights as citizen, will also ensure mine” (Berghs, 2017, p. 4).

Throughout this study I have argued that as media-makers we have a moral responsibility towards PWIDD, society and ourselves, to do better. This working protocol is intended as a start to the task of ‘doing better,’ to promote social justice and reform. These are points to consider when photographing PWIDD,

- Centre Disabled Voices. PWIDD should be considered experts on their own experience, and accessible inclusion into the media-making process can result in invaluable insights and humanising storytelling. They should be treated as potentially valuable sources, compelling protagonists and worthy subjects.

- Allow PWDs and PWIDD to speak for themselves. Where possible, speak to PWIDD directly, not only through their carers or family.
- Include direct quotes and try to include their perspectives and images in stories you create, if appropriate and where relevant.
- Frame stories about PWIDD from their perspective where possible. Do not, for example, tell their stories through the eyes of others. Try not to convey their experience through the perspective of a neurotypical source or subject.
- Treat PWIDD as complex humans with many roles in society and layers to their identities. As such, they can be included in media about topics other than disability.
- Avoid cliches, stereotypes and tropes. Get to know the ways that PWIDD have been stigmatized in the media and avoid perpetuating the tropes. Ask yourself, am I portraying this person as 'more or less than human' (Gartner & Joe, 1987, p. 2). Be aware of these stereotypes and social stigma of PWIDD, it's the context in which you create.
- Avoid focusing only on PWIDD's impairment's and treating their disability as an individual ailment which must be 'fixed'. While their disability should not be dismissed and erased, do not ask inappropriate or invasive questions. Uphold their right to dignity.
- Don't play into the 'inspiration-porn' cliché. Avoid superficial labelling of PWD as "inspirational" or "heroic" for achieving some form of 'normalcy'. This can be a kind of 'soft bigotry of low expectations' (Washington Post, 2000). Instead, foreground their truly unique achievements and contributions to society. For example, instead of idolizing PWDs for overcoming obstacles to normal life, interrogate what systemic problems are making their lives so difficult.

- Be careful not to portray IDD as an inhuman trait by describing PWIDD as either angelic or demonic. We deny PWIDD's personhood and agency when we refer to them in 'magical' or 'cherubic' or 'freakish' terms.
- Don't use impairment as a metaphor for societal concerns, or as plot devices to drive narratives. Ask yourself if the media you create serves only an assumed neurotypical, non-disabled audience.
- Avoid framing PWDs and PWIDD as objects of pity. Acknowledge that there is more to the experience of disability than suffering and agony.
- Make the process inclusive and accessible. Most neurotypical people have little experience talking to or spending time with PWIDD. So, we don't always know how to treat them, talk to them or include them in the media-making process. Here are a few tips and tricks I've picked up from PWIDD I've worked with, as well as experts in the field. Of course, PWIDD are not all the same and so this is not a one-size-fits-all set of guidelines.
- Take your time. PWIDD oftentimes take a little longer to grasp concepts or complete tasks. Make sure you set aside enough time to avoid putting pressure on them.
- Consider sensory needs. In some cases, PWIDD can have particular sensitivities to stimuli like bright light, noise, crowded spaces etc. Take these into consideration, ask if you suspect something might bother them.
- Use plain, simple language. But be aware that you are not speaking to PWIDD as you would a child. When using a term you suspect they may not understand, follow it up with a concrete example or alternative explanation.
- Approach communication as a collaborative effort. In instances of confusion, it can be helpful to point out how you are struggling and ask for help. For example, saying "I'm not sure if I have the word right, but it's like this or that, you know? How would you put it?"

This could avoid making the PWIDD feel inept or anxious and acknowledges that the endeavor is collaborative.

- When trying to communicate about abstract ideas, try being descriptive. For example, instead of introducing yourself as a “documentary filmmaker”, you could elaborate that you make movies about real people and things that happen in the world and then those movies are sometimes put on television and people can watch them and learn about the things in the movies. Instead of asking how they want to be portrayed, you could ask what they want people to think when they see/hear/read the media. Instead of saying “what are the challenges you experience” you might ask “what is hard about your life? Or what is not nice for you sometimes?”
- Approaching the topic of a PWIDD’s disability can be tricky. They may not relate to the word ‘disability’ for example. Sometimes it helps to break down the concept in practical terms, like “sometimes people find it a bit harder to learn” or “it could take them a bit more time to understand something” or “maybe you find some things a bit harder to do than other people”. It is also recommended that you ask the person who has recommended the PWIDD as a subject how they understand their disability and which words they use to describe it.
- Carers and family can be useful interpreters between PWIDD and media-makers, as well as provide support for PWIDD during your interactions. Ask PWIDD if they would like to be accompanied by someone they trust.
- Treat them and their representations with the dignity and respect you would show a neurotypical or non-disabled person. Be aware of how the media and society can stigmatise them, and try not to play into those harmful tropes. Try to make the process of working

with you as accessible as possible and when in doubt...ask. Just use plain language when you do.

This list is the culmination of a collaborative project with PWIDD behind the lens and in front of the lens. Together we established what was most important to them, with this I took to reflecting on my own practice as a media-maker and what may be possible.

And this was, Figure 22, Figure 23 and Figure 24.

Figure 22

Natalie wants you to see her like a princess. (de Beer-Procter, 2019a)



Figure 23

Loren wants you to know that she is happy (de Beer-Procter, 2019b)



Figure 24

Fred (de Beer-Procter, 2019c)



Chapter VII: Conclusion

Throughout this study, the critical role media has to play in shaping public perceptions of marginalised groups like people with physical, intellectual and/or developmental disabilities was reiterated through the literature, contemporary media and interviews with the participants. Further inquiry into this power seemed to necessitate deep introspection by media-makers into our representational practice, especially if we're committed to using the power of the media for the advancement of a diverse and inclusive public sphere.

In this endeavour, the results of this study may indicate great potential for a mutually beneficial relationship between the fields of media studies and disability studies to interrogate and improve our media industry. My investigation into what these expansive knowledge systems had to say about 'disability', 'representation', 'the media' and 'stigma' offered a nuanced view into the interconnected nature of these phenomenon.

Employing the principles of feminist disability theory and participatory action research to guide this investigation offered novel suggestions for facilitating PWIDD's participation in the media, especially by prioritising accessibility, dignity, diversity and inclusion. These suggestions contributed greatly to the collection and refinement of the working protocol for media-makers regarding the representation of PWIDD. The suggested protocol revolved largely around accessibility and inclusion, dignity and respect, and awareness of stigma and representations of PWIDD. These guidelines, it must be noted, are 'working' guidelines because they warrant further investigation and could benefit greatly from contributions by other media-makers, PWIDD and activists for disability rights.

While the generalisability of the study's results is limited due to the small sample size, the wealth of data it generated suggests great potential for future applicability of participatory action research to inform inclusive, ethical media practice, especially as it relates to representing PWIDD. The participants who took part in this study offered unique and valuable insights into the relationship

between media representations and their social marginalisation, and they could speak about how they wanted to be represented. This underscored the need for PWIDD to be included in the transformation of the media industry and showed the value of viewing them as experts on their own experience. It would, however, be interesting to investigate the applicability of these results over a broader sample range, possibly including people with differing levels of IDD, such as moderate or profound. Furthermore, these results emphasise the ethical imperative of researchers to include PWIDD in research which concerns them.

Another key takeaway from this study was how participation in the media can be an empowering experience for PWIDD. The participants, as well as subjects with IDD which I encountered in the photojournalistic process, approached the photographic and storytelling process with great enthusiasm. Additionally, many of the media-makers I engaged with on the topic of ethical representations of PWIDD showed interest in learning more. Further inquiry into potential gaps in media education regarding representation and disability could present future researchers with useful information on how to reform the media industry.

It is my hope that this research can advocate for the need not only to 'talk about Ballen' but to speak about our (media-makers') ethical responsibilities towards marginalised members of our society. I hope that this study will contribute to lively discussion and ongoing contemplation on the power of representation and the practical applications of our media ethics. There is much to do to reform our industry and a wealth of exciting opportunities to tell original and compelling stories with and about PWIDD, this is only the beginning.

Significance of the Study

As we've seen throughout this study, media representations of PWIDD are important as they impact on their marginalization in society. This study provides insights into how PWIDD want to be represented and how media-makers can engage with them to create destigmatizing representations. The preliminary protocol presented in this thesis can provide a useful basis for future study on ethical representational practices and inclusion of PWIDD in the media. Additionally, the participatory approach taken in this study could provide insight into the benefits and challenges associated with including PWIDD in research and media about them. This is particularly significant given the lack of participation-centered studies and media about PWIDD. The successes with regards to the collaboration between myself (as a researcher and photojournalist) and the participants also underscores not only PWIDD's right to be included in media and research about them, but the benefits of doing so.

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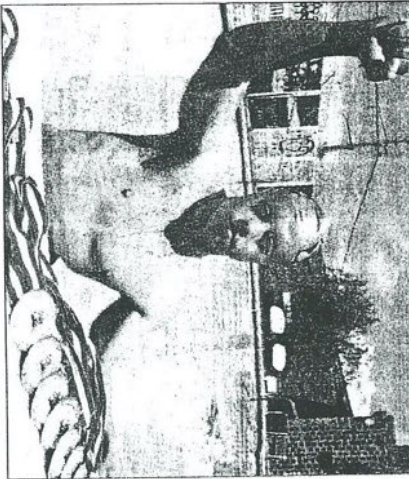
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Appendix A

Fred Won Gold [newspaper clipping]

Down's boy scoops heap of medals in British pool

BY KASHIEFA AJAM



Talented ... "I felt so happy and very proud when I stood on the podium and they handed me my medals," said Fred Gamble. PHOTO: ALAN TAYLOR

Nine medals - that is the harvest of Down's syndrome pupil Fred Gamble at an international swimming contest in England. Gamble (20), from Wynberg, Cape Town, was one of 10 South Africans to compete at the Down's syndrome swimming championships in Berkshire last month. Three team members were from Cape Town.

His father, Ray Gamble, who flew to England to support Fred at the finals, raised more than R20 000 from local businesses to enable the team to attend the championships. Fred won four gold medals for the relay races, another two for the freestyle and butterfly events, and one silver medal for the individual medley.

He also won two bronze medals for competing in and completing two other individual medley races. Fred attends the Glendale School for

Specialised Education in Heathfield. Glendale principal Catherine Friedlander said: "Fred was swimming long before he came to Glendale in 1992, but it was here that he started swimming competitively. "He is not only good at swimming, he reads well and excels at mathematics. "He is truly a talented young man," said Friedlander.

Fred's head hung low yesterday - not because he was sad, but because the medals around his neck were heavy - as his classmates cheered and applauded their hero. His class teacher, Ian Morrison, said Fred had made the school proud and "he has reached a potential that one would not have thought possible".

So what does this champion have to say for himself? "I felt so happy and very proud when I stood on the podium and they handed me my medals. I will gladly do it all again next year."

NESS World Summit went over budget by R213m

Hosting the World Summit on Sustainable Development cost the government R513-million - far more than the R300-million which had been budgeted, members of parliament heard yesterday.

JSE All Share 9561.81 (-0.77%)
Dow (8.20pm) 8702.13 (+2.17%)

The Star
5 Nov. '02.



Appendix B
Information Sheet

To whom this may concern

My name is Chris de Beer-Procter, I'm a photographer in the beginning phases of a research project for a Masters of Sociology and Social Anthropology from Stellenbosch University. I'm contacting you because I'd like to tell you about my research and speak about the possibility of working with someone you care for.

This year, I will be doing research on the representational power of photographic portraiture. With a high emphasis on collaboration with my participants, I want to create positive, complex and humanising studio portraits of people with intellectual disabilities in Cape Town.

In short, the study will comprise of three elements: interviews, Photovoice (description below) and a final, formal, studio portrait of the participant taken by myself, and conceptualised with their collaboration. The final product of this study will be a series of photographs to be shown in an exhibition.

It's important for me going in to this process and, knowing I am working with a vulnerable population, that I have support from organisations which work in the field of intellectual disabilities. I am committed to going through this process ethically and carefully.

Please do read through this and engage with me on any questions you may have.

A general summary of the study:

This study is concerned with representations of people with intellectual disabilities, specifically through photography. What my research aims to find out is:

How do people (specifically the individual participants I will work with) with intellectual disabilities want to be represented?

How can we use these findings as well as what we know about the representational power of photography to create complex, humanising and unique portraits of each of the participants.

NB: This whole process will be overseen by my research supervisor, Professor Leslie Swartz of the Psychology Department at Stellenbosch University, as well as my co-researcher, Dr Charlotte Capri who is a clinical psychologist who is an expert in the field of intellectual disabilities. Ethical consent will be obtained with this support. Participants can retract consent at any time during the process, before the images have been published. Any negative experiences or consequences of the research will be dealt with in an ethical manner with the support of clinicians in the field.

What will happen in the study?

Participants will be identified and interviewed. Interviews will take place at the residential home of the participant. The interview time will be used to introduce myself and the study, outline the process, find out more about the participant and their unique characteristics which could inform the production of the final image and finally to give them a digital camera which they will be taught to use.

Participants will then have one week to photograph their daily life with this camera. This process is called Photovoice. I will also be sure to teach the participants about acceptable camera etiquette. For example, to never photograph someone without their permission.

I will return to the participant to collect the images.

Upon receiving the images, I will analyse the images for patterns and themes. I will brainstorm some ideas of how to integrate objects/symbols/people of interest into the final portrait.

I will then have another meeting with the participant to discuss the images and concepts which may have emerged for the studio portrait.

I will then photograph the participant at a studio in Cape Town, Sunshine Co. who have committed to making the space accessible for our participants and to cater to their specific support needs.

One image from the shoot will be chosen and printed and framed as a gift for the participant. A discussion will then be had with then upon presentation of this image. We can reflect on the process and resulting image. They will be given the opportunity here to retract consent for the image to be published. They may do this without any negative consequences. Any information which could accompany the images will also be run by management/guardians of the participant to ensure that no confidential/sensitive information is shared which could be damaging to the participant.

Should you have any questions, please don't hesitate to contact me via any of the channels below:

What to know if you are a guardian of someone considering taking part in the study:

Any questions may be directed at myself, Chris de Beer-Procter, as the principal investigator.

Email: info@chrisphotographer.co.za

Phone: 083 292 9473

Should you wish to speak to someone other than myself about any concerns with the study, you may contact my research supervisor, Prof Leslie Swartz on 082 459 3559 or Ms Maléne Fouché from the Stellenbosch University Division for Research Development on 021 808 4622.

There will be an outside psychology clinician specialising in work with people with intellectual disabilities who will be available should any participants require support as a result of the study. His name is Dr Ockert Coetzee and he can be contacted on 021 503 5027. His e-mail is Ockert.Coetzee@westerncape.gov.za.

There will be a consent form and image release form that participants and guardians will be asked to sign to protect the participants and research team. In the release form, participants and their guardian will have the chance to choose how they would like their image to be used and how it should not be used, this means, for example, that they can opt in to displaying their photographs in the exhibition, but not in any promotional materials for the exhibition.

Thanks for your time and looking forward to hearing your thoughts.

Kind regards,

Chris de Beer-Procter

Appendix C

Consent Form - Written



UNIVERSITEIT • STELLENBOSCH • UNIVERSITY
jou kennisvenoot • your knowledge partner

STELLENBOSCH UNIVERSITY: CONSENT TO PARTICIPATE IN RESEARCH

You are invited to take part in a project conducted by Chris de Beer-Procter, from the Sociology and Social Anthropology Department at Stellenbosch University. You were approached as a possible participant because you are a person with an intellectual disability living in Cape Town.

PURPOSE OF THE STUDY

We don't think that there are enough photographs and pictures and stories about people with intellectual disabilities in the world, and when there are some, they aren't often very nice or true. This study wants to make nicer pictures of you and other people with intellectual disabilities for other people to see. I want to do this so that people can know more about you and your life and so they can know that you are important. I want to make these pictures with your help and let you make decisions about how we show the pictures to the world. We will do it together.

WHAT WILL BE ASKED OF ME?

If you agree to take part in this study, you will be asked to give some time to sit with me and tell me about yourself. This interview will be recorded so I don't miss or forget anything you say. I won't share the recording with anyone and will only use information if you say I'm allowed to. You will also be given a camera to use for two weeks, until it's time to give it back.

You will be asked to use this camera to take pictures of your life, of things you care about, things you love or things that matter in your life. We can then talk about what you take pictures of and come up with ideas of how I can take your picture. We will then go to a studio, it's like a special indoor camera office, which is where you take pictures sometimes, and I will take your picture. We will probably be working together until winter-time. The whole study will probably take a few months.

When our work together is finished, we will want to show people the pictures you took and the one I took of you so that they can also get to know you and see you how you want to be seen. We will want to put these pictures up in a show with pictures of other people who also worked with me. People will be invited to come and look at the pictures.

The show is called an exhibition. What happens is a couple of pictures are put up on walls in a room, like how we hang pictures on our walls in our homes. This room will be only to show these pictures. People will come and walk around the room and look at the pictures and read about them. Exhibitions are a way of sharing art and pictures with lots of people.

WHERE WILL THE PHOTOGRAPHS BE SHOWN?

Your pictures will be put up with pictures of other people with intellectual disability who also did the study in an exhibition. I will write some words about you with the pictures like your name and something interesting about you. You can help me decide what to write and what to leave out. I will not share any information about you that you don't want me to share. I will show you what I will put up of you (pictures and words) and give you the chance to change it, or even to say "no, I don't want to do this anymore, don't use my things" and withdraw from the study. You will not get into trouble and no one will be cross with you if you decide to stop being in the study. You will still get a printed picture of you. People will be invited to come see the exhibition, people like nurses and occupational therapists and psychologists who work with people with ID, journalists, the people who make the stories in the newspapers, and students who might write stories and take pictures.

These people can learn about intellectual disability so they can represent people with ID better. You can also tell me if there are people you'd want to come or not and we will try to get them to see the exhibition.

Besides the exhibition space, the pictures might be seen in other places like magazines, newspapers, posters and on the internet. This is so that we can share the work we did together with more people and have them learn about intellectual disability and to get them to come to the show. In the other form (called a release form) you will be asked to sign at the end of the study, you will have a choice about where you want your pictures to be shown. I cannot promise that people will not share the pictures they see at the exhibition by themselves on the internet, but ask them not to if you want.

POSSIBLE RISKS AND DISCOMFORTS

There is a chance you might not like what we do together. That's ok. Maybe you find out that you don't like having your picture taken, or maybe you feel scared of the studio. There's also a chance that you might change your mind about the pictures that are shown to people. We will do whatever we can to make sure you are safe and feel good. You can have a friend or family or carer go with you to do any of the things we will do together. You can stop doing this project with me at any time until we show the pictures to people at the end. We will do our best to make sure you always have the chance all the time to tell us how you are feeling, if something bothers you, or if you need anything. You can talk to someone else completely outside of the study if you want help with how you are feeling in the study. His name is Dr Ockert Coetzee. His phone number is 021 503 5027. His e-mail is on Ockert.Coetzee@westerncape.gov.za. If you don't want to call him yourself, I can do it for you and help you see him.

POSSIBLE BENEFITS TO PARTICIPANTS AND/OR TO THE SOCIETY

At the end of the project you will get the best picture I took of you. It will be yours. It will be printed out big and put in a frame so you can hang it on the wall or do whatever you want with it. I will also print the pictures you took that are your favourite, and you can keep them. We hope that you will have fun doing the project and that you will feel good about our work together and the picture we took. We hope that in the end you will feel like people care about you and know who you really are. We also hope that your picture and the pictures of other people we do the project with will teach the world about you as a person, and also teach people to take better pictures and write better stories that are the truth about people with intellectual disabilities. We hope that they will know that you should be part of the world in the world.

PAYMENT FOR PARTICIPATION

You will not get any money for doing this project with us. But you will get some of the pictures for free to keep. We will pay for a car to fetch and bring you to wherever you need to be for the project and take you back.

PROTECTION OF YOUR INFORMATION, CONFIDENTIALITY AND IDENTITY

This study is about showing people who you are. At the end of our work together they will see your name, face and whatever you choose to share with them about your life. But if you decide to leave the project at any time before it's finished, I will not show your pictures or tell your information to any other people. You will not get into trouble if you choose to stop being the study. What you tell me when we talk in interviews will be kept between you and me unless you want me to tell someone. I will ask you before I tell about or show anyone what we did in the project.

At the end of the project I will publish the pictures. This means we will show them to people. This might be done in an exhibition, like a show in a museum. You and I won't be able to decide what other people say about the picture. This is why you and I will both make sure together that the pictures and stories are what you want to share. You can change your mind at any time while we are working together. But when the pictures are in the show, then it is too late to make people not look at them.

As far as I can, I will try to take good care of the pictures and let the right people see them. Like people who work with people with intellectual disabilities. And like journalists – they take pictures and write stories so that more people can learn about intellectual disabilities.

PARTICIPATION AND WITHDRAWAL

You can choose whether to be in this study or not. If you agree to take part in this study, you can stop at any time without getting into trouble or having to give anything to me. You can also choose not to be a part of this study without getting into trouble. When I ask you questions, you don't have to answer if you don't want to, but you will still be allowed to be in the project and have the pictures you or I have taken. If you choose to leave the study, I will not share any pictures I have taken or share any information that you shared with me with anyone.

RESEARCHERS' CONTACT INFORMATION

If you have any questions or worries about the work we will do together, you can talk to me, Chris de Beer-Procter, by calling me on the phone on 083 292 9473. Or you can call the co-researcher Charlotte Capri on 084 441 5208 or the supervisor Professor Leslie Swartz on 082 459 3559. If you want to talk to an outside person who is not a part of this study about how the study makes you feel, even after, you may call psychologist Ockert Coetzee on 021 503 5027 and email him on Ockert.Coetzee@westerncape.gov.za.

RIGHTS OF RESEARCH PARTICIPANTS

You can stop being in the project if you want and won't get into trouble if you don't want to do it. If you have questions about your rights as a research participant, you can contact Ms Maléne Fouché [mfouche@sun.ac.za; 021 808 4622]. She works at the Division for Research Development.

DECLARATION BY THE PARTICIPANT

As the participant I confirm that:

I read the above information and it is written in a language that I am comfortable with.

I had a chance to ask questions

My questions were answered.

All issues related to privacy, and the confidentiality and use of the information I provide, have been explained.

By signing below, I _____ (name of participant) agree to take part in this research study, as conducted by _____ (name of principal investigator).

Signature of Participant Date

DECLARATION BY THE PRINCIPAL INVESTIGATOR

As the principal investigator, I hereby declare that the information contained in this document has been thoroughly explained to the participant. I also declare that the participant has been encouraged (and has been given ample time) to ask any questions. In addition I would like to select the following option:

	<p>The conversation with the participant was conducted in a language in which the participant is fluent.</p>
	<p>The conversation with the participant was conducted with the assistance of a translator (who has signed a non-disclosure agreement), and this “Consent Form” is available to the participant in a language in which the participant is fluent.</p>

Signature of Principal Investigator

Date

Appendix D Consent Forms - Illustrated

Consent Forms - Illustrated



UNIVERSITEIT•STELLENBOSCH•UNIVERSITY
jou kennisvennoot • your knowledge partner

1

STELLENBOSCH UNIVERSITY CONSENT TO PARTICIPATE IN RESEARCH

You are invited to take part in a project conducted by Chris de Beer, from the Sociology and Social Anthropology Department at Stellenbosch University. You were approached as a possible participant because you are a person with an intellectual disability living in Cape Town.

1. PURPOSE OF THE STUDY

We don't think that there are enough photographs and pictures and stories about people with intellectual disabilities in the world, and when there are some, they aren't often very nice or true. This study wants to make nicer pictures of people with intellectual disabilities for people to see. I want to do this so they can know more about you and your life and so they can know that you are important. I want to make these pictures with your help and let you make decisions about how we show you to the world. We will do it together.



2. WHAT WILL BE ASKED OF ME?

If you agree to take part in this study, you will be asked to give some time to sit with me and tell me about yourself. You will also be given a camera to use for a two weeks. You will be asked to use this camera to take pictures of your life, of things you care about, things you love or things that make a big difference in your life.



We can then talk about what you take pictures of and come up with ideas of how I can photograph you. We will then go to a studio, which is where you take pictures sometimes, and I will take your picture. The whole study will probably take a few months. When it is done, we will want to show the pictures you took and the one I took of you to people so they can get to know you and see you how you want to be seen.



We will want to put the pictures you took and the one I took up with other pictures of people who did the project in an exhibition. People will be invited to come look at the pictures.

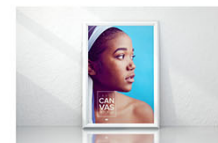


3. POSSIBLE RISKS AND DISCOMFORTS

There is a chance you might not like what we do. Maybe you find out that you don't like having your picture taken, or maybe you feel scared of the studio. You might change your mind about the pictures being shown to people. We will do whatever we can to make sure you are safe and feel good. You can have a friend or family or carer be with you to do the things we will do. You can stop doing this project at any time until the end. We will do our best to make sure you have the chance to tell us how you are feeling or you need.

4. POSSIBLE BENEFITS TO PARTICIPANTS AND/OR TO THE SOCIETY

At the end of the project you will get the best picture I took of you printed out big and framed so you can hang it on the wall or do whatever you want with it. I will also print your favourite pictures you took for you to keep. We hope that you will get fun out of the project and that you will feel good about the picture we took. We hope that you will feel like people care about you and know who you really are.



We also hope that your picture and the pictures of other people we do the project with will teach the world not only about who you are but also teach them to take better pictures and write better stories about people with intellectual disabilities. We hope that they will know that you should be included in the world.





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5. PAYMENT FOR PARTICIPATION

We will not pay you for doing this project with us. But you will get printed pictures for free to keep. We will pay for a car to bring you to wherever you need to be for the project.

6. PROTECTION OF YOUR INFORMATION, CONFIDENTIALITY AND IDENTITY

This study is about showing people who you are, and so at the end of the project, they will see your name, face and whatever you choose to share with them about your life. But if you choose to leave the project at any time before the end, I will not share your pictures or information with any more people. What you tell me in interviews will be kept between you and me unless you want me to tell someone. I will ask you before telling or showing anyone what we did in the project.



At the end of the project I will publish the pictures. This means we will show people. This might be done in an exhibition in a museum. I won't be able to control what people say about the picture and neither will you. This is why we will make sure that the pictures and stories are what you want to share. You can change your mind at any time except once the exhibition is shown and then we cannot stop people from seeing them.

As far as I can, I will try to take care of the pictures and let the right people see them.

7. PARTICIPATION AND WITHDRAWAL

You can choose whether to be in this study or not. If you agree to take part in this study, you can stop at any time without getting into trouble or having to give anything to me. When I ask you questions you don't have to answer if you don't want to, but you will still be allowed to be in the project and take the pictures.



8. RESEARCHERS' CONTACT INFORMATION

If you have any questions or concerns about this study, you can talk to Chris de Beer by calling me on the phone on 083 292 9473 and/or the co-researcher Charlotte Capri on 084 441 5208 or the supervisor Professor Leslie Swartz on 082 459 3559.

9. RIGHTS OF RESEARCH PARTICIPANTS

You can stop being in the project and won't get into trouble if you don't want to do it. If you have questions about your rights as a research participant, contact Ms Maléne Fouché [mfouche@sun.ac.za; 021 808 4622] at the Division for Research Development.



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DECLARATION OF CONSENT BY THE PARTICIPANT

As the participant I confirm that:

- I have read the above information and it is written in a language that I am comfortable with.
- I have had a chance to ask questions and all my questions have been answered.
- All issues related to privacy, and the confidentiality and use of the information I provide, have been explained.

By signing below, I _____ (name of participant) agree to take part in this research study, as conducted by _____ (name of principal investigator).

Signature of Participant Date

DECLARATION BY THE PRINCIPAL INVESTIGATOR

As the principal investigator, I hereby declare that the information contained in this document has been thoroughly explained to the participant. I also declare that the participant has been encouraged (and has been given ample time) to ask any questions. In addition I would like to select the following option:



The conversation with the participant was conducted in a language in which the participant is fluent.



The conversation with the participant was conducted with the assistance of a translator (who has signed a non-disclosure agreement), and this "Consent Form" is available to the participant in a language in which the participant is fluent.

Signature of Principal Investigator Date

Appendix E

Model Release Form

MODEL RELEASE FORM- STUDY PARTICIPANT

Representations of Intellectual Disability: a study in the subversive power of portraits

This is an agreement between you (the model) and me (the photographer) about the pictures that you took with the camera we gave you, and/or the pictures I took of you in the studio. I need to ask you if I can put the pictures out in the world for other people to see. This form and agreement is also to protect you and me. It means that you give me the right/permission to use the pictures you and I took in the ways you want. It's like what we spoke about in the study. I can only share your pictures with the world if you say it's ok for me to do that / if you give me permission like we spoke about in the study. This will only count for the pictures you and I agree on together. We won't use any of the pictures that you don't like. You can tell if there are any pictures you don't want in the show. Those pictures then will not be "released" to me and I will not be allowed to use them. You can also decide to let me use the pictures for one thing but not anything else. That means you can, for example, let me put them up in the show (the exhibition where we put pictures up on the wall for people to come and see), but not use them to tell people about the exhibition, like on a poster or advertisement. It is really important that you understand what/why you are signing and that you ask any questions. After you sign this form, I will then also be able to use the pictures anywhere in the world (worldwide) even after you and I have said goodbye and we won't see each other again (for perpetuity). You are also saying that it won't be my fault if someone uses the picture in a way you don't like (liability), even though I will try my best to make sure that this won't happen.

I, _____ (the model) and _____
(the legal guardian of model) hereby grant _____ (photographer)
irrevocable, perpetual and worldwide permission to publish and all legal rights to photographs of me
taken during their study, Representations of Intellectual Disability: a study in the subversive power of
portraiture, undertaken in fulfilment of their Masters degree at Stellenbosch University and hold
harmless the aforementioned any liability which may result in the sharing of these images on the
following terms:

I agree to the following usage of my images: (please draw an “x” on the circle if you agree)

On show in the resulting exhibition, no matter when or where the show is. (This means that the
whole show can move somewhere else and shown again and again, in other countries in the world at
other times)

To use in marketing/advertising of the show/exhibition in posters, magazines, on the internet or
social media (like Facebook). (This means that we can use your picture to invite people to come see the
exhibition).

For editorial and academic international use in the world and national in South Africa . (This
means that when people write or make stories about the exhibition or what it means to people, they
can use one or more of your pictures to show people what they are talking about. So, if someone writes
a story about how intellectual disability is usually shown in pictures, they might want to use a picture of
you from this study. This could happen in magazines, websites or academic journals)

For unlimited print and display (this means that I can print the pictures more times after this
study and maybe have them shown in other places. I will ask you before I do this and you can say no and
I won't do it)

Please keep telling me about these images are used.

I promise that I am 18 years old or older and am competent to sign this release. I read this release, had any /all of my questions answered, and fully understand the implications (what will, can or might happen if give permission.

Model: _____

LEGAL GUARDIAN CONSENT

As the legal guardian and legal support of the model, I _____ (guardian) hereby affirm that I am 18 years or older and am competent to co-sign this release in the best interest of _____. I have read and fully understand the release and its implications.

If you ever want to talk about how I use the pictures, or about this agreement (form), you can contact me, Chris de Beer-Procter on the phone: 083 292 9473. Or my supervisor Prof Leslie Swarts on the phone: 082 459 3559, or Ms Maléne Fouché from the university on 021 808 4622. She works at the Division for Research Development.

Signed on the date of _____ (day, month, year).

Please can I have your email and phone number so that I can tell you how the project is going, or tell you how the pictures are used fill in contact details to keep you updated on the project and use of the images:

Email: _____

Phone: _____

Appendix F

Tables of Illustrative Quotes

Table 2

Theme 1: It is important to me that you get to know me

Sub-themes:	Illustrative quotes
1.1 I know who I am, my likes and dislikes	<p>"The way I treat people, the way I respect people. The way I am towards people. I like who I am"</p> <p>"my good side, that's how ... I'm a gentleman...and kind and deeply proud"</p> <p>"That I'm pretty and I'm nice and I'm a very sweet person, very gentle"</p> <p>"then I cry very easily because I'm a very sensitive person"</p> <p>"Very friendly. And lovable and caring and supportive."</p> <p>"Because I'm always joking and cracking jokes and playing the fool with people and making people laugh. I'm not a serious person, I try not be."</p> <p>"I just like myself."</p> <p>"Dance music and not rave, I'm not a rave person."</p> <p>"I'm happiest when I rest actually"</p> <p>"I like looking nice... if I'm going out somewhere to make my hair, [I] like to look pretty when I go out"</p> <p>"I'm good at computers... I also like to type."</p> <p>"I love going out and I love to see the nature... Flowers, plants, animals, all sorts of things, the water, the sea"</p> <p>"I love music. My favourite thing is music."</p> <p>"I like colouring in. And drawing. I'm good at making homemade cards and things like that"</p> <p>"I love Mamma, Abba, Mamma Mia and the sound of Music and Annie and all that kind musicals. I love musicals!"</p> <p>"I like people to hug me but not very tight hugs"</p> <p>"It feels different to others, because I mean, I can cope on my own but with this what I've got is sometimes bringing me down when I'm at work. Like, I feel very small with everybody else at work. Like they think they perfect than me"</p> <p>"when people used to not greet me I would go mad when people ignore me I used to go mad, when people avoid me I used to go mad and all sorts of things."</p> <p>"I'm so tired of these trains. When I come home from work during the week because it's like always the delays and cancels and power failures"</p> <p>"What the other [outfit can] be my favourite soccer team... Liverpool"</p>
1.2 I know my strengths and weaknesses	<p>"Ja, angry yes..., like peas in a pot when it's boiling... I don't know how to get out of it."</p> <p>"because I have this one, like if someone makes me angry at work then I have this, this flair up, like, like I'm like a bomb explosion at work. I start shouting and I swear a lot. Which isn't really good but when people make me angry at work and I don't like it, what they've said to me then I will swear... I've got these tablets to help me calm down a bit at work but I haven't had that at the moment... I haven't had any explosions yet"</p> <p>"I was I used to find my behavior very hard to control and now it's a lot easier. There's not really any hard things I just wish I could learn the write, agh learn to read and write...that's a bit hard."</p> <p>"Ja, some people say that I do [speak softly], actually... I try to, to work on that, actually."</p> <p>"I've been trying to do new things this year since the first of May and I've been doing very well... I'm a person who used to get angry. And I used to be very sensitive and all that and now I'm trying to control it. [REDACTED]s been having sessions with me on a Wednesday. And its really been helping"</p> <p>"I'm a very happy, cheerful person at times. I'm very happy. The only thing that will probably disappoint them from me is if I'm angry. And I get upset very easily."</p> <p>"The only thing I cannot do is drive. Yes. I cannot drive."</p> <p>"I even, when I was at school I even made my own gown, my own duvet cover, my own apron, my own skirt and top, I was in a sowing class at school. I even know how to work the electric</p>

machine.”

“I’m a very good wood chopper... I can also use the weed eater... I milk the cows... not just that, I can even also, um manage to use the chainsaw”

““Can I tell you about the swimming?” “I had a big gala in England”

“That I’m a very good one [swimmer]”

“[I like] that I can I can do things. Ja.”

1.3 My gender matters

“I know [chopping wood] keeps [me] busy but what I like ... that it can

keep my biceps... Because I don’t like it when they go down... it’s not to impress people, but, I just like to have them.”

“there’s many who don’t have [a beard] I have to have one ‘cause I have to be that man.... so I can I stand out”

“my good side, that’s how... I’m a gentleman”

“I get spoilt quite a lot... cos I’m the only girl in this house amongst all these men... It’s alright but sometimes there’s one person that irritates me... because he calls me by a nickname, “Kitty”.

And my name is not Kitty... my mom didn’t bring me up as a kitty, my mom brought me up as a human being”

“And I’m not really interested in men at the moment because to me, I mean, people at my work like to rush me to get a man in my life. They said to me, “you must have a man because you’re getting older now” so I said to them the other day, “I’m not in a hurry to get somebody because then my life is wasted. Because I want to, if I’ve got a guy in my life then that means I’ve got to spend money on him all the time instead of myself”

“I want to, like, one day meet a guy, not now, but somebody who’s got a car and who’s got money... And also to treat me nice. Cos I’ve had bad experiences”

“It’s very like, girly room. Like a very, like, not a child’s bedroom but a very like a, a feminine bedroom.”

“I love jeans and I love cauderoy. And I love smart wear and I love to wear dresses and smart clothes.”

“I like to be a helpful woman.” [hanging up washing]

1.4 I want to show you

“That’s my brother, he always likes to start the cars... He’s part of me”

“Like there, I’m always depressed on a Sunday, then it’s back to work the next day”

“What I was thinking maybe was if [REDACTED], when she’s on duty or [REDACTED] come to my work one day of the week ...and take a photo of me while I’m working”

“I thought let me just take a photo so I can show the people where I live. Where my room is. You see how neat and tidy it is?”

“Yeah I like it, I wanted to take it. I want to show you guys, I taken. That’s a nice picture of my teddy... my sister in law gave it to me... it was for my mom”

“That’s my mother. It’s a picture of my mother. I thought let me just take a picture of my mother and show you. That is her”

“That’s a vegetable garden. That’s where they let the vegetables grow and then we, I think they take it to the kitchen and then we boil it or cook it or something”

“Okay this is everybody in my workshop”

“Oh that’s one of the floor covers that we make. I think I took two photos. Yes, there’s, there. That’s one of the floor covers that we make at work so I can show them what we even do at work.”

“That’s where you saw me, sitting... Called Farmer’s rest”

“[Chopping wood] That’s what I do.”

“another work day... By the dairy”

“Not, maybe I could take a picture on the train, like me at the station or something take a walk to the station. Just now maybe later on with my two brothers and take a photo”

“I just like to talk to people and tell them about my life.”

Table 3*Theme 2: It is important to me that you know that I am valuable*

Sub-themes:	Illustrative quotes
2.1 I do meaningful work	<p>"Tell me about yourself"</p> <p>"I... work at a place called [redacted] ... and I make gift bags for, like, Cardies shops."</p> <p>"I make bags during the week (laughs) which I don't think [other people] can"</p> <p>"I like looking nice, I mean, even [redacted] says to me the other day I look very smart for work."</p> <p>"I'm a very good wood chopper... I can also use the weed eater... I milk the cows... not just that, I can even also, um manage to use the chainsaw"</p> <p>"I work at [redacted]...I work there. I'm in the sowing room. I sow, I cut, I paint, I trace, all sorts of like neck rests for the baby blocks for the floor covers I do all sorts of things... It's very interesting. I couldn't cut, I couldn't paint, I couldn't trace and beginning of last year I was taught and now I can do it."</p>
2.2 My contribution takes sacrifice	<p>"And it's a long day from the time I start to the time I come home and I mean, I travel public transport, which I am very capable of doing and I have to battle with the crowds"</p> <p>"I travel everyday... I leave early, I mean, twenty-five passed, twenty-five to six"</p> <p>"I'm so tired of these trains. When I come home from work during the week because it's like always the delays and cancels and power failures"</p> <p>"Like there, I'm always depressed on a Sunday, then it's back to work the next day"</p> <p>"They're [cats and dogs] very like, they eat sleep and play all day, and they don't have to go to work like what we do"</p> <p>"I'm just a bit sleepy... [waking up early] for the cows"</p>
2.3 I contribute to society	<p>"Can I tell you about the swimming?" "I had a big gala in England"</p> <p>"That I'm a very good one [swimmer]" "I want to be in the newsletter, actually... I want [my medal] around my neck."</p> <p>"[Voting in elections] was very nice. I voted for the right kind, for the right party."</p> <p>"Okay this is everybody in my workshop"</p> <p>"Oh that's one of the floor covers that we make. I think I took two photos. Yes, there's, there. That's one of the floor covers that we make at work so I can show them what we even do at work."</p> <p>"[Chopping wood] That's what I do."</p> <p>"There is when the, every year, me and [redacted] go to [redacted] [redacted school name] and we give a talk and then the [redacted] children"</p> <p>"another work day... By the dairy"</p> <p>"And today my good deed is "carry someone's groceries"</p>

Table 4

Theme 3: It is important to me that you appreciate my dreams and aspirations

Theme:	Illustrative quotes
3. It is important to me that you appreciate my dreams and aspirations	<p>"I just wish I could learn the write, agh learn to read and write... That's the one thing that I find very difficult."</p> <p>"I'd love to go see Australia maybe...I just wanna see what the place looks like and I want to see it, I'd just like to go see it. And America cos my Auntie stays in San Diego"</p> <p>"Like one day if I ever have a house of my own, then I'll do this sort of thing [hanging up washing]."</p> <p>"people ask me would you ever go and stay by yourself. So, I said, not at the moment. Not capable of doing that at the moment."</p> <p>"I want a car, a home, a wife and kids. Maybe someday, my own business. This dream never seemed like a reality, but now for the first time it could be."</p> <p>"I want to, like, one day meet a guy, not now, but somebody who's got a car and who's got money... And also to treat me nice."</p>

Table 5*Theme 4: It is important to me that I am seen in a positive light*

Sub-themes:	Illustrative quotes
4.1 I know how I want to be seen, and not	<p>"That I'm pretty and I'm nice and I'm a very sweet person, very gentle"</p> <p>"[I want them to see that] I'm a pretty girl"</p> <p>"That I'm happy and that I'm calm and collected"</p> <p>"I want them to be proud"</p> <p>"Like, say if I look half asleep or something, or, or if my hair is a mess and I haven't brushed it, then I don't like that picture. Or if I've got dirty clothes on or something."</p> <p>"maybe a shortish kind of dress, because long dresses don't really suit me"</p> <p>"Yes, [I've had a photo taken that I didn't like] ... Because I was in the bath."</p>
4.2 I have opinions on the media	<p>"Erm, I once see them in wheelchair, I don't find that so nice actually... cause I was in one also..."</p> <p>"I think I think it's [pictures of disability] just sad actually.... only like just like one hand, or, ja"</p> <p>"Yes I have seen on the TV... It makes me feel sad sometimes, sometimes I get up and I walk away... its very sad because I'm not like that, why they like that?"</p> <p>"Like a complete vegetable... Yeah, some are in a wheelchair some can't walk or talk and some can't do things for themselves some are trying to learn to do things for themselves, I've seen it."</p> <p>"they shouldn't be like that they could be also normal people... Like you and Charlotte and my family just that they can be able to do things for themselves but then they can't they can't."</p>

Table 6*Theme 5: It is important to me that I am treated like an equal*

Sub-themes:	Illustrative quotes
5.1 I know stigma	<p>"It feels different to others, because I mean, I can cope on my own but with this what I've got is sometimes bringing me down when I'm at work. Like, I feel very small with everybody else at work. Like they think they perfect than me"</p> <p>"I don't know why but, some people say that I can't do certain things, but I think I can, do a lot actually... I can be very able"</p> <p>"Like, they say sometimes that I'm a very stupid person at work. I mean, I've got this, this what's it, this cerebral palsy... like I'm very handicapped in a way..."</p> <p>"Yeah and then [when they bully me] they think they perfect and the whole world belongs to them"</p>
5.2 I know respect	<p>"when people used to not greet me I would go mad when people ignore me I used to go mad, when people avoid me I used to go mad and all sorts of things."</p> <p>"This girl didn't want to be in the photo, I had to apologise to her."</p>

Table 7 Theme 6: It is important to me that you know that I love and am loved*Theme 6: It is important to me that you know that I love and am loved*

Sub-themes:	Illustrative quotes
6.1 I am loved	<p>"My friends think I'm a very sweet person"</p> <p>"people love me for who I am"</p> <p>"My family are very good to me in every way."</p>
6.2 I love	<p>"I love people. I love to spend time with my friends. I love to talk to people. I'm a sociable person I like to socialize."</p> <p>"I love to have photographs of people, especially my family."</p> <p>"[My family are] very special. And they mean a lot to me. They mean the world to me."</p> <p>"I love people. I love to spend time with my friends. I love to talk to people. I'm a sociable person I like to socialize."</p> <p>Interviewer: "And what's the hardest thing about being you?"</p> <p>"My real mother... Ja. That she went up to heaven".</p>

Table 8.*Theme 7: It is important to me that I participate*

Sub-themes:	Illustrative quotes
7.1 I can make media, too	<p>Interviewer: "it's just such a cute picture "</p> <p>"That's the right word, that's why I did that"</p> <p>"enjoyed it... Took quite a few."</p> <p>"I like to, like, be creative"</p> <p>"Because I feel very special afterwards, after the photo's taken"</p> <p>Interviewer: "what do you think about this picture?"</p> <p>L: "It's very nice. Did I take it nicely?"</p> <p>"So, I can do it. I wish I could have my own one [camera]."</p> <p>"Did I take that photo okay because I tried to and I was sickeling [struggling]. I think I took two of it because I wasn't sure which one come out nice. There. (agreement from room) I think this one is better. That one didn't. The first one didn't take, cut nicely. I didn't get the whole word in"</p> <p>"That's a bit blurred. I didn't even know it was like that. That you can delete."</p> <p>"Yoh. I can't believe it's over. I really enjoyed it."</p> <p>"feel very much like a photographer"</p> <p>"Yes, the first day when I first saw this camera, ██████ showed me the camera, my eyes lit up... Because they the first time I'm working a fancy camera."</p> <p>"Like see a different part of me through the glass... A pretty part"</p> <p>"I just felt like messing around with the camera."</p> <p>"Not in a suit."</p> <p>"I can look for something like Quicksilver or Adidas"</p> <p>"Also a flag"</p> <p>"I can try and find the same tracksuit like this maybe."</p> <p>Interviewer: So, like if you could imagine that there was a picture that people could look at and then they would say "oh that's Natalie. I now understand who Natalie is" can you imagine what would be in that picture?</p> <p>N: No.</p> <p>Interviewer: if someone asked me "hey, what's Natalie like?" What would you want me to say about you?</p> <p>N: "That I'm pretty and I'm nice and I'm a very sweet person, very gentle and I like people to hug me but not very tight hugs"</p> <p>"[I want to look] like a princess"</p> <p>"High heeled shoes hurt my toes and also it will make my feel tired, or I might fall over"</p>
7.2. There are things I need to participate	<p>"Uh, where in Cape Town [is the studio]... Is that area safe there?"</p> <p>"But I like photos but, but not if a flash goes in my face then it hurts my eyes...Because if a, like a orange flash goes in my eyes then it infects my eyes because I've got weak eyes. Like one long sighted and one short sighted"</p> <p>"So, so the day of the studio, would ██████ and ██████ be able to come with?... I trust both of them. I mean these are the two people that I trust mostly... specially like if I'm upset or I'm feeling anxious about something or, or somethings not going my way or something, then ██████ and ██████ are the two people that I can talk to and have a private little conversation with"</p> <p>"Is this camera that you're going to give me a difficult camera..."</p> <p>"if I have too much makeup on then it makes my face itchy and then I want to wipe it off"</p> <p>"okay, then I'll get ██████ or ██████ to help me to use this, whoever's on duty"</p> <p>"But I'm not a makeup person but I do, I will wear makeup that day. Cos I'm not a makeup person I only wear lipstick and nail polish."</p> <p>I noted approaches to accessible language for communicating with PWIDD in field notes taken while consulting expert sources: "like learning a new way of speaking, repeat and rephrase sentences if subject is confused, or to provide explanation of term or concept you're unsure they grasp. Support understanding. Preempt possible confusion."</p> <p>"Use simple words, plain language, not childish language or tone. Short, simple sentences. Concrete expressions of ideas, not abstract. As in avoid abstract terms like "media" rather use</p>

descriptive language like “in magazines and on TV, photographs and newspapers” ”
“be aware that what a PWIDD says is not always what they want to express, eg. ‘my heart is sore’
could express either physical or emotional distress. Ask more questions to ascertain meaning”.

Table 9.

Theme 8: It is important to me that the 'D-word' be handled with care

Sub-themes:	Illustrative quotes
8.The 'D-word'	<p>I noted: "Before I got to the first interview I was nervous about : How do I name the disability? Is it important to name it to have an honest and ethical interaction with them about the project? And to find out how they want their disability represented and engaged with."</p> <p>"What is that one?"</p> <p>Interviewer: Sorry?</p> <p>"The one you're talking about"</p> <p>Interviewer: What is it?</p> <p>"The one you're saying now."</p> <p>Interviewer: Oh, intellectual disabilities?</p> <p>"What's that one?"</p> <p>Interviewer: Or maybe they need to hear something two times before they can understand it.</p> <p>"Oh, okay. Oh yeah like, um, like ██████."</p> <p>Interviewer: Okay. Are there other people like ██████ here?</p> <p>"Um, I'm not sure."</p> <p>I noted: "healthcare professional who was an expert source for PWIDD and Covid19, unfamiliar with abbreviation PWIDD, response to explanation was that there are many terms, this a new one to them"</p> <p>"I don't know why but, some people say that I can't do certain things, but I think I can, do a lot actually... I can be very able"</p> <p>"this cerebral palsy that, that I don't know that, if you know what that means ...I don't know what it is but it's like, like I'm very handicapped in a way..."</p> <p>"I've got this, this what's it, this cerebral palsy that"</p> <p>"And with a very weak eye sight, too. So that's why I can't drive a car because of my weak eyesight."</p> <p>"I was I used to find my behavior very hard to control and now it's a lot easier. There's not really any hard things I just wish I could learn the write, agh learn to read and write, I'd help with that's a bit hard."</p>