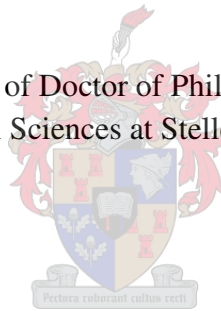# THINKING ABOUT INTELLECTUAL DISABILITY CARE: AN INTERSUBJECTIVE APPROACH

CHARLOTTE CAPRI

Dissertation presented for the degree of Doctor of Philosophy (by publication) in the Faculty of Arts and Social Sciences at Stellenbosch University

Promotor: Professor Leslie Swartz

March 2016

DECLARATION

By submitting this dissertation, I declare that the entirety of the work contained therein is my own original work, that I am the sole author thereof (save to the extent explicitly otherwise stated), that the reproduction and publication thereof by Stellenbosch University will not infringe any third party rights (save to the extent explicitly otherwise stated), and that I have not previously in its entirety or in part submitted it for obtaining any qualification.

March 2016

....
Date

DEDICATION AND ACKNOWLEDGEMENTS

To Mr AB who, but for his own, had not a soul in the world.

With many thanks to the participants without whom there would be nothing to write – their words gave shape and experiences gave fuel to the research. Thanks also to the research sites that allowed access to participant voices. Many experienced colleagues gave valuable insight, and my personal therapy and supervisions offered precious reflective spaces for coming to terms with the material. I could not have asked for a promotor better suited to helping me frame my thoughts and negotiate ways of presenting work that often brought up strong emotions. To the editor who took on her part of the work, a very big thank you. The same to the transcriber for his many, many hours of listening; and to the students for their help. I give tremendous credit to my very patient husband whose mad ways of thinking I can only admire. I would like to share this with my sister and her family, and my friends and my mother. Thanks dogs, the walks you take me on allowed ideas to follow us home. In loving memory of my dad whose capacity for empathy and size of his heart was only eclipsed by the expanse of his mind.

TABLE OF CONTENTS

**CHAPTER TWO: Literature Review (Part 1) – What do we know about
epidemiology, policy, socioeconomics, services, aetiology, and co-morbidity
regarding intellectual disability in South Africa?**   **32**

ABSTRACT

Of the many challenges facing persons with intellectual impairment in South Africa, disabling care continues to confront individuals who live and work with intellectual disability. Intellectual impairment care can be conceptualised as more than the performance of tasks involving giving and receiving, but can be understood as intersubjective and relational person-making exchanges that also unfold in broader socio-political spaces. Important voices have been marginalised in discourses on intellectual disability, and, in South Africa, traditional hegemonies of knowledge dominate thinking spaces that are yet to be taken up by the opinions of intellectually impaired individuals and care workers. Since experiences of care have been rarely voiced or validated by intellectually impaired individuals themselves, making and taking care should also refer to our capacity for reflection regarding our participation in many of its practices.

This study opens up possibilities for fresh perspectives on psychiatric intellectual disability care by bringing together apparently disparate fields of relational psychoanalysis and intersubjectivity on the one hand, and contemporary models of disability on the other. The research collaboratively tracks the voices of its primary speakers, and touches on problematic aspects of care by foregrounding subjective experiences of living and working with psychiatric intellectual impairment, and by exploring the making of disabled and disabling care. It then becomes possible to see how dynamics of psychiatric intellectual disability care can both complicate and be addressed by a relational and intersubjective conceptualisation of ethical care. It was the task of the researcher, as scribe of this study, to facilitate conditions in which expert voices on intellectual disability care could be raised. In such intersubjective spaces the experience of impairment is no longer simply given or bestowed, but voiced by the *real* experts – those who live and work with intellectual impairment in a disabling world.

OPSOMMING

Te midde van vele uitdagings wat mense met intellektuele gestremdheid in Suid-Afrika in die gesig staar, word individue wat leef en werk met intellektuele gestremdheid voortdurend met bestremmende sorg gekonfronteer. Intellektuele gestremdheidsorg kan gekonseptualiseer word as meer as die blote uitvoering van take wat die gee en neem van sorg behels, maar kan verstaan word as intersubjektiewe en relasionele persoon-skeppende uitruilings wat ook in breër sosio-politieke ruimtes ontvou. Belangrike stemme word gemarginaliseer in intellektuele gestremdheid diskoerse, en, in Suid-Afrika, word dink-ruimtes wat ingeneem moet word deur die menings van intellektueel gestremde individue en sorgwerkers steeds deur tradisionele kennishegemonieë oorheers. Sedert ervaringe van sorg selde uitgespreek of bekragtig word deur intellektueel gestremde individue hulself, hoort sorgskepping en sorgneming ook te verwys na ons kapasiteit vir besinning rakende ons aandeel in menige sorgpraktyke.

Hierdie studie stel moontlikhede voor vir vars perspektiewe insake psigiatriese intellektuele gestremdheidsorg deur klaarblyklik uiteenlopende velde van relasionele intersubjektiwiteit aan die een kant, en kontemporêre modelle van gestremdheid aan die ander, te vereenselwig. Deur gesamentlik die stemme van primêre sprekers na te spoor en problematiese aspekte van sorg aan te spreek, bring hierdie navorsing subjektiewe ervaringe van leef en werk met psigiatriese intellektuele gestremdheid tot die voorgrond terwyl die skep van bestremmende sorg verken word. Dit word dan moontlik om te sien hoe die dinamiek van psigiatriese intelektuele gestremdheidsorg 'n relasionele en intersubjektiewe konseptualisering van etiese sorg kan kompliseer, maar ook kan aanspreek. Dit was die taak van die navorser, as skrywer van die studie, om omstandighede te fasiliteer waarin deskundige intellektuele gestremdheidsorg stemme gelig kon word. In sulke intersubjektiewe ruimtes word die ervaring van gestremdheid nie meer eenvouding gegee of gegun nie, maar deur die *werklike* kenners uitgespreek – deur diegene wat met intellektuele gestremdheid leef en werk in 'n bestremmende wêreld.

CHAPTER ONE
Introduction and methodology

We sit together by the table, Tomás hovering insistently over me. "What shall I write?" I ask.
Valerie Sinason (2010, p.155).

I wanted to...participate in the suffering within the room...at last...hear the meanings [the patients] gave to their experience in their own words.
Marco Marzano (2007, p.421).

1.1.   INTRODUCTION

This study is about intellectual impairment and intellectual disability; about people in care who live with intellectual impairment and psychiatric illness or what is termed dual diagnosis (Molteno, Adnams, & Njenga, 2011); about individuals who provide care for people with intellectual disability in a psychiatric institutional context; and about the exchange of care on psychiatric intellectual disability inpatient wards. This research tries to understand the exchange of this care by bringing together apparently disparate fields of relational psychoanalysis and intersubjectivity studies on the one hand, and contemporary models of disability on the other. In doing so a host of very complex issues are raised, including those of citizenship and emancipatory research, which the study attempts to contain and address within an intersubjective and relational ethics of care frame.

This meant expressing and including my subjectivity and emotion as an objective voice throughout the text. In my work as a clinical psychologist and psychotherapist, professional experiences of institutional psychiatric intellectual disability care problematise my writing about important and emotive issues in an austere way. The samples in this study may be small, but the issues they elicit are big and similar to those brought up by Eva Feder Kittay and Joan Tronto. Doing the work every day confronts me with human experiences by which I am strongly moved personally and politically, and I cannot bracket this off. Whilst studying my own anxieties around engaging emotionally and therapeutically in relationship with institutionalised adults living with intellectual disability and psychiatric illness, I had to find a way of writing systematically in an organised way. In writing here I am making myself vulnerable to credible critics of unconventional or unusual approaches to academic research. By containing the anxieties of such emotive work within an intersubjectivity informed frame, I hope to show that it can be possible for these to become part of the objective study. I hope that the problematic of writing "coolly" or academically whilst feeling heartbroken is

circumvented adequately enough by maintaining a reflexive position without compromising the data (Behar, 1996).

To further my anxiety, I have found myself building an argument throughout the text from data sets on opposite sides of the providing-receiving care exchange continuum. The ease by which this text can become disjointed is even further augmented by taking the form of a "PhD by publication", still a rarity in South Africa. The chapters to follow have thus been prepared as publishable independently from one another. This means that similar descriptions of theoretical framing, research methodology, data collection, participants, and ethical issues, for example, appear in more than one place. At this time the research has produced three publications, and true to the format of this dissertation, the peer reviewed journal articles compromise three of the nine chapters presented here. At the beginning of each of the journal article chapters, a description of how they tie into the dissertation as a whole is offered to facilitate continuity for the reader. I am aware of breaking with the conventions of thesis writing by taking the decision to present the work in this way, and by making use of disparate theoretical traditions and sets of data, but I believe it important to do so in order to describe and hold the complexities of taking up study in a field that requires ranges of lenses and data.

Just as there are different ways of thinking about intellectual impairment, and thoughts offered here are but some, there is no "one kind" of intellectually impaired person (McDonaugh, 2008; Nakken & Vlaskamp, 2007). Some individuals can resist subordination, practise self-determination, participate autonomously as researchers or voters, and achieve their potential with little assistance; whilst others require support in such endeavours which need not, for this reason, be denied (Nonnemacher & Bambara, 2011; Reeve, 2006a; Shaw & Ogden, 2008; Stainton, 2005; Stein & Stein, 2007; Uys& Loots, 2008; Walker, 2013; Watson, Wilson, & Hagiliassis, 2013). Others still, with little independence and higher care needs, may require full dependency care. But all people have intrinsic human worth regardless of necessary support levels, contingent on enabling or disabling environmental factors in turn.

The term *developmental disability* is an "umbrella term that refers to any disability starting before the age of 22 and continuing indefinitely ... while this includes intellectual disabilities such as Down Syndrome, it also includes conditions that do not necessarily have a cognitive impairment component" (Human Rights Watch, 2015, p. ii). *Intellectual disability* is

2

"[c]haracterised by significant limitations in intellectual functioning (reasoning, learning, problem solving) and adaptive behaviour, covering a range of everyday social and practical skills. *Intellectual disabilit*y forms a subset of *developmental disability*, but the boundaries are often blurred as many individuals fall into both categories to differing degrees and for different reasons" (Human Rights Watch, 2015, p. iii). Intellectual impairment originates before the age of 18, and entails limitations in intellectual ability and adaptive behaviours that can include limited receptive, expressive, and written communication skills; personal, domestic, and community daily living skills; gross and fine motor skills; and limited social skills comprising interpersonal relationships, use of play and leisure time, and coping skills.

To its credit, the American Psychiatric Association (APA) no longer categorises intellectual impairment by quantified performances on intellectual ability assessments (APA, 2013). Individuals now shift along a continuum of domains that include conceptual, social, and practical functioning; and that inform on mild, moderate, severe, or profound intellectual impairment – perhaps as envisaged by L. Swartz, Van der Merwe, Buckland, and McDougall's "continuum of changing states of impairment and health" prior to the DSM-5 changes (2012, p. 951). As an ever-expanding artefact of the medical model, the DSM-5 has finally replaced *mental retardation* with *intellectual disability*, but it might be a while before *disability* is replaced with *impairment*. This discussion applies a distinction between impairment and disability as informed by a reading of the social model that views discriminatory attitudes toward impaired citizens as key obstacles to socio-political inclusion, and that locates disablement in difficult to navigate political and social environments (Barnes, 2012; Goodley, Hughes, & Davis, 2012; Kelly, 2013; Shakespeare, 2006; Stein & Stein, 2007).

Such *ableism* refers to dominant societal attitudes that devalue and limit the potential of persons with impairment, and give rise to practices and beliefs that assign inferior value to intellectually impaired individuals (Reeve, 2006a, 2012). Ableist societies negatively evaluate impaired individuals against able-bodied standards, resulting in socio-political environments that essentially exclude impaired individuals by means of attitudinal or systemic barriers (Smith, Foley, & Chaney, 2008; stopableism.org; Wolbring, 2008). Critics of ableism focus on the acts and conduct of discriminators without referring to the impaired person – the focus is on the discriminator's prejudice, not impairment (Harpur, 2009).

3

In this discussion, *care* is conceptualised as more than just a task but also refers to our capacity for reflection on the nature of our participation in many of its practices. We take care by reflecting critically on barriers that "undermine or interfere with the freedom to exercise whatever capacities one has or can develop" (Kittay, Jennings, & Wasuna, 2005, p. 458). Care can be good or bad, but all care is person-making (Tronto, 2010). Morris (2001) refers to Kitwood and Bredin (1992, p. 44) to explain that "'[b]ad' care fails to take personhood seriously, and allows the individual to fall apart, a prey to the dire combination of cognitive impairment and emotional distress. 'Good' care honours personhood and provides increasing interpersonal compensation and reassurance as individual powers fail." But evaluations of care have been very rarely researched and legitimised by, or sourced from, intellectually impaired individuals; and viewing them as incompetent to pass judgement perpetuates disabling and discriminatory treatment (Kittay, 2009, 2011; Tronto, 2010). Hitching our declarations of care to a Bill of Rights located in a liberal constitution might no longer suffice (Republic of South Africa, 1996). Within an ethics of care model we are required to conduct ourselves constitutionally, recognise a common humanity, and consider the kinds of personhoods our research and caring produce.

In thinking about intellectual disability and working in institutions, I find myself wondering about the kinds of emotional, cognitive, and social impediments that individuals living with intellectual impairment may face; what the effect of real and perceived abandonment might entail; if daily rejections occur despite desperation to relate; and what the internalised effect might be if injurious shame results: "Find me, but you mustn't look at me" (Sinason, 2010, p.161). Kittay (2009) posits that intellectually impaired individuals, as moral persons, should be free "to make claims of justice and receive the resources and protections that justice is meant to guarantee" (p. 624). Susceptible to marginalisation and inequality, however, intellectually impaired individuals may easily find themselves outside of power structures in systems where the distribution of services, care, and other scarce resources hardly occurs in their favour and very seldom adequately (Adnams, 2010; De Vries, Venter, Jacklin, & Oliver, 2013; McKenzie, McConkey, & Adnams, 2013a; Molteno, Adnams, & Njenga, 2011; Njenga, 2009). Amidst infantilising care, intellectually impaired adults are morally demoted when referred to as children, yet are often denied the enforceable rights bestowed on those they are likened to (Kittay, 2009). This is quite disconcerting, since intellectually impaired individuals may be at perpetual risk due to an often lifelong dependence on caregivers; not only emotional but also social insecurities; a comparatively disempowered, silent, and

4

disabled position in society (Calitz, 2011; Reeve, 2006b); and little opportunity and ability to assert access to recourse and resources without assistance.

It has been argued that even unintentional exclusion of intellectually impaired individuals from access to good services and resources – disablist practices – are on par with those of racism and sexism, just as discriminating, and an equally serious contravention of a basic human right (Kittay, 2009; Kittay et al., 2005; L. Swartz et al., 2012; Tronto, 2010). Kittay (2009) finds it morally abusive when policies impacting individuals with intellectual impairment are "formulated on the basis of the denial of the moral personhood of individuals who do not have a place at the table where their fates may be decided" (p. 620). The point is that individuals may be intellectually or physically impaired, but it is their political and social environments that do the disabling (Shakespeare, 2006). Swartz explains that in the social model of disability, the impairment alone "is not sufficient for disablement to occur. What disables people – what *makes* people disabled – is how society responds to the impairments" (own italics for emphasis – L. Swartz, 2010, p. 27, 28). An intellectually impaired adult only becomes disabled when the environment restricts his or her status as a citizen, hampers access to resources, or obstructs his or her right to a humane life.

I wonder whether individuals living with dual diagnosis (intellectual disabilities and psychiatric illness) may experience such marginalisation in an amplified manner – sequestered as members of disabling societies, as less interesting yet more bothersome patients in institutional facilities similar to the research sites in this study. Given the direction of power in such settings, any protest on their part or "suggestions...they might make...about care are likely to be taken as resistance or obstruction" (Tronto, 2010, p. 165), confirming their status as less than equal adults.

Sinason (2010) helps us understand how such institutional care spaces may actually be devoid of dignifying care – where its absence limits becoming a dignified adult, and where an absence of reflecting critically on care practices limits being thought about in dignifying ways. Tronto (2010) explains that, realistically, care is rarely without serious problems and conflicts. But institutional care especially faces two dangers: paternalism (caregivers assuming to know better than care receivers what their needs are) and parochialism (caregivers developing preferences for care receivers who are closer to them) (Tronto, 2010). If care performance is recognised "as *relational*", then attention must be paid to the purpose

5

of care as well as to the direction of power during its practice (original italics – Tronto, 2010, p.161). In an earlier article, Kittay and colleagues (2005) address this relational aspect of caregiving as it occurs in psychological and social contexts that historically shaped, and continue to shape, the experiences of participants in the caring practice. Care work can be a frustrating and thankless job, occuring mostly in an asymmetrical relationship in which intellectually impaired individuals may often be unable, but not necessarily unwilling, to reciprocate (Kittay et al., 2005).

Caregiving also seems gendered around the practice of paying attention to and meeting the needs of others, activities which are viewed as obstacles to the "project of masculinity" (Tronto, 2010, p.166; also see Sinding, 2010). Where care finds institutional expression through carers who themselves carry South African histories of marginalisation in terms of race and gender, and still in terms of mental health professional status; and where the global economy of care sees caregiving resources migrate from developing to industrialised countries (a "care drain" further disabling South African care recipients), thinking about the needs of intellectually impaired South Africans and their carers is further warranted (Kittay et al., 2005, p. 450). If care work remains poorly compensated and the occupation of less well-off and more marginal groups, its "invisible" and secondary status in society requires political reflection (L. Swartz, 2012, p. 954). In terms of power relations in care, would it be radical or ideal for intellectually impaired adults, with the power to compel care performance, to select their carers themselves...especially as their self-identified needs for care change; for carers to have both frustrating and rewarding aspects of their work received and acknowledged by managers and patients without reproach; for carers to have some input in the ways institutional controls above them are implemented; or to engage with institutional care workers systemically by co-producing new patterns of non-exploitation and non-exclusion (Kittay et al., 2005; Sinding, 2010; L. Swartz et al., 2012; Tronto, 2010)? If care became less of a commodity or trade at the most economical price, and its relational processes better appreciated and practiced, could it become possible for participants in intellectual impairment care to create care that need not be guided by financial cost (Tronto, 2010)? These topics will be taken up further in Chapters 6 and 7 of this research.

Swartz and colleagues explain that "traditional hegemonies of knowledge require subversion" and that "important voices have been marginalised in discourses on disability" (L. Swartz et al., 2012, p. 952), whilst Sinason (2010, p. 3) reminds us that "[w]hen there are people who

cannot think, remember, speak, or write, it matters that others take up the scribe function". Kittay and colleagues (2005, p.456) call for a "vocabulary for expressing the value...of those persons who cannot be self-reliant, autonomous, or productive in the ways that are commonly valued" (see also Kittay, 2011). In this, a role for both research and therapeutic engagement crystallises. Therapeutic interaction can be employed to help dually diagnosed individuals make their way in the world (or ward), whilst research has an obligation to inform policy and "help shape a world that will accept [these individuals]" – one that is enabling (Kittay, 2009, p.611). I often wonder what intellectually impaired voices would need or want to say, if anything; which words would be used for expressing ways in which they would like to be valued, or for which values would they want words?

1.1.1.   Rationale of the study

In systematic reviews of research on intellectual disability, paucities are repeatedly found in South African work published in scientific and research literature on policies and available services for intellectually impaired individuals, despite a greater South African prevalence rate than in high-income countries (Adnams, 2010; De Vries et al., 2013; Lund, Kleintjes, Kakuma, Flisher, et al., 2010; McKenzie et al., 2013a; Molteno et al., 2011; Njenga, 2009). This amplifies the imperative of recognising and remedying this vacuum in vital information (see also Carulla et al., 2011; Meekosha, 2011).

Despite slow progress regarding researching disability psychotherapies and the dearth in our knowledge of how to help (Beail, Warden, Morsley, & Newman, 2005; Brown, Duff, Karatzias, & Horsburgh, 2011; Dagnan, 2008), intellectually impaired adults living in institutional settings may have been trying to make themselves heard. For the moment, referrals to psychological services citing "behaviour problems" on the part of intellectually impaired individuals, as opposed to citing unmet high behavioural support needs, occupy a disabling textual space. "Challenging" and difficult to manage behaviour observed among intellectually disabled institutionalised patients may in part be an enactment of protesting but awkwardly channelled attempts at advocacy, making alternative intersubjective avenues and processes of expression important. Kittay (2009) helps us appreciate such "misbehaviour" in a different way: that intellectually disabled individuals may have a sense of (in)justice and self-worth aligned with an innate awareness that they could (and should) be recognised, considered, and treated with respect as dignified adults and not, due to lacking "higher-level cognition", as "nonpersons" (p.607).

7

In my work as a clinical psychologist and psychotherapist with individuals of various ages living with intellectual disability, as well as with their families, and through work with colleagues as part of multi-disciplinary mental health teams in institutional settings, questions around lack of voice for intellectually impaired individuals and care workers repeatedly came to the fore. Exploring the experiences of intellectually impaired individuals and caregivers intersubjectively might allow for the development of a work product that is a co-creation of participant and researcher subjectivities. Where collaborative research between enabled researchers and impaired individuals holds a potential start "for producing new perspectives on disability" (L. Swartz et al., 2012, p. 951), such work can track and give voice to the primary speakers as participants, or as the true experts on intellectual disability.

1.1.2.   Aim of the study

In this research I do not conduct an outcome study of therpaeutic effectiveness, but rather explore and think about voices on intellectual disability by taking an intersubjective approach during the formulation of the research, collection of narrative and observational data, and interpretation of the results. Initially this meant learning about the experiences of care from institutionalised individuals who live with dual diagnosis, and to focus on this one source of information and subsequent data set. But as the work unfolded, it became increasingly difficult to build an argument about intellectual disability psychiatric inpatient care without involving the carers. In order to study care, to explore "it" by observing how it is exchanged and among whom, the project had to grow by including other care participants. This meant including psychiatric intellectual disability nurses as care workers and research participants, and, as spaces in which care is exchanged, also had to include the wards as participants in care. This resulted in developing an argument from three different sets of data – sessions with residents, interviews with nurses, and observations on wards – in order to capture emergent voices on psychiatric intellectual disability care.

It is hoped that collecting these voices can be operationalised by eliciting participant first hand experiences and expertise. Such first person accounts can be initiated and developed by asking and thinking about the experiences of intellectually impaired individuals and caregivers in institutional environments. Whilst Chapters 4 and 5 explain how this might be made possible, others offer these expert voices on working (Chapter 6) and living (Chapter 7) with psychiatric intellectual disability. The research seeks to contribute to counter-hegemonic

texts on intellectual disability, and open up academic writing to multiple audiences by foregrounding subjective experiences of living and working with intellectual impairment. Intersubjectively, it will be the task of the researcher – as scribe of this study – to facilitate conditions in which the unconscious, co-created "analytic third", introduced below, can co-develop and help raise as yet silent but expert voices on intellectual impairment (Ogden, 1994, p.463; Sinason, 2010; S. Swartz, 2006). In an intersubjective space the experience of impairment is no longer simply given or bestowed, but ultimately voiced by the *real* experts – those who live with intellectual impairment in a disabling world.

1.1.3.   Theoretical point of departure: Developing an intersubjective frame for disability work

Since the development of interest in intersubjectivity as a field of scholarly enquiry, there is increasingly strong support for intersubjective evidence that can approach therapeutic engagements as social and political processes in emphasis of anti-discriminatory practice – essential in intellectual disability work (Reeve, 2006b). Disability researchers emphasise the importance of moving studies about disabled persons from a third-person reporting style, toward counter-hegemonic discursive texts where the experience and expert voice of impaired individuals shape the core of such forums (Davis, 2006; Dye, Hendy, Hare, & Burton, 2004; French & Swain, 1997; Hall, 2011; Smith-Chandler & Swart, 2014; L. Swartz, 2010; L. Swartz et al., 2012; Watson, Roulstone, & Thomas, 2012). By continuing to take a "speaking for" position rather than one of "speaking with" or "speaking by", well-meaning mental health professionals and researchers may unwittingly contribute to *institutional and scientific silencing* – further incapacitating already subdued voices. "What is less clear, though", we are warned, "is how we get to this voice"; or, in avoidance of discriminatory assumptions of homogeneity, *voices* (L. Swartz et al., 2012, p. 956; see L. Swartz, 2010, p. 62).

Reeve (2006b) suggests that intellectually disabled individuals would be most empowered by a therapeutic approach that recognises the potential for power imbalance and oppression within care participants' relationships – for example among institutional care workers, intellectually impaired residents, and psychotherapists. In the relatively new field of therapies for people living with intellectual impairment, there remains a poor empirical and theoretical understanding of the role and potential complexities of such relationships (Jones & Donati, 2009). In reflecting on these concerns, intersubjectivity seems a fitting approach – it

endeavours to investigate worlds of emotional experience as they take form in relational contexts, whilst studying the interplay of care participants' subjectivities (Siebold, 2011; Stolorow, 2011). The egalitarian developing relationship between therapist or researcher and intellectually disabled individual becomes particularly significant in cases where intersubjective interaction can create a "field" from which voices on intellectual impairment can emerge (Vaslamatzis, 2011, p.1).

Definitions of psychoanalytic intersubjectivity vary, but share two fundamental propositions: there can be no analytic neutrality or objectivity unaffected by the therapist's subjectivity; and ongoing experiences of one's subjectivity are deeply influenced by the subjectivities of those with whom one is interacting (Benjamin, 1990; Davies &Frawley, 1991; Fonagy& Target, 2007; Mitchell, 2014; Ogden, 1994, 2003; S. Swartz, 2006). The co-partnered research that can develop from the abovementioned intersubjective fields, unique to each interactive setting, would be multi-vocal, constantly shifting, part conscious and part unconscious, and difficult to describe (S. Swartz, 2006). One can expect to be confronted "up close and personal with [one's] own intolerance in quite an intense", even intolerable way (L. Swartz et al., 2012, p. 954). In thinking intersubjectively about being confronted with intellectual disability, and thus with one's own vulnerability and dependence, embodied differences between enabled therapist and disabled patient can be acknowledged and disarmed...differences that have in the past empowered some and cast others as subaltern.

Otherness, an "'us' and 'them' categorization [that] permeates our thinking...able-bodied vs. disabled", can threaten to derail therapeutic encounters in which impaired patients and therapists differ visibly (L. Swartz, et al., 2012, p. 951). It might also dissuade intellectually disabled individuals in distress from accepting and benefiting from help. This raises the question of how intellectual impairment (just as language, race, culture, gender, class and age differences between therapists and their patients) might complicate therapy (S. Swartz, 2007). But in intersubjective disability work, therapists have opportunities to hear patients "through the misunderstandings and defences" of their own enabledness, thereby enriching therapeutic encounters with the historically "othered" (L. Swartz et al., 2012; S. Swartz, 2006, p. 434). Moreover, collaboration with intellectually impaired individuals may guide explorations into previously unknown worlds of disabled lives. As Ogden (1999) helps us understand, "it is the experience of coming into being as an individual with one's own distinct and unique

qualities" that is paramount for any patient in an intersubjective therapeutic relationship (p. 490).

Intersubjectivity requires the open unconscious of all participants in care in order for their subjectivities to mutually inscribe one another (Mitchell, 2014), much like Kittay and colleagues' (2005) appreciation of how caregiving and receiving experiences are shaped in the space between institutional care worker and intellectually impaired resident. Opening ourselves up in this way, we are no longer hegemonically polarised as simply and categorically enabled (Kittay's "man") or disabled (Kittay's "beast") (2009, p. 612), but rather as two complex subjectivities that occupy different spaces on the continuum of "changing states of impairment and health" (L. Swartz et al., 2012, p. 951). By drawing on one another's knowledge and experience, it becomes possible to shift and meet on this continuum. On this range of shifting states we then no longer find ourselves positioned across from but rather relative to one another's expertise. In intersubjective moments we may "abandon our defences" and become "open to another conceptual world...able to receive new knowledge, new experiences and integrate them with our own, resulting [in] a vastly richer understanding" of living and working with intellectual impairment (L. Swartz et al., 2012, p. 958).

If intersubjectivity informed disability work results in a space in which differences in intellectual (dis)ability and power can be acknowledged and overcome, an opportunity is created in which both care worker and care dependent individual can be relieved from social constructions about disability and liberated from the "othering" myths that accompany these. In an intersubjective space, histories can be explored and reinscribed in a counter-hegemonic way to empower disabled voices (Marzano, 2007; L. Swartz et al., 2012; S. Swartz, 2005). By means of mutual inscription, subjectivities of care participants can be enabled into social action for the expression of freedom, dissatisfaction, equal (moral) rights, and individuality (Kittay, 2009). The theoretical frame introduced here runs through the research and is developed further in Chapters 5, 6, 7, and 8.

1.2.   LAYOUT OF CHAPTERS AND PUBLICATION STATUS

Within an overarching conceptualisation of care as intersubjective and relational, the chapters to follow progress in a way that facilitates a discussion of living and working with intellectual disability, and moves from this introductory chapter to a literature review that covers

scientific peer reviewed as well as "grey" literature published on intellectual disability in South Africa over the past 26 years (1989-2015). Although the initial search time span was 25 years (1989-2014), a year had passed between the literature search and the final preparation of the dissertation. In order to offer the most recent publications on intellectual disability in South Africa, it was decided to extend the included literature to July 2015. Because the returned literature spanned 26 years at an average of about six to seven returns per year, and thus resulted in an initially very long review in order to critically comment on the included literature, the literature review was split into two chapters. Part 1 of the review (Chapter 2) captures literature on epidemiology, policy, socioeconomics, services, aetiology, and co-morbidity regarding intellectual disability in South Africa; whilst Part 2 (Chapter 3) covers literature on interventions with children and adults living with intellectual disability in South Africa, and also offers a summary of the excluded literature (Table 3.1). Both review chapters end with a discussion on paucities in the South African literature, offered in more detail in the chapter on future research (Chapter 8).

The fourth chapter is comprised of a published peer reviewed journal article pausing on ethical issues involved when researching with individuals living with intellectual disability (Appendix B), and includes an example of the consent-assent form used with resident participants during the research (Appendix C). The fifth chapter also comprises a published journal article (Appendix D) which introduces the theoretical frame that runs through the research and is developed further in chapters 6, 7, and 8. Chapter 6 offers a published journal article on research with nurses who are care workers of individuals living with psychiatric illness and intellectual disability (Appendix E). Presented to Eva Kittay, other speakers, and attendees at a workshop in Stellenbosch on 21 May 2015, Chapter 7 introduces the voices of adults living with intellectual disability on psychiatric hospital wards by bringing their care experiences to the fore. Accepted as a chapter for a book, Chapter 8 discusses future research possibilities in the field of intellectual disability, for example on citizenship and emancipatory research, and also touches on some of the limitations of this study. Finally, the concluding chapter offers some last thoughts before the study is brought to its end. The chapters are introduced in more detail after offering this summary of chapter layout and publication status (Table 1.1):

Table 1.1.

Layout of Chapters and Publication Status

Chapter	Topic	Publication status	Title
1	Introduction and Methodology		
2	Literature Review: Part 1	Basis of systematic review.	**Part 1: What do we know about epidemiology, policy, socioeconomics, services, aetiology, and co-morbidity regarding intellectual disability in South Africa?**
3	Literature Review: Part 2	Basis of systematic review.	**Part 2: What do we know about interventions for children and adults with intellectual disability in South Africa?**
4	Ethical Issues	Published in African Journal of Disability *African Journal of Disability*, *1*(1), 1-4.	Capri, C., & Coetzee, O. (2012). **On the unethicality of disablism: Excluding intellectually impaired individuals from participating in research can be unethical.**
5	Theoretical Approach	Published in Disability and Rehabilitation *Disability and rehabilitation*, *36*(5), 418-423.	Capri, C. (2014). **On developing an intersubjective frame for intellectual disability work.**
6	Working with Intellectual Disability	Published in Journal of Applied Research in Intellectual Disabilities (2015) *Journal of Applied Research in Intellectual Disabilities*, *28*(3), 167-181.	Capri, C., & Buckle, C. (2015). **"We have to be Satisfied with the Scraps": South African Nurses' Experiences of Care on Adult Psychiatric Intellectual Disability Inpatient Wards.**
7	Living with Intellectual Disability	Presented to Eva Kittay at a workshop on 21 May 2015.	**An intersubjective and relational conceptualisation of care: Residents' voices raise implications for ethics of care on adult psychiatric intellectual disability wards.**
8	Future Research	Accepted as a chapter for a book on Disability and Citizenship in South Africa edited by Brian Watermeyer, Judith McKenzie, and Leslie Swartz.	**Future research opportunities: The ethics of intersubjective and relational person-making, intellectual impairment citizenship, and a reclaiming of knowledge.**
9	Concluding Thoughts		

1.2.1.   Chapter 2: Literature review (Part 1):What do we know about epidemiology, policy, socioeconomics, services, aetiology, and co-morbidity regarding intellectual disability in South Africa?

Part 1 of this literature review will begin by describing the method followed, and discusses the search strategy, inclusion criteria, exclusion criteria, and the useful help of five independent raters. It then moves on to the first part of a broader discussion on the results of the review. These include historic turns in the research literature, covering a subjugating gaze from the past and early critical comments, timing of first reports, and also briefly comments on tracking authors through time. By addressing epidemiology, policy, socioeconomics, and services, Part 1 of the review offered in this chapter touches on issues of inclusive education, community services, transition initiatives and services, health and mental health services, as well as touching on services for intellectually disabled survivors of sexual assault. A section on aetiology and co-morbidity, placed after the section on epidemiology so as to accentuate the urgent need for services, covers literature on genetic aetiology and co-morbidity, infectious illness aetiology, intellectual impairment related to FAS, epilepsy, and HIV/AIDS encephalopathy. The search returned notably more literature on children than on adults living with intellectual disability in South Africa, and literature on children was dispersed throughout the review where more relevant under different sections. Nevertheless, Part 2 of the literature review addresses interventions for children and adults living with intellectual disability, and is included in Chapter 3 as part of this review.

1.2.2.   Chapter 3: Literature review (Part 2): What do we know about interventions for children and adults with intellectual disability in South Africa?

Although the search returned notably more literature on children than on adults living with intellectual disability in South Africa, and literature on children was dispersed throughout Part 1 of the review where more relevant under different sections, separate sections on children, adults, and interventions regarding intellectual disability in South Africa is included in Chapter 3 as a second part of the review. For children, Part 2 of the review focuses on interventions (including medical, dental, and education interventions) and caregivers. For adults it also covers caregiving and interventions, with returned literature organised around topics of physical health, psychiatric health, and dental medicine. Chapter 3 winds down with a discussion on paucities in the South African literature on intellectual disability as did Chapter 2, and also ends off by offering some concluding thoughts including suggestions for further research.

1.2.3. Chapter 4: On the unethicality of disablism: Excluding intellectually impaired individuals from participating in research can be unethical

Individuals living with intellectual impairment can, and must, be researchers or at least co-researchers on issues that may affect them directly – not "just" subjects or participants – and Chapter 4 argues that they need not be excluded from intellectual disability research processes. In fact, such exclusion could be construed as unethical in that the omission of their expert voices hinder rather than enable valuable contributions and developments to improve services for intellectually impaired persons. Not asking the opinion of intellectually impaired individuals on intellectual disability matters can be interpreted as disabling, and may amount to disablist practice. Chapter 4 takes the reader through benefits of and obstacles to participation in research processes, and also addresses some solutions to exclusionary research practices. These include using augmentative aids to written words, avoiding coercion, adhering to conditions of ethicality when designing disability research, conceptualising consent and assent to participate as an ongoing process, and viewing an individual's decision not to participate in research as a sign of successful consent processes.

1.2.4. Chapter 5: On developing an intersubjective frame for intellectual disability work

This Chapter posits that an intersubjective view on disablist discourse and practice might craft an egalitarian space from which expert voices on intellectual impairment could emerge. Psychoanalytic approaches to working with intellectual disability were pioneered by practitioners like Valerie Sinason, and the research offered here attempts to further bridge (or settle in the gap between) psychoanalytic and disability studies. Although the notion that intellectually impaired individuals cannot benefit from psychoanalytic approaches has been greatly dispelled (Sinason, 2010), calls for further research on therapeutic work with individuals living with intellectual disability seem to have been met with slow progress (Beail et al., 2005; Brown et al, 2011; Dagnan, 2008). A lack of access to such services can be disabling, can contribute to excluding intellectually disabled individuals from conceiving research studies, and can limit choosing from different approaches when working within individuals living with intellectual impairment (Adnams 2010; Brown et al., 2011; Carulla et al., 2011; Gustafsson et al., 2011; Hemmings et al., 2011; Lund, et al., 2010).

From a position of intersubjectivity (a relational and radical turn of psychoanalytic theory), this chapter hopes to describe how material that emanates from a non-objectivist epistemology can equally inform on research and therapeutic approaches. As Ogden (1999) helps us understand, "it is the experience of coming into being as an individual with one's own distinct and unique qualities" that is paramount for any patient in an intersubjective therapeutic relationship, but can be especially so for individuals living with intellectual disability (p. 490).

1.2.5.   Chapter 6: Nurses' experiences of care on adult psychiatric intellectual disability wards

If nurses continue to be excluded from decision-making processes that affect duties of patient care, thereby disabling care exchanges, a disregarding of their expert voices can amount to unethical practice. Experiences held by psychiatric intellectual disability nurses have not received sufficient attention in the literature, whilst instances where their opinions are given no authority can be even more disabling (Hastings & Horne 2004; Kittay 2001; Tronto, 2010). Few qualitative research studies pertaining to intellectual disability nurses' (and therefore patients') well-being have been implemented, raising concerns about uncaptured knowledge. Given staff impact on patient care and the adverse effects of nursing migration on dependency care, South African nurses' needs and voices could be accredited more value for the purpose of both patient and nurse ethical care.

Where objectivist "hegemonies of knowledge require subversion" (L. Swartz et al. 2012, p. 952), collaborating intersubjectively with nurses within a qualitative and collaborative research design can contribute to fresh perspectives on intellectual disability care. Thompson and Rose (2011) urge researchers to focus on services for individuals with intellectual disability so as to "address this relatively neglected area of research" (p. 191). It is hoped that Chapter 6 can contribute to a fresh conceptualisation of psychiatric intellectual disability nursing, and address this paucity.

1.2.6.   Chapter 7: An intersubjective and relational conceptualisation of care: Residents' voices raise implications for ethics of care on adult psychiatric intellectual disability wards

This chapter introduces a conceptualisation of ethics of care as relational and intersubjective, and argues that intellectual disability care should not only be made to matter, but that *how* it

is made should matter even more. In aiming to further bridge psychoanalytic theory and disability studies, a relational lens was used through which to observe the complexities of intellectual disability care on adult psychiatric inpatient intellectual disability wards. Understanding the exchange of such care was enriched by applying psychoanalytic intersubjectivity theory to ethical care practice. Chapter 7 aims to show how psychiatric intellectual disability care spaces offer sites at which to observe dependency care as it reproduces (and is produced by) care exchanges that can limit the performance of ethical care. Verbatim quotes from residents included throughout this chapter also urge us to consider care participants' expressed emotional needs for comfort, containment, warmth, and reassurance that can be easily obscured by medicalisation and bureaucratised understaffed psychiatric care.

This chapter hopes to show that if decision-making about care for individuals who live and work with intellectual impairment begets disablist planning and institutions, then resultant care runs the risk of being disabling, not-ethical, and not-care. For now, sufficient care meets institutional accreditation requirements on participating wards in this study; but as illustrated during this discussion, not yet the necessary conditions for relational, person-making care.

1.2.7.   Chapter 8: Future research opportunities: The ethics of intersubjective and relational person-making, intellectual impairment citizenship, and a reclaiming of knowledge

Chapter 8 discusses possibilities for future research in the field of intellectual disability in South Africa and also touches on some of the limitations of this study. A main tenet of the discussion on further research is that socio-political thinking and decisions pertaining to resources for caring about intellectual impairment create, in turn, policy environments in which intellectual disability services will be delivered, as well as spaces for socio-political participation. By neglecting these care correlations, we perpetuate inadequate responses to intellectually impaired South Africans' assertions of personhood so closely tied to the rights, duties, requirements, and obligations of citizenship.

In response, the discussion on future research reflects on Watermeyer's (2012) call for appropriate ways of representing South African intellectually impaired personhoods. It does so by drawing on intersubjectivity, and hopes to show that claims to traditional human rights, citizenship, knowledge, policy building, and care taking in making enabled or disabled kinds

of persons could be re-explored in future intellectual disability research. The discussion also responds to Kagee's (2014) call for professional and academic psychology to address the needs of South African society, specifically of citizens living with intellectual impairment. A relational and intersubjective ethics of care model might afford a fresh framework for considering intellectually impaired citizens' participation in determining policies – by means of inclusive and emancipatory research – that inform their lives.

To operationalise claims to citizenship and knowledge on intellectual impairment, topics that can be taken forward on important South African policy informing future inclusive and emancipatory research are offered in Chapter 8. Inclusive and emancipatory ethics of care research might also open avenues for research into the *completion of care*, something dependent not only on the receipt of care but on the recipient's acceptance thereof (Eva Kittay, Workshop Communication, 21 May 2015).

1.2.8.   Chapter 9: Concluding thoughts

This chapter brings together discussions that were offered as the research progressed. It is hoped that the application of intersubjectivity in attempting to address the research question could introduce novel ways of understanding work with intellectually disabled adults; address the effects and prevention of marginalisation and disempowerment by equalising power (im)balances; and by virtue of its scientific literature base, provide a contextualised account of work with institutionalised intellectually disabled adults and their caregivers. It is hoped that the research might be useful to institutional policy and budget decision makers working with the mental health of intellectually impaired individuals; professionals from various disciplines involved in disability work and research; psychoanalytic intersubjective theorists, practitioners, and researchers; and in the professional development for intellectual disability workers and caregivers.

Relatively and temporarily able-bodied for now, we may ignorantly negate our culpability in shaping the environments that intellectually impaired individuals are disabled by on a daily basis. But as participants in care we all contribute to creating the world we *will* become impaired in, and to the people that will disable us. The voices of intellectually impaired individuals – their experiences of disabling worlds – call us on our ignorance and lack of knowledge, confront us with our own human fragility, and remind us of the inevitability of our own need for care.

1.3.   METHODOLOGY

I do not want to create the expectation that this study has been entirely collaborative in the tradition of emancipatory research. Ideally it should have been, since South Africa lags far behind the movement in the United Kingdom, for example. But I hope that I have managed to include the voices and institutional worlds of the study participants in a respectful way that honours and dignifies their experiences. When I use "research with" I do so to indicate that I considered the participants as the true experts on intellectual disability, and that I was guided by them in the data collection and validation process as opposed to having taken a directive approach. Much more thinking is done about this in Chapter 8.

So for the purposes of this study, a qualitative approach would accommodate the spirit of intersubjective ethics of care research work and writing, and afford containment for as yet "unknowable" research eventualities and results. Qualitative measures will also allow for co-created descriptions of unique intersubjective fields and voices that emerge during the course of engagement with participants. For these reasons, this study will employ a descriptive and explorative inductive qualitative approach, and follow critical realism and contextual constructionism in the spirit of creating intersubjective data (Babbie& Mouton, 2007; Burman, 1997; Hollway & Jefferson, 2013; Madill, Jordan, & Shirley, 2000). The exploratory nature of the research enables an attempt at understanding living and working with psychiatric intellectual disability (Bless, Higson-Smith, & Kagee, 2006), whilst its descriptive nature engages the reader with situations described by the researcher (Babbie & Mouton, 2007). The qualitative approach allows space not only for the researcher's reflexivity and subjectivity, but also for those of psychiatric intellectual disability nurses and adult residents (Terre Blanche, Durrheim, & Painter, 2006).

Enabling an intersubjective investigation, critical realism admits an inherent subjectivity in the co-creation of knowledge – it contends that the way researcher and participant perceive truths depends on their beliefs and the social realm in which these truths will be observed (Burman, 1997; Harper, 2008; Marzano, 2007). Contextual constructionism takes note of intersubjective meanings, and does not assume that there is only one true analysis that can be revealed by using the "correct" methodology (Erlich, 2003; Ogden, 2003). Contextualism also posits that all knowledge is local, provisional, and situation dependent, and that results will vary according to the context in which data was collected and analysed. All accounts,

researchers' and participants', are understood as permeated with subjectivity and permissive of conflicting perspectives (Johnson, Onwuegbuzie, Tucker, & Icenogle, 2014; Madill et al., 2000). To this end, the study's qualitative approach affords space in which the reflexivity and subjectivities of the researcher and participants can emerge as they co-construct their research findings (Terre Blanche et al., 2006).

Due to the setting in which data will be collected – two public psychiatric hospitals – Chapter 7 will offer work on residents' experiences of living with intellectual disability on inpatient psychiatric wards. It hopes to do so by integrating residents' individual narratives with ward observations of care performances and exchanges from an intersubjective and relational ethics of care perspective. To accommodate the abovementioned, the participatory action research (PAR) and case study method was employed during intersubjectivity informed sessions with adult residents living with psychiatric illness and intellectual disability, and results from these interactions are offered in Chapter 7 (Simons, 2014). In keeping with the intersubjective tradition, PAR seeks to establish "joint collaboration within an ethical framework" with a view to engaging participants directly in the research processes (Kagan, Burton, & Siddiquee, 2008; Rapaport, 1970, p. 499 in Terre Blanche et al., 2006). PAR emphasises open relationships, with participants having a direct voice regarding data collection and interpretation, whilst the case study method is ideal for observing salient features of the unique intersubjective fields that will unfold during interactions between researcher and participants (Kittay, 2009; Parker, 2005; Simons, 2014). Case studies of research dyads – tracking each third voice as it emerges – can afford an intensive investigation of the research-participant interactions as units of analysis in this research (Babbie& Mouton, 2007; S. Swartz, 2006).

In the spirit of intersubjective co-creation of participant material, and so as to neither limit participant responses nor make hypothetical assumptions about participant experiences of living and working with intellectual disability, carer interviews will be conducted by means of the Free Association Narrative Interview (FANI) method (Hollway & Jefferson, 2013). Applying the FANI (Hollway & Jefferson, 2013) method for interviews with nursing staff in Chapter 6 suits the study's aim of intersubjectively co-creating with participants fresh perspectives on working with psychiatric intellectual disability, and attempted to remedy a marginalised and silent posture that living and working with intellectual disability can easily be made to inhabit. In theory, intersubjectivity allows for a shared understanding mediated

through unique interaction, for collaborative research that reflects participant views, and for researcher reflexivity in a power-balanced relationship (Anderson, 2008). Ultimately, the FANI method operationalises the aim of partnering with participants who feel comfortable to share experiences unconditionally held and valued by the researcher. An overview of the research design for "data chapters" 2, 3, 6, and 7 is summarised here in table form, with data from ward observations and sessions with residents culminating in Chapter 7 (Table 1.2):

Table 1.2.

Overview of Qualitative Research Design

Research question: Can intersubjectivity informed disability work and research co-create with participants a balance of power from which the expert voices on – and expert knowledge of – intellectual disability can emerge?			
Chapter	**Operationalisation**	**Method of data collection**	**Method of data analysis**
Chapters 2 and 3	• Literature review • Gauging knowledge on intellectual disability in South Africa spanning 26 years (1989-2015)	• Electronic database searches • Hand searches • Contacting authors of "missing" papers • Integrating quantitative and qualitative research studies (mixed-method)	• Review of published peer reviewed journal articles and "grey literature" • Inclusion and exclusion criteria • Independent raters with experience and expertise in intellectual disability
Chapter 6	• Eliciting experiences of care workers of intellectually impaired individuals in institutional environments	• Free Association Narrative Interviews (FANI) of 60 minutes each • 16 individual participants	• Thematic and narrative analysis until saturation reached
Chapter 7	• Eliciting experiences of intellectually impaired residents on psychiatric intellectual disability wards	• Participant action research (PAR) and case studies • Verbal and non-verbal communication • 10 cases • 59 intersubjectivity informed individual sessions	• Thematic and narrative analysis until saturation reached • Units of analysis explored on: o predominant anxieties o defensive strategies o traumas repeated and responded to
	• Performance and exchange of care among nurses and patients on psychiatric intellectual disability wards	• Participant observations • 3 inpatient wards • 45 hours	• Field notes • Thematic analysis • Triangulation of observations with resident session and caregiver interview material

1.3.1.   Literature review

The review offered in Chapters 2 and 3 serves as the basis for a future systematic review of literature on intellectual disability in South Africa. As a starting-off point, an initial list of peer reviewed journal articles as well as "grey" literature pertaining to all research on intellectual disability in South Africa over the past 26 years (1989-2015) was compiled, where intellectual disability was the topic of study. The review followed a mixed-method of integrating both quantitative and qualitative research studies on intellectual disability in South Africa. As Harden (2010) informs, an integrative literature review that includes diverse forms of evidence can enhance the utility and impact of its results by identifying analytical themes, recognising gaps in the research literature, as well as offering recommendations for further research (also see Maulik, Mascarenhas, Mathers, Dua, & Saxena, 2011).

1.3.1.1. Search strategy

In order to find literature to review, MeSH search terms using Boolean syntax were entered into five databases (Web of Science, PubMed, Scopus, PsychInfo, and ERIC). References without electronic files were hand searched. Search terms were entered around three main topics, namely intellectual disability, South Africa, and participant age (adult or child), and were sensitised for time span and language. MeSH terms were used to search the literature by using universal terms related to "Intellectual Disability", "Developmental Disabilities"; "South Africa"; "Adult", "Middle Aged", "Young Adult", "Aged, 80 and over", "Frail Elderly", "Adolescent", "Child", and "Infant". Returns on searches are described in detail in Chapter 2.

1.3.1.2. Inclusion criteria

To be included in this literature review, the topic being studied had to be intellectual disability in South African specifically, and had to be published over that past 26 years (1989-2015). Research participants and research sites had to be South African, even if the researchers were not. Country groupings written about in any study on intellectual disability had to include South Africa if a study was to be considered for review. Deciding on which studies to include and exclude got quite complicated at times. For this reason and as explained in Chapter 2, the help of experienced and expert independent raters was sought. Studies on Foetal Alcohol Syndrome (FAS) and Autism Spectrum Disorder (ASD), for example, were particularly problematic. Again, the parameters around these are discussed in some detail in the next chapter.

1.3.1.3. Exclusion criteria

Literature on intellectual disability in Africa but not South Africa (e.g., Nigeria); literature on disability in South Africa but not intellectual disability (e.g., hearing impairment); literature on frequently co-occurring presentations of which intellectual disability is not necessarily included by definition (e.g., FAS without intellectual disability as excluded *versus* intellectual disability in Down's Syndrome as included); and irrelevant database returns (e.g., South Carolina, Southern Australia) were excluded from this study. Etiological studies on, for example, nutritional insufficiency (e.g., iodine or iron insufficiency, suboptimal nutrition, maternal or perinatal malnutrition), infectious illnesses (e.g., tuberculous meningitis), parasitic or tropical diseases (e.g., measles, polio, bacterial meningitis, malaria, encephalitis, or helminth infections), and vulnerabilities in preterm or low birth weight infants were excluded unless the topic of study was intellectual disability. Returned and subsequently excluded sources after the Independent Rater Round are offered in table form in Chapter 3.

1.3.1.4. Independent raters

After a first exclusion sweep, the remaining references were investigated for forward citations. In so doing, reference lists of peer reviewed journal articles as well as those of the "grey literature" were studied for possible inclusion of sources that met inclusion criteria but might have been missed during the initial search. After the first exclusions, the help of seven independent raters was sought to verify whether the selected sources did indeed address the review question and meet inclusion criteria. Although all seven were willing to participate and be involved in the systematic review that will develop from the review offered in Chapters 2 and 3, five raters submitted their rater forms. Raters were allocated up to 29 articles, chapters, papers, or studies to review for inclusion, and were matched as far as possible with references particular to their expertise and experience. I rated the remaining studies for inclusion. In cases where hand searches did not produce a required study, authors of the included literature were either contacted for their papers via ResearchGate, or a librarian at the University of Stellenbosch was approached to help locate studies. "Missing" papers were sent on to raters as they became retrievable. Completed and returned Independent Rater Forms were safely stored in representation of the review methodology.

1.3.2.   Nurses as care workers in psychiatric intellectual disability

An exploratory descriptive-interpretivist method was applied to investigate nurses' experiences of working with intellectual disability in a psychiatric hospital (Eatough & Smith, 2008; Thorne, 2014). Since the study was open to any perspectives of psychiatric intellectual disability nursing, an inductive approach embedded in grounded theory was appropriate and no hypotheses were made prior to data collection (Bryant, 2014; Charmaz & Henwood, 2008). Collaboration with participants regarding research design, data collection, and validation of findings was informed by the study's intersubjective theoretical framework. Participants took up roles as intellectual disability nursing storytellers, and the researcher as listener and scribe (Hollway & Jefferson, 2013). In co-creating new knowledge, the researcher did not assume a leading role but was a co-constructor of research that could not have been brought into being otherwise.

1.3.2.1. Participants

All respondents to an invitation to participate comprised the study population. Participants included 16 Black and Coloured male and female nurses from different levels in the nursing department of the particular research site, and registered with the South African Nursing Council (terminology in the Employment Equity Act, RSA 1998). Part-time nurses on adult intellectual disability wards, and nurses on outpatient or non-intellectual disability inpatient wards were excluded from participating. Participant demographics are offered in Chapter 6, but not to an extent that would compromise participant anonymity. Participants are not personally identifiable – not in the research notes, transcriptions, or write-up of the research itself.

For purposes of transparency, the researcher asked for comment and input by presenting nursing staff of the particular research site with a draft of the larger research proposal. An invitation letter was distributed among nursing staff and made available to interested parties at the hospital for the purpose of informing on the research, and to assist in allaying any anxieties potential participants may have had. This letter explained the purpose and procedures of the research, informed participants of their participation rights, and enclosed contact information in the event of any questions. The researcher also attended Inter-hospitals Intellectual Disability Forum meetings in 2012 where the research was tabled for comment by staff members from intellectual disability services external to the research site. A formal

presentation of the finalised research proposal was shared with nursing staff as potential participants in February 2013.

As shown in Chapter 6 and prior to beginning the data collection process itself, the researcher attended a meeting at the research site on 20 March 2013 for purposes of providing nursing staff with an opportunity to meet the researcher; informing nursing staff about the goals and processes of the research study; presenting a space for nursing staff to ask questions, clarify uncertainties or insecurities, and make suggestions; and providing the researcher with the opportunity to meet potential nursing participants and begin formulating an idea of the research context. This meeting seemed successful, since some of the nurses shared that the anxieties they were holding about the research had been greatly alleviated. Suggestions and helpful inputs made by nursing staff were incorporated into data collection methodology, for example, prioritising the comfort and convenience of participants during the data collection process; meeting nurses in a place familiar to them (e.g., on their wards so as to avoid disruptions to continuity of care); not impinging on tea or lunch breaks when making data collection arrangements; sharing the results of the research with participants; and collaborating on steps for disseminating research results.

1.3.2.2. Data collection

Hollway and Jefferson's (2013) free association narrative interview (FANI) method of collecting data operationalised the aim of creating between each research dyad a unique intersubjective field from which a voice on working with intellectual disability could emerge (S. Swartz, 2006). Interviews approximating 60 minutes were performed with 16 participants in privacy and convenience on their wards. With participants' permission interviews were voice recorded and transcribed. No hypothetical assumptions were made about care experiences of participants, who were only asked to "tell me about intellectual disability nursing". Since narratives elicited by free association "secure access to a person's concerns, which would probably not be visible using a more traditional method" (Hollway & Jefferson 2013, p. 34), employing the FANI method suited the study's aim of intersubjectively co-creating fresh perspectives on psychiatric intellectual disability work with participants.

1.3.2.3. Data analysis

Grounded theory stresses the importance of generating interpretation as they surface from data by means of an unbiased attending to emerging themes (Bryman 2012; Bryant, 2014;

Charmaz & Henwood, 2008). These were identified by thoroughly rereading interview transcripts, listening to the recordings, and studying field notes. Attributable to rich material and participants' similar experiences, it did not take long for thematic saturation to be reached. As interviews with nurses progressed, notes made during and after these were triangulated with audio-recordings and transcriptions (Mello 2002, Terre Blanche et al. 2006). Since "[w]e present ourselves ... in terms of our stories or narratives" (Levett 2002, p. 70), narrative formats employed during nurse interviews were both verbal and non-verbal communication (Ochs & Capps, 1996; Parker, 2005). Participant narratives served as the primary units of investigation, and narrative data were examined and interpreted for common themes (Babbie & Mouton, 2007). Shown in Chapters 6, interpretations are evidenced by verbatim participant accounts and by referencing existing literature.

1.3.2.4. Validity

Participant feedback verified the interpretations of themes as they emerged from the data, as well as the validity of subsequent results. Participants could add information to confirm aspects of data, or ask that inaccurate interpretations be removed. To further verify the findings and provide feedback to participants, results of the research with psychiatric intellectual disability nurses were offered to the participants, and other interested individuals, at research site 1 on Wednesday 1 October 2014, and at research site 2 on Friday 5 June 2015. Participants were keen for results to be disseminated in peer reviewed publication format, by means of a hospital grand round presentation on Thursday 29 October 2015, as well as by presentation to hospitals' chief executive officers.

1.3.3.   Residents as participants in care

Under the South African Mental Health Care Act of 2002 (RSA, 2002), nurses care for adults living with dual diagnoses (intellectual impairment as well as psychiatric diagnoses inclusive of personality disorders), and often with problematic medical conditions. Any combination of these may complicate treatment goals of discharging patients, in consultation with the Mental Health Review Board, into community care.

Intersubjectivity informed narratives were collected with 10 adults living with intellectual disability and psychiatric illness over 59 individual sessions from both research sites, and demographics of these individuals are offered in Chapter 7 in a manner that does not render the participants identifiable. The sessions were non-directive and open ended as informed by

an intersubjective framing described in Chapter 5, and were lead by whatever a participant wished to discuss about living with intellectual disability. Residents were nominated for participation in the study's dual aim of therapeutic interaction and research by means of referral from their multi-disciplinary mental health care teams. This opened opportunities for intersubjectivity informed interaction as described in Chapter 5 to any resident. Resident participation was entirely voluntary, and referred individuals could choose not to participate. Referred residents that met the inclusion criteria but wished not to participate in the study would still receive the same therapeutic engagement, if so wished, as would participants who elected to have their voices introduced in Chapter 7 of this study.

Referrers were very familiar with the adult residents put forward for participation, and felt that they might benefit from a space offered in the study in addition to the services already provided at the hospital. Further to the discussion in Chapter 8, a next study could endeavour to facilitate a process whereby individuals living with intellectual impairment make use of opportunities to put themselves forward, independently or with assistance, to participate in or drive future research.

1.3.3.1. Participants

Although individuals living with profound intellectual disability were not excluded from the study, and non-verbal participants could be included, male and female residents referred for participation at both research sites were living with mild, moderate, and severe intellectual disability as described in Diagnostic Criteria for Psychiatric Disorders for use with Adults with Learning Disabilities/Mental Retardation (Royal College of Psychiatrists, 2001), Diagnostic Manual-Intellectual Disability (National Association for the Dually Diagnosed, 2007), and the Diagnostic and Statistical Manual of Mental Disorders, Fifth Edition (American Psychiatric Association, 2013). Individuals with intellectual impairment younger than 18 years of age, and patients attended to at the research sites on an outpatient basis were excluded from participating in this study.

Adults living with dual diagnoses who live in public psychiatric institutions were included in data collection, provided that conditions for consent or assent could be met as described in Chapter 4. Obtaining consent from participants was always attempted first. Participants could ask the researcher any questions about any part of the research process they might not have fully understood. They were only included if both researcher and participant were fully

27

satisfied that they clearly understood what the research and their involvement entailed. As explained in Chapter 4, a patient's declining to participate in the study was indicative of an understanding that consent or assent could be given or refused. An example of the consent-assent form is included as Appendix C in Chapter 4.

1.3.3.2. Data collection

By means of intersubjectivity informed sessions, 59 hours of narratives were collected with 10 adults living with intellectual disability and psychiatric illness. The process of eliciting experiences of living in institutional environments from individuals with intellectual impairment can easily perpetuate inequality practices. As discussed in Chapter 5, psychoanalytic intersubjectivity – in principle egalitarian – seemed a fitting approach with which to engage with residents' narratives as it endeavours to investigate worlds of emotional experience that take form in relational contexts (Mitchell, 2014; Siebold, 2011; Stolorow, 2011). The developing relationship between researcher and intellectually disabled individual becomes particularly significant if therapeutic intersubjective interaction can create conditions from which an expert voice on intellectual impairment can emerge (Vaslamatzis, 2012).

1.3.3.3. Data analysis

As sessions with residents progressed, notes made during and after the sessions were triangulated with audio-recordings and transcriptions of the sessions (Mello 2002, Terre Blanche et al., 2006). Consistent with the process of studying the FANI data co-created with participating nurses as described in section 1.3.2.3., residents' narratives served as the primary units of investigation and narrative data were examined and interpreted for common themes (Babbie & Mouton, 2007). Throughout the discussion in Chapter 7, verbatim participant accounts that capture salient features of residents' experiences are included together with illustrative ethnographic field notes.

1.3.4. Ethnographic observations: psychiatric intellectual disability inpatient wards

Ethnographic data is collected on phenomena within or about communities, in this case adult inpatient psychiatric intellectual disability care communities, and a preferred strategy of investigation is often participant observation (DeVault, 2006, 2013; Griffin & Bengry-Howell, 2008; Harrison, 2014; McGibbon, Peter, & Gallop, 2010, Quinlan, 2009; Robinson, 2013; Rosenthal & Rosnow, 2008; Sinding, 2010; Tinney, 2008). By collecting observational

data, the study gains perspective on psychiatric intellectual disability care "from the direct ... observation" of care exchanges among nurses and residents on adult inpatient psychiatric intellectual disability wards in two public hospitals in the Western Cape (Babbie & Mouton, 2007, p. 279).

1.3.4.1. Participants

Three hospital wards were conceptualised as research participants during observational data collection. The three participating wards were included on recommendation by nursing staff on condition that this was voluntary. Initial meetings were held with the nursing manager, as well as area managers, operational managers, ward sisters, and registered nurses of all the wards at the particular hospital complex. In these meetings the basic framework of the research was discussed. The meetings also facilitated discussion of various queries and concerns nurses may have had, and made space for the voicing of any concerns on behalf of residents and ward staff. Having discussed this among themselves, nursing staff voluntarily put forward the wards they felt should be included in the study for reasons discussed below. Ideally, a resident delegate or spokesperson should have been representing fellow patients during these meetings. This consideration is taken up for future research in Chapter 8.

Subsequent to suggestions by nursing staff and the mutual decision that participating wards be as representative as possible of the hospital's intellectually disabled population, a mixed gender ward for patients with mild to moderate intellectual disability, a female ward for patients with moderate to severe intellectual disability, and a male ward for patients with moderate to severe intellectual disability were included. Wards could withdraw from participating in the study at any time without being convinced to continue. Ward names were changed to Ward A, B and C to uphold anonymity, and keep individuals unidentifiable. Ward residents included both male and female Black, White and Coloured individuals, and nursing staff included both male and female Black and Coloured individuals (terminology used in the Employment Equity Act, RSA, 1998).

1.3.4.2. Data collection

Forty-five observational hours were collected on three adult inpatient wards in one of two South African public psychiatric hospitals, caring for adults with differing care needs as a function of intellectual impairment, from different social groups, and representing different races and genders. To ensure consistency and replicability of the research frame, the

observation hours were spaced equally among the three wards. Each was visited for 15 hours over a period of three days, five hours per day, divided into different time slots for each day – a morning slot so as to observe ward handover (6:30am to 11:30am), an afternoon slot (11:00am to 16:00pm), and an evening slot also again inclusive of ward handover (14:00pm to 19:00pm). In order to produce the most accurate comparative data possible, the exact time slots were replicated and applied across all three wards. These time slots afforded observations of care interactions during the course of a typical day in a given ward, including routine daily living activities, and general interactions among care participants.

1.3.4.3. Data analysis

The daily care interactions between nurses and residents as units of analysis were observed and recorded in a field journal (Babbie & Mouton, 2007; Griffin & Bengry-Howell, 2008; Harrison, 2014). Notes were revised and re-read, culminating in the collection of similar themes as they unfolded across all three participating wards. In this way, aspects of care interactions relating to the research question, and to social relations inherent in intellectual disability life and work, were identified.

1.4.   ETHICAL CONSIDERATIONS

Ethical clearance for the research was obtained from the Health Research Ethics Committee of Stellenbosch University's Faculty of Health Sciences (Federal Wide Assurance Number: 00001372, Institutional Review Board Number: IRB0005239). Approval for collecting data was also obtained from the Western Cape Department of Health. In addition, the hospital ethics committees of both research sites granted ethical approval for the research on condition that, during the process of collecting ethnographic data for Chapter 7, the researcher remain unobtrusive and not initiate direct interaction with ward staff or residents.

In terms of potential risks to participants, the study does not involve invasive procedures and risk to participants is low. However, by stirring memories or arousing feelings and perceptions which otherwise may not have occurred, even verbal participation in any research project has the potential to violate participants' right to psychological integrity (Cameron & Murphy, 2007; RSA, 1996). In cognisance of this, the therapeutic nature of the research engagement is emphasised – therapeutic support to research participants is inherently designed into the study, and nursing participants could access counselling referrals if narrative material was experienced as distressing. As co-creators of counter-hegemonic

disability texts, intellectually impaired individuals and their care staff can help develop novel research, ensure that studies are not dominated by researchers' agendas, and render a scientific service on matters that directly affect them (French & Swain, 1997; Inglis & Cook, 2011; L. Swartz et al., 2012). As discussed in more detail in Chapter 4, such participation could add depth and strength to data collection, involve participants in political and social change processes, acknowledge participant contributions, and facilitate participant self-esteem (Dye et al., 2004; Inglis & Cook, 2011; Stone & Priestly, 1996). Excluding intellectually impaired individuals from such participation might deny them indirect benefits of the sense of achievement and worth gained as co-constructors of research studies, having their contributions credited, intellectual stimulation, additional attention from various professionals, and gaining awareness of their capabilities (Inglis & Cook, 2011; Sinason, 2010).

For the work offered in Chapter 6 and 7, participant anonymity was ensured, participants were not remunerated nor did they pay to participate, and no intentional harm came to them. For the work offered in Chapter 7, the researcher took care to remain respectful of relationships between staff and patients, to not impinge on the ward environment, and to not cause any upset to any person during her observations. Resident participants were free to withdraw from participation in the study's individual sessions at any point, even if they initially consented or assented to participate and attended a number of sessions. If referred residents chose not to participate in the study from the outset or withdrew during its course, but still wanted to engage in therapeutic sessions, this was made possible. Maintaining anonymity, privacy, and confidentiality were of utmost importance, but not more so than doing no harm.

CHAPTER TWO
Literature Review (PART 1): What do we know about epidemiology, policy, socioeconomics, services, aetiology, and co-morbidity regarding intellectual disability in South Africa?

2.1.   INTRODUCTION

Within an overarching conceptualisation of care as intersubjective and relational, the chapters to follow progress in a way that facilitates a discussion of living and working with intellectual disability, and moves from the introductory chapter to a literature review that covers peer reviewed and "grey" literature published on intellectual disability in South Africa over the past 26 years (1989-2015). Although the initial search time span was 25 years (1989-2014), a year had passed between the literature search and the final preparation of this manuscript. In order to offer the most recent publications on intellectual disability in South Africa, it was decided to extend the included literature to July 2015.

In her review of literature and official websites on the epidemiology, policies, and services for children and adults with intellectual disability in South Africa, Adnams (2010) found a paucity of published literature on intellectual disability despite suggestions that the prevalence rate of intellectual disability in South Africa is greater than in high-income countries. Since Adnams (2010) found a lack of evidence-based publications that describe intellectual disability in South Africa within her review period of 12-18 months, the primary aim of this chapter is to report on the literature published on intellectual disability in South Africa over the past 26 years (1989-2015).

As did Adnams (2010), Njenga (2009), Molteno et al. (2011), and McKenzie et al. (2013a) found a dearth in the literature relating to research and evaluation studies of intellectual disability in Africa. Although this review is limited to studies of intellectual disability in South Africa, issues for further investigation identified by McKenzie et al. (2013a) include understanding intellectual disability in African contexts (e.g., the need to draw on informal and traditional forms of care and participation), access to education and health care, the provision of appropriate assistance and support, and income generation. Of importance, and also identified as a topic for future research by this review, McKenzie, McConkey, and Adnams (2013b) advocate for including the expertise and opinion of individuals living with intellectual disability in the development of research agendas and service priorities.

As an important area of public health need, De Vries et al. (2013) also considered the clinical research landscape in terms of the resources and priorities associated with intellectual disability in African countries like South Africa. As did Adnams (2010), they estimate that rates of disability in Africa may be significantly higher than in higher-income countries. De Vries et al. (2013) also draw importance to considering potential causes or aetiologies of intellectual disability that might be very different from those in higher-income settings, such as Foetal Alcohol Spectrum Disorder (FASD), which has a prevalence as high as 6–9% in the Western Cape of South Africa; and HIV/AIDS, with proposed rates as high as 14% in individuals with intellectual disability in South Africa (Adnams, 2010).

Given the imperative of recognising this "information gap...in order to plan for and meet the needs of those with intellectual disability across the lifespan" (Adnams, 2010, p. 436), this study's literature review chapters also aim to balance what we do know about intellectual disability in South Africa with possible dearths in the current literature. Finally, in conjunction with those set by authors such as Tomlinson et al. (2014), this review aims to identify further opportunities for future research as they emerge from the literature under review here.

Of the many challenges facing persons with intellectual disability in South Africa, high prevalence, discrimination, and access to justice and education are key considerations – and without exception, these are "coupled with poor resource allocation" (Njenga, 2009, p. 457). Recurring calls for improved South African intellectual disability resource allocation and services require not only critical examination by intellectually disabled and non-disabled researchers alike, but the serious consideration and implementation of 26 years' worth of credible, peer-reviewed research and recommendations (Adnams, 2010; De Vries et al., 2013; Kagee, 2014; McKenzie et al., 2013a; Molteno et al., 2011; Tomlinson et al., 2014).

The returned literature spanned 26 years at about an average of six to seven returns per year, and resulted in an initially very long review in order to critically comment on the included literature. For this reason, the literature review was split into two chapters. Part 1 of the review (Chapter 2) captures literature on epidemiology, policy, socioeconomics, services, aetiology, and co-morbidity regarding intellectual disability in South Africa; whilst Part 2 (Chapter 3) covers literature on interventions with children and adults living with intellectual

disability in South Africa, and also offers a summary of the excluded literature (Table 3.1). Both review chapters end with a discussion on paucity in the South African literature, which is taken up in more detail in the chapter on future research (Chapter 8).

Part 1 of this literature review will begin by describing the method followed, and discusses the search strategy, inclusion criteria, exclusion criteria, and the useful help of five independent raters. It then moves on to the first part of a broader discussion on the results of the review. These include historic turns in the research literature, covering a subjugating gaze from the past and early critical comments, timing of first reports, and also briefly comments on tracking authors through time. By addressing epidemiology, policy, socioeconomics, and services, Part 1 of the review offered in this chapter touches on issues of inclusive education, community services, transition initiatives and services, health and mental health services, as well as touching on services for intellectually disabled survivors of sexual assault. A section on aetiology and co-morbidity, placed after the section on epidemiology so as to accentuate the urgent need for implementation of identified service needs, covers South African literature on genetic aetiology and co-morbidity, infectious illness aetiology, as well as intellectual impairment related to FAS, epilepsy, and HIV/AIDS encephalopathy.

The search returned notably more literature on children than on adults living with intellectual disability in South Africa, and literature on children was dispersed throughout the review where more relevant under different sections. Nevertheless, Part 2 of the literature review addresses interventions for children and adults living with intellectual disability, and is included in Chapter 3 as part of this review. For children, the review further focuses on interventions (including medical, dental, and education interventions) and caregivers. For adults it also covers caregiving and interventions, with returned literature organised around topics of physical health, psychiatric health, and dental medicine. Both Chapters 2 and 3 wind down with discussions on paucities in the South African literature on intellectual disability, and end off by offering some concluding thoughts with suggestions for possible future research.

2.2.   METHODOLOGY

The review chapters also serve as the basis for a future systematic review of literature on intellectual disability in South Africa which will be undertaken separately from this PhD project. For the review offered here, an initial reference list of peer reviewed journal articles

as well as "grey" literature pertaining to all research on intellectual disability in South Africa over the past 26 years, where intellectual disability was the topic of study, was compiled as a starting point. The mixed-method review integrates both quantitative and qualitative research studies on intellectual disability in South Africa. As Harden (2010) informs, an integrative literature review that includes diverse forms of evidence can enhance the utility and impact of its results by identifying analytical themes, recognising gaps in the research literature, and offering recommendations for further research.

2.2.1. Search strategy

In order to capture the literature offered in this review, MeSH search terms using Boolean syntax were entered into five databases (Web of Science, PubMed, Scopus, PsychInfo, and ERIC). References without electronic files were hand searched. Search terms were entered around three main topics of intellectual disability, South Africa, and participant age (adult or child), and were sensitised for time span and language. MeSH terms were used to search the literature by using universal terms related to "Intellectual Disability", "Developmental Disabilities"; South Africa; "Adult", "Middle Aged", "Young Adult", "Aged, 80 and over", "Frail Elderly", "Adolescent", "Child", and "Infant". The search returned 539 possible references on intellectual disability in South Africa over the past 26 years, and is summarised as follows:

Table 2.1

Search by Entry Terms

- **TOPIC:** ("intellectual* disab*" or "mental* retard*" or "mental* handicap*" or "learning disab*" or "learning handicap*" or "mental* impair*" or "intellectual* impair*" or "learning impair*" or "development* disab*" or "development* impair*" or "development* delay*" or "moron*" or "idiot*" or "imbecile*" or "subnormal*" or "sub-normal*")
- *AND* **TOPIC:** (South Africa*)
- *AND***TOPIC:** ("adult*" or "child*")
- **Timespan:** 1989-2015
- **Search language=**English

			Original search entry terms	
WEB OF SCIENCE	**Scopus**	**Pubmed (NCBI)**	**PsycArticles**	**ERIC**
187	269 document results (Scopus) + 8 secondary documents (277)	**295 with time limits (1989-2015)** **341 without time limits**	**295** results for **Any Field**: "South Africa*" **285** results for **Any Field**: "South Africa" **4** results for **Any Field**: "intellectual* disab*" or "mental* retard*" or "mental* handicap*" or "learning disab*" or "learning handicap*" or "mental* impair*" or "intellectual* impair*" or "learning impair*" or "development* disab*" or "development* impair*" or "development* delay*" or "moron*" or "idiot*" or "imbecile*" or "subnormal*" or "sub-normal*" *AND* **Any Field**: South Africa* *AND* **Any Field**:	**43 with time limits**

35

"adult*" or "child*" *AND* **Year**: 1989 *TO* 2015 *AND* **Peer-Reviewed**
Journals Only

N=1054: When collated and cross-referenced on RefWorks (duplicates deleted) = 539 sources

Table 2.2

Search by MeSH Terms

- **TOPIC:** *"Intellectual Disability*"[Mesh] OR "Developmental Disabilities"[Mesh]
- *AND* **TOPIC:** "South Africa"[Mesh] *(includes Republic of South Africa [Mesh])*
- *AND* **TOPIC:** "Adult"[Mesh] *(includes Aged"[Mesh] "Middle Aged"[Mesh] "Young Adult"[Mesh] Aged, 80 and over"[Mesh] "Frail Elderly"[Mesh])***OR** "Adolescent"[Mesh] **OR** "Child"[Mesh] *(includes "Child, Preschool"[Mesh])***OR** "Infant"[Mesh] *(includes "Infant, Newborn"[Mesh])*

Search entries are MeSH terms				
WEB OF SCIENCE	**Scopus**	**Pubmed (NCBI)**	**PsycArticles**	**ERIC**
72 without booleans 103 with booleans (exported to Refworks)	70 with booleans + 4 secondary documents (74)	**139 no limits** **104 with limits**	**1** result for **Any Field**: "Intellectual disability" or "Developmental disabilities" *AND* **Any Field**: "South Africa" *AND* **Any Field**: "Adult" or "Adolescent" or "Child" or "Infant"	**5**

N=322

2.2.2. Inclusion criteria

To be included in this literature review, the topic being studied had to be intellectual disability in South African specifically, and had to be published over that past 26 years (1989-2015). Research participants and research sites had to be South African, even if the researchers were not. Countries, for example medium- and low-income countries, written about in any study on intellectual disability had to include South Africa if a study was to be considered for review. Deciding on which studies to include and exclude got quite complicated at times. For this reason and as will be explained further shortly, the help of experienced and expert independent raters was sought. Studies on Foetal Alcohol Syndrome (FAS) and Autism Spectrum Disorder (ASD), for example, were particularly problematic.

The Foetal Alcohol Syndrome (FAS) question: FAS is the most easily preventable cause of intellectual disability. But although intellectual impairment is common in the phenotype of individuals living with FAS, it does not occur in *all* individuals and is not a requirement in order to make the diagnosis of FAS (Royal College of Psychiatrists, 2001). Level of intellectual ability is variable according to the severity of the condition. In most cases of FAS, low or average intellect is more common than intellectual disability (Royal College of

Psychiatrists, 2001). Having said this though, a reference was included, for example, if FAS was an etiological contributor to intellectual disability as the topic of study. FAS studies were thus not included unless the study was on intellectual disability. Similarly, studies were not included unless, for example, HIV/AIDS was an etiological contributor to intellectual disability being studied in the example of HIV encephalopathy; or if a study was on intellectual disability with a genetic aetiology of which impairment is not always an outcome.

The Autistic Spectrum Disorder (ASD) question: As a developmental disorder, ASD is separated from intellectual disability in view of the recognition that the developmental disorder may not be the underlying cause of the person's intellectual disability (Royal College of Psychiatrists, 2001). For example, although a pervasive developmental disorder may coexist with intellectual disability, ASD is not invariably associated with intellectual disability. ASD might be associated with presentations of impairment in individuals living with intellectual disability, or with Fragile X Syndrome for example, but not all individuals with ASD have intellectual disability. Like FAS, ASD is an additional and separate disorder and is recognised as such. In this review, literature could be included if intellectual disability is studied with co-morbid or underlying ASD. ASD as the topic of study, as opposed to investigations of intellectual disability, was not included in this literature review.

In contrast to both ASD and FAS questions, Down's Syndrome is the commonest genetic syndrome causing intellectual disability and is invariably associated with intellectual disability. Intellectual disability is recognised as a phenotypal expression of Down's syndrome – any study on Down's Syndrome would therefore implicitly be about intellectual disability, and would therefore be included in this review (Royal College of Psychiatrists, 2001).

2.2.3.   Exclusion criteria

After duplicates and overlaps were deleted, the abstracts of returned references were read. A number of these references were excluded based on the following criteria: literature on intellectual disability in Africa but not South Africa (e.g., Nigeria); literature on disability in South Africa but not intellectual disability (e.g., hearing impairment); literature on frequently co-occurring presentations of which intellectual disability is not necessarily included by definition (e.g., intellectual disability in Down's Syndrome as included versus FAS without intellectual disability as excluded); and irrelevant database returns (e.g., South Carolina,

Southern Australia). Etiological studies on, for example, nutritional insufficiency (e.g., iodine or iron insufficiency, suboptimal nutrition, maternal or perinatal malnutrition), infectious illnesses (e.g., tuberculous meningitis), parasitic or tropical diseases (e.g., measles, polio, bacterial meningitis, malaria, encephalitis, or helminth infections caused by different species of parasitic worms transmitted by eggs present in human faeces which contaminate the soil in areas where sanitation is poor – see Kvalsvig & Albonico, 2013), and vulnerabilities in preterm or low birth weight infants were excluded unless the topic of study was intellectual disability. Returned and subsequently excluded sources are offered, with help from the seven independent raters, in Table 3.1 in Part 2 of this review (Chapter 3).

2.2.4.   Independent raters

Up to this point, a total of 1054 sources were returned after the first search with original Boolean syntax and MeSH entry terms. After collating, cross-referencing, and deleting duplicates returned from all the databases, 539 sources remained. The abstracts of these returned references were read, resulting in the first exclusions as explained above. After this first exclusion sweep, the remaining references were investigated for forward citations. The reference lists of all peer reviewed journal articles as well as those of the "grey literature" were studied for inclusion of possible further references that might meet the inclusion criteria, but perhaps missed by the initial search (resulting in the inclusion of a further eight studies). This left a possible 233 articles, chapters, papers, or studies for inclusion in the review.

At this point, the help of independent raters was sought for a second sweep to verify whether the remaining selected articles indeed address the review question and thus meet the criteria for inclusion of a review of literature published on intellectual disability in South Africa over the past 26 years (1989-2015). These raters will also be involved in the systematic review that will develop from the literature review offered here. The following individuals with experience in the field of intellectual disability in South Africa were approached and agreed to act as independent raters: Colleen Adnams (CA), Judith McKenzie (JM), Ockert Coetzee (OC), Manny Saptouw (MS), Andrew Hooper (AH), Lameze Abrahams (LA), and Leslie Swartz (LS). Each rater was allocated up to 29 articles, chapters, papers, or studies to review for inclusion. Five raters returned their rater forms, and I reviewed the remaining material. As far as possible, raters were matched with references particular to their field of expertise and experience in intellectual disability in South Africa.

Each rater was furnished with a specifically selected set of Independent Rater Forms, their particular reference list, and copies of the corresponding literature. The Independent Rater Forms contained each paper's abstract, and were organised according to first author surnames in alphabetical order. The rater's initials (together with the list number of each particular paper) served as a code that corresponds with the author and title of the papers in the rater's reference list, rater forms, and the provided literature for inclusion review. For example, an entry in Judith McKenzie's Independent Rater Forms would have look like this (Appendix A of this chapter):

> **JM14** Kromberg, J., Zwane, E., Manga, P., Venter, A., Rosen, E., & Christianson, A. (2008). Intellectual disability in the context of a South African population. *Journal of Policy and Practice in Intellectual Disabilities, 5*(2), 89-95. doi:10.1111/j.1741-1130.2008.00153.x
>
> Provided for review as: **JM14** Kromberg et al. 2008.pdf

As per the literature review's inclusion criteria, raters were asked whether the study, chapter, paper, or article is about intellectual disability; whether it is about intellectual disability in South Africa; and whether it was published between 1989 and 2015. In cases where hand searches did not produce a required study, authors of the included literature were contacted for their papers via ResearchGate or a librarian at the University of Stellenbosch was approached for help. "Missing" papers were sent on to raters as they became retrievable. Completed and returned Independent Rater Forms were safely stored as representative of the review methodology.

2.3.   RESULTS

Of the 233 articles, chapters, papers, or studies sent to the independent raters, 163 sources were retained. Table 3.1 in Chapter 3 offers the 70 references that were identified for exclusion in the review of literature on intellectual disability in South Africa published over the past 26 years (1989-2015). Figure 2.1 summarises this process:

Collating returns
Cross-referencing
Duplicates deleted   Independent Raters

1054 ⟶ 539 ⟶ 233 ⟶ 70 (excluded)
                                        163 (retained)
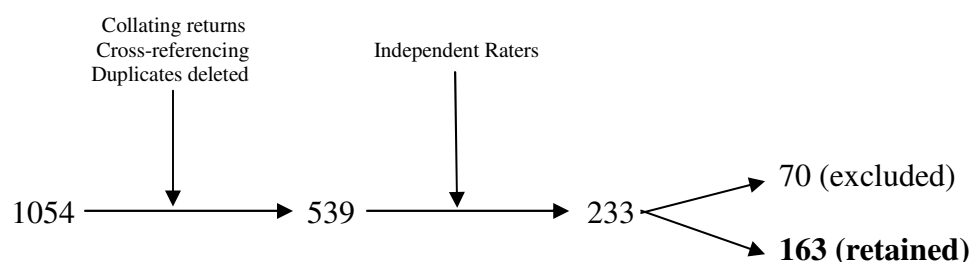
"Sweep 1"   "Sweep 2"

Figure 2.1. Application of inclusion and exclusion criteria

From an average of six to seven articles published per year over the past 26 years on intellectual disability in South Africa, it became possible to organise the included peer reviewed and "grey" literature around the following identified themes: historic turns in the research literature indicative of shifts in research and nomenclature (some authors have also made contributions over large time spans); epidemiology, services, policy, and interventions; aetiology and co-morbidity; the socio-economics of intellectual disability in South Africa; intellectual disability and children; and intellectual disability and adults. Linking to the chapter on future research offered in Chapter 8, some opportunities for further investigation are also mentioned toward the end of this review.

2.3.1.   Historic turns in the research literature

In following Sinason's (2010) exploration of the United Kingdom (UK) literature, names by which intellectual impairment was described also changed during the course of the South African literature, with the term "intellectual disability" signifying the most recent turn. This would include:

- 1988: "idiot" and "imbecile" (Government of the Republic of South Africa, 1988, p. 123);

- 1974 – 2011: "mentally retarded" (Brown, 1991; Calitz, 2011; Cartwright, 1992; Cartwright, Nelson, & Fryns, 1991; Christianson et al., 1999; Dawood, Bhagwanjee, Govender, & Chohan, 2006; Friez et al., 2000; Heckmann, Carr, & Bell, 1995; Op't Hof, 1983; Op't Hof et al., 1985; Pillay & Kritzinger, 2008; Power, 1977; Reinecke, Mienie, Hitzeroth, & Op't Hof, 1983; Roelofse & Van der Bijl, 1994; Sleigh, 1978; Slone et al., 1998; Slone et al., 1999; Van der Bijl & Roelofse, 1992; Van Der Merwe & Roux, 1987; Venter, Gericke, Dawson, & Op't Hof, 1981; Viljoen & Smart, 1993; Wagner, 1974);

- 1984 – 1997: "mentally handicapped" (Cartwright, van Rijlaarsdam, Wagner, & Rothberg, 1988; Molteno, Roux, Nelson, & Arens, 1990; Nash & Navias, 1992; Parekh & Jackson, 1997; Pretorius, 1984; Schoub, Johnson, McAnerney, & Blackburn, 1993);

- 1999: "intellectual handicap" (Leary, Riordan, Schlegel, & Morris, 1999);

- 2009: "mentally impaired" (Meel, 2009); and

40

- 1997 – 2014: "intellectual disability" (Adnams, 2010; Calitz et al., 2007; Christianson et al., 2002; Dada, Huguet, & Bornman, 2013; De Vries et al., 2013; Donohue, Bornman, & Granlund, 2014; Engelbrecht et al., 2003; Fujiura, Rutkowski-Kmitta, & Owen, 2010; Gara, 2007; Kock, et al., 2012; Kromberg, Christianson, & Manga, 1997; Kromberg et al., 2008; McKenzie, 2013a; McKenzie & MacLeod, 2012a, 2012b; McKenzie et al., 2013a; McKenzie & Adnams, 2014; McKenzie, McConkey, & Adnams, 2013b; McKenzie, McConkey, & Adnams, 2014a, 2014b; Molteno et al., 2011; Molteno, Molteno, Finchilescu, & Dawes, 2001; Moss, 2009; Nel, Kempen, & Ruscheinski, 2011; Ngwena & Pretorius, 2012; Njenga, 2009; Phasha, 2009; Phasha, 2012, 2013; Phasha & Nyokangi, 2012; Phasha & Myaka, 2014; Pillay, 2010; Pillay, 2012a, 2012b; Pillay & Siyothula, 2011; Robertson, Hatton, Emerson, & Yasamy, 2012; Shabalala & Jasson, 2011; Terblanche & Boer, 2013; Tomlinson et al., 2014; Yoo, Valdovinos, & Schroeder, 2012).

Historic turns in the research literature indicate shifts in both research topics and the nomenclature of what we currently term intellectual disability. Sources included under this heading precede the time span included in this review, and should strictly speaking not be included in this discussion at all. These were retained, however, at my discretion for a number of reasons: By reviewing research questions in the past one can sense an overt, albeit historic, subjugating gaze through which intellectual disability work was titled and published in the past (for example, a racialised gaze in considering the causes, by race, of moderate and severe intellectual disability) whilst following authors who critically commented on this; one can identify the timing of first South African case studies and reports; appreciate how nomenclature has shifted, and how study topics have shifted from eugenics-like genetic preventative investigations and reports to increasing socio-political comment on different levels; and one can track authors that have contributed work to the field over many decades and inclusive of the time span – some may have contributed to the mentioned shifts, and some are still actively publishing.

2.3.1.1. Subjugating gaze from the past and early critical comments

Subjugating gaze: In the Immorality Amendment Act (No. 2 of 1988) for example, individuals living with intellectual disability were not only prohibited by law from engaging in sexuality, but were legally termed "idiot[s] or imbecile[s]" (Government of the Republic of South Africa, 1988, p. 123). Furthermore, The Abortion and Sterilisation Act of 1975 gave

legal sanction for the sterilisation of men and women with a "mental handicap" (Nash & Navias, 1992, p. 437). By 1989, 1 817 "retarded" individuals had been sterilised in South Africa, since they were deemed "unable to comprehend the consequential implications of or bear the parental responsibility for the fruit of coitus", or would bear children suffering from a physical or mental defect of such a nature that "it" would be "seriously handicapped" (Nash & Navias, 1992, p. 437). Earlier than did Nash and Navias (1992), Van der Merwe and Roux (1987) also called for assurances that legislation pertaining to the sterilisation of the "mentally retarded" not lead to abuse or ignorance of the many ethical complexities involved (Van der Merwe & Roux, 1987, p. 489). If menstrual hygiene in women was a pertinent factor, hysterectomy was the method of choice rather than sterilisation by tubal ligation. This method also reportedly resulted in "more calm, cooperative, productive, and less irritable" women – possibly more to the relief of these individuals' carers (Van der Merwe & Roux, 1987, p. 489). Although "a multidisciplinary team approach to the decision making process and the individualisation of each case" was "essential to protect the rights of the mentally retarded", and inputs from mental health professionals were required, opinions on the matter from individuals living with intellectual disability themselves were neither asked for nor considered (Van der Merwe & Roux, 1987, p. 489).

Whilst Shulman (1977) was the first to report on homocystinuria, an inherited metabolic disorder, in the "South African negro" (p. 127); Christianson (1997) and Christianson and Kromberg (1996) were the first to investigate delayed diagnosis and maternal non-recognition of Down's Syndrome in Black South African infants. At the time, Down's Syndrome was one of the commonest causes of "mental retardation in Caucasoids", but only "rarely described in Africa" (Christianson & Kromberg, 1996, p. 141). Until 1982, Down's Syndrome had been considered rare in Black African populations and only during the 1990s was it shown to have a high incidence in Black South African neonates (and in some studies higher) than seen in high-income countries at the time of Christianson's 1997 paper. Christianson (1997) concluded that difficulties experienced by medical and nursing staff in diagnosing Down's Syndrome in Black neonates extended into infancy and childhood, but that the clinical features of Down's Syndrome in Black South African infants and children did not differ in any way from those in other "ethnic groups" (Christianson, 1997, p. 992). Such underdiagnosis was a problem, since the prevalence of congenital heart disease in children with Down's Syndrome suggests that it is a significant cause of mortality.

In making a Eurocentric comparison, Power (1977) investigated the pattern of additional handicap and the extent to which Coloured children of school-going age in the Cape Town suburb of Athlone, living with severe "mental retardation", received adequate management (p. 30). The author concluded that "[w]hile the level of residential care available was comparable to that provided in Europe, the provision of day training facilities was grossly deficient" (p. 30).

Early critical comment: Rubin and Davis (1986) studied and critiqued such inadequate health care services during and prior to the 1980s in Soweto, South Africa. Critically commenting on such inadequacy (dare one say neglect), the authors found that preventable aetiologies of intellectual disability, such as infections and metabolic consequences of acute gastroenteritis, could be preventable through provision of adequate nutrition, mass immunisation campaigns, and adequate primary health care services including antenatal and obstetric management (Rubin & Davis, 1986; see also the finding that "acquired causes [of intellectual disability] were noted to be more prevalent among the black ethnic group" by Molteno et al., 1990, p. 98).

Also during early 1980s, and in early comment of disabling environments, Cartwright, Jukes, Wilson, and Xaba (1981) surveyed and critiqued the education of Black primary school children with learning problems on the East Rand of South Africa. The authors found that intellectual disability might not be the only major contributor to children's experience of learning problems but commented on possibly disabling learning environments, suggesting that improving teachers' skills and reducing the number of children per class might improve the education of children with learning problems.

In later work, Cartwright et al. (1988) found that, as opposed to White children, inadequate attention was being given to providing care for Black, Coloured, and Indian children living with intellectual disability in the Witwatersrand area. The author addressed issues of diagnosis, placement, and management, and surveyed facilities that were available to children at the time. They reported that such facilities were adequate for "69.7% white, 26% Indian, 9.3% Coloured and only 7.6% Black children" (Cartwright et al., 1988, p. 26). They advocated that urgent attention be given to providing more care for these children, especially children living with profound intellectual disability; and suggested that an adaptation class in

a mainstream school would be the most appropriate environment for children living with mild and moderate intellectual disability (Cartwright et al., 1988).

2.3.1.2. Timing of first reports

The first South African reports of genetic syndromes that might result in intellectual disability were published in 1972, 1981, and 1986. Published in 1972, Shnier, Sims, and Zail (1972) presented the first case description of Lesch-Nyhan Syndrome in a South African family, by describing two brothers (aged 14 and 10 years) living with intellectual disability. Lesch-Nyhan Syndrome is a genetic disorder associated with three major clinical elements of an overproduction of uric acid, neurologic disability, and behavioural problems. Behavioural problems, such as aggression and impulsivity, are related to intellectual disability and patients may also develop persistent and severe self-injurious behaviour.

The South African advent of studying Fragile-X Syndrome and its links to intellectual disability was made in 1981 by Venter, Gericke, Dawson, and Op't Hof. Fragile-X Syndrome (or Martin-Bell Syndrome), a hereditary condition, is characterised by an X chromosome that is abnormally susceptible to damage, especially by folic acid deficiency. Affected individuals tend to have limited intellectual functioning. The authors' report describes the first cases of X-linked mental retardation with a marker X chromosome seen in South Africa, at a time when "[t]he attention of human geneticists everywhere is focused on various aspects of this fascinating phenomenon" (Venter et al., 1981, p. 807). Although the authors state that, at the time, the "association of mental retardation with the marker X chromosome is unknown" (Venter et al., 1981, p. 807), they hoped to eventually provide prenatal diagnosis and possibly prevention. By 1983, this ambition might have contributed to the systematic diagnostic/genetics programme that was implemented at various institutions for the severely "mentally retarded" within the framework of a comprehensive genetic service with the aim to prevent and manage "mental retardation" (Op't Hof, 1983, p. 8; Op't Hof et al., 1985). By 1986, a national screening programme for Fragile-X Syndrome had been introduced in South Africa after the first cases were diagnosed (Venter, Op't Hof, & Coetzee, 1986). The authors went on to explain that Fragile-X Syndrome is a common cause of "mental retardation", and that "prevention of mental retardation is possible if all the involved families could be identified" (Venter et al., 1986, p. 597).

44

The first known South African case of Sanfilippo's Syndrome, a hereditary metabolic mucopolysaccharide disease, was published in 1986 (Petersen, 1986). At the time, the author warned that many cases may yet have been unrecognised, undiagnosed, or simply labelled as cases of "nonspecific mental retardation" (Petersen, 1986, p. 63), and urged South African clinicians to develop a greater awareness of the existence and often subtle presentation of the condition.

2.3.1.3. Tracking authors over time

In reviewing the literature it becomes possible to track authors who have contributed work to the field of intellectual disability over decades inclusive of the 26 year time span. The examples of the timing of their contributions offered here relate to the inclusion and exclusion criteria for this review, and in no way represents the mentioned authors' entire body of work. It also by no means represents all authors who have ever published on intellectual disability in South Africa. As examples, the individuals are mentioned here as primary or contributing authors. Not only have these authors contributed to previously mentioned shifts in the South African intellectual disability literature, a number are also still actively publishing. These contributors include, for example, Adnams (2001, 2006 (twice), 2007, 2010, 2011, 2012 (thrice), 2013 (thrice), 2014); Cartwright (1981, 1988, 1991, 1992); Christianson (1994, 1996 (twice), 1997, 1998, 1999 (twice), 2000, 2002, 2008); Engelbrecht (1993, 1996, 2003, 2006 (twice)); Kromberg (1974, 1984, 1994, 1996, 1997, 1998, 2000, 2002, 2008); McKenzie (2012, 2013 (thrice), 2014); Molteno (1989 (twice), 1990, 1993, 1996, 1997,1999, 2001 (twice), 2006 (twice), 2008, 2011, 2012, 2013, 2015); Op't Hof (1981, 1983 (twice), 1985, 1986, 1991); Phasha (2009, 2012, 2013, 2014); Pillay (1991, 1997, 2008, 2009 (twice), 2011, 2012, 2013, 2014); and Venter (1981, 1985, 1986, 1991, 1997, 2000, 2002, 2008, 2013).

2.3.2.   Epidemiology, policy, socio-economics, and services

Individuals with intellectual disability in South Africa face many challenges whilst high prevalence, discrimination, and complex access to justice and education are key considerations that are inextricably coupled with poor resource allocation (Njenga, 2009). As Adnams (2010) and De Vries et al. (2013) have pointed out, recognition of and provision for the needs of individuals living with intellectual disability carries low priority despite the finding that the prevalence rate of intellectual disability in South Africa is greater than in high-income countries. Tomlinson et al. (2014), for example, have estimated the prevalence

of intellectual disabilities to be at 10.4/1000 worldwide with higher rates among children and adolescents in resource restrained countries like South Africa. Notwithstanding the existence of policies and services for individuals with intellectual disabilities in South Africa, this lack of priority precludes an accurate description of the prevailing epidemiology and burden of disablement. De Vries et al. (2013) argue that data on resources are almost as limited as those on need, explaining that in South Africa there are approximately 35 specialist Child and Adolescent Psychiatrists and 10 Developmental Paediatricians for a total population in excess of 50 million. The number of Clinical Psychologists specialising in the field of intellectual disability has not yet been established. Such numbers are difficult to ascertain, since intellectual disability is yet to be formally recognised as a subspecialty of psychiatry in South Africa despite its formal recognition in UK countries, for example, that are leading the field of intellectual disability research.

Furthermore, Molteno et al. (2011) acknowledge that psychiatry has in the past suffered from relative neglect associated with the stigmatisation of mental illness, but recognise that there has been additional neglect and even more severe stigmatisation of intellectual disability within psychiatry. Although intellectual disability contributes significantly to the global burden of disease which includes African countries, throughout Africa specialised health care knowledge, training and service provision has lagged significantly behind that of other health areas, resulting in a further marginalised sector with unmet or poorly met health and other needs. Postgraduate programmes for professionals working and studying in the field of intellectual disability have been established in the UK, Europe, and the United States of America, with most established programmes having a strong mental health component or falling within the realm of mental health. In South Africa, at the time of writing this review, there was only one postgraduate intellectual disability health and mental health programme offered, with no existing programmes in other countries on the African continent.

It should be mentioned at this point that authors included in this review – Theresa Lorenzo and Jane Cramm, together with Judith McKenzie and Colleen Adnams – are affiliated to the Disability Studies Academic Programme at the University of Cape Town (UCT), South Africa. In terms of developing capacity, research, and services, this initiative offers the only postgraduate intellectual disability health and mental health programme of its kind on the African continent (Molteno et al., 2011), and seeks to "take specific focused action with disability organisations [like the WCFID] in order to address the inequities faced by disabled

youth to ensure their inclusion in development to the same degree as their non-disabled peers" (Lorenzo and Cramm, 2012, p. 578).

De Vries et al. (2013) urge us to consider the sobering discrepancy between the scale of need and available expertise, and raise the question of how best to increase skills and capacity in intellectual disability services in South Africa. The long-term and diverse nature of required services reflects the magnitude and scale of the challenge that lies ahead for intellectual disability in a resource constrained country like South Africa. As De Vries et al. (2013) advocate for scientific meetings to promote awareness, education, advocacy, and the development of international clinical and research networks, Molteno et al. (2011) urge that integrated policies and planning, communication, and consultation between primary, secondary, and tertiary care are essential. For both sets of authors, it would seem that such a model of care can be achieved through training of subspecialists in intellectual disability who work within a multidisciplinary team with outreach to primary (community health care clinics) and secondary (regional hospitals) health care settings.

2.3.2.1. Epidemiology

Although statistics are critical in holding governments accountable for the well-being of citizens with disability and international initiatives are underway to improve the quality of disability statistics, meaningful data on intellectual disability is still exceptionally rare (Fujiura et al., 2010). Whilst epidemiology (or incidence) is a measure of the probability of occurrence of intellectual disability in a population within a specified period of time, prevalence (or prevalence of proportion in epidemiology) is the proportion of a population found to have intellectual disability. Prevalence rates are usually arrived at by comparing the number of people found to have the condition with the total number of people studied.

In support of Fujiura and colleague's (2010) finding, data on the prevalence of intellectual disability in South Africa from the 2011 national censuses fared no better than that of the 2001census due to "limited questions on disability in Census 2011" (Statistics South Africa [SSA], 2014, p. 24). "Intellectual disability was not measured directly" and "[s]tatistics on children with disabilities aged 0–4 were not profiled" (SSA, 2014, p. 23). But if 3.2% of persons aged five years and older were reported at national level as having mild and 1% as having severe difficulties "in remembering or concentrating", then we can cautiously estimate

that the South African prevalence rate for "difficulty in remembering or concentrating" in persons aged five years and older could be 4.2% (SSA, 2014, p. 34).

As in the 2001 South African census (Adnams, 2010), individuals living with intellectual disability in institutional settings were also not included in the 2011 census because "[t]he question on general health and function was asked in households only ... persons with disabilities could have been underestimated, since a number of persons with severe disabilities tend to be institutionalised. [T]he profile of persons with psychosocial disabilities could not be ascertained" either (SSA, 2014, p. 24). A lack of epidemiological studies and inadequate capturing on prevalence of intellectual disability in South Africa during census counts is cause for alarm, since available information suggests that rates of intellectual disability in South Africa may be significantly higher than in higher-income countries (De Vries et al., 2013).

For example, in the seminal Bushbuckridge two-phase study that investigated the prevalence of intellectual disability in a very rural region of South Africa, Christianson et al. (2002) screened 6 692 children aged 2–9 years by using the Ten Question Questionnaire. After screening, 722 children were referred for further paediatric assessment and neurodevelopmental evaluation using the Griffiths Scale of Mental Development. Intellectual disability was diagnosed in 3.56% of children, giving a minimum observed prevalence of 35.6 per 1000 children in this population, a rate significantly higher than typical rates in high-income settings at the time (Christianson et al., 2002). As Rubin and Davis (1986) critically commented in 1986, Christianson et al. (2002) proposed that socio-economic factors, perinatal problems, prematurity, infections and trauma could have contributed to these increased rates. The Bushbuckridge prevalence study provided an initial factual insight into intellectual disability and its associated disabilities for healthcare, social service and educational policy planners. Its authors also provided a basis for the initiation and development of appropriate and integrated services for the care of individuals living with intellectual disability, and added that their study could have value for possible prevention of intellectual disability in South Africa (Christianson et al., 2002).

Earlier data from the same study also highlighted a higher prevalence of epilepsy in the rural childhood population investigated than recorded in most similar studies from sub-Saharan Africa (Christianson et al., 2000). Of the children diagnosed with epilepsy, associated

48

intellectual disability was recorded in 35 affected children (71.4%), including eight (16.3%) in whom this was moderate to severe. More than half of the children with epilepsy (57.1%) did not receive anticonvulsant medication. With epilepsy as an etiological contributor to intellectual disability which will be discussed in more detail later in the discussion, the authors raise concern over the poor utilisation of appropriate anticonvulsant treatment (Christianson et al., 2000). From the same data, Kromberg et al. (2008) found that many of the affected children were not receiving treatment or education, resulting in a reduction in their quality of life. Traditional healers were attempting to treat epilepsy and seldom referred affected children to hospital, although effective treatment was available there (Kromberg et al., 2008). Earlier than the seminal Bushbuckridge study, Leary et al. (1999) already reported a prevalence of secondary epilepsy as higher than that found in developed countries. As did Christianson et al. (2000, 2002), Kromberg et al. (2008) stressed that appropriate health, diagnostic, treatment, educational, and supportive services are required for children with intellectual disabilities, and awareness of their needs and the resources to meet them should be increased in their community. Prior to these calls, Leary et al. (1999) identified the need on community level for preventive measures aimed at reducing the prevalence of perinatal insults, meningitis, tuberculosis, parasitic neurocysticercosis, and cerebral trauma since these are etiological contributions to secondary epilepsy and intellectual disability.

Whilst helpful epidemiological studies assisted Op't Hof, Venter, and Louw (1991) to calculate the number of amniocenteses required for various maternal age groups to affect the prevention of Down's Syndrome, for example, prevalence rates derived from the 2001 South African census a decade later are still regarded as inaccurate due to under-reporting and a lack of consistent statistical coverage beyond the urban areas (Adnams, 2010; Fujiura et al, 2010). Not including individuals living with intellectual disability when making population counts, or even acknowledging intellectual disability as a term in a National Census document, is quite disconcerting. It is well established that individuals with intellectual disability have a greater prevalence of both general health and mental health problems than the general population (De Vries, et al., 2013; Molteno et al., 2011). The recognition of psychopathology or dual diagnosis in people with intellectual disability further emphasises the need for specialised informed psychiatric treatment (also see Yoo et al., 2012). It is reported that between one-third and two-thirds of people with intellectual disability in representative community samples have significant degrees of psychopathology, whilst between 8% and 15% have serious psychiatric disorders. This might even be a conservative

estimate, since the diagnosis of psychiatric illness, especially that of schizophrenia and other psychotic disorders, is easily obscured and particularly difficult to make in individuals living with severe and profound intellectual disability (Molteno et al., 2011; also see Yoo et al., 2012).

An estimate of mental health problems in the Western Cape suggested prevalence rates in the region of 17.0% for children and adolescents, and Giarelli, Clarke, Catching, and Ratcliffe (2009) found that more learners than originally estimated might have special educational needs and may benefit from special educational programmes. Adult prevalence rates for mental health problems in the Western Cape are estimated to be in the region of 25.0%, and for both adults and children, an annual prevalence rate of 3% has been established for intellectual disability (Kleintjes et al., 2006). If the current South African population is measured at 54 001 953 individuals (World Bank, 2014), and we estimate the South African prevalence rate for "difficulty in remembering or concentrating" at 4.2% (SSA, 2014), then approximately 2 268 082 individuals may be living with difficulties remembering or concentrating in South Africa. If between one-third and two-thirds of people with intellectual disability in representative community samples have significant degrees of psychopathology (756 027 and 1 512 055 people in South Africa respectively), whilst between 8% and 15% have serious psychiatric disorders, there might be between 181 447 and 340 212 people who live with intellectual disability and serious psychiatric illness, or dual diagnosis, in South Africa.

2.3.2.2. Policy

In reference to South Africans living with intellectual impairment, the *Twenty Year Review, South Africa, 1994-2014 Background Paper on Disability* admits to "limited national strategies to address their needs and a low prioritisation of resources for persons with intellectual disabilities" (Van Der Byl, 2014, p. 32). Similarly, the *National Mental Health Policy Framework and Strategic Plan 2013-2020* commits to "[e]liminating stigma and discrimination based on mental disability and promoting the realisation of the United Nations Convention on the Rights of Persons with Disabilities", but little mention is made of how this commitment will be put into action (Government of South Africa, 2013, p.50). Kagee's (2014) call for professional and academic psychology to address the needs of South African society, specifically of citizens living with intellectual impairment against an arguably ableist socio-political background, becomes particularly relevant.

Bateman (2012) brought to recent attention that scarce rehabilitation services for individuals with intellectual disability living in rural areas of South Africa are " being undermined by 'one size fits all' policies that starve [resolute therapists'] departments of staff, budgets and vehicles, therefore shortening patients' lives and reducing their chances of any lasting quality of life" (p. 200). As did authors earlier in this review, Bateman (2012) too comments on the difficulty of obtaining "accurate, up-to-date adult disability data ... i.e. Census 2001" and also uses Kromberg et al. (2008) to juxtapose this state of "'one size fits all policies" against the finding that intellectual disability is the commonest childhood disability in rural African children, affecting 41 per 1 000 individuals aged 2-9 years (Bateman, 2012, p. 2000). As Adnams (2010) and De Vries et al., (2013) have pointed out, recognition of and provision for the needs of individuals living with intellectual disability in South Africa continues to carry low priority. Disconcertingly, Bateman (2012) reported a dearth of schools for children with special needs in rural areas and one year later, De Vries et al. (2013) remind us about the discrepancy between the scale of need and available resources. This reiterates Njenga's (2009) earlier point, namely that of all the challenges facing persons with intellectual disability in Africa, poor resource allocation remains the most common in every country including South Africa.

In challenging low prioritisation and biases against intellectual disability, and since poverty concomitant with intellectual disability creates an even more vulnerable position for individuals with impairment in society (particularly women and children), Mcfadden (1994) raised concern two decades ago about the social activity and policy of governments and nongovernmental organisations regarding way(s) in which individuals with intellectual disability were being treated. Seemingly little has changed, and in writing about school-based sexual violence experiences of female learners with intellectual disability, Phasha and Nyokangi (2012) contradict common misconceptions and bias that people with intellectual disability "do not understand what is happening to them" (p. 309).

Mcfadden (1994) continued by frankly admonishing "a glaring lack of interest" in addressing the needs of individuals living with intellectual disability. Earlier than Mcfadden (1994), Cartwright (1992) grappled with the reality of South African society's indifference and ignorance toward individuals living with intellectual impairment who "are most in need of society's support, [but] least likely to obtain it ... we cannot expect the State to be particularly

concerned with the plight of the mentally retarded" (p. 4). Given this dilemma, Cartwright called for "parent power" in identifying service gaps and driving service delivery, and suggested the urgency of undertaking research into community attitudes towards intellectual disability in South Africa in order to gauge acceptance of these individuals and understanding of their need to be in the community (22 years later, see how McKenzie et al., 2013b, 2014a and 2014b have taken this up).

As did Rubin and Davis (1986), Cartwright (1992) also identified key policy areas that would contribute to decreasing numbers of preventable cases of intellectual impairment, including better antenatal and perinatal care; specific attention to children under the age of two years; seeking out and identifying children with special needs; full immunisation of all children; addressing the issues of tuberculosis, syphilis, rubella and meningitis; and reducing the toll of head injuries in motor vehicle accidents. Whilst Mcfadden (1994, p. 48) criticised development planning aimed at the "able", stressing the neglected goal of providing "housing, employment, and services" to individuals living with intellectual disability, Cartwright's (1992) use of the ideas of universality makes the point that general socioeconomic improvements would advance the health of all South Africans, not just that of individuals living with intellectual disability. Broader policy issues were identified as maternal education and development (e.g., alcohol consumption during pregnancy, early childhood development), improving the supply of clean water, nutrition and food, and "decent housing" (Cartwright, 1992, p. 4).

In suggesting priorities for early childhood development in countries like South Africa, Olusanya (2011) maintains that concerted initiatives targeted at children with intellectual disability are urgently required. The author explains that such a focus would require appropriate national early childhood development policies, and collaboration with multidisciplinary and cross-sectional initiatives. As in the example of the Western Cape Forum for Intellectual Disability's (WCFID) case for inclusive education made against the Government of the Republic of South Africa, such collaboration can ultimately drive legislation, policy, and implementation – albeit with intervention by the Western Cape High Court. What this particular case also highlighted, Ngwena (2013) argues, is the South African State's ambivalence towards inclusive education.

2.3.2.2.1. Inclusive education. South Africa has interpreted international declarations and has used these declarations to formulate an explicit statement of principles to guide the transition towards greater inclusion in education. This is enshrined in the Constitution of the Republic of South Africa (Act 108 of 1996), the South African Schools Act (84 of 1996), Education White Paper 6, and Guidelines for Full-Service/Inclusive Schools (Department of Education 2001, 2010; Nel et al., 2011). Consequently, there has been a shift from the learner who has to adjust to the demands of the system, to the system having to be flexible in order to accommodate the needs of the diverse learner population as inclusively as possible (Department of Education, 1999, see p. 3). *White Paper Six: Special needs education* (Department of Education, 2001, see p. 31) draws attention to the importance of a flexible curriculum and an assessment policy that can be accessed by all learners, irrespective of their learning needs, as curriculum design is often "the most significant barrier to learning and exclusion for many learners" (Nel et al., 2011, p. 191). Conversely, curriculum differentiation, differentiated instructional practices for teaching in diverse classrooms, and differentiated learning not only address the diversity of educational needs among learners living with varying levels of intellectual disabilities, but ultimately enable inclusive practice and educational inclusion (Nel et al., 2011).

Ngwena (2013, p. 482) describes inclusive education as a "paradigm shift in education philosophy and praxis" that requires the "radical transformation of an education system which has historically separated, marginalised or excluded certain groups of learners" – in this case, learners with intellectual disability. As early as 2003 (Engelbrecht, Oswald, Swart, & Eloff, 2003) and 2006 (Engelbrecht, Oswald, & Forlin, 2006), we were warned that operationalising the basic rights of all South African children – not only children with intellectual disability, but children with severe to profound intellectual disability – to be accommodated in inclusive school communities would remain a challenge. Engelbrecht et al. (2006) suggested that these challenges could not be appreciated without considering the "unique complexities, problems and assets of the different school communities" (p. 121). But where "[a]ll children . . . have a right to education", these unique complexities and problems extended beyond differences among school communities and requires the school system of a country to adjust in order to meet the needs of all children (Education for All, 2005, p. 13).

Ngwena (2013) later highlighted the persistent dangers of what he called "an embedded double discourse of inclusive education" that continues to perpetuate the historical exclusion

of intellectually disabled learners (p. 473). He rightly criticised this double discourse as made up of state speeches and actions that sound and appear outwardly committed to inclusive education on the one hand, but remain inwardly separatist by not operationalising and implementing any of these commitments on the other. The implementation of inclusive education might have addressed the right of some groups of intellectually disabled learners (living with mild to moderate intellectual disability), but not so that of others (learners living with severe to profound intellectual disability) (Ngwena, 2013). But since Section 29(1) of the South African Constitution guarantees everyone a right to basic education, including adult education (RSA, 1996), and the State did not establish any schools for children with severe and profound intellectual disabilities, it excluded and discriminated against learners with severe to profound intellectual disabilities by deeming them "not entitled to State support on the ground of lack of intellectual capacity to benefit from education" (Ngwena, 2013, p. 475).

One very important lesson gleaned from this South African case on intellectual disability is avoiding the reconstruction of discriminating dichotomies and exclusionary practices that persist in separating some from others, even if the word *apartheid* is no longer used. Ngwena and Pretorius (2012) urge us to guard against intellectual disability becoming a "site of severe discrimination" in South Africa and to speak out against any state policy that claims to be advancing a transformative agenda, only to become a legitimising instrument for disabling discourse (p. 81). This has been echoed by Human Rights Watch (2015) in a document that "outlines multiple ways in which children with disabilities are discriminated against, refused access to school, or made to wait years to access public schools" (p. 110). Further to the silencing and marginalising effect of not being included in census counts as described in section 2.3.2.1., Statistics South Africa is urged to "[i]nclude children and young adults who are registered in social or foster care institutions ... and boarding or hostel facilities in special and public ordinary schools ... in data collections" (Human Rights Watch, 2015, p. 92).

As will be explored in the chapter on opportunities for future research, taking constitutional rights to equal access seriously requires positive evidence that the education and health system adequately accommodates the needs of learners living with intellectual disability, in conjunction with a significant commitment of state resources – not less or leftover. However, limited resources and past policies can "easily provide the state with excuses rather than valid justifications for not meeting" these needs, especially if disability is misunderstood as not associated with larger policy systems and socio-economic environments (Ngwena &

Pretorius, 2012, p. 81). Should the latter be the case, this could exemplify how ableist state policy becomes complicit in disability.

2.3.2.3. Socio-economics

Although the social and medical models of disability configure the relationship between disability and impairment differently, McKenzie (2013a) argues that neither model provides a comprehensive enough theoretical or practical basis for grappling with intellectual disability in South Africa. In positing that models emphasising the interactive nature of disability seem to be more promising, McKenzie (2013a) suggests that these appear to be related to dynamic, environmental conceptions of disability where competence is built through constructive interaction with the socio-economic environment. This perspective views impairment as an interaction between individuals and their environment and, as does the social model, postulates that competence is a function of context, rather than a property of the individual (McKenzie, 2013a). But what it also suggests is that during these interactions, the environment should equally take on and integrate feedback from impaired individuals. In South Africa, children with intellectual disability who experience socioeconomic disadvantage may be particularly vulnerable due to their cognitive impairments and inability to garner necessary resources (Donohue et al., 2014). So given its dynamic nature, the reciprocal exchange between individuals and the South African socio-economic environment within McKenzie's (2013a) Interactive Discourse can easily depress potential, since children living with intellectual disability in South Africa are more likely to have poor nutrition and live in socio-economically distressed areas known to predispose them to further developmental delay (Pillay & Siyothula, 2011; Slone, Durrheim, Lachman, & Kaminer, 1998).

In their examination of the demographic, clinical, and social context variables of clients seeking intellectual disability screening assessments within a context of regional social deprivation (the KwaZulu-Natal midlands of South Africa), Pillay and Siyothula (2011) investigated 100 consecutive attendees seeking intellectual disability examinations at state mental health facilities. The authors found that 51% of the attendees lived with moderate or severe intellectual disability; 52% lived in homes with more than six people; and 52% lived in homes where nobody was employed. Families' reliance on social grants was high (85%), and of the 100 participants' households, a quarter (26%) reported "going without food for days" (Pillay & Siyothula, 2011, p. 589). Although 26% of the individuals in Pillay and

Siyothula's (2011) study were living with mild intellectual disability, Slone et al. (1998) warn that "mild mental retardation referrals [are] underrepresented in low socioeconomic areas" (p. 535), and that these difficulties may stem from problems with accessing services where appropriate assessment and referral to available regional, or even secondary and tertiary, services can be made. To remedy this, Slone et al. (1998) suggested service development of community-based intervention programmes. Almost two decades later, calls for such services are still being made (Adnams, 2010; De Vries et al., 2013; Kagee, 2014; McKenzie et al., 2013a; Molteno et al., 2011; Tomlinson et al, 2014).

2.3.2.4. Services

The solution to the "problem" of intellectual disability in Europe and North America during the 1800s was to launch large segregated establishments aimed at instituting self-contained and self-supporting colonies that would admit individuals with intellectual disability across the lifespan (Molteno et al., 2011, p. 1). After the Second World War, a significant shift in emphasis occurred with the introduction of the normalisation principle, proposed in Denmark in 1959, and based on critique of the view that being intellectually disabled remanded one to a static state that can only be met with institutionalisation. Subsequently, deinstitutionalisation processes across Europe and North America commenced during the 1990s with the proposal that hospital care would be seen as a component of regional and district comprehensive management, with treatment in hospital focused on discharge into the community after management of psychiatric disorders in intellectual disability (Molteno et al., 2011).

However, in Africa the practice of custodial care in institutions with subsequent deinstitutionalisation was largely bypassed, and large scale urban migration placed compounded strain on families caring for individuals with intellectual disability. To mainly cater for largely urban populations some institutions were established, but in rural villages most care for people with intellectual disability continued to be provided by families who received little formal support or recognition. Subsequent to a lag in development or implementation of formal policies and plans, this has resulted in a current "severe shortage of services for people with intellectual disability" (Molteno et al., 2011, p. 1).

Although research on intellectual disability from high income countries is useful, service provision for people with intellectual disabilities in Africa is not always well served by

insights obtained from western research agendas. To date, however, comparatively few African and South African research and evaluation studies have been undertaken (even less so by or with individuals living with intellectual disability) despite intellectual disability being the largest impairment grouping on the African continent (McKenzie et al., 2013a). Particular service delivery issues identified by McKenzie et al. (2013a) must be understood in the context of South African intellectual disability, mainstreamed, and prioritised in both impairment and non-disability programmes. These service delivery issues include access to education and health care, the provision of appropriate assistance and support, income generation, the importance of families in care settings, and drawing on informal and traditional forms and knowledge of intellectual impairment care and participation not yet studied.

In confronting unmet service needs of South African township children with intellectual disability, Saloojee, Phohole, Saloojee, and IJsselmuiden (2007, p. 230) were able to calculate that children with motor impairments were statistically more likely to receive intervention services than those with intellectual impairment (44% vs. 8%, $P < 0.0001$). The authors specified services that have remained unmet due to inadequate attention from the South African government, particularly from the departments of health, education, and social welfare (Saloojee et al., 2007). Apart from insufficient finances and limited awareness about available services, bureaucratic obstacles were one of the main reasons offered by caregivers for the low utilisation of what little public services and resources were available. In light of McKenzie and colleagues' (2013a) inclusion of local contributions, Saloojee et al. (2007) call for innovative service delivery strategies, ways in which caregivers can be better informed, as well as community recognition of, and support for, the requirements of impaired children in order to address these unmet needs.

2.3.2.4.1. Community services. Perhaps one innovative way of linking children living with intellectual disability with service delivery has been described in the literature by Henley (1999). The author reported on a home visit programme with two purposes: one was to offer fifth year medical students from UCT the opportunity to learn, first-hand, from children and their families about living with chronic disease and intellectual disability support needs; the other was to deliver comprehensive evaluations and management plans of the impact of chronic disease and disability on a child and family. Most students felt the programme should carry on in the future, which could continue to encourage future medical professionals to

reflect, beyond the medical model, on aspects of care for individuals and families living with chronic illness and intellectual disability (Henley, 1999).

A further possibly helpful way of operationalising and executing Saloojee and colleagues' (2007) calls for innovative service delivery strategies, and McKenzie and colleagues' (2013a, p. 1750) abovementioned "indigenous" suggestions for intellectual disability service delivery and knowledge collection in South Africa, might be to turn to a 1993 report on the successes of primary health care practices of the Alexandra Health Centre (Ferrinho, Robb, Cornielje, & Rex, 1993). The aim of staff at the Centre was to increase accessibility to healthcare, improve compliance, and ensure the working of care programmes. The Centre's outreach system maintained focus on residents of the particular township, including individuals with intellectual disability, who experience difficulties getting to the Centre itself. To prevent the exclusion of such individuals from service delivery and care, outreach services included support of community organisations, promotion of community participation, and community education. Importantly, and linking to McKenzie and colleagues' (2013a) suggestions for drawing on traditional knowledge of intellectual impairment care, the Alexandra Health Centre (Ferrinho et al., 1993) also enabled research on these outreach and community services, together with collecting information from community sources for the establishment of a health support and information system.

In order to better assess the support and social assistance needs of children with intellectual disability in South Africa, Berry and Smit (2011) call for an improved assessment instrument after finding that the existing South African eligibility assessment instrument, compared to others used elsewhere, under-identifies these needs by almost 50%. The current Care Dependency Grant assessment procedure has many inconsistencies and limitations – the grant's purpose and eligibility criteria are limited in scope, poorly articulated and understood, and based solely on a medical model of assessment. The current assessment instrument relies solely on, and gives greater priority to, the assessing medical practitioner's interpretation of need whilst making it easy to disregard the circumstances of the child and caregiver. Berry and Smit (2011) argue that the current Care Dependency Grant assessment procedure is thus unable to accurately measure childhood disability and functioning, and that it cannot address the specific, variable, or extra care needs of children with disabilities (e.g., therapies or assistive devices).

In later research, Van der Linde, Swanepoel, Glascoe et al. (2015, p. 188) evaluated the accuracy of "the only nationally implemented developmental 'screening' tool for developmental delays and/or disabilities", integrated as part of "The Road to Health Booklet" (RTHB), against a standardized international tool. The authors found that the RTHB developmental checklist failed to identify more than half the infants at risk of delays or disorders, and concluded that the nationally implemented developmental checklist is ineffective at identifying at-risk infants (Van der Linde et al., 2015). Perhaps as would Berry and Smit (2011), the authors recommend that RTHB developmental checklist be "adapted and validated or replaced in order to improve identification" of infants at risk for developmental delay and intellectual disability (p. 188).

While evidence confirms that developmental surveillance should be incorporated into the ongoing health care of South African infants between the ages of 0 and 2 years, such services are not consistently provided in health care settings and, if provided, the delivery thereof suffers from significant inadequacies (Leech, Van Wyk, & Uys, 2007a). This can result in inadequate service delivery; unidentified and poorly understood aetiologies of intellectual disability, cases of atypical development, and of infants in need of specific intellectual disability care and the future care and referral complexities this entails; and ultimately unmet service needs further into life. Leech et al. (2007a) usefully describe the responsibilities of community nurses, within the parameters of their legal scope of practice, with regard to their required and expected (necessary and sufficient) management of developmental needs of infants in South African primary health care clinics. In doing so, they were able to conclude that infant developmental care and monitoring is not included to its fullest potential in the health care delivered to infants and their families, thereby indicating that community nurses do not meet the standards of the profession with regard to the management of infant developmental needs (Leech et al., 2007a).

This service domain is not that of the nurses alone – Leech et al. (2007a) recommend that health service managers necessarily review their commitment and type of support to their community nurses if infant developmental care, as part of community nurses' responsibilities, is to be effective and of high quality. Whilst Olusanya (2011) called for concerted initiatives informed by collaborative multidisciplinary and cross-sectional initiatives targeted at children with intellectual disability earlier in this review, Leech et al. (2007a) urge community nurses and other health care professionals to recognise the potential of inter-professional

collaboration to ensure positive outcomes for infants with developmental delays and disabilities. In a subsequent article, Leech, Van Wyk, and Uys (2007b, p. 104) describe the development of implementable "best practice" guidelines (DEFINE HOPE) for use by community nurses in order to improve the quality of developmental care for South African infants and their families.

2.3.2.4.2. Transition initiatives and services. As described in the literature reviewed here, intellectual disability can limit access to education in South Africa, and if it is possible to take up educative spaces, access to transitional spaces beyond education can also be limited (Cramm, Nieboer, Finkenflügel, & Lorenzo, 2013, p. 31; Lorenzo & Cramm, 2012; Nel, Van der Westhuyzen, & Uys, 2007). Ultimately, barriers to these spaces lead to "economic and social exclusion [and] disproportionate disadvantage", and barriers to transitional spaces must be identified in order to to solve problematic access (Cramm et al., 2013, p. 31). In terms of specific barriers to education among youth with intellectual disability, significant associations included social exclusion; whilst for youth with multiple disabilities, these associations were exclusion by design. The authors suggest that reducing negative social attitudes and social exclusion can be effected by aiming interventions at teachers and families of disabled youth; whilst exclusion by design can be reduced through appropriate and suitable information about schools, less cumbersome admission systems, improved access, and elimination of physical obstacles (Cramm et al., 2013).

Even if education was accessed by overcoming these barriers, transition from a structured school environment into sustainable employment has historically been an outcome for very few individuals who complete their education at Schools for Learners with Special Educational Needs (i.e., intellectual disability) in South Africa. In addressing this service lag and based on models successfully implemented elsewhere, Nel et al. (2007) developed and piloted a transition model that would best address the range of transition needs of youth with intellectual disability in the South African context. Identified as a major barrier throughout the reviewed literature, the authors circumvented the insufficiently developed South African service infrastructure by including a full range of services in their programme (e.g., Occupational Therapy and Coaching). In doing so, they found their "single-unit longitudinal approach" very meaningful in ensuring successful transition (Nel et al., 2007, p. 13). Should their model be applied in the wider South African context, the authors hope that this will extend the mandate to integrate graduating learners with intellectual disability into the South

African employment sector and society as whole. As they rightly say, their model should ideally be applied in the "development of a government-driven transition service [since] the school infrastructure is barely able to sustain such a service" (p. 18).

Such transitional progression might not only reduce social and economic exclusion, but also increase access to Lorenzo and Cramm's (2012) five livelihood assets (Human livelihood assets: health facilities and education; Social livelihood assets: support systems and free time; Financial livelihood assets: work and sources of income; Physical livelihood assets: living conditions and access to facilities and services; Natural livelihood assets: resource-based activities). Among other valuable findings, Lorenzo and Cramm (2012) established that far fewer intellectually disabled than non-disabled youth attended and completed school; that unemployment was much more common among intellectually disabled than among non-disabled youth; and that poor health and lack of skills development were barriers to accessing employment for youth with intellectual disability. Ultimately, Lorenzo and Cramm (2012) show that youth with intellectual disability in South Africa have a greater struggle to access livelihood assets than non-disabled peers.

2.3.2.4.3. Health and mental health services. Because of the complex interactions between health and mental health in intellectual disability, the health care of persons with intellectual disability requires comprehensive management of often complicated and long-term multi-disabling conditions that include medical, psychiatric, and behavioural disorders. As long time advocates with decades of psychiatry expertise in the field of intellectual disability, Molteno et al. (2011) believe that services should "move towards a community based, comprehensive, regional approach, where primary care is available to all and referral to tertiary services occurs within an integrated health system" (Molteno et al., 2011, p. 1).

The authors explain that the recognition of psychopathology in people with intellectual disability, the identification of which raises manifold difficulties as well as implications for allocation of service resources, emphasises the need for specialist psychiatric treatment (Slone, Durrheim, Kaminer, & Lachman, 1999; also see Yoo et al., 2012). This service need becomes more urgent if we consider that individuals with intellectual disability have a greater prevalence of both general and mental health problems than the general population, whilst psychotropic medications are widely used and frequently misused in order to control symptoms rather than contribute to person centred care (Molteno et al., 2011).

The profile of intellectual disability in Africa cuts across areas of major public health importance, including HIV/AIDS and substance use disorders. But throughout Africa specialised health care knowledge, training and service provision in intellectual disability has lagged significantly behind that of other health areas, resulting in a further marginalised sector with unmet or poorly met health and other needs. Molteno et al. (2011) maintain that the establishment of post-graduate training programmes, in addition to the UCT programme mentioned earlier, would not only address deficits in specialised healthcare delivery, but would also be a step towards addressing the human right to equity in healthcare for people with intellectual disability as enshrined in the United Nations Convention on the Rights of Disabled Persons of which South Africa is a signatory.

McKenzie et al. (2013b) reiterate that intellectual disability is a relatively high-incidence disability with an increased risk of poor physical and mental health (see also Schoub et al., 1993), and that individuals with intellectual disability also have lifelong support needs that must be met. In a survey of 2 098 participants with intellectual disability over the age of 18 years living in residential facilities in the Western Cape (less than 2% of the estimated population of persons with intellectual disability in the province), McKenzie et al. (2013b) were able to draw extremely valuable conclusions about health conditions and support needs of adults with intellectual disability in the South African context. Participants experienced a wide range of health conditions (notably mental health and behavioural issues) but have limited access to general health care and rehabilitation services, as well as limited supports required for an acceptable quality of life. Again, credible research findings highlight the need for better health and support provision to persons with intellectual disability in South Africa (Molteno et al., 2011).

In 2004, Petersen identified areas in primary health care where specialised psychological services are lacking, despite the availability of psychological referral services at primary health care level in South Africa. The author suggests that particular areas in which there is a dearth of specialised psychological services are those of assessment, intervention, and referral services for individuals in need of intellectual disability care (Petersen, 2004). Tackling this unmet service need at primary health care level could also address Molteno and colleagues' (2011) earlier call for South African intellectual disability services to be "available to all and referral to tertiary services occurs within an integrated health system" (2011, p. 1). This

might also include health and mental health services to intellectually disabled survivors of sexual assault, as higher rates of a posttraumatic stress disorder and a higher intensity of stressor related symptoms were found in a group of individuals with intellectual disability and a history of sexual abuse (Shabalala & Jasson, 2011). Shabalala and Jasson (2011) urge that therapeutic interventions following sexual abuse should be offered, and given the high rates of sexual violence in the country despite under-reporting (Phasha, 2013), such services could also be incorporated into those suggested by Petersen (2004) above.

2.3.2.4.4. Services for intellectually disabled survivors of sexual assault. Dickman and Roux (2005) describe the gains made by The Sexual Abuse Victim Empowerment programme at Cape Mental Health, a project established in 1990 to assist complainants with learning disabilities in sexual assault cases in Cape Town, South Africa. The authors report an increase in the utilisation of the project by justice personnel and complainant preparation for court; whilst psychologists advise investigating officers and prosecutors, and provide expert testimony (Dickman & Roux, 2005). By 2005, reporting on 100 cases over a 10 year period, the authors found that a "conviction rate of 28% was almost identical to the best conviction rate in such cases in the general population in South Africa", and that the cases appear to have been vigorously pursued (Dickman & Roux, 2005, p. 138).

Pillay (2012b) reiterates that crimes of sexual violence are known to result in rather difficult court experiences for survivors, but some years after the Dickman and Roux publication of 2005, found disappointingly low conviction rates. These issues are compounded when the rape survivor lives with intellectual disability. Pillay (2012b) explains that courts seem to require more from intellectually disabled individuals than they do from non-disabled survivors, whilst "shortcomings and discrepancies in the medical and legal definition of mental retardation make the position of [individuals living with intellectual disability] even more difficult" (Calitz, 2011, p. 66). Amidst advances made in legislation and public awareness around intellectual disability, individuals with intellectual disability appear to be easy targets for perpetrators of sexual violence – sexual abuse of teenagers with intellectual disability is widespread, yet these individuals experience compounded difficulties when navigating legal proceedings in their search for justice (Calitz, 2011; Phasha, 2009, 2013; Pillay, 2012a).

Courts question the competency of individuals with intellectual disability to testify during legal proceedings, who are subjected to forensic mental health examinations before being

permitted to give evidence against their violators. Pillay and Kritzinger (2008) appreciate that the rape of individuals with intellectual disability poses challenges for both the judicial system and the survivors themselves. But considering that these individuals have already suffered significant trauma, it would seem unusual that they have to undergo mental health evaluation before the trial can begin (Pillay, 2008). Questions posed to mental health experts by the courts relate to the cognitive assessment of the rape survivor, the survivor's ability to testify, and her/his capacity to consent to sexual intercourse. Pillay and Kritzinger (2008) engage in critical discussion of the issues involved in such forensic examinations, and consider the implications for the expert witness and her/his approach to such examinations – a fuller understanding of intellectually disabled rape survivors' perceptions of the criminal act and their perception of the right to demand justice, for example (Pillay, 2010). Pillay (2012b) also questions the extent to which current approaches to such litigation are fair and in line with basic human rights, arguing that access to the courts ought to be made easier rather than more difficult for individuals with intellectual disabilities.

In attempting to address "[u]nanswered questions ... about clinical factors associated with a rape victim's ability to testify in court, and the quality of care offered to rape victims", Phaswana, Van der Westhuizen, and Kruger (2013, p. 343) aimed to undertake a preliminary exploration of the referral system between the court and mental health services, as well as to determine the clinical factors that are associated with a rape survivor's ability to testify in court. In their retrospective study of 70 rape survivors referred by the court for psycho-legal assessment, Phaswana et al. (2013) compared the clinical characteristics of rape survivors who were recommended as able (53.6%) and those recommended as unable (46.4%) to testify in court. The authors established that only residential category (i.e. victims from rural areas) and a diagnosis of intellectual disability (i.e. severe intellectual disability) were statistically significantly associated with the rape survivors' ability to testify in court (Phaswana et al., 2013). Variables that did not show a statistically significantly association when comparing the two groups included gender, race, marital status, highest level of education, with whom the survivor was living, place of rape incident, relation to perpetrator, number of rape incidents, and psychiatric treatment given before final evaluation. Of the survivors who had a diagnosed general medical condition co-morbid with intellectual disability, epilepsy was found to be the most common (35.5%). The authors recommend that decisions about a survivor's ability to testify should be individualised and not solely based on the two

statistically significant variables, and that optimal mental health and legal services should be offered to rape survivors (Phaswana et al., 2013).

Prior to these studies, Meel (2009) was already arguing that "much still needs to be done for the safety of mentally impaired [intellectually disabled] children" (p. 3). In a study that ran from 2001 to 2005 at the Sinawe Centre, the only centre in the Mthatha area that provided care for sexually assaulted persons at the time, the records of 1 268 attendees were reviewed. Meel (2009) found that 32 of the attendees were profoundly intellectually disabled, and 12.5% were HIV positive as a result of the assault. Of these individuals living with intellectual disability, 28 (87.5%) were below the age of 18 years with a male to female ratio of 1:15. A close relative was implicated in 90.6% of the cases of sexual assault on a child living with intellectual disability (Meel, 2009).

Phasha and Myaka (2014) report on teachers', school nurses', social workers', parents', a traditional healer's, a spiritual diviner's, and a clinical psychologist's views regarding factors contributing to the vulnerability of teenagers with intellectual disability to sexual abuse in rural KwaZulu-Natal. Interview findings revealed six emergent themes, namely that people with intellectual disability have a high sex drive, are sexually attractive, possess unusual power, and feel no pain; that sexually abusing teenagers with intellectual disability is an act of pity; and that sex with teenagers with intellectual disability can cure disease (Phasha & Myaka, 2014). The existence of vulnerability factors suggests that efforts to mitigate the problem of individuals with intellectual disability being sexually abused should occur at various levels with which an individual is interacting. Considering that traditional healers are held in high esteem among African cultures, and because they are viewed as "having a special ability to get in touch with the spiritual world", negative notions damaging to individuals with intellectual disability can be remedied within these powerful groups of authorities (Phasha & Myaka, 2014, p. 163). Dispelling these unfortunate notions could also positively affect services and the way policies are implemented to support teenagers with intellectual disability in rural areas of South Africa. Phasha and Myaka (2014) importantly recommend that individuals with any disability be acknowledged as sexual beings also, given that sexual expressions are a natural, healthy and important part of any human life. The authors also inform that individuals with any disability should be assisted in developing meaningful relationships, and afforded opportunities to learn about appropriate, safe, and healthy sexual expressions (Phasha & Myaka, 2014; see also Phasha, 2013).

2.3.3. Aetiology and co-morbidity

The aetiology of intellectual disability varies in range and can include prenatal, perinatal (e.g., spina bifida), and postnatal origins (e.g., hypoxic ischaemic encephalopathy) (Buccimazza, Molteno, & Dunne, 1999; Molteno & Lachman, 1996; Thompson et al., 1997); maternal trauma in early pregnancy (Viljoen, 1995); genetic aetiologies invariably associated with intellectual disability (e.g., Down's Syndrome); infectious illnesses; neurological deterioration due to metabolic conditions (Haarburger, Renison, Meldau, Eastman, & van der Watt, 2013); inborn errors of cholesterol synthesis (Solomon, Jones, De Jong, & Marais, 2015); the introduction of poisons or toxins (e.g., FAS); intra-uterine infection; maternal and/or placental disease, including pregnancy-induced hypertension; placental insufficiency; intra-uterine growth retardation; chromosomal anomalies (Viljoen & Smart, 1993); and etiologies of unknown origin. Amongst other co-morbidities, intellectual disability can present with epilepsy and HIV/AIDS, which may both also be etiologically contributing factors (e.g., HIV encephalopathy). As in many countries around the world, the association between post-natally acquired intellectual disability, and social and environmental deprivation cannot be discounted (Molteno et al., 1990).

In exemplifying the latter, Loffstadt, Nichol, and De Klerk (2006) report the discovery of a "feral" family living in isolation in the Free State region of South Africa referred to in this way due to the mother, three sons, and daughter's display of "primitive and ape-like behaviour" (p. 231). After evaluation, affected members of the family were found to be living with various degrees of intellectual disability. The etiological contributions of genetic predisposition and a paucity in environmental stimulation is explained in appreciation of cognitive deficits, poor mastery of language, and decrease in brain size often found in "feral" children (Loffstadt, Nichol, & De Klerk, 2006). The authors discuss environmental effects on various aspects of neural development in children, with particular reference to the results of insufficient neuro-stimulation concomitant with other insults to the brain during critical phases of plasticity.

In a retrospective test of a numeric scoring system for assessing neonatal hypoxic ischaemic encephalopathy (brain injury in newborns due to loss of oxygen and/or reduced cerebral blood flow), Thompson et al. (1997) considered the value of such a score in predicting neurodevelopmental outcome inclusive of intellectual disability at 12 months of age. After evaluating 35 infants 12 months of age by a full neurological examination and the Griffiths

Scales of Mental Development, Thompson et al. (1997) found that the hypoxic ischaemic encephalopathy score was highly predictive for outcome: "a peak score of 15 or higher had a positive predictive value of 92% and a negative predictive value of 82% for abnormal outcome, with a sensitivity and specificity of 71% and 96%, respectively" (p. 757). By means of this study, the authors were able to offer clinicians working without sophisticated technology a scoring system that is both useful for assessment of infants with hypoxic ischaemic encephalopathy, and for prognosis of neurodevelopmental outcome. Thompson and colleagues ' (1997) suggested manner of assessment for neurodevelopmental outcome (including intellectual disability) in South African infants will be useful in areas where diagnostic equipment, like cranial ultrasound examining equipment, is unavailable.

2.3.3.1. Genetic aetiology and co-morbidity

Genetic syndromes or anomalies can be an inherent (e.g., Down's Syndrome; Lesch-Nyhan Syndrome) or invariable aetiology of intellectual disability (e.g., Dyggve-Melchior-Clausen Syndrome; isovaleric acidemia; vascular disruption in the late embryonic period – see Gregersen, 2006; autosomal recessive inheritance – see Heckmann et al., 1995). By 1999, Christianson and colleagues were able to report that 150 X-linked intellectual disability conditions had been documented (Christianson et al., 1999). In their report, the authors describe a five generation South African family with X-linked intellectual disability, comprising 16 affected males and 10 carrier females. Profound intellectual disability was a clinical feature common to all 16 males. Of the 10 obligate female carriers of the gene located between markers DXS424 (Xq24) and DXS548 (Xq27.3), three had mild mental retardation (Christianson et al., 1999). However, Friez et al. (2000) were able to provide evidence that a "dodecamer duplication in the gene HOPA in Xq13 [an X-linked anomaly] is not associated with mental retardation" (p. 36). Their study was published subsequent to one suggesting that such a duplication in exon 42 of the HOPA gene in Xq13 may be a significant factor in the aetiology of Fragile X-linked intellectual disability. Most significantly, the results of Friez and colleagues' (2000) study in four different populations (one being South African) did not corroborate the previous study's findings, and indicate that the HOPA dodecamer duplication does not convey an increased susceptibility to intellectual disability (Friez et al., 2000).

Beighton (1990) explains that Dyggve-Melchior-Clausen syndrome (DMC) is a rare, dwarfing, skeletal dysplasia characterised by a coarse facies, bulky jaws, short trunk, and

barrel chest. Although rare, the abnormal gene has a wide geographical distribution including South Africa. Inheritance is autosomal recessive, and the presence or absence of intellectual disability might be an indication of heterogeneity. This means that intellectual disability is a variable feature of the syndrome, but if present, is a main clinical problem resulting in delayed developmental milestones (Beighton, 1990). Cartwright et al. (1991) also delineated an example of a distinct syndrome of inherited intrauterine dwarfism (also an autosomal recessive syndrome) with profound intellectual and physical disability, prenatal growth retardation, severe postnatal growth failure, characteristic face and acral limb deficiencies with poorly keratinized nails, and hypoplastic distal phalanges.

Dercksen et al. (2012) report that isovaleric acidemia is one of the most common organic acidemias found in South Africa and invariably linked to intellectual disability (a group of metabolic disorders that disrupt normal amino acid metabolism, causing a build-up of acids usually not present). Since 1983, a significant number of isovaleric acidemia cases have been identified in approximately 20,000 "Caucasian" patients screened for metabolic defects. In their study, Dercksen et al. (2012, p. 1) were able to conduct phenotypic and genotypic investigation of 10 isovaleric acidemia patients and three carriers. Despite the genetic homogeneity of this South African isovaleric acidemia group for a single mutation, the clinical presentation varied widely and ranged from severe intellectual disability to an asymptomatic state (Dercksen et al., 2012).

Down's Syndrome is an invariable etiologic contributor to varying levels of intellectual disability, and is the most common chromosomal abnormality occurring in humans. Anomalous brain development, function, and resulting intellectual impairment associated with Down's Syndrome appears to result from the genetic imbalance created by the trisomy of chromosome 21 (Moore, 2008). In addition, up to 77% of children with Down's Syndrome have associated gastrointestinal abnormalities. Functional motor disturbances of the esophagus and colon are not uncommon and may be congenital or acquired in nature. The most prominent of these include esophageal dysmotility syndromes (difficulties with swallowing, food regurgitation, and spasm-type pain) as well as a higher incidence of chronic constipation and Hirschsprung's disease (part or all of the large intestine, or antecedent parts of the gastrointestinal tract, have no ganglion cells and therefore cannot function) (Moore, 2008). The author explains that although possible links between the brain, gastrointestinal process, and enteric nervous system involvement were not entirely clear at the time of

publication, processes affecting the enteric nervous system in Down's Syndrome affect not only the micro-anatomy, but also nerve function. Moore (2008) further explains that chromosome 21 itself was thought, at the time of the study, to be the site of a modifier gene for Hirschsprung's disease.

2.3.3.2. Infectious illness aetiology

With a view to establishing areas amenable to remedial intervention, Schoeman, Herbst, and Nienkemper (1997) evaluated and compared different degrees of cognitive and motor impairment in children surviving tuberculous meningitis (occurring when tuberculosis bacteria infect the membranes and fluid surrounding the brain and spinal cord), and found marked generalised impairment of both cognitive and motor development. With no specific areas amenable to early remedial intervention, and although shortened treatment regimens of 9-12 months were effective, the authors recommend that the prevention by vaccine of tuberculous meningitis as a contributor to intellectual disability aetiology remains a priority.

Since cerebral infarction (a type of ischemic stroke resulting from a blockage in the blood vessels supplying blood to the brain) is an important cause of intellectual disability in childhood tuberculous meningitis, Springer et al. (2009) investigated the neurodevelopmental outcome and development of sequelae in tuberculous meningitis-related cerebral infarction. The authors found an association between the presence, number, and size of hemispheric strokes, and impairment. However, location of single basal ganglia infarcts did not correlate with motor outcome (Springer et al., 2009). By using the Griffiths general developmental quotient (GQ), it was established that general development was significantly lower in children with bilateral and multiple unilateral multiple infarcts, compared to children without infarcts. The general development of children with unilateral single infarcts was not significantly lower than those without infarction. Springer et al. (2009) conclude that infarct characteristics should be taken into account when prognosticating neurodevelopmental outcome (including intellectual disability) in tuberculous meningitis. Young age, unilateral multiple or bilateral infarction at one month of age, advanced stage of tuberculous meningitis, and the Glasgow coma score are the best predictors of neurodevelopmental outcome, which includes intellectual disability, at six months of age (Springer et al., 2009).

Van Toorn and Schoeman (2009) demonstrated that encephalitis lethargica (first written about in 1931), an atypical form of encephalitis that is characterised by high fever, headache,

double vision, delayed physical and mental response, lethargy, and even coma, also occurs sporadically among previously well South African children. In conjunction with cognitive outcomes, clinical features of this acute encephalitic illness include associated sleep disturbance, extrapyramidal basal ganglia signs, oculogyric crises, opthalmoplegia, respiratory irregularities, and neuropsychiatric symptoms (obsessive-compulsive behaviour, akinetic-mutism). Diagnosis is based on the exclusion, by negative findings on neuro-imaging, of known infective, biochemical, autoimmune, and metabolic causes of acute childhood encephalopathy. Of the five South African children who participated in Van Toorn and Schoeman's (2009) study, all survived but three were diagnosed with intellectual disability caused by the infectious illness.

2.3.3.3. Intellectual impairment related to Foetal Alcohol Syndrome (FAS)

Alcohol crosses the placenta and blood-brain barrier, and exerts teratogenic effects on the developing foetus through various mechanisms (Roussotte et al., 2012). Although it has been established that Foetal Alcohol Syndrome (FAS) is the most easily and common preventable cause of intellectual disability (Adnams, 2010; Lebel et al., 2012; Mead & Sarkar, 2014; Paley & O'Connor, 2011), the effects of critical timing and quantity of foetal exposure in maternal prenatal alcohol use have remained vague. Prenatal alcohol exposure can result in a range of lifelong impairments known as Foetal Alcohol Spectrum Disorders (FASD). FAS, which adversely affects the neurodevelopmental, physical, and social capabilities of individuals, is the most severe diagnosis in the foetal alcohol spectrum. Foetal alcohol spectrum disorders have also been found transmittable though genetic and epigenetic mechanisms (Mead & Sarkar, 2014). Rates of FAS in the Northern Cape (Urban et al., 2008) and Western Cape have been reported as among the highest in the world (Adnams, 2010; De Vries et al, 2013; Katwan, Adnams, & London, 2011; May et al., 2013; May & Gossage, 2001). However, it is evident that a considerable burden may be posed by less severe consequences of prenatal alcohol exposure manifesting in a FASD continuum (Katwan, Adnams, & London, 2011; Mead & Sarkar, 2014). Given the considerable variability in the manifestations of in utero alcohol exposure across individuals, Paley and O'Connor (2011) remind us that FASD should comprise the conditions of FAS and partial FAS, alcohol related neurodevelopmental disorder, and alcohol related birth defects.

In light of necessarily more concise, accurate measures of maternal prenatal alcohol use in order to better understand FASD, May et al. (2013) compared measures of drinking by

mothers of children with specific FASD diagnoses and mothers of randomly-selected controls; correlated these measures with physical, cognitive, and behavioural outcomes; and empirically identified and correlated drinking measures with specific child outcomes (including intellectual disability). The authors found that alcohol use variables, when applied to each trimester and three months prior to pregnancy, provide insight on critical timing of exposure. Measures of drinking, especially bingeing, correlate significantly with increased dysmorphology and negative outcomes in children, especially low non-verbal IQ, poor attention, and behavioural problems. Importantly, May et al. (2013) were able to link first trimester drinking (as opposed to no drinking) with FASD, which increased the likelihood of FASD 12 times. They also found that first and second trimester drinking increases FASD outcomes 61 times; and drinking in all trimesters increased the likelihood of FASD outcomes 65 times. It was also established that drinking only in the first trimester makes the birth of a child with a FASD five times less likely than drinking in all trimesters (May et al., 2013).

As did May et al. (2013), Lebel et al. (2012) also concluded that alcohol use, especially heavy use, should be avoided throughout pregnancy. Lebel et al. (2012) used structural magnetic resonance imaging (sMRI) to measure and compare brain volume change longitudinally in a cohort of children and youth with prenatal alcohol exposure, and in a group of unexposed control subjects. In doing so, Lebel et al. (2012) were able to demonstrate that the normal processes of brain maturation are disrupted in individuals whose mothers drank heavily during pregnancy. The alcohol-exposed participants showed primarily cortical volume loss, with decreased cortex plasticity. Smaller volume changes between scans were associated with lower intelligence and worse facial morphology in both groups, and were related to the amount of prenatal alcohol exposure during each trimester of pregnancy in the exposed group. The authors demonstrated "that measures of IQ and facial dysmorphology predict, to some degree, the structural brain development that occurs in subsequent years" (Lebel et al., 2012, p. 15243).

Although rates of FAS in the Western Cape have been reported as among the highest in the world (Adnams, 2010; De Vries et al., 2013; Katwan, Adnams, & London, 2011; May et al., 2013; May & Gossage, 2001), Urban et al. (2008) found that a very high proportion (nearly 1 in 10) of Grade 1 learners in the Northern Cape Province had FAS or partial FAS, with the rate in De Aar being the highest yet (64/536) described in South Africa at the time (2008). Overall, 67.2 per 1 000 children in the Northern Cape had full FAS features. The authors also

found that mothers of children with FAS were less likely to have fulltime employment or have attended secondary school, had lower body mass index, and that over two-thirds of all pregnancies had been unplanned (Urban et al., 2008).

In addition to reduced brain volume, intellectual disability, small head circumference, growth retardation, motor delay, facial dysmorphia, and behavioural challenges, children living with FASD may also be living with communication disorders. In investigating this, De Beer, Krtitzinger, and Zsilavcz (2010) described the communication profiles of five young children with foetal alcohol spectrum disorder (FASD) and intellectual disability from four to 58 months of age. The authors found that all the participants presented general developmental delays and delays regarding all aspects of their communication abilities. An increase in the severity of the spectrum disorder across the participants' combined communication profiles was identified as well (De Beer et al., 2010). The authors also discuss the importance of early identification, diagnosis, and assessment of infants and young children prenatally exposed to alcohol; the identification of precursors to communication impairment at a very early age; and the need for individualised early communication intervention in order to improve developmental outcomes within a family-centred approach (De Beer et al., 2010).

Apart from interventions for communication impairment in FASD, "research on behavioural interventions for FASD has lagged behind" (Paley & O'Connor, 2011, p. 64). The authors reviewed empirically tested interventions, methodological challenges, and suggestions for future directions in research on the treatment of FASD that were current at the time of their study. Since the notion of a continuum of disorders related to foetal alcohol exposure highlights the considerable variability in how FASD manifests across different individuals, it can be expected that individual responses to interventions will also differ. Such factors might include individuals' positions on the FASD continuum; their particular profile of neurocognitive deficits and level of intellectual disability; and the presence or absence of co-morbid psychiatric conditions, parental involvement or commitment, social support, and availability of community resources (Palley & O'Connor, 2011). Elucidating how these factors might play a role in treatment outcomes will allow researchers and clinicians to refine interventions so that they may better serve affected individuals and their families. Although they demonstrated some positive post-treatment effects, many of the studies reviewed by Paley and O'Connor (2011) did not include follow up assessments. Examining consolidation

of treatment outcomes and maintenance of treatment gains, especially in less predictable environments than highly controlled research settings, would be valuable.

Most research based interventions for the population of individuals living with FASD have focused on school aged children (De Beer et al., 2010; Urban et al., 2008), and there is a need to develop treatments for younger children, as well as for adolescents and adults. Treatments for alcohol exposed infants and toddlers have the potential to capitalise on early neuroplasticity, and mitigating some of the early manifestations of FASD (e.g., poor self-regulation and heightened response to stress) may help pave the way for more positive developmental trajectories (Paley & O'Connor, 2011). Interventions for individuals with FASD and intellectual disability transitioning into adulthood are critical because substance use problems, high risk sexual behaviour, and illegal activities may emerge or worsen during this developmental period. Treatment approaches aimed at decreasing engagement in high risk activities might focus on enhancing skills in decision making, problem solving, and behavioural regulation in adolescents and adults with FASD and intellectual disability; and might better equip parents to supervise their children's whereabouts, activities, and peer associations (Paley & O'Connor, 2011).

Finally, it is imperative that interventions with established efficacy are translated and evaluated in community settings in order to increase the accessibility of services for individuals living with FASD and intellectual disability, especially in South Africa where such service gaps have been identified (Adnams, 2010; De Vries, et al., 2013; McKenzie et al., 2013a; Molteno et al., 2011). If health care providers are aware that there are effective treatment options available for individuals with FASD and intellectual disability, they may be more vigilant in early identification of signs of the disorders and may better appreciate the potential benefit in referring families for available appropriate services.

2.3.3.4. Intellectual impairment related to epilepsy

Hemiconvulsion-hemiplegia-epilepsy (HHE) syndrome, secondary to febrile partial status in children younger than four years, is an etiological contributor to intellectual disability with a significant neurological morbidity in South African children. HHE syndrome is a rare epileptic disorder characterised by prolonged unilateral seizures in children under four years of age, who subsequently develop a transient or persistent hemiplegia. Later epilepsy is often observed. The incidence of HHE syndrome has declined considerably in developed countries

over the past 20 years. This is ascribed to "improved therapeutic management of status epilepticus, reduced incidence of febrile seizures due to immunisations, and improvement in general health" (Van Toorn, Van Rensburg, Solomons, Ndondo, & Schoeman, 2012, p. 143). In contrast, HHE syndrome is still prevalent in South Africa and the authors allude not only to its preventability, but also highlight the need for "improved emergency care of status epilepticus" (Van Toorn et al., 2012, p. 142). In their description of the clinical features, neuroradiology, and outcome in eight South African children with HHE syndrome, Van Toorn et al. (2012) found that moderate to severe intellectual disability ensued in the majority of children. The severity of the intellectual disability correlated with the degree of motor deficit and occurred irrespective of the cerebral hemisphere involved (Van Toorn et al., 2012).

Notwithstanding Van Toorn and colleagues' (2012) call for improved therapeutic management of status epilepticus (p. 143), the safety and use of psychopharmaceutical substances to treat maternal epilepsy remains a contentious issue, with a tension to be held between maternal mental health and the protection of the foetus from toxins. Cases of prenatally acquired intellectual disability with a psychopharmaceutical aetiology have been identified in the literature, for example in cases where valproic acid was used to manage maternal epilepsy during pregnancy (ironically, poor therapeutic management or unmanaged epilepsy can contribute to reduction in intellectual ability with each seizure). Christianson, Chesler, and Kromberg (1994) presented the clinical and neurodevelopmental features of four children, from two sibling pairs, who were exposed in utero to valproic acid. Three of the children were living with global developmental delay that included intellectual disability and language delay, and had dysmorphic features consistent with foetal valproate syndrome. The fourth child had some dysmorphic features consistent with foetal valproate syndrome and intellectual functioning within normal range, but attended a school for learners with special educational needs given his verbal ability being significantly below non-verbal ability.

2.3.3.5. *Intellectual impairment related to HIV/AIDS encephalopathy*

By 1991, effects of HIV on neurological functioning in individuals with intellectual disability had not been well documented in South Africa. Brown (1991) studied the cases of five individuals who had been living with intellectual disability prior to being infected with HIV, placing particular emphasis on neuropsychological functioning, and its interaction with management and treatment. Although the "cognitive status" of individuals with intellectual

disability creates unique treatment and management difficulties, Brown (1991, p. 165) suggests that the development of HIV-related encephalopathy is no different in individuals living with intellectual disability than in the typically developed population. The author discounts the hypothesis that individuals already living with intellectual disability are at greater risk for developing neurological complications due to HIV (Brown, 1991).

There are complex layering aetiologies that are frequently part of managing patients with HIV. Multiple pathologies occur independently and in response to the consequences of HIV, and interacting pathologies potentially contribute to intellectual disability (Samia, Petersen, Walker, Eley, & Wilmshurst, 2013). In light of the aetiological contributions of epilepsy to intellectual disability, and the burden of disease of HIV/AIDS in South Africa on individuals living with intellectual disability (Adnams, 2010; Brown, 1991; De Vries et al., 2013; Molteno et al., 2011), Samia et al. (2013) draw attention to the finding that "at least 50% of children with HIV-type 1 have central nervous system involvement" including epilepsy, and that the "prevalence of HIV-associated seizures is estimated between 2% and 20% in adult and paediatric studies" (Samia et al., 2013, p. 297). Seizure activity in patients living with HIV may occur from opportunistic infections, tumours, medications, metabolic and electrolyte disturbances, or resulting from HIV itself. Intellectual disability and neuroregression are documented as presenting features of HIV encephalopathy in up to 80% of cases of children with cognitive delays (Potterton, Stewart, Cooper, & Becker, 2010; Samia et al., 2013).

In children infected with HIV who are at additional risk for tuberculous meningitis and other opportunistic infections, the frequency of acute bacterial meningitis is high. Seizures usually occur as part of the acute disease course and the insults sustained from such neuroinfections, and these disease events predispose the child to develop epilepsy. Although children infected with HIV who also live with epilepsy are at particular risk for the adverse effects of antiepileptic drugs, large studies in children living with both epilepsy and HIV are lacking (Samia et al., 2013).

In their retrospective study of 354 HIV infected South African children with an average age of 20 months (range 8 to 87 months), Samia et al. (2013) identified a subgroup of 27 children with seizure activity. Mild, moderate, and severe intellectual disability with further neurologic deficits were significantly more common among children with HIV and seizures

as compared to those with HIV and no seizures; and features of developmental delay in the seizure cohort were documented twice as frequently as that of the non-seizure group (Samia et al., 2013). In addition, children with HIV and intellectual disability living in South Africa are more likely to have poor nutrition and to live in demographically distressed areas known to predispose them to developmental delay (Pillay & Siyothula, 2011; Slone et al., 1998).

In South Africa, HIV/AIDS has resulted in scores of children being infected with the virus and/or orphaned as its consequence (Shead, Potterton, & Stewart, 2010, p. 33). Because HIV is both neurotrophic and lymphotrophic, infected children are at risk of developmental delays and growth impairments, compounded by a high incidence of poverty, limited basic resources and malnutrition. Shead et al. (2010) compared the neurodevelopment and anthropometric measurements of HIV-uninfected children, to vertically infected HIV children taken into care and not on antiretroviral treatment. The results showed that HIV-infected children scored significantly lower than HIV-uninfected children in measures of neurodevelopment, specifically "mental" and psychomotor development (Shead et al., 2010, p. 33). Conclusively, HIV "affects the neurodevelopment (both mental and motor) and growth of HIV-infected children, particularly height-for-age" (Shead et al., 2010, p. 33), thereby contributing to aetiology of intellectual disability.

By 2012, neurodevelopmental delay including intellectual disability had been documented in up to 97.5% of HIV-infected children in Soweto who were not yet on antiretroviral treatment (ART). "With growing numbers of children in South Africa being successfully treated with ART", Lowick, Sawry, and Meyers (2012, p. 599) set out to investigate the effects of ART on neurocognitive functioning in children. By comparing the extent of neurodevelopmental delay in stable HIV-infected preschool children (aged 5 to 6 years) receiving ART to an apparently healthy (unconfirmed HIV-status) group of preschool children, Lowick et al. (2012) found that children in the HIV infected group presented with a 7.88-fold increased likelihood of severe developmental delay, including intellectual disability. The authors argue that early initiation of ART in HIV-infected infants may improve cognitive functioning among this group, and also recommend that intervention strategies that optimise early cognitive development for all children in the area be urgently considered (Lowick et al., 2012; also see Banks, Zuurmond, Ferrand, & Kuper, 2015).

As reiterated by Samia et al. (2013) above, in earlier work Potterton et al. (2010) illustrated that HIV potentially causes a "significant encephalopathy and resultant developmental delay in infected children" which includes intellectual disability (p. 547). In anticipating Lowick et al.'s (2012) call for intervention strategies that optimise early cognitive development, Potterton and colleagues' (2010) randomised controlled trial aimed to determine whether a home-based intervention programme could have an impact on the neurodevelopmental status of children (aged less than 2 years 6 months) infected with HIV, with suboptimal nutritional status and from poor socioeconomic backgrounds. The authors found that children in the experimental group showed significantly greater improvement in cognitive and motor development over time than children in the comparison group, and conclude that a home stimulation programme taught to the caregiver can significantly improve cognitive and motor development in young children infected with HIV (Potterton et al., 2010).

In later research, Donald et al. (2015) reiterate that in countries like South Africa, where many children have not been initiated on antiretroviral treatment early, HIV Encephalopathy remains a significant clinical problem. Amongst a cohort of children referred to Red Cross War Memorial Children's Hospital during 2008 to 2012, the diagnosis of HIV Encephalopathy was disconcertingly unrecognised in the general medical services – even in its most severe form. Most notably, school failure and developmental delay, including intellectual disability, were major presenting problems.

Hanass-Hancock (2009) convincingly reveals that people with disabilities are very vulnerable to contracting HIV yet lack access to information, testing, and treatment. Vulnerability and accessibility have been investigated, but few prevalence studies are available. Although a certain amount of work has focused on individuals living with hearing impairment, the author (2009) found that little study has been undertaken for individuals from other disability groups, including individuals living with intellectual disability. Hanass-Hancock (2009) noted that a growing area of concern is sexual abuse and exploitation of people with disabilities, but that only a few studies or interventions focus on this area. Even less focus on individuals living with intellectual disability and HIV. In their meta-review, De Beaudrap, Mac-Seing, and Pasquier (2014) provide evidence that people with disabilities, including intellectual disability, do not have a lower risk of contracting HIV when compared to the general population, and that women with disabilities are especially affected.

77

Rohleder and Swartz (2009) inform that individuals with intellectual disability may be at increased risk for HIV infection, yet remain excluded from HIV prevention campaigns. In their study that explores the challenges expressed by participants who provide sex education for individuals with intellectual disability, the authors found that individuals with intellectual disability have historically been constructed as either a-sexual or sexually uninhibited, and that sex education was considered to be unnecessary or potentially harmful. Ultimately, Rohleder and Swartz (2009) revealed a tension between a human rights discourse and a discourse of restriction of sexual behaviours. By means of sex education in the context of HIV/AIDS, and thereby unwittingly potentially constructing sex as dangerous, the authors caution us against echoing past constructions of disabled people's sexuality as problematic (Rohleder & Swartz, 2009).

A further source used in the aforementioned Hanass-Hancock (2009) review, Dawood et al. (2006) investigated the knowledge, attitudes and sexual practices of adolescents with mild intellectual disability in relation to HIV/AIDS. Their study revealed "critical gaps and erroneous beliefs regarding knowledge of HIV/AIDS" (Dawood et al., 2006, p. 1), especially with regard to its existence, transmission (e.g., transmission through insects or non-sexual contact) and cure (e.g., "sex with a virgin") (Dawood et al., 2006, p. 3). Participants indicated a high degree of exposure to various sources of information, particularly media messages. Results from the research indicate that gender-role prescriptions and prevailing social constructions of immorality have had a negative influence on the attitudes and behaviour of participants, particularly with regard to sexual practices and preventative risk behaviours. Participants were also found to have low levels of self-efficacy in relation to sexual negotiation and decision-making, specifically with regard to condom use – of the participants that were sexually active, the use of contraceptives was extremely low (Dawood et al., 2006).

2.4. DISCUSSION: Paucity in the South African literature on intellectual disability

Historic turns in the research literature are indicative of shifts in both research topics and the nomenclature of what we currently term "intellectual disability". By reviewing past research questions one can sense an overt, albeit historic, subjugating gaze through which intellectual disability work was titled and published and the authors who commented on this; one can identify the timing of first South African study and case reports; one realises how nomenclature has shifted, and how study topics have shifted from genetic preventative investigations and reports (e.g., "a knowledge of the causes of mental handicap forms the

basis of preventive measures" in Molteno et al., 1990, p. 98; see also Hubbard, 2006; Saxton, 2006), to increasing socio-political comment on different levels. In reviewing the literature it also becomes possible to track authors that have contributed work to the field of intellectual disability in South Africa over decades inclusive of the timespan (e.g., C. Molteno's publications spanned across the 26 year review period, from 1989 to 2015).

For almost three decades, research on intellectual disability in South Africa has provided credible critical comment on the social activity and policy of government and nongovernmental organisations in the way(s) individuals with intellectual disability are treated. Statistics are critical in holding governments accountable for the well-being of citizens with disability and international initiatives are underway to improve the quality of disability statistics, but meaningful state generated, current data on intellectual disability in South Africa remains exceptionally scarce. Although intellectual disability contributes significantly to the global burden of disease, throughout Africa specialised health care knowledge, training and service provision has lagged significantly behind that of other health areas, resulting further marginalising a significant sector with already unmet or poorly met health and other needs. In South Africa, there is currently one postgraduate intellectual disability health and mental health programme offered, and no programmes exist in other countries on the African continent.

The aetiology of intellectual disability varies in range and can include prenatal, perinatal, and postnatal origins; maternal trauma in early pregnancy; genetic aetiologies invariably associated with intellectual disability; infectious illnesses; neurological deterioration due to metabolic conditions; the introduction of poisons or toxins; intra-uterine infection; maternal and/or placental disease; placental insufficiency; intra-uterine growth retardation; chromosomal anomalies; and aetiologies of unknown origin. As in many countries around the world, the association between postnatally acquired intellectual disability and social and environmental deprivation cannot be discounted. Amongst other co-morbidities, intellectual disability can present with epilepsy and HIV/AIDS, which may also both be aetiologically contributing factors.

Research included in this review has conclusively shown that HIV affects the growth and neurodevelopment of HIV-infected children, thereby contributing to aetiology of intellectual disability. HIV infected children live with an eight-fold increased likelihood of severe

79

developmental delay, including intellectual disability. Early initiation of ART might improve cognitive functioning in HIV-infected infants. Mild, moderate and severe intellectual disability with further neurologic deficits were significantly more common among children with HIV and seizures as compared to those with HIV and no seizures; and features of developmental delay in the seizure cohort were documented twice as frequently as that of the non-seizure group. Although children infected with HIV who also live with epilepsy are at particular risk for the adverse effects of antiepileptic drugs, large studies in children living with both epilepsy and HIV are lacking.

Most research based interventions for individuals living with FASD and intellectual disability have focused on school aged children, and the review found a need to develop interventions not only for children younger than school going age, but for adolescents and adults as well. Treatments for alcohol exposed infants and toddlers have the potential to capitalise on early neuroplasticity, whilst mitigating some of the early manifestations of FASD may help pave the way for more positive developmental trajectories.

In the early 1990s we were warned that operationalising the basic rights of all South African children – not only children with intellectual disability, but children with severe to profound intellectual disability – to be accommodated in inclusive school communities would remain a challenge. Schools for children with special needs remain rare, and extremely so in rural areas, further highlighting the discrepancy between the scale of need and available resources. Despite political speeches and actions that sound and appear outwardly committed to inclusive education, a lack of operationalising and implementing this commitment runs the risk of perpetuating separatist attitudes. Taking constitutional rights to equal access seriously requires positive evidence that the education and health system adequately accommodates the needs of learners living with intellectual disability, and a significant commitment of resources from the state. In South Africa, children with intellectual disability who experience socioeconomic disadvantage may be particularly vulnerable due to their cognitive impairments and inability to garner needed resources. The reciprocal exchange between individuals and the South African socio-economic environment can easily depress developmental potential, since children living with intellectual disability in South Africa are more likely to have poor nutrition and live in socio-economically distressed areas known to predispose them to further developmental delay.

Because of the interface between health and mental health in intellectual disability, the health care of persons with intellectual disability requires comprehensive management of often complex and long-term multi-system and multiply disabling conditions, including medical, psychiatric and behavioural disorders. The recognition of psychopathology in people with intellectual disability, the identification of which raises manifold difficulties as well as implications for allocation of service resources for individuals with dual diagnosis, emphasises the need for specialist psychiatric treatment. This service need becomes more urgent if we consider that individuals with intellectual disability have a greater prevalence of both general and mental health problems than the general population.

Moreover, crimes of sexual violence are known to result in rather difficult court experiences for survivors, with disappointingly low conviction rates. These issues are further compounded, however, when the rape survivor has an intellectual disability. Despite gains made by such programmes as The Sexual Abuse Victim Empowerment programme at Cape Mental Health, a lag in development or implementation of similar projects, policies, and plans – despite credible and helpful research – contributes to severe shortages of services for people with intellectual disability in South Africa. Particular service delivery issues that have been highlighted include access to education and health care, the provision of appropriate assistance and support, transitional spaces from care to increased independence with care (such transitional progression might not only reduce social and economic exclusion, but also increase access to livelihood assets), income generation, and the importance of support to families in informal and formal care settings. It has also been posited that intellectual disability care in South Africa should shift towards a community based, comprehensive, regional approach, where primary care is available to all and referral to tertiary services occurs within an integrated health system. Supported by psychosocial rehabilitation, psychotherapy should be directed towards the re-introduction of the patient back into the family and community when well. In lieu of state mandated service delivery, informal innovative service delivery strategies and indigenous solutions to intellectual disability care have emerged, seemingly out of necessity.

But amidst scores of references to insufficiently developed South African service infrastructure, identified as a major barrier throughout the reviewed literature, there have been some highlights: like that of successful primary health care practices of the Alexandra Health Centre, projects that assist individuals with intellectual disability to transition from a

structured school environment into sustainable employment, as yet untapped indigenous and informal knowledge on and solutions to the complexities of intellectual disability care, and dedicated clinicians and researchers who invest years of hard effort into intellectual disability work.

2.5.   CONCLUSION

Most striking is the emphasis on prevention in writing on intellectual disability and the relative lack of attention to unpreventable intellectual disability of unknown aetiology. Perhaps it is being wished away in ways described better by Sinason (2010) – perhaps as opposed to acknowledging the human right of intellectually disabled individuals not only to exist, but to expect, demand, and receive equal treatment and adequate services for often high support needs whilst honouring corollary obligations of citizenship. Can a lack of services with seemingly little formal response in meeting these, mentioned throughout the 26 year span of this review with little report, be comment on a possible assumption that intellectual disability is not supposed to exist?

Further to necessary research on early intervention approaches that make rational, efficient, and effective use of scarce resources; the need of addressing preventable causes of poor health in individuals living with intellectual disability; and calls for developing specific approaches to identify intellectual disability among children in low- and middle-income countries like South Africa, this review aimed to identify additional opportunities for future research that are taken up in more detail in Chapter 8.

High prevalence, discrimination, and access to justice and education are but some of the challenges facing persons with intellectual disability in South Africa, and these seem inseparable from poor resource allocation. A severe shortage of services for people with intellectual disability in South Africa continues to confront us in the literature despite individuals who work very hard in this field of care. This demands not only examination by intellectually disabled and non-disabled researchers alike, but time to insist on implementation of 26 years' worth of credible, peer-reviewed research and recommendations.

Part 1 of this literature review began by describing the method followed, and discussed the search strategy, inclusion criteria, exclusion criteria, and the useful help of independent raters. It then moved on to a discussion of historic turns in the research literature, covering a

subjugating gaze from the past and early critical comments, timing of first reports, and also briefly commented on tracking authors through time. By addressing epidemiology, policy, socioeconomics, and services, the review touched on issues of inclusive education, community services, transition initiatives and services, health and mental health services, as well as on services for intellectually disabled survivors of sexual assault. A section on aetiology and co-morbidity, placed after the section on epidemiology so as to accentuate the urgent need for services, covered literature on genetic aetiology and co-morbidity, infectious illness aetiology, intellectual impairment related to FAS, epilepsy, and HIV/AIDS encephalopathy. The search returned notably more literature on children than on adults living with intellectual disability, and literature on children was dispersed throughout the review where more relevant under different sections. Nevertheless, a separate section on children and adults living with intellectual disability is offered in Part 2 (Chapter 3) of this review.

APPENDIX A: Example - Independent Rater Form

Review title	Systematic review of peer reviewed literature on Intellectual Disability in South Africa published between 1989 and 2015.
Rater	J.M.
Study I.D. JM14	**Kromberg, J., Zwane, E., Manga, P., Venter, A., Rosen, E., & Christianson, A. (2008).** Intellectual disability in the context of a South African population. *Journal of Policy and Practice in Intellectual Disabilities, 5*(2), 89-95. doi:10.1111/j.1741-1130.2008.00153.x

Abstract:

Childhood disabilities, including intellectual disabilities (ID), are thought to occur in 5–17% of children in developing countries around the world. In order to identify and describe the childhood disabilities occurring in a rural South African population, as well as the context in which they occur, a study was carried out in the Bushbuckridge district in the poor northeast part of the country. Altogether, 6,692 children were screened in their homes in eight villages using the Ten Questions questionnaire. This questionnaire was used by local-trained field-workers in interviews with mothers and other carers, to screen children for five disorders (viz., intellectual, hearing, visual and movement disorders, and epilepsy). Altogether, 722 (10.8% of the total sample) children, who screened positive, were examined at clinics in their villages by a pediatrician for diagnostic, treatment, and referral purposes. In addition, 100 traditional healers in the district were interviewed with a specially designed schedule of questions to assess their attitudes toward disabilities and their management of affected children. The results showed that 291 (4.3%) children had at least one of the five disabilities. ID occurred in 3.6%, epilepsy in 0.7%, visual disorders in 0.5%, movement disorders in 0.5%, and hearing disorders in 0.3%. More boys than girls with hearing disorders were receiving special education. Many of the affected children were not receiving treatment or education, resulting in a reduction in their quality of life. Traditional healers were attempting to treat epilepsy and seldom referred affected children to hospital, although effective treatment was available there. Genetic factors were involved in about half the conditions, but genetic services were negligible. Appropriate health, diagnostic, treatment, educational, and supportive services are required for children with disabilities, and awareness of their needs and the resources to meet them should be increased in this community.

Eligibility of Study			
Study is about Intellectual Disability	**YES X**		NO
Study is about Intellectual Disability in South Africa ○ Participants / research sites are South African (even if researchers aren't) ○ Countries written about include South Africa	**YES X**		NO
Study was published between 1989 and 2014	**YES X**		NO
Study meets eligibility criteria for inclusion in the systematic review ○ 1 x "No" = EXCLUDE ○ 1 x "Unclear" = UNCLEAR	**YES X**	NO	UNCLEAR
Reason for exclusion or "unclear":			

CHAPTER THREE
Literature Review (PART 2): What do we know about interventions for children and adults with intellectual disability in South Africa?

3.1.   INTRODUCTION

Part 1 of the literature review offered in the previous chapter described the method followed, discussed the search strategy, inclusion criteria, exclusion criteria, and the useful help of five independent raters. Although the search returned notably more literature on children than on adults living with intellectual disability in South Africa, and literature on children was dispersed throughout Part 1 of the review where more relevant under different sections, separate sections on children, adults, and interventions regarding intellectual disability in South Africa is included here in Chapter 3 as a second part of the review. For children, Part 2 of the review focuses on interventions (including medical, dental, and education interventions) and caregivers. For adults it also covers caregiving and interventions, with returned literature organised around topics of physical health, psychiatric health, and dental medicine. As did Chapter 2, this third chapter winds down with a discussion on paucities in the South African literature on intellectual disability, and also ends off by offering some concluding thoughts with suggestions for further research. In addition, Table 3.1 offers a summary of the literature that was excluded after the Independent Rater Round process described in the previous chapter.

3.2.   RESULTS
3.2.1.   Children with intellectual disability

Developmental monitoring of children is an important strategy for the early detection and management of intellectual disabilities in high-income countries, and Robertson and colleagues' (2012) review summarises the literature on identifying children with intellectual disabilities in low- and middle-income countries. South African validations of specific screening tools were included, yet studies were restricted to the seminal 1990s Bushbuckridge work by Christianson et al. (2002) and Kromberg et al. (2008). The authors found that reviewed studies were mainly concerned with identifying child disability, and suggested that research and development should develop specific approaches to identifying intellectual disability among children in low- and middle-income countries like South Africa (Robertson et al., 2012), perhaps by developing context sensitive measures in lieu of an over-

reliance on Eurocentric measures. Perhaps a search of the latter screening tools precluded those that made use of, for example, the Molteno Scale.

With the objective of determining the prevalence of intellectual disability (and associated disabilities) in rural South African children aged 2-9 years, researchers from two Universities (Witwatersrand and Free State) (Christianson et al., 2002; Kromberg et al., 1997; Kromberg et al., 2008) undertook a study in eight villages in the Mhala district of Bushbuckridge, Northern Province, South Africa. Representing the first data at the time on the prevalence of intellectual disability and associated disabilities in rural South African children, findings were comparable with results from a study performed in one other African country (Zambia), as well as those from other developing countries.

The seminal Bushbuckridge study was completed over a 3.5-year period from 1993 to 1996, and comprised of two phases (Kromberg et al., 1997). During phase 1, researchers went house-to-house and screened children by conducting interviews with mothers or caregivers using the Ten Question Questionnaire for detecting childhood disability in developing countries. The second phase consisted of a paediatric neurodevelopmental assessment of children who screened positive during the first phase of screening. A total of 6 692 children were screened – 722 (10.8%) had a paediatric evaluation and 238 children were diagnosed with intellectual disability, resulting in a minimum observed prevalence of 35.6 per 1000 children in this population (Christianson et al., 2002). This prevalence rate, at the time, was significantly higher than typical rates in high-income settings. The authors proposed that socio-economic factors, perinatal problems, prematurity, infections, and trauma could have contributed to these increased rates (Christianson et al., 2002). From the same data, Kromberg et al. (2008) found that many of the children living with intellectual disability were not receiving treatment or education, resulting in a reduction in their quality of life. Although effective treatment was available, traditional healers were attempting to treat epilepsy and seldom referred affected children to hospital (Kromberg et al., 2008). Regarding co-morbidity, epilepsy (15.5%) and cerebral palsy (8.4%) were the commonest associated disabilities. In terms of aetiology for intellectual disability, this was undetermined in 174 children (73.1%), acquired in 15 (6.3%), and determined as congenital in 49 of the participating children (20.6%).

The Bushbuckridge data provide an initial factual insight into intellectual disability and the service needs associated with healthcare, social service, and (inclusive) educational policy. Collected 20 years ago, the data are still used as a basis for advocating an initiation and development of appropriate and integrated services for the best possible care of individuals living with intellectual disability in South Africa. What we should bear in mind though, is that the children who were aged between two and nine years old when the data were collected are now adults between the ages of roughly 22 and 29 years old, still affected by service gaps for individuals living with intellectual disability in South Africa.

Contributions made to understanding intellectual disability in South Africa by means of aetiological and preventability investigations have been, and continue to offer, rich sources of information and knowledge that are yet to be taken into action by institutions responsible for service provision. Still, McKenzie and MacLeod (2012a) caution us against "conced[ing] to biomedical knowledge as an object of positive knowledge" and ask us to critically question an acceptance of the absolute power of the "medico-psychological gaze that calls for disability expertise in the management of [intellectual disability]" (p. 1083). The danger lies in obscuring other ways of understanding impairment and disablement, and we might appreciate that an understanding of impairment in biomedical terms, to the exclusion of other models of understanding, can itself be disabling.

3.2.1.1. Interventions for children with intellectual disability

3.2.1.1.1. Medical and dental interventions. Since most studies on spina bifida (myelomeningocele) have been carried out in high-income countries where "satisfactory social circumstances prevail", Buccimazza, Molteno, and Dunne (1999, p. 245) set out to document mental development during the pre-school period in a cohort of children with myelomeningocele, report on factors that correlate with outcome, and suggest interventions to improve developmental prognosis. As did Samia et al. (2013), the authors of the myelomeningocele study ask us to attend to the interplay between equally disabling biomedical conditions and social factors. Children who live in disadvantaged communities may lack basic hygiene and receive insufficient medical care, whilst an unfavourable environment may interfere with early cognitive development and lead to suboptimal progress during the pre-school period (Buccimazza et al., 1999). Spina bifida is one of the most common major birth defects, and associated with a complex array of disabilities. In some cases hydrocephalus results in intellectual disability, and limited access to appropriate and

necessary medical care is a major concern. Basic hygiene becomes immensely important, since the majority of children with spina bifida have some degree of motor impairment, with compromised continence due to sphincter disturbances. Loss of skin sensation below the spinal lesion may give rise to ulcers, tissue damage, and infection. Comprehensive medical care, as well as developmental intervention, is required in order to limit the disabilities and possible infectious aetiologies of intellectual disability, and to ensure optimal development.

Following their participants over a five year period, the Buccimazza et al. (1999) cohort comprised of 53 children from metropolitan Cape Town and 65 from rural areas including the previous "tribal region of Transkei" (p. 245). Early closure and delivery by caesarean section were associated with higher levels of general developmental functioning, whilst infants from rural areas were more often delivered at home and their lesions took longer to close. Central nervous system infection and the placement of more than one shunt in the presence of hydrocephalus correlated with less positive outcomes. With their results in mind, the authors conclude that development of necessary health services, particularly in rural areas, would improve the developmental outcome of children with myelomeningocele in both urban and rural areas (Buccimazza et al., 1999).

Poor oral hygiene and a high prevalence of periodontal disease, which could contribute to aetiologies of secondary illnesses, is commonly reported in individuals living with intellectual disability in institutional care settings. Chikte et al. (1991) clarify from a considerable body of evidence that the major aetiological factor in gingivitis is the presence of dental plaque and that regular and effective removal will prevent and control this condition. The use of "mechanical means" to maintain a healthy level of oral hygiene can be difficult for individuals living with intellectual disability, time-consuming, and less effective (1991, p. 281). Some individuals might be able to see to their own basic oral hygiene procedures, whilst others will always need help. Similarly, dental problems overshadowed by Wolf-Hirschhorn syndrome manifestations (developmental delay, short stature, intellectual disability, and epilepsy; variable clefts of the lip and palate) also warrant appropriate management (Roberts, Stephen, Fieggen, & Beighton., 2009).

Chikte et al. (1991) demonstrate how chemical control of plaque offers an alternative and effective method to conventional mechanical means. As a sole oral hygiene measure on plaque and gingivitis in individuals living with intellectual and physical disabilities, Chikte et

al. (1991) studied the effect of twice-daily oral sprays of 2 ml chlorhexidine (0.2%) and 2 ml stannous fluoride (0.2%). In the chlorhexidine group, reductions of 75% (on plaque indices) and 78% (on gingival indices) were achieved. In the stannous fluoride/chlorhexidine pair, only the plaque index was significantly reduced for those on chlorhexidine. Both the stannous fluoride and chlorhexidine sprays were effective in reducing plaque and gingival scores, and controlling sub-gingival micro-organisms. Moreover, the spray method was found to be easy to use and the responses of the staff and patients positive. The spray technique may affect not only the clinical result but also the likely long-term usage of the spray method by care staff (Chikte et al., 1991)

3.2.1.1.2. Educational interventions. It is generally accepted that the rate of behavioural and emotional problems in children with intellectual disability exceeds that of the general child population. These problems are distressing to the children's families and have a negative effect on their learning in a school setting. In assessing a sample of 355 children with intellectual disability attending schools for learners with special educational needs in Cape Town by means of the Developmental Behavioural Checklist-Teacher Version (DBC-T), Molteno et al. (2001) found a prevalence rate of 31% for psychopathology. Boys presented with more behaviour problems than girls, "especially in relation to disruptive, self-absorbed and antisocial behaviours"; and learners with severe and profound intellectual disability showed more behavioural difficulties than those living with mild and moderate intellectual disability (Molteno et al., 2001, p. 515). The authors report that specific behaviour problems included self-absorbed and autistic behaviours in children with profound intellectual disability, communication problems and anxiety in those with severe intellectual disability, and antisocial behaviour in children with mild intellectual disability. Epilepsy, but not cerebral palsy, was associated with higher behaviour difficulties scores. Ambulant children were more disruptive and antisocial, while non-ambulant children were more anxious. Non-verbal children had higher scores on all of the subscales except for disruptive behaviour (Molteno et al., 2001, p. 515).

In pilot studies that evaluate the usefulness of cognitive control therapy for children and adolescents living with learning and/or intellectual disability in the South African context, two experimental groups received therapy for a certain period of time while two control groups did not receive therapy but did continue with remedial programmes (Engelbrecht, 1993, 1996). Where cognitive control therapy integrates psychodynamic principles and

cognitive restructuring, thereby addressing cognition and affect simultaneously, results of Engelbrecht's (1993, 1996) study indicated improved selective attention, social interaction, academic performance, and metacognitive insight into own abilities for the experimental groups of children living with intellectual disability.

In assessing 55 preschool children with Down's Syndrome by means of the Griffiths Scale of Mental Development, researchers found that attending a stimulating playgroup or preschool centre was associated with improved developmental functioning when compared to children cared for at home during the day (Neser, Molteno, & Knight, 1989), corroborating Ngwena's (2013) argument that children with intellectual disability need not be excluded from stimulating or educational environments "on the ground of lack of intellectual capacity to benefit from education" (p. 475). However, Neser et al. (1989) also reported a significant decrease in the Griffiths developmental quotient with increasing age in children with Down's Syndrome; a negative association between developmental quotient and the number of siblings; and that scores on the hearing and speech subscales were lower than those on other subscales. Importantly, the researchers found no significant associations between developmental quotient and maternal age; or between sex, social class, or race of the child (Neser et al., 1989).

Yet the most significant barrier to learning in the inclusive education system of South Africa remains the curriculum (Nel et al., 2011). Differentiated pedagogy that addresses diversity of educational needs and thus enables inclusion has been found to be an effective adjunct to inclusive practices in schools (Nel et al., 2011). Subsequently, by providing differentiated instructional adaptations and accommodations, a school for learners with special educational needs in Gauteng implemented a fire safety programme called "Learn NOT to Burn" (LNTB) among learners with severe intellectual disability. In piloting the LNTB curriculum, the researchers necessarily had to make adaptations to the curriculum in order to address the diverse needs of learners with severe intellectual disabilities. Findings focus on the imperative of fire safety training, and on the relevance of achieving differentiated instructional practices. These inclusive practices comprise visual stimulating focused activities, hands-on learning, and the incorporation of music in ensuring access to the LNTB curriculum for learners with severe intellectual disability.

3.2.1.1.3. Augmentative and Alternative Communication interventions for children. In 1996, Bornman and Alant (1996) found a high prevalence of non-speaking children in schools for individuals with severe intellectual disability in the greater Pretoria area. The authors also identified children that were in great need of service delivery and intervention with special reference to augmentative and alternative communication (AAC) strategy implementation. Earlier, Alant described the use of "Bliss symbolics as a first step into literacy" (1994, p. 23) with four children living with Down's Syndrome in a preschool setting. The author discussed initial stages of the intervention programme, and also offered findings regarding the children's ability to read within this framework six months after commencement of the programme. Subsequent researchers argued that emergent literacy experiences correlate with later reading success, and that "emergent literacy intervention for children with special needs [Down's Syndrome] is essential" (Van Heerden & Kritzinger, 2008, p. 37; also see Muthukrishna, 1996).

3.2.1.2. Caregivers of children with intellectual disability

In focusing on caregivers' understanding of a child's disability and their expectations of the service offered at specialist neurodevelopmental outpatient clinics at Baragwanath Hospital, Soweto, Venter (1997) interviewed 61 caregivers before and after their first visit. Disconcertingly, caregivers seemed to leave consultations more confused and with less knowledge. Venter (1997) found that "[b]efore consultation the majority of caregivers had a fair understanding of the child's functional problems and the short-term complications, but after the consultation levels of understanding decreased significantly" (p. 815). Findings may be reflective of the consultative process, as professionals may be more comfortable discussing aetiology than long-term complications. Venter (1997) also surmises that caregivers in a state of shock may be unable to absorb all the information given, whilst translation from English into caregivers' home languages during consultation might also be a confounding factor in meeting caregiver support needs. The findings offer valuable insight into areas of communication that can be improved with regards to supporting caregivers of children living with intellectual disability.

Recent investigations into caregiver support needs in Limpopo (one of the poorest provinces in South Africa with limited resources for supporting caregivers or individuals living with intellectual disability) offer valuable findings with implications for both policy and practice. Sandy, Kgole, and Mavundla (2013) found that caring for children with intellectual

91

disabilities was perceived as difficult and frustrating, yet rewarding. Difficulties were compounded by caregivers' lack of skills and knowledge of children's care needs. They also experienced stigma, which sometimes involved overt acts of discrimination and social exclusion, further adding to their frustration (Sandy et al., 2013). A range of identified support needs for caregivers included financial, emotional, and practical support; and training, respite care, addressing stigma, and working in partnership with health support staff (Sandy et al., 2013). The researchers suggest that regular training and support should be offered to caregivers in order to increase their understanding of intellectual disability and enhance their caring ability, and offer that nurses are the main source of training and support during community healthcare clinic-based engagement and home visits (Sandy et al., 2013). One might surmise that meeting such support care needs could bolster resilience in caregivers of individuals living with intellectual disability in regions of South Africa other than Limpopo as well, for example of mothers in the Eastern Cape who care for children living with intellectual disability (Gara, 2007; see also Strnadová & Evans, 2008).

Greeff and Nolting (2013) studied adaptive strengths and resources of families from previously disadvantaged backgrounds in South Africa following a child's diagnosis of intellectual disability. Results of their study showed positive correlations between parental acceptance of the situation, positive patterns of family communication, commitment to the family unit, a positive attitude toward new experiences and challenges, and family adaptation (Greeff & Nolting, 2013; also see Parekh & Jackson, 1997). Where "incendiary communication is provocative and tends to intensify a situation" and "affirming communication is supportive and serves to calm a situation", the quality of family patterns of communication was found to be the most significant predictor of family adaptation (Greeff & Nolting, 2013, p.399). The findings can be used to enrich existing family interventions that promote resilience and affirm the reparative potential of families after receiving a diagnosis of intellectual disability.

3.2.2.   Adults with intellectual disability

3.2.2.1. Caregiving for adults with intellectual disability

Studies of resilience in caregivers of adults living with intellectual disability might be just as useful. Most adults with intellectual disability in South Africa are cared for by their families during the span of their lives, prompting McKenzie et al. (2014b) to explore family caregivers' perspectives of care and implications for the planning of services. Themes that

emerged from caregiver interviews included social isolation, high burdens of care, and limited opportunity for personal growth and development (McKenzie et al., 2014b). Feeling let down by formal state or government service provision, family caregivers developed informal community supports and resources. The authors found that family care for adults with intellectual disability is predominantly provided by women, and that despite differences relating to race and class, family caregivers experience similar issues of isolation and lack of support (McKenzie et al., 2014b). Given that the human rights perspective proclaimed at policy level is not reflected in community settings, the need for services targeted at supporting families rather than individuals was apparent, whilst the need for community based services beyond family care was also highlighted by the McKenzie et al. (2014b) study.

Necessary services aimed at supporting families and the need for community based services beyond family care are further accentuated by Coetzee's (2015) findings on elevated parental stress, depression, and other mental health problems in mothers who experience significant life stressors in addition to caring for their adult children with intellectual disability who also display aggression. Parents of adults who have intellectual disability and behavioural difficulties are more vulnerable to develop stress and depression (Coetzee, 2015). However, adults who have intellectual disability often continue to live with their parents long after other siblings have left home; and aggression is one of the most difficult forms of problem behaviour to manage. Such behaviours could have a negative impact on the parent-child relationship, the child's social inclusivity, and on parental psychological well-being (Coetzee, 2015). Coetzee (2015) found that psychotherapy produced moderate improvement of parental stress, but appeared more effective in reducing depressive symptoms. Interventions aimed at alleviating significant life stressors, apart from caring for an adult child with intellectual disability and aggressive behaviour, might be helpful in maintaining gains made by reducing depressive symptoms.

Community based residential settings (not governmental) for adults with intellectual disabilities in the Western Cape report difficulties accessing adequate funding, and tend to focus more on their protective role than on the promotion of human rights (McKenzie et al., 2014a). The researchers found that adult residents were generally isolated from the community, did not receive vocational and life skills development, and "were far from realising their human rights as delineated in the United Nations Convention on the Rights of Persons with Disabilities (UNCRPD)" (McKenzie et al., 2014a, p. 45). In their conversations

with the authors, adults living with intellectual disability described difficult relationships with families and caregivers, both in family and residential care. They expressed fears for their safety in the community, and women with intellectual disability reported histories of sexual abuse and rape. Although there was some evidence of self-advocacy, the participants seemed to passively accept their current situation. Many made contributions to their households through child care, chores and social grants, but expressed the feeling of being exploited rather than valued for their contribution (McKenzie & Adnams, 2014). Although the need remains for such facilities and the protective function they offer, the authors suggest that services in low- to middle-income countries should still be evaluated and developed in line with human rights principles (McKenzie et al., 2014a). In addition, McKenzie and Adnams (2014) suggest that "pathways to community inclusion can be facilitated through the recognition of the contribution adults with intellectual disability make to their households and the identification of supports for community living" (p. 347).

Yet amidst calls for deinstitutionalisation and normalisation (Molteno et al., 2011), adults living with intellectual disability in South Africa, who are in a process of becoming increasingly independent, may find themselves more exposed to the general population's negative perceptions about intellectual disability (Kock et al., 2012). In measuring felt stigma in individuals with intellectual disabilities, Kock et al. (2012) drew on participant responses from three different South African groups (Afrikaans, English, and isiXhosa). Participants responded highest to items asking whether individuals "keep away from other people because they are nasty to [them]", if "[t]he way people talk to [them] makes [them] angry", and whether "[p]eople treat [them] like a child" (Kock et al., 2012, p. 15). Given the results of the study, the authors offer evidence for the validity of felt stigma ratings reported by adults with intellectual disabilities in South Africa (Kock et al., 2012). Following this study, Ali, Kock, Molteno et al. (2015) found that interventions into self-reported experiences of stigma should target the Black African community in South Africa, and should include the reduction of both public stigma and self-reported stigma.

3.2.2.2. Interventions for adults with intellectual disability
3.2.2.2.1. Physical health. Regular physical activity is one of the modifiable risk factors for coronary heart disease in any adult, and individuals with intellectual disability and their caregivers would benefit from information on coronary heart disease risk factors (Moss, 2009). Knowledge on these risk factors and the changes a physical activity intervention may

have on these might lead to maintaining intervention programmes. In studying a cohort of 100 men and women between the ages of 21 and 73 years living with intellectual disability in a community group home in the North-West Province, Moss (2009) demonstrated that implementation of a physical activity intervention could significantly reduce risk factors for coronary heart disease. The author reported that a physical activity intervention reduced inactivity from 85% to 50% of participants, and resulted in a significant increase in cardiorespiratory fitness and a decrease in percentage body fat in both male and female participants who live with intellectual disability (Moss, 2009).

In a similar study, Terblanche and Boer (2013) set out to establish the functional fitness capacity and predictors of performance of adults living with Down's Syndrome. It is well established that there is a relationship between physical inactivity and increased risk for diseases of lifestyle, as with coronary heart disease in the Moss (2009) study. Terblanche and Boer (2013) explain that individuals with Down's Syndrome are especially at risk because of physical and health impairments, as well as perceived and real barriers to participation in exercise. With 371 participants from various intellectual disability centres and private homes in seven provinces of South Africa, the authors assessed participants' balance, flexibility, coordination, muscular strength and endurance, aerobic capacity, and functional ability. Findings of Terblanche and Boer's (2013) study provide important information on the functional capacity of adults with Down's Syndrome and show which physical attributes contribute to functional performance. The authors report that muscular strength items, especially leg strength, significantly predicted functional performance in both men and women. Aerobic capacity only predicted functional performance in men, and sit-and-reach flexibility and dynamic balance only in women. The research offers valuable information on appropriate training programmes that can be tailored for a population of adults with intellectual disability known to have poor functional fitness (Terblanche & Boer, 2013).

3.2.2.2.2. Psychiatric health. The accountability and fitness to stand trial of individuals living with intellectual disability who commit crime, is an important and complicated facet that needs to be managed by the judicial and health systems. Calitz et al. (2007) retrospectively analysed the accountability and triability of 80 individuals with intellectual disability who were awaiting trial, and were referred to the Free State Psychiatric Complex from 1993 to 2003. The reason for referral was the possibility that they were not triable or accountable. Of the participants, 62.5% were diagnosed as living with mild mental retardation, while 16%

were diagnosed as living with moderate mental retardation. The majority of participants were male, unmarried, and unemployed, with a median age of 27 years. A relatively high percentage had received some schooling and 16% had attended a school for learners with special educational needs. The most offences were of a sexual nature (78%). Significantly, Calitz et al. (2007) reported that a total of 71 of the 80 participants were found to be untriable and unaccountable. The authors very importantly highlight that triability and accountability are not only reflected by scores on assessments of intellectual ability, but also involve the individual's understanding of the environment, his/her speech and language proficiency, level of education, reasoning ability, and the manner in which the crime was committed (Calitz et al., 2007). The authors also stress the importance of noting that an IQ of 70 or less does not automatically mean that an accused individual is unfit to stand trial or is not accountable, and that it is possible for a person with intellectual disability to be held accountable in committing a crime (Calitz et al., 2007).

In a later and related study, Marais et al. (2011) address a paucity of information available in South Africa on the relationship between psychopathology associated with epilepsy, crime, and the legal aspects thereof. In their retrospective cross-sectional study of 69 individuals (of which 90% lived with co-morbid intellectual disability), the researchers set out to investigate the demographic, clinical and forensic profile of alleged offenders diagnosed with epilepsy and referred to the Free State Psychiatric Complex Observation Unit from 2001 to 2006 (Marais et al., 2011). The researchers report that offences were violent in nature and committed against a person in 75% of cases. The highest rate of criminal incapacity was found among participants with inter-ictal (between seizure activity) psychoses (85.7%) and co-morbid intellectual disability (90%).There was a direct link between epilepsy and the alleged offences in 7% of cases. Most participants (79.2%) diagnosed with generalised epilepsy were criminally liable and fit to stand trial. In only 16% of cases, participants were found unaccountable because of epilepsy (automatisms) or post-seizure confusional states (Marais et al., 2011). The study findings confirmed an increased prevalence of violent behaviour during seizure-free periods, and contribute to evidence that factors associated with epilepsy, rather than epilepsy itself, play an important role in the possible increased risk of violent behaviour in individuals with epilepsy (Marais et al., 2011).

Given the difficulty of predicting violent behaviour of psychiatric patients, Krueger and Rosema (2010) studied patient related risk factors of violence and investigated long-term

patients in a specialist psychiatric hospital that were most likely to commit violent acts. The authors relied on Nursing staff members' statistics on violent incidents and other security breaches, and collected these for 262 long-term inpatients over a 6 month period (April to September 2007) (Krueger & Rosema, 2010). Statistical analysis revealed the most significant risk factors of violence (e.g., fighting) among long-term patients was a diagnosis of intellectual disability, first hospital admission before the age of 40 years, total hospital stay in excess of 12 years, current accommodation in a closed ward, habitual verbal aggression, absence of disorganised behaviour seen in psychoses, and unsuitability for community placement (Krueger & Rosema, 2010). Despite exploring behavioural problems among adults with mental ill health in a psychiatric hospital setting, however, the study describes behavioural difficulties in a subgroup of individuals who live with intellectual disability as they were found to be "responsible for a disproportionately large number of violent acts in the hospital" (Krueger & Rosema, 2010, p. 366). Although not mentioned by the authors, their study offers valuable information on which to base the design of psychological interventions and person centred behaviour management plans in order to assist individuals living with intellectual disability, who are in need of high behavioural support from their environments and caregivers.

Regarding psychopharmacological intervention in the case of behavioural problems, Gagiano et al. (2005) examined the efficacy and safety of risperidone, a psychotropic medication, by means of a 4-week double-blind design in the treatment of disruptive behaviour disorders in adults with intellectual disability and high behavioural support needs. The authors measured efficacy at endpoint by using the Aberrant Behaviour Checklist (ABC); whilst secondary efficacy measures included the Behaviour Problems Inventory and Clinical Global Impressions scales (Gagiano et al., 2005). Risperidone was well tolerated by the participants, and those treated with risperidone demonstrated significantly greater improvement at endpoint on the ABC than those who received placebo, and also improved on the Behaviour Problems Inventory and Clinical Global Impressions ratings. Over a 48-week follow-up, there was a further decrease in behavioural problems measured by the ABC for patients who initially received risperidone, and also a decrease for participants who initially received placebo and then switched to open-label risperidone (Gagiano et al., 2005). Results were achieved with a mean modal dosage of 1.8 mg/day, and the authors were able to conclude that risperidone, albeit in the absence of psychological intervention or comparison, is

efficacious and well tolerated in managing disruptive behaviour disorders in adults living with intellectual disability (Gagiano et al., 2005).

3.2.2.2.3. Dental medicine. For many people, fear and anxiety concerning pain continue to be equated with dental procedures. These could be amplified in individuals who may find it difficult to make sense of such experiences. Roelofse and Van der Bijl (1994) reported on conscious sedation for dental restorative work and extractions with a 23 year old woman living with intellectual disability and compromised cardiovascular functioning. The individual was born with a large atrial septal defect for which she was unsuccessfully operated on at the age of two years. She sustained severe anoxic brain damage following a postoperative cardiac arrest that occurred in the intensive care unit. Due to her poor cardiovascular condition she was considered to be at too high a risk for general anaesthesia during the dental procedure, and it was therefore decided to sedate her intravenously. The researchers had previously successfully sedated her with propofol and midazolam, and she remained well-sedated during that entire procedure with no adverse effects (Van der Bijl & Roelofse, 1992). Since local anaesthesia together with sedation has been beneficial in patients with certain pre-existing medical conditions, and since the patient's cardiovascular status during the 1992 procedure was considered to pose a high risk for general anaesthesia, the authors decided to use propofol sedation during the second procedure (Roelofse & Van der Bijl, 1994). Her airway was well maintained during the entire procedure, and she again remained well sedated with no adverse effects reported. The rapid recovery after stopping the propofol infusion was noteworthy. The patient was alert and free from postoperative complications such as headache, confusion, restlessness, nausea, or vomiting – experiences that might be unpleasant for people living with and without intellectual disability alike.

3.2.2.2.4. Importance of augmentative and alternative communication for adults. Few to no psychotherapeutic interventions with especially adults with intellectual disability are described in the published literature on intellectual disability in South Africa. However, two communicative intervention studies with adults with intellectual disability can be drawn on for this review. In light of the vulnerability to sexual assault and subsequent experiences with legal proceedings discussed in Chapter 2, communicative capacity and access to being understood becomes especially important in reducing the risk of being a victim of crime in South Africa (Bornman, Nelson Bryen, Kershaw, & Ledwaba, 2011). The authors reiterate that individuals living with intellectual disability and "complex communication needs have a

heightened risk of becoming victims of crime, abuse, and neglect", and investigated the necessary vocabulary in order to disclose or report crime or abuse (Bornman et al., 2011, p. 117). In doing so, they were able to develop communication boards for this purpose in four of the 11 official South African languages (Afrikaans, English, Sepedi, and isiZulu). By means of inclusive research, 36 participants in the four respective language-based focus groups generated a list of possible words they deemed important when wanting to disclose a crime, abuse or neglect. The boards were developed using "Picture Communication Symbols (PCS)", a frequently used symbol set in South Africa with newly developed symbols for two words (swear, threaten) for which no PCS symbols previously existed (Bornman et al., 2011, p. 117; Dada et al., 2013).

3.3. DISCUSSION: Paucity in the South African literature on intellectual disability

The seminal Bushbuckridge data provided first insight into prevalence of intellectual disability in South Africa, and also highlighted subsequent service needs associated with healthcare, social service, and (inclusive) educational policy. Collected 20 years ago, the data still serves as a basis for advocating an initiation and development of appropriate and integrated services for the best possible care of individuals living with intellectual disability in South Africa. Yet children who were aged between two and nine years old during the study are now adults between the ages of roughly 22 and 29 years, still affected by service gaps for individuals living with intellectual disability in South Africa.

Despite developmental monitoring of children being an important strategy for the early detection and management of intellectual disabilities in high-income countries, the identification of individuals with intellectual impairment care needs, so that timely interventions may facilitate improved outcomes, remains problematic in South Africa. Unspecified approaches that are contextually inappropriate and an over-reliance on Eurocentric measures may obscure the development of context sensitive measures, and we run the risk of precluding monitoring strategies that make use of, for example, the Molteno Scale. Furthermore, by locating knowledge of intellectual disability in South Africa in biomedical and psychiatric experts, we risk obscuring other ways of understanding impairment as well as our contributions to disablement. We are asked to equally attend to the interplay between disabling biomedical conditions and social factors – comprehensive medical care, together with social and developmental intervention, comprise a number of requirements for limiting or even preventing some of the disabling impacts on impairment.

The development of necessary health services, particularly in rural areas, would improve the developmental outcome of children with spina bifida and intellectual disability in South Africa; and the chemical control of precipitants to periodontal disease and secondary infectious illnesses has been proven effective for use by individuals with intellectual disability. Risperidone, albeit in the absence of psychological intervention or comparison, is an effective and well tolerated intervention in the management of disruptive behaviour disorders in adults living with intellectual disability; and propofol anaesthetic infusions as an intervention during dental procedures assist adults with reducing anxiety during the procedure as well as with rapid recovery after the intervention.

Interventions associated with improved developmental functioning in children living with intellectual disability include attending a stimulating playgroup or preschool centre. For adults, this could be the equivalent of a skills development or work placement centre. Both interventions corroborate Ngwena's (2013) argument in Chapter 2 (Part 1 of the literature review) that individuals with intellectual disability need not be excluded from stimulating or educational environments on grounds of supposedly lacking capacity to benefit from enriching settings and interactions. Interventions associated with children's improved selective attention, social interaction, academic performance, and metacognitive insight into own abilities include cognitive control therapy; educational interventions aimed at differentiated pedagogy successfully addresses diversity of educational needs and enables inclusive practice; and augmentative and alternative communication (AAC) interventions for children have proven invaluable to non-speaking children living with severe intellectual disability. Vulnerability to sexual assault and subsequent experiences with legal proceedings make AAC interventions for adults important, since communicative capacity (which includes being understood by others) is especially significant in reducing the risk of being a victim of crime in South Africa. Assisting adults who live with intellectual disability realise their human rights includes interventions that decrease isolation from communities, decrease negative perceptions about intellectual disability, reduce stigma (both self-reported and from the general population), and that increase access to vocational and life skills development.

With regards to support needs of caregivers, interventions aimed at improving professionals' communication of a child's disability, possible long-term complications, and available services might aid in improving working partnerships with health support staff. Similarly,

caregivers' experienced difficulties highlight a need for interventions that can remedy a lack of respite care opportunities; address a lack of financial, emotional, and practical support; help deal with stigma (e.g., overt acts of discrimination and social exclusion); as well as interventions aimed at increasing caregivers' skill and knowledge of children's care needs. In addition, interventions aimed at supporting families following a child's diagnosis of intellectual disability might focus on assisting with adjustment to the news, engaging positive patterns of family communication, and addressing commitment to and cohesion of the family unit.

Further to necessary research on the empowerment of families that are supporting individuals living with intellectual disability in South Africa, interventions aimed at the needs of caregivers who care for adults living with intellectual disability include addressing caregivers' experiences not only of social isolation, but also of limited opportunities for personal growth and development due to demands of high burdens of care. Given the lack of such formal state or government service provision, family caregivers have developed informal community supports and resources out of necessity. Family care for adults with intellectual disability is predominantly provided by women, who experience similar issues of isolation and lack of support regardless of race and class differences. Interventions can aim to provide such support to mothers who experience elevated parental stress, depression, and other mental health problems as a result of negotiating significant life stressors in addition to caring for adult children with intellectual disability who also display aggression. Psychotherapy can produce moderate improvement in parental stress, and appears even more effective in reducing depressive symptoms.

Individuals with Down's Syndrome are especially at risk from coronary heart disease not only because of physical and health impairments, but also due to limited functional capacity, and perceived and real barriers to participation in exercise. As with any individual, diseases of lifestyle can be mitigated by physical activity. Interventions that circumvent these limitations, while decreasing inactivity and increasing cardiovascular functioning, are completely implementable.

A high rate of criminal incapacity exists among individuals with inter-ictal psychoses and co-morbid intellectual disability; and a significant risk factor of violence among long-term psychiatric inpatients was a diagnosis of intellectual disability. Accordingly, psychological

interventions and individualised management plans to assist individuals living with intellectual disability and high behavioural support needs are not only relevant in terms of health systems, caregiving, and community environments, but also in terms of judicial systems. Having an IQ of 70 or less does not automatically mean that an accused individual is unfit to stand trial, and it is possible for a person with intellectual disability to be held accountable. Assessments of criminal capacity and fitness to stand trial cannot be surmised from scores on assessments of intellectual ability only, and judicial interventions *must* account for individuals' understanding of the environment, his/her speech and language proficiency, degree and quality of educational input, reasoning ability, and the manner in which the crime was committed.

3.4.   CONCLUSION

Individuals with intellectual disability, especially those living with dual diagnosis, are often described as problematic, dangerous, responsible for violent acts, and behaving in ways that are difficult to manage and contain to the point of requiring psychotropic medication. Children with intellectual disability are described in the literature as behaviourally and emotionally more disturbed than typically developed children, and the more violent psychiatric inpatients and epilepsy sufferers also have intellectual disabilities. Yet there is a dearth in published studies on psychologically informed interventions with especially adults living with intellectual disability in South Africa. Moreover, it appears from the literature that the individual with intellectual disability must be treated and changed, as opposed to the disabling ways in which the individuals are interacted with. In a similar vein, published South African studies on what it is like for individuals to live with intellectual disability are scarce, let alone with dual diagnosis in psychiatric settings, and very few studies on what it is like to care for individuals who live with intellectual disability or dual diagnoses are currently available.

During the literature search, it emerged that there are opportunities for exploring topics of death and dying in intellectual disability in South Africa. During clinical interactions and assessments in hospital settings, elderly parents have expressed anxiety about what would happen to their adult children living with intellectual disability should they fall ill as caregivers, or who would care for their children after they pass. Preparing the person living with intellectual disability for the death of a caregiver, or facilitating a therapeutic grieving process after the death, also still needs to be addressed in the South African literature.

In terms of sexual rights and sexual health of individuals living with intellectual disability, even the right to be a parent, little has been published so far. Encouraging South African work has been done over the past decade and is hopefully gaining momentum, but still lags behind the body of work from the UK, for example. As one starting point among many, future contributions to intellectual disability work in and from South Africa should begin to include research by individuals living with intellectual disability. South African expertise remains located in non-disabled individuals, mostly at universities from which intellectually disabled individuals are still excluded, again as opposed to programmes in the UK. Individuals with intellectual disability are precluded from reading about themselves in publications by non-disabled experts-by-proxy (and therefore non-experts), because articles "about" intellectual disability, even the abstracts, remain inaccessible. The current, traditional locus of expertise not only effectively excludes individuals with intellectual disability from gaining knowledge about themselves, but knowledge held by true experts is not yet investigable by people living with intellectual disability. This effectively renders such potentially invaluable information inaccessible to proxy experts as well. If the development of research agendas and service priorities is not driven or set by individuals with intellectual disability, then their expertise and opinion must, at the very least, be included during such planning. This might set the stage for individuals with intellectual disability to participate academically in South Africa; and to have their voices and opinions received by others on policies, legislation, issues, campaigns, rights, and corollary obligations that directly affect individuals living with intellectual disability.

In light of paucities that have been identified in the South African literature on intellectual disability over the past 26 years (1989-2015), possibilities and suggestions for future inclusive and emancipatory South African research with, or by, intellectually disabled researchers as experts on living with intellectual impairment will be taken up in more detail in Chapter 8.

Table 3.1.

Exclusions Table – Initially returned literature excluded from review after the Independent Rater Round

The literature offered in this table was initially considered after reading the abstracts of all the returned sources post-search, and subsequently all were included for review by the team of independent raters (see Chapter 2). Independent raters' reasons for ultimately excluding them from the review are stated in this table under "Reasons for exclusion":

	Author(s)	Title of Paper	Reason for exclusion	Rater
1	Adnams, C. M., Kodituwakku, P. W., Hay, A., Molteno, C. D., Viljoen, D., & May, P. A. (2001).	Patterns of cognitive-motor development in children with fetal alcohol syndrome from a community in South Africa. *Alcoholism, Clinical and Experimental Research, 25*(4), 557-562.	This study garnered information about children with FAS; the majority of children had only mild cognitive impairment compared with the control group; and it pertinently mentioned that the majority of participants had only mild features of FAS. Accordingly, literature has suggested that the majority of people with FAS have borderline ID or below average intellectual ability. The study is about FAS, not ID; and ID was reported as a prominent outcome in this study. Cognitive delay is not commensurate of ID.	OC
2	Anyanwu, E. C.,	The impact of malaria infectious pathways	Precursor to ID but	AH

	Kanu, I., & Merrick, J. (2007).	on disability and child development in endemic regions. *International Journal on Disability and Human Development, 6*(3), 253-258.	the topic of the study is not ID (beyond scope).	
3	Arend, A. O., Leary, P. M., & Rutherfoord, G. S. (1991).	Alexander's disease: A case report with brain biopsy, ultrasound, CT scan and MRI findings	Study not about ID in SA specifically.	AH
4	Arens, L. J., &Molteno, C. D. (1989).	A comparative study of postnatally-acquired cerebral palsy in Cape Town. *Developmental Medicine and Child Neurology, 31*(2), 246-254.	Intellectual status mentioned in abstract is not clear – link with ID not explicit.	MS
5	Baillieu, N., & Potterton, J. (2008).	The extent of delay of language, motor, and cognitive development in HIV-positive infants. *Journal of Neurologic Physical Therapy: JNPT, 32*(3), 118-121. doi:10.1097/NPT.0b013e3181846232 [doi]	Focus of study is on HIV – cognitive delay includes ID? Focus of study not on ID.	CC
6	Ballot, D. E., Potterton, J., Chirwa, T., Hilburn, N., & Cooper, P. A. (2012).	Developmental outcome of very low birth weight infants in a developing country.*BMC Pediatrics, 12*, 11. doi:10.1186/1471-2431-12-11	The study does not refer to intellectual disability but rather to the risk of disability. This would not be specific to intellectual disability. Inclusion of this paper would depend to what extent the prevention of intellectual disability is a topic. My feeling is that it should be excluded because it might cast the net too broad. For example, literature on malnutrition would be included and perhaps other topics too.	JM
7	Barratt, J., & Ogle, V. (2010).	Recorded incidence and management of dysphagia in an outpatient paediatric neurodevelopmental clinic. *SAJCH South African Journal of Child Health, 4*(2), 38-	Although "learning disability" is mentioned as co-morbid to the topic	AH

		41.	of investigation, the study is not about ID in SA.	
8	Beighton, P. (1990).	Dyggve-melchior-clausen syndrome. *Journal of Medical Genetics, 27*(8), 512-515.	Description of a genetic syndrome that may include ID – study topic is not about ID in SA specifically.	AH
9	Booysen, F. (2004).	Social grants as safety net for HIV/AIDS-affected households in South Africa. *SAHARA J : Journal of Social Aspects of HIV/AIDS Research Alliance / SAHARA , Human Sciences Research Council, 1*(1), 45-56.	This study relates only very indirectly to intellectual disability as the topic is social grants in the context of HIV/AIDS.	JM
10	Bornman, J., &Bryen, D. N. (2013).	Social validation of vocabulary selection: Ensuring stakeholder relevance. *Augmentative and Alternative Communication (Baltimore, Md.: 1985), 29*(2), 174-181. doi:10.3109/07434618.2013.784805 [doi]	Only two of the 12 participants had a level of education below Grade VII. Other participants either completed Grade IX or Grade XII; and one participant had a university degree. The shared medical diagnoses and four had cerebral palsy. The study is about physical disability and not intellectual disability.	OC
11	Burger, M., &Louw, Q. A. (2009).	The predictive validity of general movements--a systematic review. *European Journal of PaediatricNeurology: EJPN: Official Journal of the European Paediatric Neurology Society, 13*(5), 408-420. doi:10.1016/j.ejpn.2008.09.004 [doi]	Although the literature review was published by South African authors, most of the studies that the review covered were done by international authors in different countries. The review's criteria revolved around early	OC

			neurodevelopmental screening of deficits. Although some of these studies therefore covered possible intellectual disability, other neurodevelopmental impairments such as cerebral palsy constitute co-morbid conditions.	
12	Casale, D., Desmond, C., & Richter, L. (2014).	The association between stunting and psychosocial development among preschool children: A study using the South African birth to twenty cohort data. *Child: Care, Health and Development,* doi:10.1111/cch.12143 [doi]	Is cognitive functioning ID? Study focuses on psychosocial development, not ID.	CC
13	Ceccanti, M., Spagnolo, P. A., Tarani, L., Attilia, M. L., Chessa, L., Mancinelli, R., . . . Hoyme, H. E. (2007).	Clinical delineation of fetal alcohol spectrum disorders (FASD) in italian children: Comparison and contrast with other racial/ethnic groups and implications for diagnosis and prevention. *Neuroscience and Biobehavioral Reviews, 31*(2), 270-277. doi:10.1016/j.neubiorev.2006.06.024	Although study is about ID secondary to FAS(D) and uses South African studies and data, this particular study is not about ID in South Africa.	CC
14	Christianson, A. L., & Van Allen, M. I. (1996).	Sutural exostoses, rib hyperostoses, craniosynostosis, mental retardation with focal fat deposition: Proteus syndrome? *American Journal of Medical Genetics, 66*(2), 150-153. doi:10.1002/(SICI)1096-8628(19961211)66:2<150::AID-AJMG5>3.0.CO;2-V [pii]	Genetic syndrome studied, but not ID in SA specifically.	AH
15	Clark, T., Johnson, V., & Fleming, J. W. (2002).	Parents' perception of their children's development, perception of satisfaction, social support and level of depression. *The ABNF Journal: Official Journal of the Association of Black Nursing Faculty in Higher Education, Inc, 13*(1), 13-17.	Study is not about ID in SA.	OC
16	Cluver, L., Boyes, M., Orkin, M., &Sherr, L. (2013).	Poverty, AIDS and child health: Identifying highest-risk children in South Africa. *South African Medical Journal = Suid-AfrikaanseTydskrifVirGeneeskunde, 103*(12), 910-915. doi:10.7196/samj.7045 [doi]	Study does not reference ID specifically, but more generally identifies at risk children with a focus on HIV and	LA

107

17	Couper, J. (2002).	Prevalence of childhood disability in rural KwaZulu-natal. *South African Medical Journal, 92*(7), 549-552.	The study does not use the term intellectual disability but mild perceptual disability seems to be used as a synonym. Perhaps can be explored in the next stage of the review.	JM
18	Davies, L., Dunn, M., Chersich, M., Urban, M., Chetty, C., Olivier, L., & Viljoen, D. (2011).	Developmental delay of infants and young children with and without fetal alcohol spectrum disorder in the northern cape province, South Africa. *African Journal of Psychiatry (South Africa), 14*(4), 298-305. doi:10.4314/ajpsy.v14i4.7	This study should most likely not be included because it pertains to FASD and not ID. Link to ID is tenuous, and ID not mentioned.	CC
19	De Jong, G., & Fryns, J. P. (1991).	Oculocerebral syndrome with hypopigmentation (cross syndrome): The mixed pattern of hair pigmentation as an important diagnostic sign. *Genetic Counseling (Geneva, Switzerland), 2*(3), 151-155.	Unclear whether study is about ID (even if secondary to genetic aetiology) in South Africa.	CC
20	Fenemore, B., & Potter, P. C. (2001).	Perceived and confirmed allergy in children with learning disabilities and hyperactivity. *SAMJ South African Medical Journal, 91*(12), 1043-1044.	The criteria used for a learning disabled child and hyperactivity were taken from the American Public Law94-142, the Education for All Handicapped Children Act. Not sure if this refers to intellectual disability or specific learning disorders in children of normal intelligence?	MS
21	Ferguson, G., &Jelsma, J.	*The prevalence of motor delay among HIV infected children living in Cape Town,*	Study documents developmental	LA

	(2009).	*South Africa.* International Journal of Rehabilitation Research, 32(2), 108-114.	delay (specifically motor delay) among HIV+ children recently hospitalised. However, it does not make direct reference or links to intellectual disability per se, but does refer to developmental delay which may/may not be indicative of ID as well.	
22	Finkenflugel, H., Wolffers, I., &Huijsman, R. (2005).	The evidence base for community-based rehabilitation: A literature review. *International Journal of Rehabilitation Research, 28*(3), 187-201. doi:10.1097/00004356-200509000-00001	While the topics discussed in this paper, CBR, and the location of the research, global, might include intellectual disability and South Africa, I consider these links to be rather too tenuous to include this article in the review.	JM
23	Foroud, T., Wetherill, L., Vinci-Booher, S., Moore, E. S., Ward, R. E., Hoyme, H. E., . . . Jacobson, S. W. (2012).	Relation over time between facial measurements and cognitive outcomes in fetal alcohol-exposed children. *Alcoholism, Clinical and Experimental Research, 36*(9), 1634-1646. doi:10.1111/j.1530-0277.2012.01750.x [doi]	Study is about FASD in particular, not on ID secondary to FASD, or FASD as an aetiology.	CC
24	Grantham-McGregor, S., Cheung, Y. B., Cueto, S., Glewwe, P., Richter, L., &Strupp, B. (2007).	Developmental potential in the first 5 years for children in developing countries. *Lancet, 369* (9555), 60-70. doi:10.1016/S0140-6736(07)60032-4	Even though South Africa was included in this project, it should be noted that social variables were covered from a range of LAMI across South America, Eastern	OC

			Asia and sub-Saharan Africa. Furthermore, research investigated indices of socio-economic variables, poverty and hardship – it pertains more to social variables and its impact on cognitive development than intellectual disability per se.	
25	Greeff, A. P., & Van Der Walt, K. (2010).	Resilience in families with an autistic child. *Education and Training in Autism and Developmental Disabilities, 45*(3), 347-355.	The study covers families of children with autism; as such I could not trace measurement of intellectual disability. It may be that a substantial number of participants had children with diagnoses of autism and ID.	OC
26	Gregersen, N. (2006).	Facial asymmetry with colon atresia. *Clinical Dysmorphology, 15*(1), 45-46. doi:10.1097/01.mcd.0000175604.03221.ad	Topic of study is genetic – not specifically on ID in SA.	AH
27	Grinker, R. R., Chambers, N., Njongwe, N., Lagman, A. E., Guthrie, W., Stronach, S., . . . Wetherby, A. M. (2012).	"Communities" in community engagement: Lessons learned from autism research in South Korea and South Africa. *Autism Research, 5*(3), 201-210. doi:10.1002/aur.1229	Article is on ASD as opposed to the study of ID.	JM
28	Heckler, H., Taute, C. E., Krueger, G. H. J., de Wet, D., Calitz, F. J. W., van der Merwe, L. M.,	Profile of stress factors associated with mental disorders in children and adolescents referred for evaluation and treatment to the free state psychiatric complex, 2007. *South African Journal of Psychiatry, 18*(2), 61-U3.	The study is not about ID specifically, but includes outcomes of ID identified in this particular sample of children	LA

29	Hift, R. J., Meissner, P. N., Todd, G., Kirby, P., Bilsland, D., Collins, P., . . . Moore, M. R. (1993).	Homozygous variegate porphyria: An evolving clinical syndrome. *Postgraduate Medical Journal, 69*(816), 781-786.	Although ID can be a symptom of porphyria, the study is not specifically on ID in SA.	AH
	&Raubenheimer, J. E. (2012).		and adolescents.	
30	Hoyme, H. E., May, P. A., Kalberg, W. O., Kodituwakku, P., Gossage, J. P., Trujillo, P. M., . . . Robinson, L. K. (2005).	A practical clinical approach to diagnosis of fetal alcohol spectrum disorders: Clarification of the 1996 institute of medicine criteria. *Pediatrics, 115*(1), 39-47. doi:10.1542/peds.2004-0259	Study on FAS diagnostics, not ID; not FASD as ID aetiology; no specific link studied, just mentioned.	CC
31	Hsiao, C., & Richter, L. M. (2014).	Early mental development as a predictor of preschool cognitive and behavioral development in South Africa: The moderating role of maternal education in the birth to twenty cohort. *Infants and Young Children, 27*(1), 74-87. doi:10.1097/IYC.0000000000000002	Topic of study is not ID in SA.	LA
32	Ichoku, H. E., Mooney, G., &Ataguba, J. E. (2013).	Africanizing the social determinants of health: Embedded structural inequalities and current health outcomes in sub-saharanAfrica. *International Journal of Health Services : Planning, Administration, Evaluation, 43*(4), 745-759.	Topic of study is not ID in SA.	OC
33	Katwan, E., Adnams, C., & London, L. (2011).	Childhood behavioural and developmental disorders - association with maternal alcohol consumption in Cape Town, South Africa. *South African Medical Journal, 101*(10), 724-727.	Study is on FAS of which ID is not necessarily a result. Study is not specifically on ID in SA.	AH
34	Kauchali, S., & Davidson, L. L. (2006).	Commentary: The epidemiology of neurodevelopmental disorders in sub-saharanAfrica--moving forward to understand the health and psychosocial needs of children, families, and communities. *International Journal of Epidemiology, 35*(3), 689-690. doi:dyl090 [pii]	Not specific to ID in SA, but refers to SSA…unless this explicitly includes SA (and ID in SA), most likely cannot include this study.	LA
35	Klinck, M. E., Iuris, B., Louw,	A South African perspective on children's rights: Pertinent issues in remedial and	It is not possible to assess eligibility for	JM

			inclusion on the basis of the abstract; the paper may or may not relate to ID in South Africa	
36	Lasich, A. J., & Nair, M. G. (1992).	A study of referrals of blackchildren to a general-hospital psychiatric outpatient-clinic. *Australian and New Zealand Journal of Psychiatry, 26*(3), 467-473. doi:10.3109/00048679209072072	The article was published in Australia. It seems likely that it refers to an Australian population but this cannot be confirmed without seeing the whole article. It might refer to an SA population but be published in an Australian journal.	JM
37	Laughton, B., Cornell, M., Grove, D., Kidd, M., Springer, P. E., Dobbels, E., . . . Cotton, M. F. (2012).	Early antiretroviral therapy improves neurodevelopmental outcomes in infants. *Aids, 26*(13), 1685-1690. doi:10.1097/QAD.0b013e328355d0ce	Focus of this study is locomotor, neurodevelopment, HIV. Focus is not on ID.	CC
38	Lotz, L., Loxton, H., & Naidoo, A. V. (2005).	Visual-motor integration functioning in a South African middle childhood sample. *Journal of Child and Adolescent Mental Health, 17*(2), 63-67.	Study focus on visuo-motor integration and specific learning disorders, and not intellectual disability. The developmental delays were found to be within low average intelligence levels and subsequent academic difficulties.	MS and LA
39	Lubbe, W., Van der Walt, C. S., & Klopper, H. C. (2012).	Integrative literature review defining evidence-based neurodevelopmental supportive care of the preterm infant. *The Journal of Perinatal & Neonatal Nursing, 26*(3), 251-259.	No explicit link written about between NDSC and ID; article not on ID.	CC

		doi:10.1097/JPN.0b013e3182650b7e [doi]		
40	Malan-Muller, S., Hemmings, S. M., Spies, G., Kidd, M., Fennema-Notestine, C., & Seedat, S. (2013).	Shorter telomere length - A potential susceptibility factor for HIV-associated neurocognitive impairments in South African women [corrected. *PloS One, 8*(3), e58351. doi:10.1371/journal.pone.0058351 [doi]	The study is not on ID in SA.	CC
41	Mamabolo, M. M., Magagula, T. G., Kruger, C., & Fletcher, L. (2012).	A survey of risk behaviour for contracting HIV among adult psychiatric patients. A South African study - part 1. *African Journal of Psychiatry, 15*(5), 329-334. doi:http://dx.doi.org/10.4314/ajpsy.v15i5.40 [doi]	Focus on "mentally ill", not ID.	CC
42	Manasse, B. F., Lekgate, N., Pfaffenzeller, W. M., & de Ravel, T. J. (2000).	The pallister-killian syndrome is reliably diagnosed by FISH on buccal mucosa. *Clinical Dysmorphology, 9*(3), 163-165.	Unclear on explicit etiological link to ID.	CC
43	Mason, E., McDougall, L., Lawn, J. E., Gupta, A., Claeson, M., Pillay, Y., . . . on behalf of the Every Newborn Steering Committee. (2014).	From evidence to action to deliver a healthy start for the next generation. *Lancet,* doi:S0140-6736(14)60750-9 [pii]	The paper deals more with infant mortality than with disability, although it is noted in the paper. However the link is rather too tenuous to be helpful in my view.	JM
44	Mathee, A., von Schirnding, Y., Montgomery, M., & Rollin, H. (2004).	Lead poisoning in South African children: The hazard is at home. *Reviews on Environmental Health, 19*(3-4), 347-61.	Topic of study is not on ID in SA.	OC
45	May, P. A., Gossage, J. P., Marais, A. S., Adnams, C. M., Hoyme, H. E., Jones, K. L., . . . Viljoen, D. L. (2007).	The epidemiology of fetal alcohol syndrome and partial FAS in a South African community. *Drug and Alcohol Dependence, 88*(2-3), 259-271. doi:S0376-8716(06)00425-X [pii]	Topic of study is on FAS, not on ID in SA – explicit link to ID not clear.	MS
46	May, P. A., Gossage, J. P., Kalberg, W. O.,	Prevalence and epidemiologic characteristics of fasd from various research methods with an emphasis on recent in-	Study is on FASD in the US (although SA data/studies are	CC

113

	Robinson, L. K., Buckley, D., Manning, M., & Hoyme, H. E. (2009).	school studies. *Developmental Disabilities Research Reviews, 15*(3), 176-192. doi:10.1002/ddrr.68	mentioned). Study is on FASD in particular.	
47	McKenzie, J. A. (2013).	Disabled people in rural South Africa talk about sexuality. *Culture, Health &Sexuality, 15*(3), 372-386. doi:10.1080/13691058.2012.748936 [doi]	Focus (participants) not ID.	CC
48	Mead, E. A., & Sarkar, D. K. (2014).	Fetal alcohol spectrum disorders and their transmission through genetic and epigenetic mechanisms. *Frontiers in Genetics, 5*, 154-154. doi:10.3389/fgene.2014.00154	Study is on FASD explicitly, and then on FASD in the USA, not in South Africa.	CC
49	Mkize, D. L., Green-Thompson, R. W., Ramdass, P., Mhlaluka, G., Diamini, N., & Walker, J. (2004).	Mental health services in KwaZulu-natal. *South African Journal of Psychiatry, 10*(1), 8-13.	The topic of study in this article is not ID in SA. However, the task team recommends that services for the treatment and rehabilitation of severely intellectually disabled children be the responsibility of the Mental Health Services and that children with mild to moderate intellectual disability be the responsibility of the Department of Education.	MS
50	Mohamed, Z., &Laher, S. (2012).	Exploring foundation phase school teachers' perceptions of learning difficulties in two Johannesburg schools. *Journal of Child and Adolescent Mental Health, 24*(2), 133-147. doi:10.2989/17280583.2012.735500	They seem to discuss LD in the context of ID, but define LD as a child without ID…wouldnot include this study, as it does not discuss ID specifically.	LA
51	Moolman-Smook, J. C.,	Of rain men and snowcakes: The presentation, pathology, aetiology and	Topic of study is not ID but ASD	JM

	Vermoter, C.,. . . Buckle, J., &Lindenberg, L. (2008).	management of autistic spectrum disorder. *SAJCH South African Journal of Child Health, 2*(1), 8-12.	with no explicit link.	
52	Naicker, N., Norris, S. A., Mathee, A., Becker, P., & Richter, L. (2010).	Lead exposure is associated with a delay in the onset of puberty in South African adolescent females: Findings from the birth to twenty cohort. *Science of the Total Environment, 408*(21), 4949-4954. doi:10.1016/j.scitotenv.2010.07.037	The study is not about ID in SA.	OC
53	Naidoo, P., van den Berg, H. S., & Hayes, G. (2006).	Potential contributions to disability theorizing and research from positive psychology. *Disability and Rehabilitation, 28*(9), 595-602. doi:G061U16137235205 [pii]	Topic of study is not on ID in SA.	MS
54	Nour, N. M. (2012).	Premature delivery and the millennium development goal. *Reviews in Obstetrics and Gynecology, 5*(2), 100-5.	The study does not refer to intellectual disability but rather to the risk of disability. This would not be specific to intellectual disability. Inclusion of this paper would depend to what extent the prevention of intellectual disability is a topic. My feeling is that it should be excluded because it might cast the net too broad. For example, literature on malnutrition would be included and perhaps other topics too.	JM
55	Okwundu, C. I., Okoromah, C. A., & Shah, P. S. (2013).	Cochrane review: Prophylactic phototherapy for preventing jaundice in preterm or low birth weight infants. *Evidence-Based Child Health: A Cochrane Review Journal, 8*(1), 204-249. doi:10.1002/ebch.1898 [doi]	Vulnerabilities in preterm or low birth weight infants were excluded unless the topic of study was intellectual disability.	JM

56	Ornoy, A., & Ergaz, Z. (2010).	Alcohol abuse in pregnant women: Effects on the fetus and newborn, mode of action and maternal treatment. *International Journal of Environmental Research and Public Health, 7*(2), 364-379. doi:10.3390/ijerph7020364	Study on FAS particularly as aetiology to ID, but not a South African study (although uses SA data/studies)	CC
57	Ouko, L. A., Shantikumar, K., Knezovich, J., Haycock, P., Schnugh, D. J., & Ramsay, M. (2009).	Effect of alcohol consumption on CpG methylation in the differentially methylated regions of H19 and IG-DMR in male gametes: Implications for fetal alcohol spectrum disorders. *Alcoholism, Clinical and Experimental Research, 33*(9), 1615-1627. doi:10.1111/j.1530-0277.2009.00993.x [doi]	Study is about FAS – link to ID mentioned, but not explicitly built into study design	CC
58	Park, W. H., Jeong, Y. S., &Bornman, J. (2011).	The effect of psycho-motor play on motor and body perception competence for young children with developmental delays. *South African Journal of Occupational Therapy, 41*, 13-18.	The study involves a brood category of developmental delay and not ID specifically. Of the five participants, only one had mild ID.	LA
59	Partridge, J. C., Ranchod, T. M., Ballot, D. E., Martinez, A. M., Cory, B. J., & Davies, V. A. (2005).	Intensive care for very low birthweight infants in South Africa: A survey of physician attitudes, parent counseling and resuscitation practices. *Journal of Tropical Pediatrics, 51*(1), 11-16. doi:10.1093/tropej/fmh066	This study does not refer to intellectual disability but as far as I can judge relates more to issues of mortality and whether resuscitation will be given. The link to ID seems tenuous.	JM
60	Pillay, A. L., Kometsi, M. J., &Siyothula, E. B. (2009).	A profile of patients seen by fly-in clinical psychologists at a non-urban facility and implications for training and future services. *South African Journal of Psychology, 39*(3), 289-299.	Not about ID specifically, but refers to some of the presentations seen at the clinic.	LA
61	Reid, B. C., Chenette, R., &Macek, M. D. (2003).	Special olympics: The oral health status of U.S. athletes compared with international athletes. *Special Care in Dentistry: Official Publication of the American Association of Hospital Dentists, the Academy of Dentistry for the Handicapped, and the American*	Data compared to SA athletes, but study is about ID in the USA. Not about ID in SA.	CC

		Society for Geriatric Dentistry, 23(6), 230-3. doi:10.1111/j.1754-4505.2003.tb00317.x		
62	Roberts, T., Chetty, M., Stephen, L., Fieggen, K., & Beighton, P. (2014).	The tricho-rhino-phalangeal syndrome: Oral manifestations and management. *SADJ: Journal of the South African Dental Association = Tydskrif Van Die Suid-Afrikaanse Tandheelkundige Vereniging, 69*(4), 166-169.	The article is not about ID in South Africa – intellectual impairment is a variable manifestation in TRIPS; and in the majority of cases, intellectual impairment is sporadic.	CC
63	Rohleder, P., Braathen, S. H., Swartz, L., & Eide, A. H. (2009).	HIV/AIDS and disability in southern Africa: A review of relevant literature. *Disability and Rehabilitation, 31*(1), 51-59. doi:10.1080/09638280802280585	Study not about ID – link to ID as vulnerable population re HIV.	CC
64	Roussotte, F. F., Sulik, K. K., Mattson, S. N., Riley, E. P., Jones, K. L., Adnams, C. M., . . . Sowell, E. R. (2012).	Regional brain volume reductions relate to facial dysmorphology and neurocognitive function in fetal alcohol spectrum disorders. *Human Brain Mapping, 33*(4), 920-937. doi:10.1002/hbm.21260	This is a sophisticated study that investigated localised cerebral impairment with cognitive functioning and controlled for different social variables. Although IQ assessment was conducted across three countries, impaired cognitive functioning was not constructed as "Intellectual Disability"; this study should most likely not be included because it pertains to FASD and not ID.	OC
65	Schönfeldt, H. C., Pretorius, B., & Hall, N. (2013).	*Focusing on South Africa's public health nutrition economics*. Nova Science Publishers, Inc.	Study not on ID in SA as topic specifically.	CC
66	Thompson, C. M., Buccimazza,	Infants of less than 1250 grams birth weight at Grooteschuur hospital: Outcome at 1 and	Although the topic of the study was not	LA

	S. S., Webster, J., Malan, A. F., &Molteno, C. D. (1993).	2 years of age. *Pediatrics, 91*(5), 961-968.	explicitly on ID in SA, the aim of the study was to document the morbidity, mortality, and neurodevelopmental outcome of these infants to 2 years of age.	
67	Van Schoor, A. N., Naudé, H., van Rensburg, M., Pretorius, E., & Boon, J. M. (2005).	Cognitive and learning strategies for longstanding temporal lobe lesions in a child who suffered from herpes simplex virus encephalitis: A case study over 10 years. *Early Child Development and Care, 175*(7-8), 621-634. doi:10.1080/0300443042000244064	Topic of study is not ID in SA.	OC
68	Victora, C. G., Adair, L., Fall, C., Hallal, P. C., Martorell, R., Richter, L., . . . Maternal and Child Undernutrition Study Group. (2008).	Maternal and child undernutrition: Consequences for adult health and human capital. *Lancet, 371*(9609), 340-357. doi:10.1016/S0140-6736(07)61692-4 [doi]	Vulnerabilities in preterm or low birth weight infants were excluded unless the topic of study was intellectual disability.	JM
69	Winship, W. S., & Rubin, D. L. (1992).	The dyggve-melchior-clausen syndrome in indian siblings. *Clinical Genetics, 42*(5), 240-245.	Topic of study is not ID in SA.	OC
70	Walker, A. R. (1998).	The remedying of iron deficiency: What priority should it have? *The British Journal of Nutrition, 79*(3), 227-235. doi:S0007114598000403 [pii]	The extent of the impairment in cognitive scores in children and adults is not expanded on in article. No mention of intellectual disability made or any diagnostic classification or test scores/results to support this. Also conflicting findings noted as weak evidence found between diet	MS

			and cognitive functioning and other reasons suggested for lower cognitive scores.	
		119		

CHAPTER FOUR
On the unethicality of disablism: Excluding intellectually impaired individuals from participating in research can be unethical

4.1.   INTRODUCING ARTICLE 1

Following the format of "PhD by publication", this chapter is comprised of the first of three peer reviewed journal articles that resulted from the research for this dissertation. As explained in the introductory chapter, a description of how the publications tie into the dissertation as a whole is offered at the beginning of each journal article chapter so as to facilitate continuity for the reader.

From the literature review it emerged that South African intellectual disability work should begin to include research with and by individuals living with intellectual disability. As co-constructors or researchers of studies that may affect them directly, adults living with intellectual impairment can begin to make contributions to South African intellectual disability research, and their expert voices can stand in public and scientific service on disability matters. This chapter offers a peer reviewed journal article that pauses on possible ethical issues involved when researching with individuals living with intellectual disability (Appendix B). It also includes the consent-assent form that was used with participants with intellectual disability during this research (Appendix C).

The importance of providing participants with accessible and understandable information is a significant part of the consent-assent process in intellectual disability research. Individuals with intellectual impairment may require more time to integrate information and formulate concerns before reaching an understanding of the issues involved (Inglis & Cook, 2011). As a significant part of the assent and consent process, it was my task to provide accessible and understandable information. I also had to bear in mind that obtaining consent from intellectually impaired individuals to participate in a research project should be a careful and lengthy process. Having said this, I was pleased to learn from one participant with intellectual disability, whose voice is offered in Chapter 7, that the form (Appendix C) was experienced as too long and repetitive for "higher patients like [him]" needing less than two sessions to work through it with me (Resident J). By learning from intellectually disabled co-researchers in future projects, I look forward to becoming better at researching intellectual disability . . . by improving on the content and design of consent-assent forms, for example.

There will be benefits and obstacles to participating in or driving research, but excluding adults with intellectual disability from research based on arguments of limited capacity could be construed as unethical, since such omissions can hinder rather than enable developments to improve health and services for intellectually impaired South Africans. As does any South African, intellectually impaired citizens have the right to benefit from, and contribute to, scientific progress (London et al., 2012). Inglis and Cook (2011) explain that by participating in co-creating counter-hegemonic disability texts, intellectually impaired individuals could help locate novel aspects within disability studies; ensure that studies are not dominated by disabling researchers and their agendas; and also help ensure that disability research does not only consider issues that are important to enabled professionals.

The onus to obtain consent from participants with intellectual disability was on me, and not on the participants to provide. I was aware of the significant tension that existed between ensuring that potential participants understand the nature and implications of their involvement in the research, while avoiding experiences of coercion or denigration. One indicator of a healthy consent process is evidence that potential participants choose not to take part, and I am happy to show in Table 7.3 that two residents declined to participate in this study. Although the current concept of consent is based on a dichotomous categorization (people either have or do not have capacity to consent) (Dye et al., 2004), I found it helpful to conceptualise the process of obtaining consent or assent as being on a "sliding scale" relative to the nature of impairment (please refer to Appendix B for a visual representation). To avoid the exclusion of potential participants with lower levels of comprehension and poorer ability to understand their involvement in research, assent procedures can be initiated once consent is obtained from an authorised proxy.

As discussed in the article to follow, there are a number of criteria to be mindful of regarding upholding ethicality when considering research with intellectually impaired participants. Ultimately, the voluntary nature of participation and the participant's right to make an autonomous decision about continuing or terminating his or her involvement is paramount. Apart from the core ethical principles of anonymity, confidentiality, and informed consent (L. Swartz et al., 2012), I followed Kittay's (2009) "fundamental ethical precepts" of epistemic responsibility (know the subject), and epistemic modesty (know, and admit to, what you do not know) during my research process. Fittingly, an intersubjective conceptualisation of the

121

research process not only allowed, but expected the acknowledgement and tolerance of my own ignorance and lack of knowledge. As Marzano (2007) informs, I found that disability research spaces encouraged me to confront my own identity, to reflect on the nature of the care interactions and social relations that I construct in the field, on the distribution of power within these, and on the legitimacy of my observations.

The next chapter is comprised of the second of three peer reviewed journal articles that resulted from this research. Chapter 5 will begin by offering a description of how its publication introduces the theoretical frame that will run through the remainder of the dissertation.

APPENDIX B

Published journal article – African Journal of Disability

Appendix B

On the unethicality of disablism: Excluding intellectually impaired individuals from participating in research can be unethical

Introduction

As co-constructors of studies that may affect them directly, adults living with intellectual impairment need not be excluded as co-researchers. Assuming that these adults do not have capacity to consent as participants in research due to impaired cognitive functioning presumes incapacity (Dye, Hendy, Hare, & Burton, 2004). Exclusion on the basis of impairment could be seen as discriminating and a contravention of a non-derogable human right (Constitution of the Republic of South Africa [RSA], No. 108 of 1996). This could also be construed as unethical since such omissions may hinder rather than enable developments to improve health and services for intellectually impaired persons. As does any South African, intellectually impaired citizens have the right to benefit from scientific progress...if they can contribute as experts to such progress, even more so (London, Kagee, Moodley, & Swartz, 2011). By virtue of their expertise on disability matters, their voice may stand in public and scientific service.

In following London and colleagues (2011), a human rights perspective could provide a useful view on the unethicality of either excluding or coercing intellectuality impaired individuals as research participants. All South Africans have a right to equality[1], freedom of expression[2], health care services[3], and human dignity[4]. Yet it remains the task of the researcher to hold for participants the tension between being included voluntarily and feeling coerced – the right not to be discriminated against whilst upholding that of psychological integrity (RSA, 1996). An appreciation of intellectually impaired individuals' understanding of dignity, (self)respect, and "nonhumiliation" might also contribute to better practice in the process of obtaining consent for participation (Nussbaum, 2010, p.79).

Opinions of quality of care, resources, and services are very rarely obtained from intellectually impaired individuals themselves; when viewed as incompetent to pass

---

[1] No person, nor the state, may unfairly discriminate directly or indirectly against anyone on one or more grounds including ... disability (RSA, 1996).

[2] Everyone has the right to freedom of expression, which includes freedom to receive or impart information or ideas and academic freedom and freedom of scientific research (RSA, 1996).

[3] Everyone has the right to have access to health care services (RSA, 1996).

[4] Everyone has the right to bodily and psychological integrity, which includes the right not to be subjected to medical or scientific experiments without their informed consent (RSA, 1996).

Appendix B

judgement on their own experiences, we may be contravening aforementioned human rights (RSA, 1996; Kittay, 2009; Tronto, 2011). If "the preferencing of the interests of vulnerable people and groups in ways that enable them to change the conditions of their vulnerability ... is ... [p]aramount to a human rights perspective", we can neither learn how intellectually impaired individuals experience the care quality, resources, and services they receive if not allowed to tell us; nor help raise these expert voices (London et al., 2011, p. 3). We see that Kittay (2009) finds it morally abusive when policies impacting intellectually impaired individuals are "formulated on the basis of the denial of the moral personhood of individuals who do not have a place at the table where their fates may be decided" (2009, p.620).

Individuals may be intellectually or physically impaired, but it is their political and social environments that do the disabling. Swartz (2010) explains that in the social model of disability, the impairment alone "is not sufficient for disablement to occur. What disables people – what makes people disabled – is how society responds to the impairments" (own italics for emphasis – Swartz, 2010, p.27, 28; see also Walmsley, 2001). Not being allowed to ask the opinion of intellectually impaired individuals on maters that affect them directly can be construed as disabling, and may amount to disablist practice. If located in emancipatory research, disability studies must explore ways in which individuals living with intellectual impairment can, as co-researchers, have some measure of control over studies that affect them directly (Barton,2006; Walmsley & Johnson, 2003; Walmsley, 2001).

Although the fundamental ethical principle of anonymising data might serve to protect the "welfare and dignity" of participants (Marzano, 2007, p.418), not documenting their perception of dignifying experiences could silence a possible lack of these and constitute a disavowal of living and working with intellectual disability – an unacknowledgement that raises further ethical concerns (Nussbaum, 2010). How can lived experiences on the continuum of intellectual disability become known and knowable if the bodies these experiences are lived in cannot be named? What if unilaterally deciding to protect participant identities is not in their best interest...*too ashamed to be named*? Shouldn't anonymity be negotiated with participants as a power issue, something intersubjective work enables (Swartz, Van der Merwe, Buckland, & McDougall, 2011)? Assuming that, because of weaker cognitive functioning, intellectually disabled adults lack the capacity to agree or decline to participate in research negates the right they have to inclusion and acknowledgement, and the right to claim the time and thinking of the enabled researcher (Kittay, 2009; Sinason, 2010).

Appendix B

Benefits of participation

Disability researchers emphasise the importance of moving studies about impaired persons from a third-person reporting style that continues to disable intellectually impaired voices as subaltern, toward counter-hegemonic discursive texts where the experience and expert voice of impaired individuals are at the core (Dye et al., 2004; French & Swain, 1997; Swartz et al., 2011; Swartz, 2010; Walmsley, 2004a, 2001). By continuing to take a "speaking for" position rather than one of "speaking with", well-meaning enabled researchers may unwittingly contribute to *scientific silencing* – further incapacitating already subdued voices. By co-creating counter-hegemonic disability texts, intellectually impaired individuals could ensure that disability studies are not dominated by enabled researchers and their agendas, or by issues that are *only* important to professionals (French & Swain, 1997; Inglis & Cook, 2011; Swartz et al., 2011).

In helping to locate novel aspects within disability studies, intellectually impaired co-researchers could assist in preventing inclusive disability research from becoming marginalised (Gilbert, 2004; Walmsley, 2001). Inclusive research could add depth and strength to data collection; involve participants in effecting political and social processes of change; acknowledge and credit participant opinions, ideas, and insights; and contribute to facilitating participant confidence and self-esteem (Barton, 2006; Dye et al., 2004; Gilbert, 2004; Inglis & Cook, 2011; Stone & Priestly, 1996). Excluding intellectually impaired individuals from research projects might deny them indirect benefits of pride in having their contributions credited; a sense of achievement and worth gained as co-researchers; intellectual stimulation; additional attention from various professionals; and gaining awareness of their capabilities (Inglis & Cook, 2011; Sinason, 2010).

Obstacles to participation

From the outset, the burden of the consent process must be formalised in a research proposal – the onus to obtain consent is on the researcher, not on the participant to provide. Obtaining participant consent from intellectually impaired individuals presents particular ethical challenges. A significant tension exists between ensuring that participants understand the nature and implications of their research involvement, while avoiding experiences of coercion.

Appendix B

Iacano and Murray (2003, p.49) inform that there is "a need to protect vulnerable participant groups", but that there also needs to be ways of ensuring that "demands placed on researchers are not so restrictive as to preclude valuable research" (see also Marzano, 2007). London and colleagues (2011) highlight the dilemma of restrictive ethical approval processes on research in their example of how various regulatory frameworks specify the nature of information that must be included and understood in a consent form (see also Gilbert, 2004). Although understandable from a perspective of political and human rights redress, "South African regulatory requirements [Department of Health, 2004] specify 27 elements that must be included in a consent document ... [i]n the USA, federal regulations require a minimum of eight items. Given these disparate criteria, it is ... difficult to establish an acceptable minimum standard of understanding" (London et al., 2011, p. 3). A reviewer of an earlier draft of this article pondered the need to educate ethics committee personnel on conceptualising intellectual disability and on current thinking around capacity.

Consent to participate in a research project "is only binding if it was given freely, voluntarily, and without undue influence [coercion]...[p]sychologists must ensure that the information is offered at a level which is in accordance with the client's cognitive ... abilities" (Allan, 2011, p.75). The world over, consent is valid if research participants have adequate information to make an informed decision; understand the information at a cognitive level; appreciate the situation and the consequences of the decision at an emotional level; have the ability to make a rational decision; make the decision freely and voluntarily; and can communicate their decision (Allan, 2011; Carr, O'Reilly, Walsh, & McEvoy, 2010). Meeting these requirements might pose significant challenges to the inclusion of intellectually impaired adults...even if such participation might be emancipatory and empowering (Barton, 2006; French & Swain, 1997; London et al., 2011). But if we read this correctly, criteria relating to providing consent need not exclusively be measured by (a lack of) *capacity*, nor by verbal ability.

The current concept of consent is based on a dichotomous categorization: people either have or do not have capacity to consent (Dye et al., 2004). A primary concern in the context of intellectual disability research is that participants may not understand what their involvement in a study entails, and are then unable to meet the criteria for providing informed consent (Allan, 2011; Dye et al.,2004; London et al., 2011). Individuals with intellectual impairment may find it difficult to understand what research means, as well as consequences of consenting or declining to participate. One reviewer of an earlier draft of this article brought to our attention, with helpful examples, the view that capacity to consent can vary

127

Appendix B

according to the issue being addressed. For some research topics a person could be deemed as having capacity to consent (e.g. regarding their views on where they live) whereas for other topics this is not possible (e.g. participating in the trial of an experimental drug).

In research involving child participants, good practice implies gaining children's assent to participate in addition to the requirement of parental legal consent. To avoid the exclusion of potential participants with lower levels of comprehension and poorer ability to understand their involvement in research, and without referring to such persons as children, assent procedures can be initiated once consent is obtained from an authorised proxy or legal guardian.

Although obtaining consent from intellectually impaired participants should always be attempted first, the process can be conceptualised as being on a "sliding scale" relative to the nature of impairment. Participants able to consent might be of "lesser" intellectual impairment than participants able to assent (Ockert Coetzee, Personal Communication at Alexandra Hospital, 02 March 2012). This can be illustrated as follows:

Process of participation begins here ------------------------------------►

Consent ◄───────────────────────────────────────► Assent

Mild   Moderate   Severe   Profound

◄- -

Level of intellectual impairment
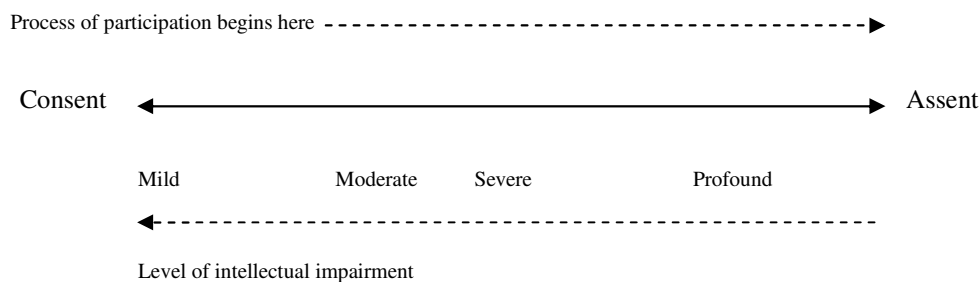
As far as the argument for *informed* consent goes, it needs to be recognised that "information alone is an inadequate predicate to meaningful choice" (Grisso & Appelbaum, 1998, p. 14 in Cameron & Murphy, 2006). Ill-explained options can be disabling – perhaps it is not so much the patient's ability to consent that is most pertinent, but the researcher's ability to explain options in a way that facilitates opportunities for making autonomous choices. It remains the researcher's task to ensure that participants have been fully informed, that they know they have a choice to decline participation, are giving informed consent to participate, and understand the consequences of deciding on non-participation (Allan, 2011; Inglis & Cook, 2011).

Obtaining consent from intellectually impaired research participants should be a careful and lengthy process. Allan (2011) informs that, in order to communicate with participants about their involvement at a level that is non-discriminating and understandable

Appendix B

without being derogatory, participants must have "enough time to make the decision" and be afforded opportunities to ask questions and consult other people if they wish to (2011, p. 75). In a similar vein to the ongoing monitoring of research ethicality post-approval by ethics committees as posited by Marzano (2007), Cameron and Murphy (2006) explain that consented participation is an ongoing process and not something established only at the beginning of contact. The greater participant control over consent at any point in the research process, the less likely it would be that research infringes the rights of participants with intellectual impairment (Cameron & Murphy, 2006; Stone & Priestly, 1996). But 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.

Conclusion

Excluding intellectually impaired individuals from participating in research based on the argument of limited capacity can be unethical and a human rights violation, especially in cases where effective measures have been put in place to assist eager individuals meet criteria for informed consent (Cameron & Murphy, 2006; Gilbert, 2004; Inglis & Cook, 2011).

In upholding ethicality when considering intellectually impaired participants as co-researchers, there are a number of criteria to be mindful of. These include planning for a prolonged and continuous process of obtaining consent and assent; adapting information sheets and consent procedures appropriately whilst avoiding deprecating use of language; assessing each potential participant's language skills in order to gauge individual levels of understanding; and communicating in participants' home language(s), or having present a person familiar to the participant who can assist with translation and communication. Of further importance would be the ongoing conceptualisation and documentation of consent (and refusal); and establishing ways of initiating, maintaining, and terminating the research relationship. Care workers' awareness of the research relationship also needs to be considered. Ultimately, the voluntary nature of participation and the participant's right to make an autonomous decision about continuing or terminating involvement is paramount.

Apart from the core ethical principles of anonymity, confidentiality, and informed consent (Swartz et al. 2011), Kittay's (2009) "fundamental ethical precepts" of epistemic responsibility or empirical adequacy (know the subject participating in the research), and epistemic modesty (know, and admit to, what you don't know) should also be considered.

Appendix B

Refreshingly, researchers might do well to acknowledge and tolerate their own ignorance and lack of knowledge (see Walmsley, 2004b). Every researcher "is still a person with [an own] stock of moral values and norms to be safeguarded" and, for that matter, to be guarded against in harmony with established ethical principles (Marzano, 2007, p.430). Ethical research practice should include peer and research supervision in addition to following relevant professional and statutory ethical codes (e.g. Ethical Rules of Conduct for Practitioners Registered under The Health Professions Act [No. 56 of 1974]). But despite containing codes, professional spaces, and guidelines, disability researchers will be required to embrace their "fear associated with the unknown and [be] willing to be vulnerable – not all-knowing [or] propped up by rules..." (Swartz et al., 2011, p.4).

A disability research space will, as Marzano (2007) informs, always force researchers to come to terms with their own identity, to reflect on the nature of the social relations that they construct in the field, on the distribution of power within these, and especially on the legitimacy of their observations.

Acknowledgements

References

Allan, A. (2011). *Law and Ethics in Psychology: An International Perspective.* Inter-Ed Publishers: Somerset West.

Barton, L. (2006). Emancipatory research and disabled people: some observations and questions. *Educational Review, 57,* 317-327.

Cameron, L. & Murphy, J. (2006). Obtaining consent to participate in research: The issues involved in including people with a range of learning and communication abilities. *British Journal of Learning Disabilities, 35,* 113-120.

Appendix B

Carr, A., O'Reilly, G., Walsh, P., & McEvoy, J. (2010). *The handbook of intellectual disability and clinical psychology practice.* Hove: Routledge.

Dye, L., Hendy, S., Hare, D., & Burton, M. (2004). Capacity to consent to participate in research – a recontextualization. *British Journal of Learning Disabilities, 32,* 144-150.

French, S. & Swain, J. (1997). Changing disability research: Participating and emancipatory research with disabled people. *Physiotherapy, 83,* 26-32.

Gilbert, T. (2004). Involving people with learning disabilities in research: issues and possibilities. *Health & Social Care in the Community, 12,* 298-308.

Grisso, T. & Applebaum, P.S. (1988). *Assessing competence to consent to treatment.* Oxford: Oxford University Press.

Iacano, T. & Murray, V. (2003). Issues of informed consent in conducting medical research involving people with intellectual disability. *Journal of Applied Research on Intellectual Disability, 16,* 41-51.

Inglis, P. & Cook, T. (2011). Ten top tips for effectively involving people with a learning disability research. *Journal of Learning Disabilities and Offending Behaviour, 2,* 98-104.

Kittay, E.V. (2009). The personal is philosophical is political: A philosopher and mother of a cognitively disabled person sends notes from the battlefield. *Metaphilosophy, 40,* 606-627.

Kittay, E.V. (2005). Dependency, difference and the global ethic of longterm care. *The Journal of Political Philosophy, 13,* 443-469.

London, L., Kagee, A., Moodley, K., and Swartz, L. (2011). Ethics, human rights and HIV vaccine trials in low-income settings. *Journal of Medical Ethics,* 1-8, [Online: 7 December 2011].

Marzano, M. (2007). Informed consent, deception, and research freedom in qualitative research: A cross-cultural comparison. *Qualitative Enquiry, 13,* 417-436.

Appendix B

Nussbaum, M. (2010). The capabilities of people with cognitive disabilities. In E.V. Kittay & L. Carlson (2010) (Eds), *Cognitive disability and its challenge to moral philosophy* (pp. 75-95). Hoboken: Wiley-Blackwell.

Republic of South Africa. (1996). *Constitution of the Republic of South Africa: Chapter 2 – The Bill of Rights*. (Act No. 108 of 1996).

Republic of South Africa. (1974). *The Health Professions Act.* (Act No. 56 of 1974).

Scottish Executive. (2000). *Adults with Incapacity (Scotland) Act. Code of Practice*. Edinburgh.

Sinason, V. (2010). *Mental handicap and the human condition: An analytic approach to intellectual disability.* London: Free Association Books.

Stone, E. & Priestly, M. (1996). Parasites, Pawns and Partners: Disability Research and the Role of Non-Disabled Researchers. *The British Journal of Disability, 47,* 669-716.

Swartz, L. (2010). *Able-Bodied: Scenes from a Curious Life.* Cape Town: Zebra Press.

Swartz, L., Van der Merwe, A., Buckland, A., & McDougall, K. (2012). Producing boundary-breaking texts on disability issues: the politics of collaboration. *Disability & Rehabilitation,* 2011, 1-8.

Tronto, J. C. (2010). Creating caring institutions: Politics, plurality, and purpose. *Ethics and Social Welfare, 4,* 158-171.

Walmsley, J. (2001).Normalisation, Emancipatory Research and Inclusive Research in Learning Disability. *Disability & Society, 16,* 187-205.

Walmsley, J. (2004a). Involving users with learning difficulties in health improvement: Lessons from inclusive learning disability research. *Nursing Inquiry, 11,* 54-64.

Appendix B

Walmsley, J. (2004b). Inclusive learning disability research: the (nondisabled) researcher's role. *British Journal of Learning Disabilities, 32,* 65-71.

Walmsley, J. & Johnson, K. (2003). *Inclusive Research with People with Learning Disabilities: Past, Present, and Futures.* London: Jessica Kinglsey Publishers.

Appendix C

ADULT WITH INTELLECTUAL DISABILITY ASSENT TO PARTICIPATE IN A RESEARCH STUDY

	STELLENBOSCH UNIVERSITY FACULTY OF HEALTH SCIENCES	

PARTICIPANT INFORMATION LEAFLET
ADULT WITH INTELLECTUAL DISABILITY ASSENT FORM

TITLE OF THE RESEARCH PROJECT: THINKING ABOUT INTELLECTUAL DISABILITY WORK: AN INTERSUBJECTIVE APPROACH

RESEARCHER NAME(S): Charlotte Capri

ADDRESS: Department of Psychology, University of Stellenbosch

CONTACT NUMBER: 084 441 5208

What is RESEARCH?

Doing research helps us find out new things about how the world works and how people work. Research helps us find out about people's feelings, thoughts, and what they like and don't like. We can also find better ways of helping all kinds of people who may not be feeling so well.

Appendix C

Some important things about research:

- You can say **YES** or **NO** about taking part in research.

- You should have a chance to say **YES!** I want to take part, or **NO!** I don't want to.

| YES! | NO! |
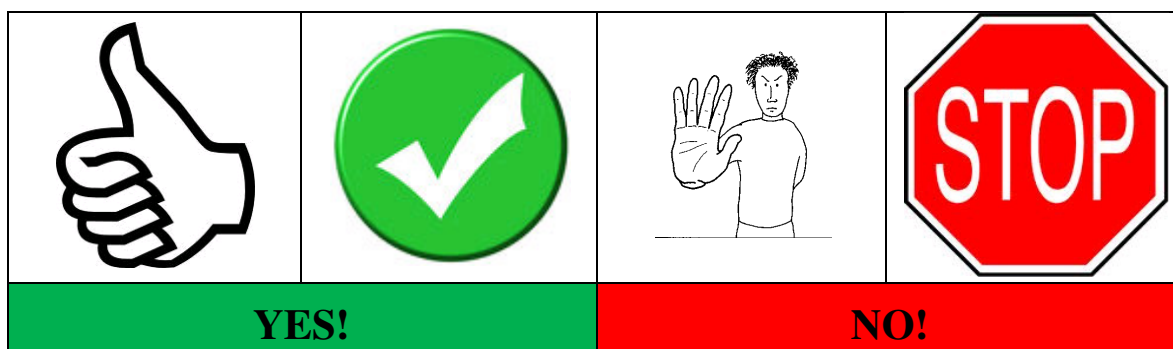
- This can be hard if it is difficult to understand things or to speak.

- Some people need more time to make a choice about research. They can take all the time they need.

Saying YES or NO:

- I have to go through this form with you, to see if you want to take part in the research.

- This will help you understand how your words can be used in the research.

- Then you can say it is ok, or not ok, for me to use your words.

- This is called giving your permission.

- Another word for permission is consent.

Who is doing the research?

- I am the researcher and my name is Charlotte. I am a psychologist.

- I am trying to find a way for you to have your say, and for more people to listen to your words.

- I am also trying to find out how to help you better.

- I must speak nicely to you and get to know you.

- To do this, I might use different ways of talking. Like pictures and signs – not just words.

Appendix C

What is this research about?

- This research is about finding ways to help you.

- One way of doing this is to listen to you. And listen to anything you want to talk about.

  - I would also like to hear about what you need where you live. And about what you need from the people who look after you.

  - I would like to find out how you are doing. And what you think about things. And how you feel about things.

Why can you help with this research?

- I need people to help me with the research.

- You can help because you live with an intellectual disability.

- That makes you an expert on intellectual disability.

- You have experiences about this that nobody else has.

What will happen to you in this study?

- This research is about finding out how to help you.

- To do this I need to find out some things about you.

- We can make a time to meet.
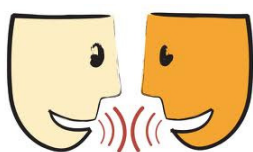
  - I will listen to anything you want to say.

  - You can talk about things you want to.

  - Together we will make sure that you are happy with your words.

- Sometimes I might need to tell other people what you say.

- I might need to talk to other people who help you.

- This is to make sure that you get the help you would like.

- I will talk to someone called Leslie about things you tell me.

- Leslie helps me with my work.

- But you must tell me if there are people that you do not want me to say anything to.

Appendix C

Can anything bad happen?
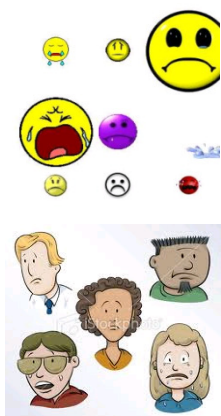
- I will try very hard to make sure nothing bad happens to you.
- Some of what you say could make you sad or angry. Or remind you of sad things. Or things you don't want to remember.
- I will try hard to listen about your sadness.
- If you want to we can talk more about it.
- Maybe there are other things that can help your sadness. We can talk about those too.

Can anything good happen?

- I hope that something good can happen to you. But I am not sure what yet.
- This is why I would like to do the research – so I can find out about helping you.

Will anyone know you are in the research?

- I will not tell anyone your name.
- I will not give out information about you.

- I will only use your words.
- I will not use your name.

- Some people will see your words but not your name. Like other people who help you. Or people who work with intellectual disability.
- But I will ask you before I let anyone see your words.
- I will keep your words safe in a file with a number on it. Not your name.
- I will lock your file away safely.

- I will keep a copy of this form.

- Your words will be put on a computer.
- This means I can make changes on the computer if we need to.

- If you want to see your words, you can just ask.
- If you want me to read you the words, you can just ask me.

Appendix C

Who can you talk to about this?
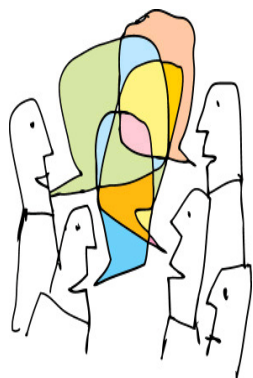
- You can talk to someone you trust about taking part in the research.
- This could be anyone. Like a friend. Or a care worker. Or another staff member. Or a family member. Is there someone like this?
- This person should check that you understand how your words will be used.
- He or she will help you understand what you are giving consent for.

What if you do not want to do this?

- You do not have to be a part of the research if you do not want to.
- You can ask me any time to stop using your words.
- If you ask me, I will not put your words on paper.
- But you can still talk to me if you want.
- Even if you said yes at the start, you can say no later.
- You will not be doing anything wrong.
- You will not get into trouble.
- You can tell me if you have any questions about our talks.
- Remember! You can say **YES** or **NO**. You decide.

Do you understand what the research is about?

138

Appendix C

Do you want to take part?

Do you have any questions about this?

Did I answer your questions?

Appendix C

Do you know that you can stop at any time?

_____   _____

Signature of participant   **Date**

CHAPTER FIVE

On developing an intersubjective frame for intellectual disability work

5.1.   INTRODUCING ARTICLE 2

This chapter comprises the second of three peer reviewed published journal articles (Appendix D) from the research, and introduces the theoretical frame that develops further and in more detail in Chapters 6, 7, and 8. The article holds a main tenet of the research, namely that an intersubjective view on disablist discourse and practice might craft an egalitarian space from which expert voices on intellectual impairment could emerge. In subsequent chapters, thoughts are offered on how such a theoretical approach can assist in the formulation of an intersubjective and relational conceptualisation of ethical care.

Using an intersubjective approach was helpful in thinking about ways to grapple with L. Swartz and colleagues' (2012) calls to challenge "traditional hegemonies of knowledge" by exploring "important voices . . . in discourses on disability" (p. 952), and I was deeply motivated to find a way of being a scribe for the voices, experiences, and opinions of "people who cannot think, remember, speak, or write" (Sinason, 2010, p. 3). Discussed in detail in the article to follow, the egalitarian ethos of intersubjectivity is facilitated by principles of power-sharing, mutually recognised subjectivity, co-creation, permissible self-disclosure and reflection on countertransference, and room for badness and the mundane. In choosing an intersubjective approach, I felt comfortable that my data collection engagements could commence in recognition of the potential for power imbalance and oppression in intellectual disability work. Working within this frame, it was expected of me to remain respectful of the research as a social and political process that emphasises anti-discriminatory practice, so essential in intellectual disability work (Reeve, 2006b).

For use in therapeutic and research encounters alike, definitions of intersubjectivity share the notion that subjectivity is central to experiencing the world (see Fonagy & Target, 2007), share scepticism about researcher neutrality or objectivity, and share the sense that research material is affected by mutual influence of researcher and participant (S. Swartz, 2006). Benjamin (1990) explains that intersubjectivity was formulated in deliberate contrast to the logic of subject and object that predominates Western philosophy and science (see Marzi, Hautmann, & Maestro, 2006; L. Swartz et al., 2012). In research and therapeutically

informed encounters, the principles of intersubjectivity theory can be applied to create the space for two people – a "third space" (Moodley, 2007, p.3) – where that which "others" us can be brought to the fore and voiced. In this way, both partners' subjectivities merge to express experiences of living and working with intellectual disability.

If intersubjective disability work can open spaces in which power differences can be acknowledged and overcome, an opportunity is created for researchers and participants (or therapists and patients) to acknowledge differences and deconstruct "othering" myths about impairment. Subjectivities of both partners can then be enabled into social action for the expression of freedom, dissatisfaction, equal (moral) rights, and individuality (Kittay, 2009). What I found most helpful in using an intersubjective frame during this research, was the way in which I was encouraged to identify and confront the defences that intellectual disability work can evoke. I was encouraged to constantly reflect on bias, stereotyping, and power differentials that may have occupied space in my countertransference, thoughts, and feelings; and to be particularly aware of how these could derail the research process (Altman, 2000).

As the research process unfolded, intersubjectivity also helped me appreciate and come to terms with the impossibility of remaining unchanged by my participants. In facing intellectual impairment, I was confronted with my own intolerance at times in very intense ways (L. Swartz et al., 2012). In thinking about such confrontations intersubjectively, it became possible to acknowledge and disarm intolerances and differences evoked by intellectual disability work . . . differences that have in the past empowered some and subjugated others. Taking on the task as scribe, I hope I was able to facilitate conditions in which the co-created "analytic third" could develop and raise an expert voice on intellectual impairment (Ogden, 1994, p.463; Sinason, 2010; S. Swartz, 2006). In Chapters 6 and 7 I hope I was able to facilitate intersubjective spaces in which the experience of impairment was no longer simply given, but ultimately voiced by the *real* experts in – those who live and work with intellectual impairment in a disabling world.

APPENDIX D

Published journal article – Disability & Rehabilitation

Appendix D

On developing an intersubjective frame for intellectual disability work

ABSTRACT

Purpose This paper aims to show how an intersubjective view on disablist discourse and practice might craft an egalitarian space from which expert voices on living and working with intellectual impairment could emerge, and attempts to further bridge psychoanalytic and disability studies.

Method The paper shares the view on dispelling the notion that intellectually impaired individuals cannot benefit from psychoanalytic psychotherapy, and speaks to the slow progression of research on intellectual disability psychotherapies. It supports disability researchers' emphasis on moving studies from a third-person reporting style toward counter-hegemonic texts, and explores a way of forefronting impaired individuals' expertise.

Results The discussion shows how subjectivities of both psychotherapist and intellectually impaired patient can intersect – thereby raising previously subdued voices to enable social action for the expression of dissatisfaction, equal (moral) rights, individuality, and freedom from disablist practices.

Conclusion Intersubjective work could offer a new way of understanding psychotherapy and research with intellectually disabled individuals differing in degree and manner of impairment; address effects of subaltern voice, marginalisation, disempowerment, and defense by equalising therapist-patient power (im)balances; and by virtue of its scientific literature base, provide a contextual clinical account of disability psychotherapy and research as anti-discriminatory political and social processes.

Appendix D

INTRODUCTION

Individuals living with intellectual impairment may face un-navigable emotional, cognitive, and social impediments; have probably experienced major abandonments, most likely suffer daily rejections, may harbour desperation to relate, and continuously internalise injurious shame: "Find me, but you mustn't look at me" [1]. Susceptible to the politics of exploitation, marginalisation, and inequality, intellectually impaired individuals are often cast as subaltern...subjugated in systems where the distribution of services, care, and other scarce resources hardly occurs in their favour and very seldom adequately [2] [3]. This is quite disconcerting, since individuals living with intellectual impairment are perpetually at risk due to an often lifelong dependence on caregivers; emotional and social insecurities; a relatively powerless, silent, and disabled position in society [4] [5]; and little opportunity and ability to independently assert access to recourse and resources.

This paper posits that an intersubjective view on disablism might invoke an egalitarian space from which intellectually impaired voices, differing in degree and manner of impairment, could emerge. As pioneered by practitioners like Valerie Sinason, it attempts to further bridge (or settle in) the gap between psychoanalytic and disability studies. Although the notion that intellectually impaired individuals cannot benefit from psychoanalytic psychotherapy has been dispelled [1], calls for research on the effectiveness of psychotherapies with these individuals seem to have been met with slow progress [6] [7] [8]. A lack of access to such services is disabling, has resulted in a historic silence by exclusion from mainstream research, and limits the availability of treatment approaches when working within this population [2] [7] [9] [10] [11] [12].

It has been argued that even unintentional exclusion of intellectually impaired individuals from access to suitable services and resources – in other words, disablist practices – are on par with those of racism and sexism, just as discriminating, and an equally serious contravention of a basic human right [13] [14] [15] [16]. The point here is that individuals may be intellectually or physically impaired, but it is their political and social environments that do the disabling. In the social model of disability, the impairment alone "is not sufficient for disablement to occur. What disables people – what *makes* people disabled – is how society responds to the impairments" (own italics for emphasis) [17]. An intellectually impaired individual becomes disabled when the environment restricts his or her status as a citizen, hampers access to resources, or obstructs his or her right to a humane life.

Swartz and colleagues explain that "traditional hegemonies of knowledge require subversion" and that "important voices have been marginalised in discourses on disability"

145

Appendix D

[15], whilst Sinason [1] reminds us that "[w]hen there are people who cannot think, remember, speak, or write, it matters that others take up the scribe function". Disability researchers emphasise the importance of moving from a third-person reporting style that continues to disable intellectually impaired voices as subordinate, toward counter-hegemonic studies and discursive texts where the experience and expert voice of impaired individuals form the core of such forums [15] [17]. By continuing to take a "speaking for" rather than a "speaking with" position, well-meaning mental health professionals and researchers may unwittingly contribute to *institutional and scientific silencing* – further incapacitating already subdued voices. "What is less clear, though", we are warned, "is how we get to this voice"; or, in avoidance of discriminatory assumptions of homogeneity in disability, *voices* [15] [17].

To date, the literature on practice-based evidence emanates from an objectivist epistemology [18]. Since the scientific development of intersubjectivity, however, Reeve explains that there is increasing support that intersubjective evidence can guide treatment, and approach research and therapeutic engagements as social and political processes emphasising anti-discriminatory practice – essential in intellectual disability work [5].

Definitions of psychoanalytic intersubjectivity vary but share two fundamental propositions: there can be no analytic neutrality or objectivity unaffected by the therapist's subjectivity; and ongoing experiences of one's subjectivity are deeply influenced by the subjectivities of those with whom one is interacting [19] [20] [21]. As Ogden helps us understand, being recognised as subjectively distinct and unique is paramount for any patient in an intersubjective therapy, but can be especially so for intellectually disabled individuals [22].

AN INTERSUBJECTIVE FRAMING

Attributable to intellectually able and impaired individuals alike, subjectivity refers to the influence of one's idiosyncrasies, personal assumptions, cultural influences, concerns and motivations upon mental activity. Definitions of intersubjectivity share the notion that subjectivity is central to experiencing the world, share scepticism about therapist neutrality or objectivity, and share the sense that therapeutic material is affected by mutual influence of therapist and patient [23] [20]. Benjamin [19] explains that intersubjectivity was formulated in deliberate contrast to the logic of "subject" and "object" that predominates Western philosophy and science [24] [15]. In egalitarian intersubjectivity, the "other" is no longer merely an object against which another's drive can be extinguished, but a subject with a separate and equivalent self [19]. Individuals living with intellectual disability are then no

Appendix D

longer containers for things we fear or despise about ourselves, but moral persons – each with a unique set of personal characteristics and distinct experiences of impairment [14] [15].

Altman [25], Aron [26], Fonagy and Target [20], Ogden [21] [22] [27] [28], Renik [29], and S. Swartz [30] [23] [31] offer a further understanding of intersubjectivity, namely that the fundamental processes motivating and organising both early development and therapeutic process originate from dyadic interactions that are co-created by participants in a relationship. Transference and countertransference are necessarily intertwined within the ever-changing therapeutic relationship, and engage against a backdrop of core psychoanalytic concepts such as projective identification (a defense almost always used by both non-verbal and verbal intellectually impaired patients) and subjective internal representations.

Intersubjectivity purposefully tracks the nature of the relationship between therapist and patient as the subjectivity and (un)conscious of both collaborate in an open manner. Eiguer [32] describes the intersubjective relationship or "intersubjective link" between therapist and patient as reciprocal, in which each unconscious is influenced by the other. The therapeutic situation remains primarily the scene of the patient's psyche, but no longer exclusively so. Whilst still emphasising the effect of the patient's inner world upon the therapeutic dyad, there is ongoing (un)conscious dialogue between patient and therapist [33]. If helpful to the therapy, the therapist may communicate her experience of the patient in a relevant and appropriate way, provided her own bias and personal agenda is investigated and contained [34].

Although attaining intersubjectivity can primarily be understood as a field created by two intersecting subjectivities, Benjamin [19] views it as a developmental progression toward achieving a capacity for mutual subjective recognition – for recognising an other and being recognised as such. The difference between subject and disempowered object then lies in the fact that an object was, during the course of a life's history, rid of its subjectivity. One can then appreciate Benjamin's [19] summary of what intersubjectivity entails, namely "where objects were, subjects must be". Ogden [22] mirrors her argument in explaining that "it is the experience of coming into being as an individual with...distinct and unique qualities" that heralds a step toward mental growth in an intersubjective therapy [35].

To illustrate how intersubjective work can bring about therapeutic change, we turn to an intersubjective hypothesis of how infants acquire knowledge about the world. Fonagy and Target [20] posit that external experience of the world is in fact one of subjectivity, as introjections of others' subjectivities are internalised. In effect, "[t]he external world thus turns out to be a world of subjectivities" [20]. Herein lies an intersubjective tool for

147

Appendix D

therapeutic change: the therapist's subjectivity is used as an external reality to be internalised as a new part of, or addition to, the intellectually disabled individual's subjectivity, inner reality, and knowledge of a world beyond the therapy room.

Similar to the notion that therapeutic material is co-created during intersubjective work, the external world is not an independently existing given to be discovered – infants gain knowledge about the world through exploration, and by using others' subjectivities (minds) to learn about the world [20]. For all practical purposes, during infancy primary caregivers *are* the world [36] [37]. Infants may assume that the knowledge they have of the world and of themselves is knowledge held by everyone. If insecurely attached infants who do not wish to know the attacking minds of their mothers go to great lengths to avoid eye contact, the kind of mind that infants with physical or intellectual impairments (and later care dependent adults) create for their caregivers warrants special attention [20] [36] [1].

Intersubjective intellectual disability work

In the relatively new field of psychotherapies for people living with intellectual impairment, there remains a poor empirical and theoretical understanding of the role and potential complexities of the therapeutic relationship [38]. Otherness, an "'us' and 'them' categorization [that] permeates our thinking...able-bodied vs. disabled", can threaten to derail psychotherapeutic encounters in which impaired patients and therapists differ visibly [15]. It might also dissuade intellectually disabled individuals in distress from accepting and benefiting from help. This raises the question of how intellectual impairment (just as language, race, culture, gender, class and age differences between therapists and their patients) might complicate a therapy [31]. Reeve [5] suggests that intellectually disabled individuals would be most empowered by a therapeutic approach that recognises the potential for power imbalance and oppression within the therapist-patient relationship.

Intersubjectivity – in principle egalitarian – seems a fitting approach as it endeavours to investigate worlds of emotional experience that take form in relational contexts, whilst studying the interplay of therapist and patient subjectivities [39] [40]. Where insight and mental growth are important, the developing relationship between therapist and intellectually disabled individual becomes particularly significant if intersubjective interaction can create conditions from which an expert voice on intellectual impairment can emerge [35]. Therapists have opportunities to hear patients "through the misunderstandings and defenses" of their own enabledness, thereby enriching therapeutic encounters with the historically "othered" [23] [15]. For Benjamin [19], working intersubjectively with intellectually

148

Appendix D

impaired individuals differing in degree and manner of impairment might make absolute sense, since such work acknowledges the differences invoked by "otherness". Ultimately, the "other" (no longer an object) exists in her own right, outside the self's inner operations. The other is then (an)other subject, with an own and separate free will [41]. Such liberating perceptions of being able, even allowed, to contemplate having free will – of separating into an independent subjectivity – might be both exhilarating and terrifying.

Intersubjective psychotherapy requires the open unconscious of both therapeutic partners to enable mutual subjective influence or inscription. Being open in this way, we are no longer hegemonically polarised as simply and categorically enabled (Kittay's "man") or disabled (Kittay's "beast"), but are two complex subjectivities that occupy different spaces on the continuum of "changing states of impairment and health" [14] [15]. It becomes possible to shift and meet on this continuum by drawing on one another's knowledge and experience. We then no longer find ourselves positioned across from, but rather relative to, one another's expertise on this range of shifting states. In intersubjective disability work we may "abandon our defenses" and become "open to another conceptual world...able to receive new knowledge, new experiences and integrate them with our own, resulting [in] a vastly richer understanding" of living with intellectual impairment [15].

The principles of intersubjectivity theory are employed to create the space for two people – a "third space" [42] – where that which "othered" us can be translated into our subjectivities and, ultimately, become our voices. In such a space our intellectual (dis)ability, physical embodiment, and artificially constructed beliefs about "otherness" are free from reproach, ridicule and revenge. In a space that facilitates shifting states of impairment and health, intersubjective work can also attempt contributions to a counter-hegemonic textual space in recognition of intellectually impaired individuals' expertise [15].

Implications for intersubjective disability psychotherapy

The intersubjective point of view has certainly brought about changes in psychoanalytic thinking over the past two decades, inducing a shift from the intrapsychic to the relational, and a purposeful change in the patient-therapist power dynamic [42]. By implication, the therapist's subjectivity and countertransference come directly into play during therapeutic encounters. In facilitating power-sharing, which should be fundamental to intellectual disability work, cautious and thoroughly considered self-disclosure on the part of the therapist (in experiencing the patient) becomes a permissible therapeutic intervention.

Appendix D

Countertransference and self-disclosure: Standard psychoanalytic technique encourages therapists to identify, restrain, and minimise the influence of their subjectivity on therapeutic functioning as far as possible; and the therapist's activity and experience should remain relatively uninfluenced by countertransference. For intersubjectivists, such a classic conceptualisation and application of countertransference compromises the extent to which a therapist's subjectivity participates in clinical events [29]. Once we recognise that therapeutic truths are co-created by partners in therapy, the rationale for complete avoidance of therapist self-disclosure becomes obsolete. Therapists can then make their experiences of a patient available to the therapy if relevant and appropriate [29].

Aron [26] explains that by disclosing aspects of inner processes and conflicts whilst working intersubjectively, therapists can conduct a self-dialogue in the presence of their patients. Such dialogue could introduce to intellectually disabled individuals the possibility of integrative or assimilative conversation between a healthy, enabled, wanted, wished for person; and the slow, rejected, abandoned, unhealthy, and impaired person [1] [43].

Power-sharing: In terms of intersubjective therapeutic collaboration with intellectually disabled individuals, something in particular around shifting the locus of expertise becomes clear [15]: intellectually impaired individuals *are* the experts on living with intellectual disability. It will be immensely problematic if the therapist as the "professional expert differs from the [patient] in what is needed"...or differs with regards to the location of the expert, embodied voice of intellectual disability [16].

Intersubjective work demands equality and a balance of power between therapy partners – it is painfully and in principle aware of the power relations that can exist between enabled/disabling therapist and impaired patient. Reeve's [5] concern is thus addressed based on the principle of a level (intersubjective) field between patient and therapist.

Rather than being an all-knowing expert on understanding the patient's psychic life, the therapist facilitates an intersubjective exchange which permits the patient to become expertly aware of *her own* psychic life. No longer the authority on intellectual impairment who cleverly reveals hidden truths to the disabled patient, therapist and patient co-create new subjective truths that can be authenticated in a more satisfactory life beyond the therapy room [28]. In following Benjamin [19], intersubjectivity asserts that only when one acknowledges and introjects projections of the other, original knowledge and co-authored truth emerge. The denial of an other's subjectivity – the infantilisation or dehumanising animalisation of intellectually disabled individuals – perpetuates the exercise of power [13] [14].

150

Appendix D

Mutually recognised subjectivity: Psychoanalysis has always maintained that a patient's subjectivity is constantly expressed within the therapeutic situation, mostly in ways of which she is unaware. Intersubjectivity accounts for the fact that the same is true for a therapist [29]. If individuation takes place through mutual subjective recognition, transference by the patient can now be understood as the "…struggle for recognition which depends on the other" [42]. In therapy, intellectually disabled individuals could use the therapist's subjectivity with which to develop new experiences of themselves in the world, making inner transformations toward mental growth [35].

Co-creation: Intersubjectivists maintains that therapist subjectivity cannot be effectively minimised, since she is constantly influenced by unconscious elements of her own personality [42] [29]. In a disability therapy this is especially true regarding reactions toward impaired individuals [1] [15] [17]. The principle of classic analytic neutrality is based on the assumption that therapists minimise their countertransference and function relatively impersonally within the clinical setting. But there lies great irony – and a location of power – in too easily assuming that patients have unconscious material that warrants examination, whilst therapists may ignore their own. In intersubjectivity, countertransference is used in the co-construction of a therapeutic experience with the patient, and need not be treated as an inconvenient or unnecessary distraction from the work. The therapeutic encounter consists of an interaction between two subjectivities – the patient's *and* the therapist's. The understanding that both gain trough therapeutic investigation is a product of interaction that could enable mental growth [35].

Intersubjective interpretations and insights are essentially mutual endeavours and always unique to the therapeutic couple that produces them. For Ogden [22], individual subjectivity and a co-created third space are devoid of meaning except in relation to one another, just as the idea of the conscious is meaningless in the absence of the unconscious.

Room for badness and the mundane: Intersubjectivity not only involves experiences in which therapist and patient feel attuned, but also allows for the voicing of dissonance. It would be doing a patient a great disfavour if unmentionable feelings of uneasiness, guilt, aggression, or disappointment (feelings that *will* challenge a disability therapy) prove a therapeutic relationship impossible or deny partners access to those aspects of their selves [44] [17]. The experience of freely voicing / vocalising or non-verbally indicating unease or

151

Appendix D

disappointment in an adaptive way could be especially enabling for individuals living with intellectual disability. Such assertion might be attempted beyond the therapy room, and, one may hope, even amiably engaged with by others.

Therapist as scribe: The activity of authoring process notes during intersubjective work with intellectually impaired individuals can be understood in light of S. Swartz's "third voice" [23]. As "textual records of encounters between mental health practitioners and their clients", the notes embody the intersubjectivity – and can pen the raised voice – that develops between psychotherapist and intellectually impaired patient [1] [23].

Overcoming disabling otherness

Defenses against embodied differences in (dis)ability will enter the therapy room [1] [15]. If left unexplored and disavowed, these defenses could derail the therapy process, alienate patients, and provoke anxiety in therapists. By fervidly commenting on the distribution of power in psychotherapeutic encounters, intersubjectivity offers a way of working with conspicuous yet often painfully silenced differences that may be glaringly present. Therapists are expected to constantly reflect on bias, stereotyping, and power differentials in their countertransference, thoughts, and feelings [25]. Intersubjectivity also allows for relational pluralism and for the appearance of multiple identities in terms of acknowledging, and therapeutically commenting on, the complex and distinctive make-up of any intellectually disabled patient's individuality [45] [46] [47].

Although the slogan "nothing about us without us" is unifying and seminal to the disability movement, we should heed caution against losing sight of the many differences among disabled persons and their experiences, and of the salient features that individuate experiences of impairment and disabling social practices [14] [17]. Where intersubjective disability psychotherapies are culminations of many intellectually disabled voices, it becomes "less important to judge which of these stories is 'correct' than to acknowledge how different they are" [15] [17]. In a collaborative and respectful way, we may discover "closer to truth; at the very least, a multi-dimensional reality" of life with intellectual impairment [15].

Within an intersubjective therapeutic frame, the encounter between therapist and patient creates a dynamic field, or third, that is constantly animated by its unique form of intersubjectivity [48]. This particular creative space in which patients can reconstruct their histories – recount memories and access their diverse meanings – is referred to in different

Appendix D

ways[5]. For such an intersubjective space to be created, Aron [26] explains that both participants must find a way from being positioned along a pendular line (disabled-abled) toward making room for the opening of psychic space…

> …transitional space, space to think, space to breathe, to live, to move spontaneously in relation to each other interpersonally. Thinking and feeling within this newly created ... space allow[s] [one] to shift from the limiting structure of a polarizing flat line to a space with possibility and depth [26].

If intersubjective therapeutic work opens up spaces in which differences in intellectual (dis)ability and power can be acknowledged and overcome, both patient and therapist can be relieved from social constructions of impairment and the "othering" myths that accompany these. In such a space, histories can be explored and reinscribed in a counter-hegemonic way to empower silenced and subaltern intellectually disabled voices [49] [50] [30]. This "third voice" [23] is raised from an egalitarian space, where once oppressed objects, experiences, and their particular meanings can be contained and reintegrated. By means of mutual inscription, subjectivities of both therapist and intellectually impaired patient can be enabled into social action for the expression of freedom, dissatisfaction, equal (moral) rights, and individuality [14].

CONCLUDING THOUGHTS

In acknowledging the effect of marginalisation on intellectually impaired individuals' subjectivities and access to voice, therapeutic spaces will be shaped and haunted by the history of abused and disabling power – in turn, patient narratives might be enacted and shaped by anxiety and defense [23]. Where an intersubjective understanding sensitises us to (dis)abling constructions of patient subjectivity, we are afforded the opportunity to understand what resides unconsciously in able-bodied therapist and disabled patient alike, to explore mutual defenses, and to question perceptions and behaviour toward individuals who can too easily be othered or constructed as different [31].

---

[5] Moodley [46] suggests calling this field a "third space", Baranger et al. (in Eiguer [32]) posit an "intersubjective field", Aron [26] mentions a "triadic intersubjectivity", Benjamin [19] writes about a "rhythmic third", Ogden about an "analytic third" [21], whilst S. Swartz introduces the intersubjective "third voice"[23].

Appendix D

Intersubjectivity emerges in a space created by partners in therapy where they, in equal parts, create S. Swartz's "third voice" [23], demanding equality and a balance of power from which to emerge. New meaning and histories are created as one projects, and, in turn, introjects the other's subjectivity. As a result, neither therapeutic partner remains unchanged. Understanding that we are never intact relates to the continual shifting states of enabledness, where being of able mind and body is actually "temporary for all of us, we get ill, we get injured, and...that othering process...the product of who we are is *always* relational" (own italics for emphasis) [15].

In facing intellectual impairment, one can expect to be confronted "up close and personal with [one's] own intolerance in quite an intense", even intolerable way [15]. In thinking about such confrontations intersubjectively, embodied differences between enabled therapist and disabled patient can be acknowledged and disarmed...differences that have in the past empowered some and cast others as subaltern. The co-created intersubjective field that uniquely develops in each therapeutic setting would be multi-vocal, constantly shifting, part conscious and part unconscious, and not easily describable [23]. But it remains the task of the therapist as scribe to facilitate conditions in which co-created "thirds" can develop and raise expert voices on intellectual impairment. In such intersubjective spaces the experience of impairment is no longer simply given, but ultimately voiced by the *real* experts – those who live with intellectual impairment in a disabling world.

ACKNOWLEDGEMENTS

DECLARATION OF INTEREST

REFERENCES

1. Sinason V. Mental handicap and the human condition: an analytic approach to intellectual disability. London: Free Association Books; 2010.

2. Adnams CM. Perspectives of intellectual disability in South Africa: epidemiology, policy, services for children and adults. Curr Opin Psychiatry 2010;23:436-440.

Appendix D

3.   Mckenzie J, McConkey R, Adnams C. Intellectual disability in Africa: implications for research and service development. Disabil Rehabil 2013;DOI: 10.3109/09638288.2012.751461

4.   Calitz FJW. Psycho-legal challenges facing the mentally retarded rape victim. S Afr J Psychol 2011;17:66-72.

5.   Reeve D. Oppression within the counselling room. Counselling and Psychotherapy Research 2006;2:11-19.

6.   Beail N, Warden S, Morsley K, Newman D. Naturalistic evaluation of the effectiveness of psychodynamic psychotherapy with adults with intellectual disabilities. J Applied Res Intellect Disabil 2005;18:245-251.

7.   Brown M, Duff H, Karatzias T, Horsburgh D. A review of the literature relating to psychological interventions and people with intellectual disabilities: Issues for research, policy, education and clinical practice. J Intellect Disabil 2011;15:31-45.

8.   Dagnan D. Psychological and emotional health and well-being of people with intellectual disabilities. Tizard Learning Disability Review 2008;13:3-9.

9.   Carulla LS, Reed GM, Vaez-Azizi LM, Cooper S, Leal R, Bertelli M, Adnams C, Cooray S, Deb S, Dirani L, Girimaji S, Kat G, Kwo, H, Luckasson R, Simeonsson R, Walsh C, Munir K, Saxena S. Intellectual development disorders: towards a new name, definition and framework for "mental retardation/intellectual disability" in ICD-11. World Psychiatry 2011;10:175-180.

10.   Gustafsson C, Öjehagen A, Hansson L, Sandlund M, Nyström M, Glad J, Cruce G, Jonsson A, Frederiksson M. Effects of psychosocial interventions for people with intellectual disabilities and mental health problems: a survey of systematic reviews. J Intellect Disabil 2011;15:31-45.

11.   Hemmings C, Inwang F, Gravestock S, Diaz Z, Lawson L, Walker, N. Treatment-resistant schizophrenia in intellectual disabilities: a case study. Advances in Mental Health and Intellectual Disabilities 2011;5:35-40.

12.   Lund C, Kleintjies S, Kakuma R, Flisher AJ, MHaPP Research Programme Consortium. Public sector mental health systems in South Africa: inter-provincial comparisons and policy implications. Social Psychiatry and Psychiatric Epidemiology 2010;45:393-404.

13.   Kittay EV. Dependency, difference and the global ethic of longterm care. J Political Philosophy 2005;13:443-469.

Appendix D

14. Kittay EV. The personal is philosophical is political: a philosopher and mother of a cognitively disabled person sends notes from the battlefield. Metaphilosophy 2009;40:606-627.

15. Swartz L, Van der Merwe A, Buckland A, McDougall, K. Producing boundary-breaking texts on disability issues: the politics of collaboration. Disabil Rehabil 2012;34:951-958.

16. Tronto J. C. Creating caring institutions: politics, plurality, and purpose. Ethics and Social Welfare 2010;4:158-171.

17. Swartz L. Able-Bodied: Scenes from a Curious Life. Cape Town: Zebra Press; 2010.

18. Arnd-Caddigan M. Toward a broader definition of evidence informed practice: intersubjective evidence. Families in Society 2011;92:372-376.

19. Benjamin J. Recognition and destruction: An outline of intersubjectivity 1990. In Mitchell SA, Aron L. Relational psychoanalysis: the emergence of a tradition. London: The Analytic Press; 1999:181-210.

20. Fonagy P, Target M. Playing with reality: IV – A theory of external reality rooted in intersubjectivity. International Journal of Psychoanalysis 2007;88:917-937.

21. Ogden TH. The analytic third: Working with intersubjective clinical facts 1994. In Mitchell SA, Aron L. Relational psychoanalysis: the emergence of a tradition. London: The Analytic Press; 1999:459-486.

22. Ogden TH. The analytic third: an overview. In Mitchell SA, Aron L. Relational psychoanalysis: The emergence of a tradition. London: The Analytic Press; 1999:487-492.

23. Swartz S. The third voice: writing case notes. Feminism & Psychology 2006;16:427-444.

24. Marzi A, Hautmann G, Maestro S. Critical reflections on intersubjectivity in psychoanalysis. International Journal of Psychoanalysis 2006;87:1297-1314.

25. Altman N. Black and white thinking: a psychoanalyst reconsiders race. Psychoanalytic Dialogues 2000;10:589-605.

26. Aron L. Analytic impasse and the third: clinical implications of intersubjectivity theory. International Journal of Psychoanalysis 2006;87:349-368.

27. Ogden TH. Re-minding the body. American Journal of Psychotherapy 2001;55:92-104.

28. Ogden TH. What's true and whose ideas was it? International Journal of Psychoanalysis 2003;84:593-606.

Appendix D

29. Renik O. Intersubjectivity in psychoanalysis. International Journal of Psychoanalysis 2004;85:1053-1064.

30. Swartz S. Can the clinical subject speak? Some thoughts on subaltern psychology. Theory & Psychology 2005;15:505-525.

31. Swartz S. The power to name: South African intersubjective psychoanalytic psychotherapy and the negotiation of racialised histories. European Journal of Psychotherapy & Counselling 2007;9:177-190.

32. Eiguer A. The intersubjective links in perversion. International Journal of Psychoanalysis 2007;88:1135-1152.

33. Brown LJ, Miller M. The triadic intersubjective matrix in supervision: the use of disclosure to work through painful affects. International Journal of Psychoanalysis 2002;83:811-823.

34. Cooper M. Towards a relationally-oriented approach to therapy: empirical support and analysis. British Journal of Guidance and Counselling 2004;32:451-460.

35. Vaslamatzis G. Object-related and intersubjective processes in psychoanalysis: a twofold perspective. International Forum of Psychoanalysis 2012;21:167-172.

36. Norman J. The psychoanalyst and the baby: a new look at work with infants. International Journal of Psychoanalysis 2001;82:83-100.

37. Trevarthen C, Aitken KJ. Infant intersubjectivity: research, theory, and clinical applications. Journal of Child Psychology and Psychiatry 2001;42:3-48.

38. Jones RA, Donati M. The therapeutic relationship in psychological therapy for individuals with learning disabilities: a review of existing literature. Advances in Mental Health and Learning Disabilities 2009;3:47-51.

39. Siebold C. What do patients want? Personal disclosure and the intersubjective perspective. Clinical Social Work Journal 2011;39:151-160.

40. Stolorow RD. From mind to world, from drive to affectivity: a phenomenological-contextualist psychoanalytic perspective in attachment. New Directions in Psychotherapy and Relational Psychoanalysis 2011;5:1-14.

41. Gerhardt J, Sweetnam A, Borton L. The intersubjective turn in psychoanalysis. A comparison of contemporary theorists: part 1: Jessica Benjamin. Psychoanalytic Dialogues 2000:10:5-42.

42. Oliner MM, Bohleber W. Intersubjectivity, recognition and the problem of the negative. International Journal of Psychoanalysis 2006;87:259-262.

Appendix D

43.   Newman D, Beail N, MacLean Jr W.E. Analysis of assimilation during psychotherapy with people who have mental retardation. American Journal on Mental Retardation 2005;110:359-365.

44.   Mitchell SA. Aggression and the Endangered Self. Psychoanalytic Inquiry 1998;18:21-30.

45.   Devisch R. A psychoanalytic revisiting of fieldwork and intercultural borderlinking. Social Analysis 2006;50:121-147.

46.   Moodley R. Outside race, inside gender: A good enough "holding environment" in counselling and psychotherapy. Counselling Psychology Quarterly 2005;18:319-328.

47.   Tatar M, Bekerman Z. The concept of culture in the contexts and practices of professional counselling: A constructivist perspective. Counselling Psychology Quarterly 2002;15:375-384.

48.   Cambray J. Who's really there? Dreams and the analytic third. Psychoanalytic Psychology 2002;19:772-776.

49.   Marzano M. Informed consent, deception, and research freedom in qualitative research: a cross-cultural comparison. Qualitative Enquiry 2007;13:417-436.

50.   Swartz L. Race, gender, and the impossibilities of care. Med Humanities 2012;38:34-37.

CHAPTER SIX

Nurses' experiences of care on adult psychiatric intellectual disability wards

6.1.   INTRODUCING ARTICLE 3

As did Chapters 4 and 5, this chapter offers a published peer reviewed journal article on research with nurses who work as carers of individuals living with psychiatric illness and intellectual disability on inpatient wards in public psychiatric hospitals (Appendix E). Drawing from the work presented in the previous chapter, Chapter 6 begins to show how an intersubjective frame can be useful when researching intellectual disability care. Specifically, the intersubjective approach is operationalised by applying Hollway and Jefferson's (2013) free association narrative interview (FANI) method, which meets the study's objective of co-creating intersubjective knowledge, foregrounding under-investigated professional contributions, avoiding "speaking for" participants, and facilitating a self-representative research environment.

Whilst individuals living with intellectual disability in South Africa are yet to be supported in taking up space as researchers in the ethics of care literature, knowledgeable nurses perform unseen but indispensable care work on inpatient intellectual disability wards – but expectations of organisational staff well-being and support remain disappointed. The nursing care drain (or migration) from South Africa to care resource and care policy rich countries is well documented, with more promising opportunities for employment having a profound effect on the availability and quality of nursing care in general and intellectual disability care specifically (Adnams, 2010, Child, 2013, Ford, 2013; Ford & Stephenson, 2014; George & Reardon, 2013; Kittay et al. 2005, Lintern, 2013, McKenzie et al., 2013a; Reynolds et al., 2013; Rispel, 2013; Stilwell et al., 2004; Tronto, 2010; Wildschut & Mqolozana, 2008). In reviewing the literature for this article, I found insufficient theory acknowledging intellectual disability nursing care experiences, with a notable dearth in the South African intellectual disability literature. Yet the needs of intellectual disability nurses are instrumental to care outcomes, and doing something important with what they have to say becomes urgent against the care drain backdrop (Kittay et al., 2005; Tronto, 2010).

In this article, I aim to highlight some of the issues that make the exchange of ethical care difficult in, for example, a South African psychiatric hospital mandated by the state to care for adult inpatients living with psychiatric illness and intellectual disability. Rose (2011) argues that to effectively support individuals with intellectual disability " . . . the system in which they live needs to be considered, and staff are one of the most important elements of the care system" (p. 403). Similarly, Kittay (2001, 2009) advocates for intellectual disability patient care by emphasising the fundamental importance of caring for their carers, and staffing issues are central to developing high-quality intellectual disability care services (Hatton et al., 1999). By offering some insight into the care conditions behind the migration of South African nurses, and what they feel needs to change, I hope I have managed to accurately capture under-researched contributions toward dependency care and intellectual disability literature by gathering nurses' self-reported concerns, insights, and knowledge.

This article's response to paucity of theory concerning nurses' psychiatric intellectual disability care experiences, which relied on a collaborative generation of knowledge between researchers and participants, was ultimately motivated by a call for counter-hegemonic perspectives on disability issues (L. Swartz et al., 2012; McCabe & Holmes, 2009). It is hoped that, as co-creators of this research, psychiatric intellectual disability nurses can have both frustrating and rewarding aspects of their care work received and acknowledged without reproach; can enforce some input in the ways institutional controls above them are implemented; and see these sources of institutional control engage with them in a way that might co-produce new patterns of non-exploitation and non-exclusion (Kittay, 2005; Sinding, 2010; L. Swartz, 2011; Tronto, 2010).

Given staff impact on patient care and the adverse effects of nursing migration on dependency care, the article credits great value to nurses' needs and voices for the purpose of both patient and nurse ethical care. Within intellectual disability care research, marginalisation could be addressed, nurse-to-patient and institution-to-nurse care practices may garner serious attention, and opportunities for improvements in intellectual disability care work may arise.

APPENDIX E
Published journal article – Journal of Applied Research in
Intellectual Disabilities

Appendix E

"We have to be satisfied with the scraps": South African nurses' experiences of care on adult psychiatric intellectual disability inpatient wards

ABSTRACT

Aim: Migrating nursing labour inadvertently reinforces South Africa's care drain, contributes to a global care crisis, and forces us to reconsider migration motivation. This paper highlights issues that complicate psychiatric intellectual disability nursing care and identifies loci for change in an attempt to redress this care challenge.

Method: An exploratory descriptive-interpretivist method investigated nurses' experiences of psychiatric intellectual disability work. 16 free association narrative interviews were collected in 2013. Thematic analysis allowed findings to emerge from the data.

Results: Findings reflect a number of themes: *'relational interaction', 'care burden', 'system fatigue', 'infantilising dynamic of care'*, and *'resources for coping'*.

Conclusion: System fatigue contributes more to negative experiences of providing care than direct patient work, and nurses experience more relational reciprocity from patients than from institutional management. Organisations should meet nurses' needs for burnout prevention, afford them impact in implementing institutional controls, and engage in a non-exploitative and non-exclusionary way.

Keywords: *intellectual disability; psychiatric hospital; nursing migration; care drain; intersubjectivity theory; FANI method*

Appendix E

INTRODUCTION

By highlighting issues that currently make intellectual disability nursing care provision difficult in a South African public psychiatric hospital, this research hopes to appreciate possible motivations behind care migration and identify potential loci for change in an attempt to redress this care challenge. By gauging and capturing the self-reported concerns, insights, and experiences of psychiatric intellectual disability nurses, the study contributes to global literature on dependency care and to South African intellectual disability literature.

Whilst knowledgeable nurses perform unseen yet indispensible work on inpatient intellectual disability wards, often with little expectation of organisational support for their well-being, mental health services and care resources are rarely distributed in favour of individuals living and working with intellectual impairment (Adnams 2010, Friedman *et al*. 2012, Kittay *et al.* 2005, Lewis & Stenfert-Kroese 2010, Mckenzie *et al*. 2013, Stenfert Kroese *et al.* 2013a). Further complicating this dispersal of care is a well documented nursing migration from South Africa, where nurses' voices in how *they* in turn are cared for remain unheard, to countries richer in care resources and policy. Although more promising, attractive employment opportunities abroad profoundly affect the availability and quality of nursing care in general, and of intellectual disability care specifically, in developing countries like South Africa (Adnams 2010, Child 2013, Ford 2013, Ford & Stephenson 2014, George & Reardon 2013, Kittay *et al.* 2005, Lintern 2013, Mckenzie *et al*. 2013, Reynolds *et al.* 2013, Rispel 2013, Stilwell *et al.* 2004, Wildschut & Mqolozana 2008).

By withdrawing labour, expertise, and training from their country of origin, migrating nurses reinforce a care drain and inadvertently contribute to a global care crisis (Kittay *et al*. 2005). Despite efforts made to date, little seems to stem this migration – two out of three nursing students intend to leave South Africa post-qualification (George & Reardon 2013, George & Rhodes 2012, Pillay 2009, Stilwell *et al.* 2003, Wildschut & Mqolozana 2008, Yeates 2011). This forces us to reconsider factors that contribute to care migration. The voices, needs, and well-being of nurses are instrumental to patient treatment outcomes (Stenfert Kroese *et al.* 2013a), and doing something important with what they have to say becomes urgent against a global care crisis backdrop (Kittay *et al.* 2005).

Individuals caring for patients living with intellectual disability may find themselves sharing experiences of stigmatisation and exploitation (Mitchell 2000). Job dependency may result in silent endurance and further subjugation since such work is rarely well-paid, and appropriate training often unattainable (Kittay 2001, 2009, Stenfert Kroese *et al.* 2013a, Tronto 2011). Although South African nurses can specialise in psychiatric nursing at a post-

163

Appendix E

qualifying level, and pre-qualifying student nurses in public service are assigned rotations on intellectual disability services (IDS) wards, recognised specialist education in intellectual disability care is not yet available.

If intellectual disability care work remains inadequately appreciated, poorly compensated, and the occupation of less respected and more marginal groups (Mitchell 2000), its "invisible" and secondary status in South African society and elsewhere requires critical reflection (Swartz *et al.*, 2012, p. 4). After all, to effectively provide care for patients, "...the system in which they live needs to be considered, and staff are one of the most important elements of the care system" (Rose 2011 p. 403). This lends further importance to the notion that South African nurses' experience, knowledge, and voices must be taken up in decisions on intellectual disability care if we are to make any inroads toward improving nurses' well-being.

Framing intellectual disability care and research intersubjectively

Intersubjective care

This study locates itself within intersubjectivity theory and hopes to further bridge psychoanalytic and disability studies. Subjectivity refers to the influence of one's idiosyncrasies, personal assumptions, cultural influences, concerns, and motivations upon mental activity (Renik 2004). In applying definitions of intersubjectivity, we see that they view subjectivity as central to experiencing the world of intellectual disability nursing, admit scepticism about the neutrality or objectivity any of us may claim to hold regarding intellectual impairment care, share the sense that care interactions are affected by mutual influence of care provider (organisational decision-makers and nurses alike) and care receiver (nurses and patients alike), and assume an ongoing (un)conscious dialogue between care participants (Brown & Miller 2002, Fonagy & Target 2007, Ogden 1994, 1999, 2001, 2003, Renik, 2004, Swartz 2005, 2006, 2007).

Ultimately never intact, we are all being created by the other just as we are creating the other during any interaction. And this applies not only to nurses' experiences of interacting with or caring for patients, but also to experiences of being interacted with or cared for in turn by institutional decision-makers and hospital managers. A decision-maker's subjectivity would include assumptions held about intellectual disability, patient needs and their care, as well as assumptions held about their nurses' care needs. In the day-to-day operationalisation of these assumptions (in the form of care resources made available and resultant working conditions for care to be performed in), they would constantly be used by

Appendix E

nurses to be internalised as experience and knowledge of a world in which their efforts at care are celebrated or disavowed.

Kittay *et al.* (2005) address this relational aspect of caregiving as it occurs in psycho-social contexts that (re)produce care participant experiences. In sharing intersubjective care spaces, and considering that we are never intact, we are reminded of our culpability in making an other person while being made into a kind of person. This leaves us wondering about the kinds of nurses that are constantly being made as a result of decision-making that influences the environments in which nurses provide care.

Intersubjective research

A call for fresh perspectives on disability care issues further motivates this study's exploration into the range of nurses' experiences, and does so by means of intersubjectivity informed research (McCabe & Holmes 2009, Swartz *et al*. 2012), which relies on a collaborative generation of knowledge between researcher and participant.

Taken up further in the method section, Hollway and Jefferson's (2013) free association narrative interview (FANI) method meets the objective of co-creating intersubjective knowledge, foregrounds under-investigated professional contributions, avoids 'speaking for' participants, and facilitates a self-representative research environment. In conceptualising this research within an intersubjective frame, we use the principles of intersubjectivity theory to create a space for two people, a "third space" (Moodley 2007, p.3), in which Swartz's "third voice" (2006, p.427) can emerge. In such a space between nurse and researcher, an intersubjective third voice on working with intellectual disability can emerge. This third space from which research unfolds can only be called into being because of the unique intersubjective interactions, or voices, that develop between participants and researcher.

Because an intersubjective research space allows for the creation of a unique dynamic field between researcher and participant, this field cannot be formulated in advance of a research encounter. Beautifully termed as a space from which a "matrix of possible stories" on working with intellectual disability can emerge, a creative space is brought into being for capturing a variety of unpredictable research outcomes and in which anything can happen (Ferro 2002 in Eiguer 2007, p.1136).

Appendix E

AIMS

Although a number of quantitative investigations validate concerns that intellectual disability staff well-being affects nursing care (Rose 2011, Skirrow & Hatton 2007, Thompson & Rose 2011, Vassos & Nankervis 2012), few research spaces have afforded intellectual disability nurses opportunities to express uncircumscribed opinions given the objectivist ontology of quantitative studies (Bryman 2012). Furthermore, individuals living and working with intellectual disability currently occupy little space in the global ethics of care and South African intellectual disability literature. An electronic database review (Web of Science, Scopus, and Pubmed/NCBI) of the South African literature published over the past 25 years (1988-2014) found a notable dearth in theory acknowledging psychiatric intellectual disability nurses' experiences when compared to a growing body of literature from other countries.

Since few South African qualitative studies pertaining to intellectual disability nurses well-being are available, concerns are raised regarding uncaptured knowledge. As researchers in South Africa, we take up Thompson and Rose's (2011) invitation to focus on services for individuals with intellectual disability in order to "address this relatively neglected area of research" (p. 191). Where "important voices have been marginalised in discourses on disability" (Swartz *et al*. 2012, p. 952), collaborating intersubjectively with nurses within a qualitative research paradigm can contribute to fresh perspectives on intellectual disability care. Intellectual disability nurses' expert voices and experiences can then be included in decision-making processes that pertain to their own as well as patient care – enabling nurses' ability to provide care, improving organisational support for their well-being, and ultimately improving patient service quality. Given the adverse effects of the nursing migration, nurses' needs and voices must be accredited more value for the purpose of both patient and carer well-being.

By offering perspectives that could challenge existing power relations, the study hopes to influence ways in which institutional controls above nurses are implemented; co-produce with nurses new possibilities for non-exploitation and non-exclusion; and identify loci for possible improvement in the well-being of nurses working with intellectual disability. It is hoped that findings also resonate with readers who plan, implement, and manage decisions on intellectual disability care, add to literature devoted to psychiatric intellectual disability nursing, and contribute to a conceptualisation of nurses' own needs for care (Kekana *et al.* 2007). By adding to an international collection of care literature as well as to South African intellectual disability literature, marginalisation could be addressed (Mitchell

Appendix E

2000), nurse-to-patient and organisation-to-nurse care practices may garner serious attention (Stenfert Kroese *et al.* 2013a), and opportunities for improvements in care policy and practice may arise.

METHOD

An exploratory descriptive-interpretivist method investigated nurses' experiences of intellectual disability work in a psychiatric hospital, with individual interview data collected from participants in 2013. Since the study was open to the unfolding of myriad perspectives on psychiatric intellectual disability nursing, no hypotheses could be made prior to data collection. Collaboration with participants regarding research design, data collection, and findings was informed by the study's intersubjective theoretical framework. Hollway and Jefferson's (2013) free association narrative interview (FANI) method of collecting data operationalised our aim of creating between each research dyad a unique intersubjective field from which a voice on intellectual disability work can emerge. Participants took up roles as nursing storytellers, and researchers as listeners and scribes (Hollway & Jefferson 2013). In co-creating research material, researchers did not assume leading roles but rather those of co-constructors of knowledge, and, within the intersubjective frame, could account for their own subjectivities in the narrative field.

Data collection and analysis

Collection Under the South African Mental Health Care Act (RSA 2002), nurses provide care for adult inpatients living with mental illness and intellectual disability in a South African public psychiatric hospital. All respondents to our invitation to participate comprised the study population. Participants included 16 Black and Coloured male and female qualified nurses registered with the South African Nursing Council (terminology in the Employment Equity Act, RSA 1998). Participant demographics are offered in Table 1, but not to an extent that would compromise participant anonymity. Part-time nurses on adult intellectual disability wards, and nurses on outpatient or non-intellectual disability inpatient wards were excluded from participating.

Free association narrative interviews approximating 60 minutes were performed with 16 participants in privacy and convenience on their wards. The interviewer is a registered clinical psychologist trained in psychotherapy. No assumptions were made about participants' experiences, who were only asked: 'Tell me about intellectual disability nursing'. Since narratives elicited by free association "secure access to a person's concerns,

167

Appendix E

which would probably not be visible using a more traditional method" (Hollway & Jefferson 2013, p. 34), applying the FANI method suited the study's aim of intersubjectively co-creating fresh perspectives on intellectual disability with participants. Ultimately, the FANI method operationalises the aim of partnering with participants who feel comfortable to share experiences unconditionally held and valued by researchers.

With participants' permission interviews were voice recorded and transcribed. English was not necessarily participants' first language, and some participants elected to be interviewed in Afrikaans (see Table 1). The interviewer was fluent in both English and Afrikaans. isiXhosa speaking participants declined the service of a translator, feeling comfortable to conduct their interviews in English. Interviews conducted in Afrikaans were translated into English. Transcripts were back translated to ensure the integrity of the original narratives, and kept securely as evidentiary research data.

Detailed notes that were made during and after interviews represent observational material that could only be called into existence by unique interactions between researcher and participants. The activity of taking interview notes is understood in light of Swartz's conceptualisation of the intersubjective "third voice" (2006, p. 427). As "textual records of encounters" between researcher and participants, the notes assist in embodying the intersubjective "third voice" that develops in the distinctive space created by each research dyad (Swartz 2006, p. 427).

Table 1: Participant demographics

Participant	Gender	Race	Nursing Rank	Years Experience	Interview Language
1	Female	Coloured	Operational Manager	11 years	English
2	Male	Coloured	Registered Nurse	21 years	English
3	Female	Coloured	Area Manager	28 years	English
4	Female	Coloured	Registered Nurse	16 years	Afrikaans
5	Female	Black	Area Manager	19 years	English
6	Male	Black	Registered Nurse	3 years	English
7	Female	Coloured	Operational Manager	15 years	Afrikaans
8	Female	Coloured	Area Manager	29 years	English
9	Female	Coloured	Operational Manager	26 years	Afrikaans
10	Female	Coloured	Registered Nurse	20 years	English
11	Female	Coloured	Operational Manager	17 years	Afrikaans
12	Female	Coloured	Registered Nurse	19 years	English

Appendix E

13	Male	Black	Registered Nurse	24 years	English
14	Female	Black	Registered Nurse	11 years	English
15	Female	Coloured	Registered Nurse	30 years	Afrikaans
16	Female	Coloured	Registered Nurse	26 years	English

Analysis Listening for emerging themes as interviews progressed, notes made during and after interviews were triangulated with the audio-recordings and transcriptions (Mello 2002, Terre Blanche *et al.* 2006). Specifically, data were analysed by means of thematic analysis, and participant narratives served as the primary units of analysis (Babbie & Mouton 2007). Since "[w]e present ourselves … in terms of our stories or narratives" (Levett 2002, p. 70), the narrative formats employed were both verbal and non-verbal communication (Ochs & Capps 1996, Parker 2005). Themes were identified by thoroughly rereading interview transcripts and notes (see Table 2). Data saturation was attributable to rich material and participants' general experiences. Interpretations are evidenced in the results and discussion section by referencing existing literature, and by verbatim participant accounts that capture salient features of nurses' experiences from different levels within the nursing department (see Table 1).

Table 2: Summary of themes

Themes	Sub-themes
Relational interaction	Fulfilment, reciprocity, meaningfulness, pride, noble self-perception
Care burden	Demanding patient behaviour , difficulty of care, threat of physical harm, constant vigilance, corporal care, violations of bodily integrity, powerlessness, ward as work environment, advocating against disabling discrimination and stigmatisation whilst being stigmatised
System fatigue (organisational factors)	Heavy work load, mental and physical depletion, critical staff shortage, chronic staffing issues, staff inadequacy
System fatigue (lack of organisational support: little care for the carer)	Feeling abandoned, exploited, unacknowledged, devalued, marginalised, scapegoated, judged, unheard regarding patient care requirements, embattled, disregarded, disrespected, unappreciated, emotionally exhausted, depersonalised
Infantilising dynamic of care	Institutional defenses including attachment injury and reducing anxiety, lack of preparation through formal training, limited opportunities for further training
Resources for coping	Internal and external sources, taking leave, designated counselling, reliable reciprocated and functional support

Appendix E

Ethical considerations

Ethical clearance was obtained from the Health Research Ethics Committee of Stellenbosch University's Faculty of Health Sciences (Federal Wide Assurance Number: 00001372; Institutional Review Board Number: IRB0005239). Approval for collecting data was obtained from the Department of Health and the hospital ethics committee. Various meetings were attended throughout 2012 where the research was open to comments from intellectual disability services external to the research site.

Potential participants met with researchers for purposes of introductions, reiterating study goals and processes, and addressing questions and uncertainties; and their inputs were incorporated into the research design. Involvement was voluntary on condition of written informed consent, and nurses were informed on risks and benefits of participating. They could withdraw from the study at any time, or ask that their narrative not be included. Anonymity was ensured, participants were not remunerated nor did they pay to participate, and no intentional harm came to them. Participants could access counselling referrals if narrative material was experienced as distressing.

Validity

Participant feedback was employed as a means of verifying findings. To this end, participants were consulted on the accuracy of interview transcriptions and on the interpretive validity of results (Babbie & Mouton 2007). They were asked for feedback on the interpretation of their narratives, and could affirm research results as credible or negate those that inaccurately reflected their experiences. Additional information to confirm or amend aspects of the data could then be volunteered. Participants were eager for positive experiences to complement those of fatigue and work stress, and emphasised that direct patient care activities contributed less to such stress than did organisational and managerial issues.

RESULTS and DISCUSSION

A qualitative researcher may decide to "present the findings on their own, without supporting discussion", or, as done here, "link the findings with the work of other researchers" (Burnard 2004, p. 178). We also acknowledge that the terms 'intellectual disability' and 'intellectual impairment' interchange in this paper, but where "*disability* is recognized as a social construction" (Casper & Talley 2005, p. 115), a reading of the social model of disability cautions us against locating disability *in* an individual rather than in the surrounds of

Appendix E

disabling social, cultural and political inhibitions that encumber impairment (Goodley *et al*. 2012, Richardson 1997).

Nurses have been conceptualised as "frontline workers" who often carry the burden of stress in helping individuals with intellectual disability "live their day-to-day lives" (Vassos *et al*. 2013, p. 3884). Despite paucity in literature on South African intellectual disability nurses' subjective experiences, colleagues in other countries enjoy some presence in quantitative publications on burnout along psychosocial dimensions of emotional exhaustion, depersonalisation, and little sense of personal accomplishment (Hastings & Horne 2004, Kozak *et al*. 2013, Maslach *et al*. 2001, Rose *et al*. 2012, Skirrow & Hatton 2007, Thompson & Rose 2011, Vassos & Nankervis 2012, Wahl & Newmark 2009); and along dimensions of stress and burnout associated with absenteeism, leaving employment, lower productivity, and poorer quality of care (Vassos & Nankervis 2012, Vassos *et al*. 2013).

It has been suggested that intellectual disability nurses face challenges in reconciling patient care with role ambiguity, control over workload demands, resources, workplace support, low job status, coping skills and emotional exhaustion, interpersonal conflicts, and job security (Devereux *et al*. 2009, Kekana *et al*. 2007). Following equity theory's relational reciprocity determined by contributions to and gains from a relationship with either positive or negative outcome, staff perceiving work-based relationships as lacking in reciprocity experience higher levels of burnout and are more likely to resign (Disley *et al*. 2012, Thomas & Rose 2010). Narratives offer participant experiences of reciprocity from patients, with seemingly little forthcoming from institutional management.

Positive outcomes of intellectual disability nursing work may mitigate negative outcomes (Hastings & Horne 2004), but research on rewarding experiences occupies little space in the literature. Data on gratifying aspects of intellectual disability nursing emerged from experiences of relational care interaction. Participants also revealed stressful experiences, as support for abovementioned factors of burnout surfaced from narratives of emotional and physical depletion. Apart from positive outcomes, our findings address research aims via additional themes of care burden, system fatigue due to organisational factors and a lack of organisational support, and an infantilising dynamic of care; and suggest internal and external sources of coping with intellectual disability nursing demands (see Table 2). Most significantly, system fatigue seemingly contributed more to nurses' negative experience of providing intellectual disability care than did working with often difficult to care for patients. Limitations of the research and suggestions for further research are discussed prior to offering some concluding thoughts.

Appendix E

Relational interaction

Dependency "[c]aregiving involves a direct, intimate relationship between two or more people. It is both deeply emotional and a rational, pragmatic, and practical endeavour" (Kittay *et al*. 2005, p. 444), and participants find fulfilment in being "*actively involved*" in "*the caring part of nursing*" patients (P7). Its proximity confronts them with human fragility, whilst its emotional significance can moderate the physicality of mundane daily care practices as underscored in watershed moments: "*After a month he put out his hand and smiled. I thought: 'This is what I'm here for'. That was a big thing...a milestone...I was happy*" (P1).

Although some patients cannot verbalise: "*We don't know how they feel...it makes it more difficult*" (P1), participants tell of reciprocal interactions that travel beyond hands-on carer and cared-for, and hold a capacity for communicating with little need for words: "*Somehow...they try to respond*" (P1). Although patients may vocalise or employ body language to make themselves understood, they may find it difficult to understand nurses' attempts at communicating. Mutual understanding can be achievable if nurses and patients are attuned to one another. Where responding to care requirements remains frustrating, the availability of simple augmentative communication devices could serve to mediate care communication (Hemsley *et al*. 2001).

Taking reciprocal meaning from intellectual disability work whilst improving patients' well-being brings to mind Wahl and Newmark's (2009) "paradox of caring" – nurses both give and receive care that improves their state of mind and patients' lives. Feeling needed provides fulfilment and incentive to continue confronting intellectual disability work's challenges. Coetzee and Cilliers (2001) advise that meaningfulness, where challenges are worth energy expended in meeting them, could serve as psychofortigenic protection against demanding work environments: "*It's not easy working with clients like that...I enjoy the challenge*" (P1); "*I feel proud*" (P10); "*I enjoy doing the work*" (P12), "*I feel good, because I meant something to someone ... it's my passion to work with the patients*" (P9), "*to help people...who can't help themselves...it's a blessing to me*" (P6).

Pride in intellectual disability work might reflect a noble self-perception of caring for wholly dependent adults (P1, P6, P10, P13, P15). The ambivalent nature of intellectual disability nursing is expressed by participant ten: "*I love my work, because who's going to do it?*", indirectly recognising the contradiction of loving a kind of work that entails caring for individuals who can be difficult to love. The nobility in intellectual disability work, because

172

Appendix E

or in spite of its challenges, might contribute to personal accomplishment protecting against burnout (Maslach *et al*. 2001).

Care burden

Challenging, aggressive behaviours that inflict physical and psychological harm upon nurses are often elevated among patients with intellectual disability in institutional settings (Knotter *et al*. 2013). Individuals caring for patients with unpredictable behaviours experience considerable work stress, and perceptions of challenging behaviour are predictive of burnout (Chung & Harding 2009, Farrell *et al*. 2010, Knotter *et al*. 2013, Noone & Hastings 2009). Participants experience demanding patients as difficult to care for (P6, P7, P8, P12, P16), and frequently described "*low functioning*" (P4), aggressive, violent, and self-injurious behaviours with patients often injuring themselves: *"...one client knocked his head against the Perspex glass*" (P1).

Patients fight one another, and hit, kick, or challenge staff (P4, P8). Both are in equal danger of being attacked or bitten, and hurt by or thrown with objects: "*One moment it's a block to play with, the next you get thrown with it*" (P1); "*This client just grabbed a chair and threw me with [it]*" (P10). Assault on staff has occurred: "*One client just came behind me and grabbed me, trying to loosen my pants. I was screaming...it was very scary...it was traumatic, I had to go to counselling*" (P14), justifying fear of aggressive patient behaviour: "*I was very scared I could be hit. They know you're afraid*" (P10). A constant vigilance pervades: "*There are guys that you will always be cautious around...expecting anything to happen*" (P14), and the impact of watchfulness and fear obviates caregiving: "*What he did is still affecting me. I can end up not giving quality care*" (P14). No longer able to successfully perform care duties might evoke feelings of inefficacy and ultimately constrict nurses' care activities, expended effort, and capacity to persevere amidst difficult work, thereby encumbering patient care and nurses' psychological well-being (Coetzee & Cilliers 2001).

Nursing adults with intellectual disability and cerebral palsy is a corporal, taxing endeavour: "*The patient just lies there. You must do everything, then you are very tired*" (P9), as is working with elderly intellectual disability and diplegic patients (P4, P7, P16): "*We had to lift...some needed 110% care*" (P10). Working at the 'back wards' with residents with multiple disabilities can be professionally stifling: "*For my own sanity and my development, I cannot go to the back [wards]*" (P11). Auto-coprophagic patients are difficult to care for, even for experienced nurses: "*You won't expect someone to eat his own faeces. For me it's nothing*

Appendix E

new. It just puts you off at times" (P1), and invasion of boundaries results in uncomfortable experiences: "*He's got this way of coming up to you with his lips...to kiss you*" (P1).

Participants feel overwhelmed by noisy, restless, hyperactive, and disruptive patients who break things, steal each other's meals, and chew paper or diapers when unsupervised. This can be particularly hard to contain when patients resist attempts at discipline or struggle to learn limits: "*You're trying to show: 'I'm not angry...tell me your problem'. It doesn't work, and the patient wants to fight*" (P14). Feeling unable to manage patient behaviours, nurses may fear being overpowered by patient responses to limit setting. Such a sense of powerlessness could cause nurses to perceive themselves as ineffective and unproductive, further complicating patient care. Where demanding patient behaviours may adversely affect carer well-being and treatment outcomes, the importance of supporting nurses in acquiring self-identified coping resources is crucial (Bilgin & Gozum 2009, Farrell *et al*. 2010, Hemsley *et al*. 2001, Ingham *et al*. 2013).

Intellectual disability work requires acclimatisation to the sensory onslaught of its sights, smells, and sounds. Participants mention the effect of daily patient-related noise levels on their well-being (P7): "*I had a headache...I realised it's the noise*" (P14), and emphasise wards' malodour: "*I must first take a breath before I can come inside*" (P9). One participant relayed her shock upon first arriving on a ward for individuals living with severe intellectual disability: "*When they put me in [ward number] I had a massive shock then I said: 'Is there people like this?'*", and novice and new nurses leave quickly: "*When we get new staff and place them in [ward number]...minute notice...they're gone*" (P11).

Calls for action against patient violation are reported as participants advocate against disabling discrimination (P2, P8): "*These are human beings, not animals!*" (P3), but being associated with intellectual disability, nurses and the hospital itself are "*undermined*" (P5) and stereotyped even by fellow professionals: "*They ask: 'Where are you working?' and then you say [hospital's name], and they say 'die malhuis!?' [the madhouse!?]...they believe that, when you work there you're also mad*" (P3). Such stigmatisation is evident (see also Mitchell 2000): "*They mock at us also...people label me*" (P8) and plausible given Northway's (1997) explanation that "people are often judged by their profession" (p.738), whilst stigmatising "*nasty comments*" (P3) may corrupt work experiences once proudly held in esteem.

System fatigue

Organisational factors A heavy work load can lead to emotional fatigue (P4, P8): "*Sometimes it feels so overwhelming*" (P1), further burdening the weighty responsibility for multiple wards:

Appendix E

"*One of our area managers was resigning, because he couldn't deal*" (P1) (Kekana *et al.* 2007). Secondary to mental and physical depletion (P4, P13, P15), stress-related skin rashes, physical pain, and back problems associated with lifting are participants' reality (P8, P12), whilst 12-hour shifts consume family hours: "*You get tired, working long hours...when you get home you don't really have time for your family, you just want to get in the bath and into bed*" (P10), and participants find themselves being unintentionally "*miserable*" to family members (P8).

Contributing to participants' stress and fatigue, staffing issues include a grossly inadequate number of nurses across the hospital's intellectual disability service, nurses' safety concerns, work overload, covering for absent colleagues, lack of discipline, staff confrontations, little cooperation, low staff morale, and few male nurses (P4, P5, P6, P7, P8, P9, P12, P13, P15, P16). In reference to gender issues contributing to nurses' stress (Stenfert Kroese *et al.* 2013b), female participants explain that aggressive patients are mostly male, and that clusters of male patients make them nervous. Situations can rapidly escalate when uncontained patients disregard female nurses: "*...they won't listen to anything women say*" (P14).

Managerial participants convey challenges of staffing difficulties: "*Absenteeism*" (P5), "*different dynamics, personalities, ages...it's extremely exhausting*" (P11), and older nurses' attitudes on account of age can be tricky to manage (P4, P5, P7, P9): "*They know better and you can't tell them that. Sometimes it's difficult for a younger professional nurse to manage*" (P3). Participants frustratingly have to repeat themselves, or experience aggravation upon arriving on a ward to find neglected duties of care among "*lazy...selfish*" (P11) and nonchalant staff: "*I know certain staff that just don't care...they know somebody else can do [the work]*" (P3).

Staff inadequacy pertains to insufficient numbers of nurses on wards and ill trained staff (P4, P7), with little professional resources for patient care and few personal resources for handling inadvertent ward situations (P5) (Stenfert Kroese *et al.* 2013a). Amidst staff cuts (P4, P5, P8) leaving a single nurse on night duty per ward, every participant reported a shortage of nurses across the intellectual disability service, rendering the provision of quality care impossible: "*There's times when there's just one [nurse] on a shift*" (P1); or "*...with 30 patients ... and then we are only four people. We are two on that [male] side [of the ward] and two on this [female] side*" (P11). If one nurse is expected to care for seven or eight mobile adult psychiatric patients with intellectual disability, a sense that "*the system is failing*" (P8) gravely problematises above illustrated care demands.

Lack of organisational support: little care for the carer Mascha (2006) explains that "staff working in the field of human services have to deal constantly with the physical,

175

Appendix E

mental and emotional problems of their clients and...without proper support, can experience extensive psychological and emotional pressure" (p.191). This can result from feeling surveilled, marginalised, unacknowledged, exploited and undervalued despite having "*sacrificed [a] whole life*" (P8). Participant eight feels that her "*own colleagues fail*" her, whilst others do not experience support by peers, superiors, or hospital executives (P4, P6, P7, P12, P13, P15): "*Nobody supports us. When something happens in a ward…the nurses are pushed down*" (P9), feeling exploited within the larger hospital system: "*They properly exploit me, I sometimes feel so abused ... like floor polish*" (P11). Whilst a perceived lack of support from colleagues and supervisors relates to burnout, participant experiences of support are ambiguous at best (Kekana *et al.* 2007, Skirrow & Hatton 2007).

Disley *et al.* (2012) explain that nurses may experience stress due to scrutiny in intellectual disability organisational settings. Participants report that patient incidents are investigated as if nurses are at fault, and they often feel surveilled. On one ward in particular, Closed Circuit Television monitoring is used to do so. Managers must write statements on ward incidents even if not on duty at the time, nurses feel blamed for incidents despite being upset by them (P2, P4, P8, P13, P15), and reports are subsequently discussed in their absence.

Moreover, participants feel judged by other hospital professionals: "*Sometimes [the doctors are] very nasty...they laugh about ID things or they criticise*" (P3). Examples abound of requesting items necessary for care duties, engaging in years-long struggles to have caregiving requirements met (P5, P6, P7, P8, P13, P15, P16). These include enough nurses, enriching age appropriate interactive material (patients may become violently uncontained when bored), linens when ordered (intact seasonal clothing, correctly sized footwear, blankets in winter), adult disposable diapers *versus* cloth diapers (for patient and staff health – soiled cloth diapers already in short supply are sluiced by hand, and adult patients use many per day), and requests for security guards on locked wards with volatile patients (for patient and staff safety). Although nurses can access care essentials, and are eventually allocated some requested care resources, this typically involves a lengthy administrative "*battle*" (P14) during which nurses must strenuously "*motivate and complain*" (P11) before requests are heard: "*The nurse's voice is not always so important unless it's the doctor... if it's a nurse who sees there's a need then they won't jump to help you*" (P14).

Blumenthal *et al.* (1998) already associated emotional exhaustion with staff beliefs that their opinions are neither received nor considered by their organisation, leaving them feeling as if "*[n]obody cares*" (P6), and that they should rather "*leave this institution*" (P4). A narrative of abandonment ensues...since "*no-one listens*" (P4), nurses

176

Appendix E

> *have totally no say ... nobody wants your ideas ... even if you are told you are the backbone of the hospital, you are like a dog that needs to be placed there and must do that ... it doesn't make sense. Even if you say how you feel, nobody takes note. People at the top have no clue what's going on. Sometimes you feel: 'Must I still work here?'* (P5).

Compared to other countries, intellectual disability mental health care (and its nurses) remains subjugated within psychiatry as an unrecognised specialty, or even sub-specialty, in South Africa:

> *The entire institution makes me angry, because they treat IDS like a stepchild. We have to motivate harder to get things...be satisfied with the scraps. Psych will always get better because those patients can speak and complain. We complain because our patients cannot. We must always wait longer...we feel like the stepchild of the hospital* (P11).

Participants feel neither acknowledged nor appreciated when providing care beyond the circumscribed burden of duty, even when producing evidence for additional inputs. The relevance of invaluable yet unappreciated 'invisible labour' becomes clear. Nurses may perceive themselves as giving more than they receive from institutions in return. Thomas and Rose (2010) warn that this perceived lack of reciprocity – little care for the carer – drains emotional resources and nurses' "investments in the working relationships, by responding to patients in a depersonalised way ... the helping relationship deteriorates and a lack of personal accomplishment ensues as failures increase" (p. 168).

As participant four explains, "*I like these clients, but ... I can't give them what I want*". Participants narrate emotional exhaustion, depersonalisation, and system fatigue – the result of fighting to do good work in unworkable systems, extinguishing nurses' energy for the patients in their care: "*We'll do only what we are here for*" (P14) "*...because this is not new...this problem is known...we don't feel taken care of*" (P6). Where Skirrow and Hatton (2007) predict burnout in intellectual disability nurses who are "giving more than they received in return" from institutions (p.138), participant five continues to "*do the work, do my best, and don't expect anybody to recognise it*". But since burnout may negatively affect care interactions and quality, and patient treatment outcomes in turn, it is crucial that intellectual disability nurses be seen and heard by institutional management, considered in care decisions, and validated for supererogatory efforts in a withholding care system – "*doing the work of two people ... not taking lunch or tea breaks*" (P12), or taking up the slack of housekeeping and kitchen duties (P4, P5, P16).

177

Appendix E

Infantilising dynamic of care

An infantilising care dynamic emerged powerfully during the free association narratives. Participants remind themselves that "*forty year old*" patients "*with the mental age of a three or five year old*" (P4) may not appreciate behavioural antecedents or consequences: "*It does not help to get angry...it is their illness*" (P11); "*They don't know what they're doing*" (P1). Formal training did not prepare participants for the realities of intellectual disability care (P4), and witnessing "*adults wearing nappies*" was a "*rude awakening*" (P1, P6), whilst bursaries, opportunities, and time for further training are made available arbitrarily (P2, P4). Nurses habitually cast adults with intellectual disability as children, remanding them to a care relationship that negates developmental experiences of maturing and benefiting from treatment as adults with adult privileges.

Caring for adult patients with intellectual disability as eternally childlike might serve two functions. In intellectual disability work, a nurse-patient bond may closely resemble one shared between mother-carer and child, with patients pulling from nurses an attachment essential for survival. Where patients cannot verbally and timely communicate needs, such attunement is invaluable (Hemsley *et al*. 2001) and as a treatment and care variable, affords the anticipation of patient needs by reading body language(s) or by familiarity with patients' personality (P7). Not initiated consciously but now institutionally ubiquitous, infantilisation might also help nurses resolve anxiety provoking daily confrontations with realities of intellectual impairment. Not disavowing the potential negative impact on individuals living with intellectual disability, (Askheim 2003, Malacrida 2009; McConkey *et al.* 1999; Salari 2008), infantilisation may assist nurses with maintaining esteem whilst facing life engulfing disability – patients are no longer adults with a tragic impairment, but less distressingly held in mind as "*special children stuck in a phase*" (P1).

Participants describe Ainsworth's (1969, p. 2) "affectional tie" with patients in simulation of a parent-child bond: "*I grew attached quickly...I'm a mommy at work*" (P1); "*I came to love them, they are my children...this is your home, you look after the children, you are the mother*" (P11). The tenet that attachment requires a desire for proximity that otherwise suffers distress (Fonagy 2001) is illustrated: "*We have to prepare them for the community, but when they go...I am very sad...I have to walk away*" (P11), and despair followed a patient death: "*I couldn't function. He left a gap in the ward*", an event that justified support for staff (P5).

178

Appendix E

A typical attachment bond involves a mother's affinity to indulge her child, relishing in its joy and perhaps in her power to please or compensate. As 'mothers', nurses take pleasure in occasionally cosseting patients since "*any child likes to be spoiled*" (P1), whilst taking pleasure in patients' delight: "*Last year I bought [play material]...it was like Christmas! I felt good, doing something for them*" (P1). Participant eleven concurs: "*We will think: 'Okay it's your birthday, I'll bake for you'...or I will think I have a jacket at home, this one needs a nice jacket*". In supererogatory care acts, participants travel beyond circumscribed duties to meet their and patients' needs for care amidst withholding ward life (P5, P7).

Notwithstanding infantilisation's possibly defensive counter to demanding intellectual disability care work, one ponders the impact on professionalism of work 'mommies' minding 'cute' perpetual adult-infants. The value of attachment as part of the human condition and moderator of treatment outcome is not denied, but an even unconscious infantilising care dynamic might thwart treatment goals of ultimately discharging dignified adult patients into community care.

Resources for coping

Participants "*must continue, [and not] become discouraged*" (P11), and even when "*sick with the flu*" (P12) or "*very tired ... still give 100%*" (P10). Internal and external resources for coping with work demands were identified, an absence of which could ironically collapse intellectual disability mental health nurses' own mental health. Faith (P6, P7, P8), integrity and introspection (P4, P5), multitasking or "*a simple thank you*" (P12), dedication and determination (P4, P5, P6, P8, P12, P16), experience (P4, P8), informal support groups (P6, P12), structure (P16) and endurance may serve as coping resources where intellectual disability nurses must "*pull through*" (P9) and "*just go on*" (P10).

A helpline is available but participants rarely use it, although counselling could mitigate work stressors (P4, P7, P8): "*It would have been nice to know that there would be someone sitting there that...if I'm having this feelings that I'm bottling up...I can go talk to. We don't have that*" (P14). Having a designated mental health professional was suggested to meet this need – in a field that trades in mental health, intellectual disability nurses' need for such a service remains paramount. Taking time off helps participants cope: "*It feels so overwhelming ... like now I feel I need a leave*" (P3), but the lack of adequate intellectual disability nurses invariably affects leave opportunities (P12, P16).

Appendix E

Participants reiterate the importance of reciprocal and functional support in alleviating work stress (Kekana *et al*. 2007). To subsequently deliver quality care, nurses must be able to rely on colleagues and institutional management in order to cope with daily intellectual disability work stressors.

Limitations and future research

Free association interviews allowed an unconstrained unfolding of perspectives on intellectual disability nursing. The research's capacity for holding intellectual disability care ambiguities in its findings by not demarcating participant responses is seen as a strength. But the repercussions for generalisability cannot be denied, and narratives might have been subject to social desirability. Moreover, participants were very experienced day-shift nurses and the majority were female – shift and gender bias cannot be discounted (see Stenfert Kroese *et al.* 2013b), and newer nurses' possibly idealised experiences could not be included. Drawing a sample from a single psychiatric facility further impedes generalisability by excluding participant experiences from other research sites.

Many topics introduced here can be taken forward by ascertaining more generalisable findings. Future research could investigate positive experiences of intellectual disability nursing in alleviating stress and mitigating migration, and develop coping interventions for numerous intellectual disability work demands to enable quality patient care. Further research should address professional marginalisation, gain more ground for attending to institution-to-nurse care practices, and identify additional opportunities for recruiting and retaining South African nurses by improving psychiatric adult intellectual disability care working conditions. South African intellectual disability nurses' experiences can be compared to those of nurses working in the same field in other countries, or to those in other fields of nursing care, in order to investigate if and how caregiver experiences and motivations to migrate differ.

CONCLUSION

Often undervalued in the South African mental health community, intellectual disability nurses hold invaluable yet unrecognised knowledge on psychiatric intellectual disability care. Continuous rewarding-frustrating care interactions require an ability to hold ambiguity and take what consolation nursing interventions can offer. Intellectual disability nurses guard against physical and emotional exhaustion, but also against system fatigue – needing the system in which to do their work, but battling the same system so that they can do their work. A significant finding from this research suggests that system fatigue contributed more to

Appendix E

nurses' negative experience of providing intellectual disability care than did working with often difficult to care for patients.

Ultimately, South African psychiatric intellectual disability nursing is a sub-specialty deserving of respect and, in acknowledgement of its practitioners' specific knowledge, skills, and expertise, might do well to gain recognition as a specialty in its own right. The identified necessary resources for managing its demands requested for the sake of patient care must be attributed managerial attention, gravitas, and budget – at the very least, equitable distribution of these. Should patient needs and intellectual disability nurses' efforts at meeting them remain marginalised, the care drain might persist. Additionally, training should attend to preparation for the realities of psychiatric intellectual disability work (Stenfert Kroese *et al.* 2013a) whist care institutions should seriously consider nurses' self-identified coping resources against burnout and system fatigue.

Since nurses seemingly experience more relational reciprocity from patients with intellectual disability than they do from institutional management, results suggest that nurses should have more input in ways institutional controls above them are implemented, and be engaged with in a non-exploitative and non-exclusionary way. Findings underscore the necessity of modifying institutional processes so as to better accommodate intellectual disability nurses' care needs and improve nurses' well-being in an attempt to retain their expertise, knowledge, and service amidst a global care crisis.

Author contributions: All authors have agreed on the final version and meet the following criteria [recommended by the ICMJE (http://www.icmje.org/ethical_1author.html)]:
- substantial contributions to conception and design, acquisition of data, or analysis and interpretation of data
- drafting the article or revising it critically for important intellectual content

Conflict of interest: No conflict of interest has been declared by the author(s).

Appendix E

REFERENCES

Adnams C.M. (2010) Perspectives of intellectual disability in South Africa: epidemiology, policy, services for children and adults. *Current Opinion in Psychiatry* **23,** 436-440.

Ainsworth M.D.S. (1969) Object relations, dependency, and attachment: a theoretical review of the infant-mother relationship. *Child Development* **40,** 969–1025.

Anderson K.T. (2008) Intersubjectivity. In The SAGE Encyclopaedia of Qualitative Research Methods (Given L.M., ed) doi:10.4135/9781412963909.

Askheim O. P. (2003) Personal assistance for people with intellectual impairments: experiences and dilemmas. *Disability & Society* **18**, 325-339.

Babbie E. & Mouton J. (2007) *The Practice of Social Research*. Oxford University Press, Cape Town.

Bilgin S. & Gozum S. (2009) Reducing burnout in mothers with an intellectually disabled child: an education programme. *Journal of Advanced Nursing* **65,** 2552–5261,

Blumenthal S., Lavender T. & Hewson S. (1998) Role clarity, perception of the organisation and burnout amongst support workers in residential homes for people with intellectual disability: a comparison between a National Health Service trust and a charitable company. *Journal of Intellectual Disability Research* **42**, 409–417.

Brown L. J. & Miller M. (2002) The triadic intersubjective matrix in supervision: the use of disclosure to work through painful affects. *International Journal of Psychoanalysis* **83**, 811-823.

Bryman A. (2012) *Social Research Methods* (4th ed). Oxford University Press, New York, New York.

Burnard P. (2004) Writing a qualitative research report. *Accident and Emergency Nursing* **12,** 176–181.

Appendix E

Casper M. J. & Talley H.L. (2005) Preface: Special Issue: Ethnography and disability studies. *Journal of Contemporary Ethnography* **34,** 115–120 doi:10.1177/0891241604272323.

Child, C. (2013) Nursing in SA is in crisis. *The Times,* 29 July 2013. Available at: http://www.timeslive.co.za/thetimes/2013/07/29/nursing-in-sa-is-in-crisis?service=print (accessed on 21 January 2014).

Chung M.C. & Harding C. (2009) Investigating burnout and psychological well-being of staff working with people with intellectual disabilities and challenging behaviour: the role of personality. *Journal of Applied Research in Intellectual Disabilities* **22,** 549–560.

Coetzee S. & Cilliers F. (2001) *Psychofortology: Explaining coping behaviour in organisations.* Available at: http://www.siop.org/tip/backissues/TipApr01/08Coetzee.aspx (accessed on 12 October 2013).

Devereux J., Hastings R. & Noone S. (2009) Staff stress and burnout in intellectual disability services: work stress theory and its application. *Journal of Applied Research in Intellectual Disabilities* **22,** 561–573.

Eiguer A. (2007) The intersubjective links in perversion. *International Journal of Psychoanalysis* **88,** 1135-1152.

Disley P., Hatton C. & Dagnan D. (2012) Inputs and outcomes: what do staff in services for people with intellectual disabilities perceive they bring to and receive from their work-based relationships? *Journal of Intellectual Disabilities* **16,** 297–306.

Farrell G.A., Shafiei T. & Salmon P. (2010) Facing up to 'challenging behaviour': a model for training in staff–client interaction. *Journal of Advanced Nursing* **66,** 1644–1655,

Fonagy P. (2001) Introduction to attachment theory. In *Handbook of Attachment: Theory, Research, and Clinical Applications* (Hack R.D., ed), Guilford Press, New York, New York, pp. 1–18.

Appendix E

Fonagy P. & Target M. (2007) Playing with reality: IV – A theory of external reality rooted in intersubjectivity. *International Journal of Psychoanalysis* **88**, 917-937.

Ford, S. (2013) Quarter of trusts seeking nurses overseas, claims RCN. *Nursing Times,* 24 September 2013. Available at: http://www.nursingtimes.net/nursing-practice/clinical-zones/management/quarter-of-trusts-seeking-nurses-overseas-claims-rcn/5063539.article (accessed on 21 January 2014).

Ford, S. & Stephenson, J. (2014) Year starts with multiple warnings of staff shortages. *Nursing Times,* 11 January 2014. Available at: http://www.nursingtimes.net/nursing-practice/clinical-zones/management/year-starts-with-multiple-warnings-of-staff-shortages/5066977.article (accessed on 21 January 2014).

Friedman S.L., Helm D.T. & Woodman A.C. (2012) Unique and universal barriers: hospice care for aging adults with intellectual disability. *American Journal on Intellectual and Developmental Disabilities* **117,** 509–532.

George G. & Reardon C. (2013) Preparing for export? Medical and nursing student migration intentions post-qualification in South Africa. *African Journal of Primary Healthcare and family Medicine* **5,** 1-9.

George G., & Rhodes B. (2012) Is there really a pot of gold at the end of the rainbow? Has the Occupational Specific Dispensation, as a mechanism to attract and retain health workers in South Africa, leveled the playing field? *BMC Public Health* **12,** 613 -621.

Goodley D., Hughes, B. & Davis, L. (2012) Introducing disability and social theory. In *Disability and Social Theory: New Developments and Directions* (Goodley D., Hughes, B. & Davis, L., eds), Palgrave Macmillan, New York, New York, pp. 1-14.

Hastings R. & Horne S. (2004) Positive perceptions held by support staff in community mental retardation services. *American Journal of Mental Retardation* **109,** 53–62 doi:10.1352/0895-8017(2004)109<53:PPHBSS>2.0.CO;2.

Appendix E

Hemsley B., Sigafoos J., Balandin S., Forbes R., Taylor C., Green V.A. & Parmenter, T. (2001) Nursing the patient with severe communication impairment. *Journal of Advanced Nursing* **35,** 827–835,

Hollway W. & Jefferson T. (2013) *Doing Qualitative Research Differently: A Psychosocial Approach* (2nd ed) Sage, London, England.

Ingham B., Riley J., Nevin H., Evans G. & Gair E. (2013) An initial evaluation of direct care staff resilience workshops in intellectual disabilities services. *Journal of Intellectual Disabilities* **17,** 214–222.

Kekana H.P.P., du Rand E.A. & van Wyk N.C. (2007). Job satisfaction of registered nurses in a community hospital in the Limpopo Province in South Africa. *Curationis* **30,** 24-35.

Kittay E.F. (2009) The personal is philosophical is political: a philosopher and mother of a cognitively disabled person sends notes from the battlefield. *Metaphilosophy* **40,** 606-627.

Kittay E.F., Jennings, B. & Wasunna, A.A. (2005) Dependency, difference and the global ethic of longterm care. *The Journal of Political Philosophy* **13,** 443-469.

Kittay E. F. (2001) When caring is just and justice is caring: justice and mental retardation. *Public Culture* **13,** 557–579.

Knotter M.H., Wissink I.B., Moonen X.M.H., Stams G.J.M. & Jansen G. (2013) Staff's attitudes and reactions towards aggressive behaviour of clients with intellectual disabilities. *Research in Developmental Disabilities* **34,** 1397–1407.

Kozak A., Kersten M., Schillmöller Z. & Nienhaus A. (2013) Psychosocial work-related predictors and consequences of personal burnout among staff working with people with intellectual disabilities. *Research in Developmental Disabilities* **34,** 102–115.

Levett A. (2002). Problems of cultural imperialism in the study of child sexual abuse. In P. Reavy & S. Warner (Eds.). *New feminist stories of child sexual abuse: Sexual scripts and dangerous dialogue.* Routledge, New York.

Appendix E

Lewis S. & Stenfert-Kroese B. (2010) An investigation of nursing staff attitudes and emotional reactions towards patients with intellectual disability in a general hospital setting. *Journal of Applied Research in Intellectual Disabilities* **23,** 355−365.

Lintern S. (2013) NHS facing potential nurse workforce crisis, study warns. *Nursing Times,* 19 February 2013. Available at: http://www.nursingtimes.net/nursing-practice/clinical-zones/management/nhs-facing-potential-nurse-workforce-crisis-study-warns/5055044.article (accessed on 21 Jnauary 2014).

Malacrida C. (2009) Gendered ironies in home care: surveillance, gender struggles and infantilisation. *International Journal of Inclusive Education* **13**, 741-752.

Mascha K. (2006) Staff morale in day care centres for adults with intellectual disabilities. *Journal of Applied Research in Intellectual Disabilities* **20,** 191–199.

Maslach C., Schaufeli B. & Leiter, M. (2001) Job burnout. *Annual Review of Psychology* **52,** 397–422.

McCabe J.L. & Holmes D. (2009) Reflexivity, critical qualitative research and emancipation: a Foucauldian perspective. *Journal of Advanced Nursing* **65,** 1518–1526.

McConkey R., Morris I. & Purcell M. (1999) Communications between staff and adults with intellectual disabilities in naturally occurring settings. *Journal of Intellectual Disability Research* **43,** 194-205.

Mckenzie J., McConkey R. & Adnams C. (2013) Intellectual disability in Africa: implications for research and service development. *Disability & Rehabilitation* **35,** 1750-1755

Mello R. A. (2002) Collocation analysis: A method for conceptualising and understanding narrative data. *Qualitative Research* **2**, 231-243.

Appendix E

Mitchell D. (2000) Parallel stigma? Nurses and people with learning disabilities. *British Journal of Learning Disabilities* **28,** 78-81.

Moodley R. (2007) (Re)placing multiculturalism in counselling and psychotherapy. *British Journal of Guidance and Counselling* **35**, 1-22.

Noone S.J. & Hastings R.P. (2009) Building psychological resilience in support staff caring for people with intellectual disabilities. *Journal of Intellectual Disabilities* **13,** 43–53.

Northway R. (1997) Disability and oppression: some implications for nurses and nursing. *Journal of Advanced Nursing* **26,** 736–743.

Ochs E. & Capps L. (1996) Narrating the self. *Annual Review of Anthropology* **25**, 19-43.

Ogden T. H. (1994) The analytic third: Working with intersubjective clinical facts. In S.A. Mitchell & L. Aron (1999) (Eds), *Relational psychoanalysis: The emergence of a tradition* (pp. 459-486). The Analytic Press, London.

Ogden T. H. (1999) The analytic third: An overview. In S.A. Mitchell & L. Aron (Eds), *Relational psychoanalysis: The emergence of a tradition* (pp. 487-492). The Analytic Press, London.

Ogden T. H. (2001) Re-minding the body. *American Journal of Psychotherapy* **55**, 92-104.

Ogden T. H. (2003) What's true and whose ideas was it? *International Journal of Psychoanalysis* **84**, 593-606.

Parker I. (2005) *Qualitative psychology: Introducing radical research*. Open University Press, Berkshire.

Pillay R. (2009). Retention strategies for professional nurses in South Africa. *Leadership in Health Services* **22,** 39-57.

Appendix E

Republic of South Africa. (1998) *Employment Equity Act 55 of 1998.* Available at: http://bee.b1sa.co.za/docs/The%20Employment%20Equity%20Act%201998.pdf (accessed on 22 May 2014).

Republic of South Africa. (2002) *Mental Health Care Act 17 of 2002.* Available at: http://www.justice.gov.za/legislation/acts/2002-017_mentalhealthcare.pdf (accessed on 27 April 2013).

Renik O. (2004) Intersubjectivity in psychoanalysis. *International Journal of Psychoanalysis* **85**, 1053-1064.

Reynolds J., Wisaijohn T., Pudpong N., Watthayu N., Dalliston A., Suphanchaimat R., Putthasri W. & Sawaengdee K. (2013) A literature review: the role of the private sector in the production of nurses in India, Kenya, South Africa and Thailand. *Human Resources for Health* **11,** 1-12.

Richardson M. (1997) Addressing barriers: disabled rights and the implications for nursing of the social construct of disability. *Journal of Advanced Nursing* **25,** 1269–1275.

Rispel L. (2013) *Quality of Patient Care and the Activities of Hospital Nursing Unit Managers in South Africa: A Paradox?* Theta Tau International's 24th International Nursing Research Congress, Prague, Czech Republic, 25 July 2013.

Rose J. (2011) How do staff psychological factors influence outcomes for people with developmental and intellectual disability in residential services? *Current Opinion in Psychiatry* **24,** 403–407.

Rose J., Mills S., Silva D. & Thompson L. (2012) Client characteristics, organizational variables and burnout in care staff: the mediating role of fear of assault. *Research in Developmental Disabilities* **34,** 940–947.

Salari S. M. (2008) Infantilization as elder mistreatment: Evidence from five adult day centers. *Journal of Elder Abuse & Neglect* **17,** 53-91.

Appendix E

Skirrow P. & Hatton C. (2007) 'Burnout' amongst direct care workers in services for adults with intellectual disabilities: a systematic review of research findings and initial normative data. *Journal of Applied Research in Intellectual Disabilities* **20,** 131–144.

Stenfert Kroese B., Rose J., Heer K. & O'Brien A. (2013a) Mental health services for adults with intellectual disabilities – what do service users and staff think of them? *Journal of Applied Research in Intellectual Disabilites* **26,** 3-13.

Stenfert Kroese B., Rose J., Heer K. & O'Brien A. (2013b) Gender issues for people with intellectual disabilities and mental health problems: asking what service users and staff think. *Advances in Mental Health and Intellectual Disabilities* **7**, 181-190.

Stilwell B., Diallo K., Zurn P., Vujicic M., Adams O. & Dal Poz M. (2004) Migration of health-care workers from developing countries: strategic approaches to its management. *Bulletin of the World Health Organisation* **82,** 595-600. Available at: http://www.scielosp.org/scielo.php?script=sci_arttext&pid=S0042-96862004000800009&lng=en&nrm=iso (accessed on 21 January 2014).

Stilwell B., Diallo K., Zurn P., Dal Poz M. R., Adams O. & Buchan J. (2003) Developing evidence-based ethical policies on the migration of health workers: conceptual and practical challenges. *Human Resources for Health* **1**, 1-8.

Swartz L., Van der Merwe A., Buckland A. & McDougall K. (2011) Producing boundary-breaking texts on disability issues: the personal politics of collaboration. *Disability & Rehabilitation* **34,** 951–958.

Swartz S. (2007) The power to name: South African intersubjective psychoanalytic psychotherapy and the negotiation of racialised histories. *European Journal of Psychotherapy & Counselling* **9**, 177-190.

Swartz S. (2006) The third voice: Writing case notes. *Feminism & Psychology* **16**, 427-444.

Swartz S. (2005) Can the clinical subject speak? Some thoughts on subaltern psychology. *Theory and Psychology* **15**, 505-525.

Appendix E

Terre Blanche M., Durrheim K. & Painter D. (Eds.) (2006) Research in Practice. University of Cape Town Press: Cape Town.

Thomas C. & Rose J. (2010) The relationship between reciprocity and the emotional and behavioural responses of staff. *Journal of Applied Research in Intellectual Disabilities* **23,** 167−178.

Thompson L. & Rose J. (2011) Does organizational climate impact upon burnout in staff who work with people with intellectual disabilities? A systematic review of the literature. *Journal of Intellectual Disabilities* **15,** 177−193.

Tronto J. C. (2011) Creating caring institutions: politics, plurality, and purpose. *Ethics and Social Welfare* **4,** 158−171.

Vassos M.V. & Nankervis K.L. (2012) Investigating the importance of various individual, interpersonal, organisational and demographic variables when predicting job burnout in disability support workers. *Research in Developmental Disabilities* **33,** 1780−1791.

Vassos M.V., Nankervis K.L., Skerry T. & Lante K. (2013) Work engagement and job burnout within the disability support worker population. *Research in Developmental Disabilities* **34,** 3884–3895.

Wahl S. & Newmark R. (2009) Die self-waargenome lewensgehalte van versorgings-personeel by 'n fasiliteit vir volwassenes met intellektuele gestremdheid [The self-perceived quality of life of staff caring for adults with intellectual disabilities]. *Tydskrif vir Geesteswetenskappe* **49,** 287−304. Available at: http://www-scopus-com.ez.sun.ac.za/record/display.url?eid=2-s2.0-68849109955&origin=inward&txGid=5333FE7E1D0B1D5765E51CD5359CE9E0.ZmAySxCHIBxxTXbnsoe5w%3a5 (accessed on 26 March 2013).

Wildschut A. & Mqolozana T. (2008) Shortage of Nurses in South Africa: Relative or Absolute? In: *A multiple source identification and verification of scarce and critical skills*

Appendix E

in the South African labour market. Commissioned by the Department of Labour. HSRC, Pretoria.

Yeates N. (2010) The globalization of nurse migration: policy issues and responses. *International Labour Review* **149,** 423-440.

CHAPTER SEVEN

An intersubjective and relational conceptualisation of care: Residents' voices raise implications for ethics of care on adult psychiatric intellectual disability wards

Making care matter(s): Caring about the people we make, making people with care

We human beings are the sorts of beings we are because we are cared for by other human beings.
Eva Feder Kittay (2009, p.625)

7.1.   INTRODUCTION

Whilst the previous chapter demonstrated how an intersubjective frame can be useful when researching care experiences of intellectual disability work, Chapter 7 begins to think about ethical care as relational and intersubjective. As discussed in the literature review and addressed in Chapter 4, research by or co-constructed with true experts on living with intellectual disability in South Africa is yet to gain momentum. Presented to Eva Kittay, other speakers, and attendees at a workshop in Stellenbosch on 21 May 2015, this chapter introduces the care experiences of adults living with intellectual disability on psychiatric hospital wards by bringing their voices to the fore. On adult psychiatric intellectual disability wards in the Western Cape we are attempting to move toward patient-centred care, but amidst limitations on ethics of care training and beleaguered nursing care, I wonder whether implementing and practicing ethics of care has a chance. This chapter aims to show how psychiatric intellectual disability care spaces can offer sites at which to observe dependency care as it reproduces (and is produced by) care exchanges that may limit the performance of ethical care. Verbatim quotes from nurses and residents, as well as field note entries included throughout the discussion, also urge us to consider care participants' expressed emotional needs for comfort, containment, warmth, and reassurance so easily obscured by medicalisation and bureaucratised understaffed psychiatric care.

Although *apartheid* as an institution has been formally dismantled, it lingers as we reproduce power differentials in the politics of human worth. In an aged yet salient example, the 2001 National Census Survey found a 0.5% prevalence of intellectual disability but excluded individuals in institutional care, effectively remanding them to a silent non-entity that literally does not count (Adnams, 2010). Since "[i]ntellectual disability was not measured directly" and "[s]tatistics on children with disabilities aged 0–4 were not profiled" (SSA, 2014, p. 23), the 2011 census fared no better. Omissions of care spaces and care dependent persons also obscure their carers, rendering them all invisible in the South African discourse of living and

working with intellectual disability. Although individuals may be intellectually impaired, disablement is better located in difficult to navigate political and social environments – we run the risk of perpetuating exclusions as exemplified by the National Census Survey if we neglect to question the production and reproduction of ruling relations pertaining to intellectual disability care (Goodley et al., 2012; McGibbon et al., 2010). As this chapter hopes to show, if decision-making about care for individuals who live and work with intellectual impairment begets disablist planning and institutions, care can be disabling, not-ethical, and not-care.

We have made some progress: physical abuse, exploitative patient labour, and shaming behavioural interventions are no longer sanctioned, but we are not at ethical care yet:

> ***No more sanctioned physical abuse:***
> RJ: *You're not allowed to hit them [people] like in the early years. If a patient is rude, then the nurses tell you: "hit him, give him a good hiding". Then we hit him. In the olden times, but not anymore. (Resident J)*
> ***...sanctioned exploitative labour:***
> RJ: *In olden times we worked hard. On your hands and knees, with old-fashioned wax...it made the floors shine.*
> CC: *Did you have to polish the floors until they shine?*
> RJ: *No, I polished, and a different one just made it shine. (Resident J)*
> ***...sanctioned shaming behavioural interventions:***
> RJ: *If you didn't want to work in the olden days, then you get the nightie.*
> CC: *What does a nightie look like?*
> RJ: *What the women folk wear, night clothes. You put that on.*
> CC: *Then everyone knows you didn't want to work.*
> RJ: *Hmm. Embarrassing, ja. It's not like that anymore.*
> CC: *So things have changed.*
> RJ: *I am happy. (Resident J)*

The National Core Standards for Health Establishments in South Africa (National Department of Health, 2011) ensures "quality nursing and clinical care and ethical practice", reduces " unintended harm to health care users or patients in identified cases of greater clinical risk", prevents or manages "problems or adverse events", and supports "any affected patients or staff" (2011, p. 4). Furthermore, "[d]octors, nurses and other health professionals constantly work to improve the care they provide through proper support systems" (2011, p. 7). For now, sufficient care meets institutional accreditation requirements on our wards; but as illustrated during this discussion, not yet the necessary conditions for relational, person-making care. Although still unfamiliar, and requiring awareness- and capacity-building, we are not yet practicing ethical care. But intellectual disability care should be made to matter, and *how* it is made matters even more.

As the discussion progresses, I hope to show how dynamics of psychiatric intellectual disability care can complicate, but might also be addressed by, a relational and intersubjective application of ethical care. Confounding factors to such care will be shown to include a lack of ethics of care training, lack of appropriate nursing training, and care staff limitations. Further confounding factors will be shown to include infantilisation; ways in which gender and race are performed; issues in continuity of care; scripted but unperformed daily activities; and remote controlled care. In illustration of the discussion, quotes from nurses and residents, as well as field note entries, bring care practices to life and are included verbatim where useful.

7.1.1. Introducing ethics of care as relational and intersubjective

In attempting to bridge psychoanalytic theory and disability studies, a relational lens was used through which to observe the complexities of intellectual disability care during this research. Understanding the exchange of such care was enriched by applying psychoanalytic intersubjectivity theory to the practice of ethical care. Attributable to intellectually able and impaired individuals alike, subjectivity refers to the influence of one's idiosyncrasies, personal assumptions, cultural influences, concerns, and motivations upon mental activity (Renik& Spillius, 2004). In applying definitions of intersubjectivity intriduced in Chapter 5, we see that they view subjectivity as central to experiencing one's world, admit scepticism about care participant neutrality or objectivity, share the sense that care interactions are affected by mutual influence of caregiver and care receiver, and assume an ongoing (un)conscious dialogue between care participants (Brown & Miller, 2002; Fonagy & Target, 2007; Ogden, 1994, 1999, 2001, 2003; Renik& Spillius, 2004; S. Swartz, 2005, 2006, 2007). Never intact, we are all being created by the other just as we are creating an other during any interaction. As an intersubjective marker for ethical care, we can remain mindful that our subjectivity is constantly being used by others (adults with intellectual disability) as an external reality to be internalised as a new part of, or addition to, their subjectivity, inner reality, knowledge of themselves, and knowledge of a world beyond the ward:

> RN: *Look, everyone is here for a purpose, in here.*
> CC: *Ja? How so?*
> RN: *Us patients, we are here for a purpose, hey.*
> CC: *What is the purpose?*
> RN: *To maybe learn a little something about life, get a bit of experience – something like that I think. To know your self [author's own spelling] a bit better. (Resident N)*

Kittay and colleagues (2005) address this relational aspect of caregiving as it occurs in psychosocial contexts that historically shaped, and continue to make, care participants. RN says:

> RN: *Us patients are here by our own disadvantage.*
> CC: *How do you mean?*
> RN: *We are here because we did something wrong. Or are we here because we are ill or what? Have problems?*
> CC: *Maybe sometimes it's like you said, to give people a chance to sort themselves out a bit.*
> RN: *Yes. And for example, my parents can't sort me out at home, then I stay put here. Can you see that? (Resident N)*

During care exchanges we are essentially creating our own and others' selves, and in sharing intersubjective relational care spaces, we are making an other person while being made into a kind of person. By implication, the valence of relational exchange between care participants can thus produce and sustain enabled or disabled selves (Tinney, 2008). All care is relational, good or bad, and both influence the kinds of persons made during its planning and practice (see Tronto, 2010). And as we are *all* care participants, each one of us is responsible for the people we make. What we think about people (e.g., insignificant) makes a kind of person (devalued). The danger is that people we create in this way might start believing this of themselves (Fanon, 1961/2004).

The psychological defence of projective identification, a process that must involve at least two people while they relate to one another, is also used by individuals living with intellectual impairment and often in lieu of verbal expressive abilities (Sinason, 2010). During projective identification, unconscious phantasy is at work between partners and has "good" or "bad" aspects of the self (i.e., internal or subjective aspects) first split off, then expelled into an external object or person outside of the self. The projected aspects, now located in the other person and causing them to feel good or bad in turn, may still be felt by the projector as good or bad, and a link in relatedness is established (McWilliams, 2011). In my work I become more easily aware of feeling intolerable anger, hate, paranoia, fatigue, and incapability since I do not consciously regard myself as a particularly angry, hateful, paranoid, tired, or incapable person – although I do feel these ways at times. In my personal supervision and therapy spaces I am able to make sense of and track these feelings' origins, sometimes they are mine and often they are not. They might not have been mine to begin with, but expulsions from someone I might have interacted with therapeutically during the day and subsequently internalised. And then I wonder: if damaging projections that are

195

unconsciously taken in feel bad, could positive introjections then feel good? After years of psychoanalytic psychotherapy it was brought into my conscious awareness that I find feelings of mastery, pride, and achievement rather intolerable and must remain consciously aware of how, and by what means, I project them into people I relate to. And that holds me responsible for the kinds of people I contribute to making, just as I am made. If what we think and feel about a person makes a kind of person, and people we create in "good" or "bad" ways begin believing themselves as being good and valued, or bad and devalued, I cannot help but wonder what might happen if others' restorative or reparative subjectivities are available to be internalised by adults living with intellectual disability in psychiatric settings (Mancillas, 2006; Waska, 2007).

Sinason (2010) helps us further understand that institutional care spaces themselves, where projective identification is probably at work among care participants, may be neither restorative nor reparative but disabling. We all contribute to creating the spaces made available for intellectual disability care to emerge from – through an intersubjective lens these spaces come into focus as dynamic care fields, located in wards, and held in place by nurses, patients, decision-makers, even researchers, and the subjective assumptions we all hold of intellectual disability (see Aron, 2006; as well as Moodley, 2007). Ethical care can only move into spaces that we create conditions for. Shifting our thinking about intellectual disability might then bring about shifts in the care fields that will be occupied by its care practices.

7.1.2.   Aim of the study

In following McGibbon et al. (2010), this chapter explores the making of disabled and disabling care, and aims to identify possible foci for change by paying direct attention to ingredients of the intellectual disability care problematic. The research aims to understand and interpret the exchange of intellectual disability care among a group of people in the context of their daily lives on adult inpatient wards in two Western Cape public psychiatric hospitals. In doing so, it seeks to reconcile observed care practices with a formulation of ethical care as relational and intersubjective that will be offered toward the end of the discussion. Where decisions pertaining to resource distribution create specific care environments for practicing intellectual disability care, the organising and operationalisation of this kind of dependency care on our wards could elucidate the degree to which it lends itself toward ethical care practice (DeVault, 2006, 2013; McGibbon et al., 2010; Strandberg&

Jansson, 2003). By observing and identifying possible contributors to the ethical care problematic, and by appreciating problems and attempting to understand their history, this study also hopes to inform on the exchange of care and perhaps influence service delivery by adding to new knowledge – even if only in a small way (Robinson, 2013).

7.2. METHODOLOGY

To respond to the question of whether ethical care stands a chance on adult inpatient psychiatric intellectual disability wards, data on care performance and exchange were gathered during 2013 and 2014 from three sources within two psychiatric intellectual disability care sites in the Western Cape – from nurses as spatiotemporal carers, adult inpatients as residents, and wards as ethnographic participants. One of the two research sites is a 740 bed public psychiatric hospital mandated with two services, separating itself into Psychiatric Services and Intellectual Disability Services (IDS). The other research site is a specialist hospital for adults living with intellectual disability and psychiatric illness. Both research sites are described and discussed in more detail later in the discussion.

It is acknowledged that the terms "intellectual disability" and "intellectual impairment" interchange in this chapter, but where "*disability* is recognized as a social construction" (Casper & Talley 2005, p. 115), a reading of the social model of disability cautions us against locating disability *in* an individual rather than in the surrounds of disabling social, cultural and political inhibitions that further encumber impairment (Goodley et al., 2012).

Collaboration with participants regarding research design, the collection of intersubjective data, and a co-creation of knowledge rested at the heart of this study's methodological framework. An explorative and descriptive research method is employed by following a contextual constructionist qualitative research design. Contextual constructionism takes note of intersubjective meanings, and does not assume that there is only one true analysis that can be revealed by using the "correct" methodology (Erlich, 2003; Ogden, 2003). Contextualism also posits that knowledge is local, provisional, and situation dependent, and that results will vary according to the context in which data was collected and analysed. This approach allows researchers to account for their subjectivity, whilst permitting conflicting perspectives (Madill et al., 2000). The exploratory nature of the research enables an attempt at understanding intellectual disability care (Bless et al., 2006), whilst its descriptive nature

engages the reader with situations narrated by participants and inscribed by the researcher (Babbie & Mouton, 2007).

Three methods were used to gather data on the performance and exchange of intellectual disability care (see Table 7.1). Data were collected by means of participant observation (45 care interaction hours were gathered from three adult psychiatric inpatient intellectual disability wards); 16 Free Association Narrative Interviews were captured with 16 nurses as carers; and by means of intersubjectivity informed therapeutic interactions, 59 hours of narratives were collected with 10 adults living with intellectual disability and psychiatric illness.

Table 7.1.

Qualitative Research Methodology and Data Collection

Research method	Participants	Data collection	Data capturing	Data treatment	Data analysis
A. Ethnography	Wards	• Care participant observation • 3 wards • 45 hours	• Field journal	• Interpreting field notes • Triangulating with B and C	Observational data were examined and interpreted for common themes
B. Narrative	Nurses	• Free Association Narrative Interviews • 16 nurse participants • 14.9 hours	• Digital voice recorder • Research journal	• Transcription • Triangulating with A and C	Narrative data were examined and interpreted for common themes until saturation reached
C. Narrative	Residents	• Intersubjectivity informed therapeutic interactions • 10 resident participants • 59 hours	• Digital voice recorder • Research journal	• Transcription • Triangulating with A and B	Narrative data were examined and interpreted for common themes until saturation reached

Care data were elicited by the researcher who is a Health Professions Council of South Africa (HPCSA) registered Clinical Psychologist with psychotherapeutic training, and data were filtered through a psychoanalytically informed intersubjective and relational lens. This process revealed dilemmas that both problematise *and* can be remedied by an intersubjective and relational ethics of care frame. In illustration of the discussion, quotes from nurses and

residents, as well as field note entries, bring care practices to life and are included verbatim where useful.

7.2.1. Participants

7.2.1.1. The wards

On condition that this was voluntary, nursing staff members made recommendations about wards they felt should be included in the study. In order to discuss the basic framework of the research, meetings were held with nurses from various levels within the Nursing Department and from all the wards at the particular hospital complex. This enabled nurses to share any queries and concerns they may have been holding about the research. Subsequent to the discussions, nursing staff voluntarily put forward the wards included in the study for reasons discussed below. Taken up in Chapter 8 as a suggestion for further research, a resident representative should ideally have been representing fellow patients during these meetings.

As recommended by nursing staff members, a mixed gender ward for patients with mild to moderate intellectual disability, a female ward for patients with moderate to severe intellectual disability, and a male ward for patients with moderate to severe intellectual disability were included. The names of wards were changed to Ward A, B and C to uphold anonymity, and care participants are unidentifiable. As care participants, ward residents included both male and female Black, White and Coloured individuals (terminology used in the Employment Equity Act, Republic of South Africa, 1998); and nursing staff included both male and female Black and Coloured individuals. Wards could withdraw from participating in the study at any time without being convinced to continue.

The architecture of intellectual disability care sees patient dorms spread along wings meeting in a central area comprising the nurses' station, dining room, and kitchen. In mixed wards, these communal areas separate male and female wings. Visiting areas or activity rooms are frequently occupied by ward rounds. Treatment rooms are located between the nurses' station and patient dorms, whilst the nurses' tea room and unit manager office can be some distance from patient areas. As Nurse 9 explains, "*nurses have to be able to get away from patients. To catch their breath...have a break*". Despite some single rooms for patients, "wash time" in shared bathrooms limit opportunities for privacy and countless intrusions must be tolerated (Tinney, 2008). Some wards have designated security guards to control access and come to

the aid of nurses or patients in the event of aggressive or violent patient behaviour. Wards not assigned guards may telephonically request that one be sent when necessary.

Ward A. Ward A is a mixed gender ward of patients living with psychiatric illness and mild to moderate intellectual impairment. Its adult patients are allowed to move about hospital grounds unsupervised, or independently attend treatment sessions in other buildings.

> *Affirming life quotes serve as greetings upon entering. The ward*
> *appears clean but barren, and some odours are familiarly*
> *unpleasant. In equal ratio of male to female, there are 14 patients*
> *who are tactile and excited at the presence of the researcher.*
> *Initially weary, the nurses become welcoming. There were six on*
> *duty, but this unusually large amount includes rotating student*
> *nurses. (Field notes, 2013)*

In reality wards are critically understaffed, a common theme throughout the discussion to follow.

Ward B. This ward holds within its walls a different world. Flaking child-like murals represent characters from popular fairytales and classic *Walt Disney* scenes.

> *The ward appears bedraggled, almost abandoned of life but for the*
> *malodour. Few personal touches mark the presence of its people.*
> *Four female nurses care for 23 female patients living with*
> *moderate to severe intellectual impairment, dependent of full*
> *bodily care. Curious and intrusive, friendly women in worn out but*
> *clean clothing appear excited to see the researcher. Weary nurses*
> *become familiar with her as she is shown around the locked ward*
> *patients may not leave without supervision. (Field notes, 2013)*

Ward C. This male ward carries a daunting history of death and disciplinary investigations. As the doors are unlocked, one is struck by reactionary institutional management of timeously preventable incidents. The ward is newly refurbished, exceptionally clean, and sports an aluminium glassed-off nurses' station. A battery of Closed Circuit Television (CCTV) cameras enables nurses to observe patients without interacting personally, whilst nurses are surveilled by hospital managers.

> *The ward is locked to the outside world and in itself. Patients are*
> *contained in its rooms, or separated and hovering in its passages.*
> *One or two sit on the reception area floor. Some of the 23 men*

> *living with severe intellectual impairment wear helmets, and all*
> *wear matching "jumpsuits" or "boiler suits", secured at the back*
> *and branded with the hospital's name in orange letters... (Field*
> *notes, 2013)*

... much like Goffman's (1961/1991) inmates. The jumpsuits and helmets attempt to interrupt self-injurious behaviours – coprophagia or head banging, for example. As Nurse 2 explains, the suits *"prevent patients from getting into their nappies"*. All 23 male patients are dependent on three female and one male nurse for every activity of daily living. The security guarded ward is stark, with no personalised markers of its people's presence.

7.2.1.2. The nurses

Nurses provide care for adult inpatients living with intellectual disability and mental illness, who get terribly many pills: *"Hulle kry verskriklik baie pille"* (Nurse 7). For purposes of transparency and prior to beginning data collection, I presented nursing staff of the particular research site with a draft of the larger research proposal and asked for comment and input. In order to inform on the research and to assist in allaying any anxieties potential participants might have had, an open invitation letter was distributed to nursing staff and interested parties at the hospital. The letter informed potential participants of their participation rights, explained the purpose and procedures of the research, and contained my contact information in the event of any questions. I also attended Inter-hospital Intellectual Disability Forum meetings in 2012 where the research was tabled for comment by staff members from other intellectual disability services external to the research site. A formal presentation of the finalised research proposal was shared with nursing staff as potential participants in February 2013.

As explained in Chapter 1 (section 1.3.2.1.), all respondents to the invitation to participate in the research comprised the study population. Participants included 16 Black and Coloured male and female nurses, from different levels in the nursing department, and registered with the South African Nursing Council (RSA, 1998). Nurses who work part-time on adult intellectual disability wards, or who work on outpatient or non-intellectual disability inpatient wards did not meet the study's inclusion criteria. Participant demographics are offered in Table 7.2, but not to an extent that would compromise participant anonymity.

Table 7.2

Nursing Participants' Demographics

Participant	Gender	Race	Nursing Rank	Years Experience	Interview Language
Nurse 1	Female	Coloured	Operational Manager	11 years	English
Nurse 2	Male	Coloured	Registered Nurse	21 years	English
Nurse 3	Female	Coloured	Area Manager	28 years	English
Nurse 4	Female	Coloured	Registered Nurse	16 years	Afrikaans
Nurse 5	Female	Black	Area Manager	19 years	English
Nurse 6	Male	Black	Registered Nurse	3 years	English
Nurse 7	Female	Coloured	Operational Manager	15 years	Afrikaans
Nurse 8	Female	Coloured	Area Manager	29 years	English
Nurse 9	Female	Coloured	Operational Manager	26 years	Afrikaans
Nurse 10	Female	Coloured	Registered Nurse	20 years	English
Nurse 11	Female	Coloured	Operational Manager	17 years	Afrikaans
Nurse 12	Female	Coloured	Registered Nurse	19 years	English
Nurse 13	Male	Black	Registered Nurse	24 years	English
Nurse 14	Female	Black	Registered Nurse	11 years	English
Nurse 15	Female	Coloured	Registered Nurse	30 years	Afrikaans
Nurse 16	Female	Coloured	Registered Nurse	26 years	English

7.2.1.3. The adult residents

Under the South African Mental Health Care Act of 2002, nurses care for adults living with intellectual impairment as well as psychiatric diagnoses inclusive of personality disorders, and often with problematic medical conditions (RSA, 2002). Any combination of these may complicate treatment goals of discharging patients, in consultation with the Mental Health Review Board, into community care. Individuals with intellectual impairment younger than 18 years of age, and patients attended to at the research sites on an outpatient basis were excluded from participating in this study.

Resident participants' demographic information is offered in Table 7.3 below. Information pertaining to age, residential years, and psychiatric diagnoses would have rendered the patients easily identifiable, and was therefore not included. As explained in Chapter 1 (section 1.3.3.), residents were identified for voluntary participation in the study's dual aim of research-therapeutic interaction by means of a routine referral process from members of their multi-disciplinary mental health care teams. This opened access to the therapeutic service offered by the study to any resident in need of such a space. Resident T provides some feedback on his participation:

> RT: Hello.
> CC: How are you doing?

> *RT: Well thanks.*
> *CC: Ja? If you say you're doing well, what do you mean?*
> *RT: Uhm...it's...it's because I have spoken about all of these angries...*
> *CC: Oh, ok...*
> *RT: ...and about these problems, spoken about them a bit, now it's going well. (Resident T)*

Residents who chose to interact therapeutically with the researcher, but preferred not to have their narratives included for research purposes, would still receive the same therapeutic engagement as would study participants.

Table 7.3.

Resident Participants' Demographics

Participant	Gender	Race	Research site	Level of ID	Interview Language	Consent or Assent
Resident J	Male	White	2	Mild	Afrikaans	Consent
Resident J2	Female	Coloured	1	Moderate	Afrikaans	Assent
Resident N	Male	White	2	Mild	Afrikaans	Consent
Resident E	Female	White	2	Moderate	Afrikaans	Consent
Resident G	Male	Coloured	1	Moderate	Afrikaans and English	Declined
Resident R	Male	Coloured	1	Severe	Afrikaans	Assent
Resident W	Male	Coloured	2	Mild	English	Consent
Resident T	Male	White	2	Moderate	Afrikaans	Consent
Resident G2	Male	White	2	Moderate	English	Declined
Resident D	Female	White	2	Mild	English	Consent

7.2.2. Data collection

7.2.2.1. Ethnographic data (wards)

Ethnographic data is collected on phenomena within or about communities, in this case adult inpatient psychiatric intellectual disability care communities, and a preferred strategy of investigation is often participant observation (DeVault, 2006, 2013; McGibbon et al., 2010; Quinlan, 2009; Robinson, 2013; Rosenthal & Rosnow, 2008; Sinding, 2010; Tinney, 2008). By gathering data in this way, perspective is gained on intellectual disability care by "direct observation" of care exchanges between nurses and ward residents as care participants (Babbie & Mouton, 2007, p. 279).

Forty-five observational hours were collected on three adult inpatient wards in one of two South African public psychiatric hospitals, caring for adults with differing care needs as a function of intellectual impairment, from different races and genders, and representing

different social groups. To ensure replicability of the research frame, observation hours were equally spaced among the three wards. Over a period of three days each ward was visited for 15 hours, five hours per day – a morning slot so as to observe ward handover (6:30am to 11:30am), an afternoon slot (11:00am to 16:00pm), and an evening slot also inclusive of ward handover (14:00pm to 19:00pm). In order to produce accurate comparative data, the exact time slots were replicated and applied across all three participating wards. These time slots afforded observations of care interactions during the course of a typical day in a given ward.

7.2.2.2. Nurses: Free Association Narrative Interviews (FANIs)

Hollway and Jefferson's (2013) free association narrative interview (FANI) method of collecting data operationalised the goal of creating a unique intersubjective field between each research dyad from which a voice on intellectual disability care could emerge. Since narratives elicited by free association "secure access to a person's concerns, which would probably not be visible using a more traditional method" (Hollway & Jefferson, 2013, p. 34), applying the FANI method suited the study's aim of intersubjectively co-creating fresh perspectives on intellectual disability with participants. Free association narrative interviews approximating 60 minutes were performed with 16 participants. With their permission, the interviews were voice recorded and transcribed. No hypothetical assumptions were made about participants' care experiences prior to data collection, and participants were only asked to "tell me about intellectual disability nursing".

7.2.2.3. Adult narratives: Intersubjectivity informed therapeutic interactions with residents

The adults participating in this study are resident inpatients on psychiatric intellectual disability wards in two public hospitals in the Western Cape, and are cared for as mandated by the South African Mental Health Care Act of 2002 (RSA, 2002). These participants live with intellectual impairment and psychiatric diagnoses:

> RJ   *I am, after all, a child of the state.*
> CC: *What does it mean to be a child of the state?*
> RJ: *You fall under government.*
> CC: *And what does it mean to fall under government?*
> RJ: *I am under the state. You're under supervision. They look after you. (Resident J, session 1)*

By means of intersubjectivity informed therapeutic interactions, 59 hours of narratives were collected with 10 adults living with intellectual disability and psychiatric illness. Even though profound intellectual disability was not an exclusion criteria for the study, male and female

residents referred for participation at both research sites live with mild, moderate, and severe intellectual disability as described in DC-LD (2001)[6], DM-ID (2007)[7], and DSM-5 (2013)[8].

The process of eliciting experiences from individuals with intellectual impairment who live in institutional environments can easily perpetuate inequality practices. As discussed in Chapter 5, psychoanalytic intersubjectivity – in principle egalitarian – seemed a fitting approach for engaging with residents' narratives since it endeavours to investigate worlds of emotional experience that take form in relational contexts (Tronto, 2010). The developing relationship between researcher/therapist and intellectually disabled individual becomes particularly significant if intersubjective interaction can create conditions from which an expert voice on intellectual impairment can emerge (Vaslamatzis, 2011). In terms of intersubjective research collaboration with intellectually disabled individuals, a shift in the locus of expertise can take place (L. Swartz et al., 2012): intellectually impaired individuals *are* the experts on living with intellectual disability. It will be immensely problematic if the researcher "differs from the [intellectually disabled participant] in what is needed"...or differs with regards to the location of the expert, embodied voice of intellectual disability (Tronto, 2010).

7.2.3.   Data analysis

7.2.3.1. Ethnographic data

During ethnographic observational data collection, the wards were conceptualised as research participants. As units of analysis, the care interactions between nurses and residents were observed and recorded in a field journal (Babbie & Mouton, 2007). These notes were revised and studied, making it possible to collect similar themes as they unfolded across the participating wards. Aspects of care interactions relating to the research question, and to social relations inherent in intellectual disability life and work, could thus be identified.

7.2.3.2. Narrative data

As interviews with nurses and intersubjectivity informed interactions with residents progressed, notes made during and after these were triangulated with their audio-recordings

---

[6] Royal College of Psychiatrists (2001). Diagnostic Criteria for Psychiatric Disorders for use with Adults with Learning Disabilities/Mental Retardation. London: Gaskell.
[7] National Association for the Dually Diagnosed (NADD) in association with the American Psychiatric Association (APA) (2007). *Diagnostic Manual-Intellectual Disability: A textbook of diagnosis of mental disorders in persons with intellectual disability*. New York: NADD Press.
[8] American Psychiatric Association (2013). Diagnostic and Statistical Manual of Mental Disorders, Fifth Edition. Washington, DC: American Psychiatric Association.

and transcripts; and narrative data were triangulated with the ethnographic data and field notes (Mello, 2002; Terre Blanche et al., 2006). Participant narratives served as the primary units of investigation, and narrative data were examined and interpreted for common themes that were identified by thoroughly rereading interview transcripts and notes (Babbie & Mouton, 2007). Data saturation was attributable to rich material and participants' general experiences. Together with illustrative ethnographic field notes, verbatim participant accounts that capture care experiences are included throughout the discussion to follow.

Although the slogan "nothing about us without us" is unifying and seminal to the disability movement, I heeded caution against losing sight of the many differences among disabled persons and their experiences, and of the salient features that individuate experiences of impairment and disabling social practices (Kittay, 2009; L. Swartz, 2010). Where a collection of intersubjectivity informed intellectual disability narratives are culminations of many participant voices in this study, it becomes "less important to judge which of these stories is 'correct' than to acknowledge how different they are" (L. Swartz, 2010; L. Swartz et al., 2012).

7.2.4.   Ethical considerations

Ethical clearance was obtained from the Health Research Ethics Committee of Stellenbosch University's Faculty of Health Sciences (Federal Wide Assurance Number: 00001372, Institutional Review Board Number: IRB0005239).

7.2.4.1. The wards: Ethnographic observations

Approval for collecting data was obtained from the Department of Health and hospital ethics committee on condition that I remain unobtrusive and not initiate direct interaction with ward staff or residents during data collection. I took care to remain respectful of relationships between nurses and residents, to not impinge on the ward environment, and to not cause any upset to any person during the observations.

7.2.4.2. The Nurses: Free association narrative interviews

Meetings were arranged with potential participants for purposes of introductions, reiterating study goals and processes, and addressing questions and uncertainties; and their inputs were incorporated into the research design. Involvement was voluntary on condition of written informed consent, and nurses were informed on risks and benefits of participating.

Participants could withdraw from the study at any time, or ask that their narrative not be included. Anonymity was ensured, participants were not remunerated nor did they pay to participate, and no intentional harm came to them. Participants could access counselling referrals if narrative material was experienced as distressing.

7.2.4.3. The residents: Adult inpatient narratives

Obtaining consent from participants with intellectual disability was always attempted first. Participants could ask the researcher any questions about any part of the research process they might not have fully understood. They were only included if both researcher and participant were fully satisfied that the aim of the research, as well as the manner of participant involvement, was clearly comprehended. As discussed in Chapter 4, a resident's declining to participate in the study was indicative of an understanding that consent could be given or refused:

> CC: I apologise, it's going to take me a while to learn your speech. If I don't understand you well, that's my fault, ok?
> RG: Don't want to talk.
> CC: That's ok. (Resident G, session 1)
>
> CC: Hi G2, are you ready to talk?
> RG2: It's not necessary.
> CC: It's not necessary? Ok, ok. But I'm glad you're telling me it's not necessary, ok?
> RG2: Ok. (Resident RG2, session 2)

Following the principle in Chapter 4 that consent to participate is an ongoing process, as many explanations were provided as necessary to create conditions for continuous consent or assent to be met. For resident J this could be up to four sessions, while Resident R is just as curious about the digital voice recorder:

> CC: Do you want me to come [to talk], or do you want me not to come?
> RW: You can come.
> CC: I can come? Ok. Do you want to put your name on the paper to say I can come?
> RW: Yes.
> CC: Ok. Can I show you again what the paper looks like?
> RW: Yes.
> CC: Here [on the form] you can say it's ok if I come, or here you can say it's not ok.
> RW: It is ok. (Resident W, session 2)
>
> CC: Everything that you and I talk about is private and confidential. In other words, nobody...
> RJ: ...will be told.
> CC: Do you have any questions about my work?
> RJ   So what work do you actually do? (Resident J, session 2)
>
> CC: Thank you, J. Is there anything else you still want to ask me about why I come here?

RJ: *So for what reason do you come here to see me? (Resident J, session 2)*

RJ: *What do you play on that thing [digital voice recorder]?*
CC: *I am recording our conversation so that I don't forget anything. Because everything you say is important.*
RJ: *So where do you take that thing? And only you are going to listen?*
CC: *Because what you and I discuss is private. Nobody else is allowed to listen except you and I.*
RJ: *Exactly. (Resident J, session 3)*

CC: *What is it like for you when they wake you up to talk with me?*
RJ: *It's alright.*
CC: *Are you sure?*
RJ: *Hmm.*
CC: *Because, remember, you're allowed to say if it isn't alright.*
RJ: *No, I know.*
CC: *I wouldn't mind.*
RJ: *I'm not bothered. They must wake me up. (Resident J, session 4)*

CC: *Would you like me to show you how this [digital voice recorder] works?*
RJ: *No, then you have to re-do everything again.*
CC: *Let me quickly show you how it works.*
RJ: *Ok.*
CC: *Are you ready?*
RJ: *Yes. (Resident J, session 4)*

RJ: *But you're capturing everything that I'm saying, hey. That is good. Tape it, yes, and then you play it yourself. Now when you take the things home and you type it up, where does it go? (Resident J, session 5)*

CC: *I see you're looking at this [digital voice recorder]. Do you know what it is?*
RR: *Cell phone.*
CC: *Voice recorder. What you say is important. I don't want to forget anything. Is that ok with you?*
RR: *[Nods]. (Resident R, session 1)*

Residents were free to withdraw from participation in the study at any point, even if they initially consented to participate and attended a number of sessions. If referred residents chose not to participate in the study from the outset or withdrew during its course, but still wanted to engage in therapeutic interactions, this was made possible.

7.3.   RESULTS

A qualitative researcher may decide to "present the findings on their own, without supporting discussion", or, as done here, "link the findings with the work of other researchers" (Burnard, 2004, p. 178). Dynamics of psychiatric intellectual disability care were found to complicate, but might also be addressed by, a relational and intersubjective application of ethical care. Confounding factors to such care include lacking ethics of care training, appropriate

intellectual disability nursing training, and care staff limitations. From Nurses 7, 8, and 9, ideas about quality of training are offered:

We used to have very nice nurses that worked with us. Very dedicated. That old staff that we used to have. Not like I can compare now with those today that you had those years. (Nurse 8)

N9:   *Their [nursing] qualifications man. They might have left school at grade 4 or 5. And they didn't develop any further.*
CC: *So you feel there's a gap in the training?*
N9:   *In the training, yes. And in their general education.*
CC: *It makes things difficult for you.*
N9:   *Very difficult, yes. (Nurse 9)*

CC: *So how do you feel about the training?*
N7:   *I feel, those days we had good training.*
CC: *And these days?*
N7:   *You get people that are already nursing sisters, who can't write reports properly. These days, I don't think people are getting all the information. Those days, you must have been able to do everything [stitches, bloods, drips, catheters]. Now...there's only a certain part they can do. So, I feel it's different. I don't know.*
CC: *So the training feels like...the standard is different?*
N7:   *The standard is different, yes. Or people's attitudes are different. I think people's attitudes are different.*
CC: *Different how?*
N7:   *When we had our training, we were even taught how to behave in public in uniform, hey. You weren't allowed to smoke or to eat in public. Nurses these days can do anything. Things have changed. People have changed with the times.*
CC: *How do you think it affects patient care?*
N7:   *You get the good ones and you get the bad ones. You get those that are a bit lax, and you get those who are really good. So we hope, after all, that the hospital takes the good ones.*
CC: *Is that what happens?*
N7:   *How do you mean?*
CC: *Do the good ones get taken on?*
N7:   *I think so, you're not going to take a rotten apple.*
CC: *What will happen if one does that?*
N7:   *I don't think they would. You're not going to take someone with a disciplinary record or who comes late, or who is non-caring. I think it's time I write my staff thank you letters for the things they do. The staff I have now, really, I must thank them. (Nurse 7)*

Further confounding factors include an infantilising care dynamic; how gender and race are performed; issues in continuity of care; scripted but unperformed daily activities; and remote controlled care.

Being associated with intellectual disability, nurses and the hospital itself feel "*undermined*" (Nurse 5) and stereotyped even by fellow professionals. Participants explained how the patients and psychiatric hospital (due to its care provision for intellectually impaired individuals) are often stigmatised and discriminated against: "*...people out there think that*

209

they're maybe better than these ones" (Nurse 3). Nurse 5 is disturbed by stigma: *"I really get upset with people...because it's another human. That's a human being and there's nothing to be ashamed about. ... I think people do feel ashamed"*. Nurse 4 stated that: *"I think they [people who stigmatise] don't have insight, man. Because these, these are human beings, it's not animals!"* Individuals caring for patients living with intellectual disability may also find themselves sharing experiences of stigmatisation and exploitation (Goffman, 2006; Mitchell, 2000; Kroese et al., 2013). As exemplified in Chapter 6, Nurse 4 illustrated how members of the nursing staff are stereotyped and stigmatised due to their association with caring for intellectually impaired individuals, sometimes by fellow professionals:

> *If you meet people and they ask you, "where are you working" and then you say [hospital's name], and then they say "[hospital's name], die malhuis!?" [the madhouse!?]...their next question is, "how long are you working there?" because they believe that...when you work a certain amount of years, like five or ten years, then you're also mad. People are saying that. (Nurse 4)*

Participant accounts of feeling stigmatised-by-association are plausible in light of Northway's (1997) statement that "people are often judged by their profession and certain positions will bring with them power and prestige in social as well as professional circles", while others will not (p. 738). Although one cannot merely assume that will adversely affect nurses' care work, stigmatising *"nasty comments"* (Nurse 4) may darken intellectual disability care experiences once held in esteem.

7.3.1.   Can relational interaction on wards be handled with care?

Ideally, any care task could be engaged in with the significance of its relational and intersubjective impact in mind. Care creates intersubjective spaces in which people who are never intact are constantly being made, and these should be created mindful of peoples' experiences of what happens to them during care interactions. Relational care affords reflective, person-making spaces in which to foster care relationships and experiment with senses of self without ridicule. Reducing powerlessness lies, in part, in dignity-making interactions and respect for care participant choices (Kittay, 2011; Tinney, 2008; Tranvåg, Petersen, & Nåden 2013; Tronto, 2010).

The nature and frequency of care communications on participating wards gave me pause to consider an indiscriminate need for human relatedness; varying from nurses and residents conversing in reciprocal and personalised ways on Ward A, to communicative starvation where residents are cared for in silence on Ward C:

> *Patients are directed in silence then taken back to their rooms . . .*
> *communicative starvation seemingly prevailed. (Field notes, 2013)*

Communication with adults with severe intellectual disability is at constant risk of becoming authoritative, even hostile. This affords scant relational opportunity for essential *and* economical person-making sources of autonomy, esteem, self-determination, pride, and mastery:

> CC: *So, R. What you need is to listen to music, smoke cigarettes, to have friends.*
> RR: *Yes.*
> CC: *Would you be able to tell Sr P?*
> RR: *Don't know. (Resident R)*

Of course boundaries and behavioural limits must be set, but these can be achieved whilst avoiding the reproduction of care exchanges that deplete patients' sense of self, or leave them with little choice but to take up subjugated roles. In turn, nurses' voices on how they are cared for remain unheard, with little expectation of organisational support for their well-being:

> *Sometimes they [doctors] are very nasty...they laugh about ID [intellectual disability] things or they criticise. (Nurse 3)*

> *Nursing managers should stand up for us. I don't feel we have any support, us nurses. Nobody cares...we are all gonna be happy when our voice has been heard. (Nurse 6)*

> *I do the work, do my best, and don't expect anybody to recognise it. (Nurse 5)*

> *We don't have a say. (Nurse 2)*

"No-one listens" (Nurse 4), and a narrative of abandonment ensues from nurses that risks being internalised in turn by residents who may already feel, or have literally been, abandoned: *"On this ward, it's only like three patients out of 23, whose family come visit. Nobody's interested"* (Nurse 2). Early care literature already associated emotional exhaustion with staff beliefs that their opinions are neither received nor considered by their organisation (Blumenthal et al., 1998). Financial dependency may result in silent endurance and further subjugation, whilst appropriate training is often unattainable (Capri & Buckle, 2015):

> *We have been applying how long now for study leave. We don't get, we don't get. I have been applying for study leave for 13 years! These people working here, they will never give you study leave. (Nurse 2)*

> *I must go study to empower myself. I can't just work in the wards. I need to empower myself. (Nurse 8)*

But if we are all being created by the other just as we are creating the other during any interaction, this applies not only to nurses' experiences of interacting with or caring for

residents, but also to experiences of being interacted with or cared for in turn by institutional decision-makers. One participant explains that nurses:

> *...have totally no say ... nobody wants your ideas ... even if you are told you are the backbone of the hospital, you are like a dog that needs to be placed there and must do that ... it doesn't make sense. Even if you say how you feel, nobody takes note. (Nurse 5)*

> *We can't make magics here. No-one is listening...that is why I don't bother...struggling...wrestling...it feels bad. (Nurse 6)*

A decision-maker's subjectivity would include assumptions held about intellectual disability, self-expressed patient needs and their care (for example Resident R's wish for music, cigarettes, and friends), as well as assumptions held about nurses' care needs. Operationalisation of these assumptions – care resources made available, and the resultant working conditions for care to be performed in – would constantly be internalised by nurses as a celebration or disavowal of their care efforts. If *"99.5% of the people here get treated like shit"* (Nurse2), this should leave us seriously concerned about the kinds of nurses that are constantly being made.

Residents may also experience care as conditional, let alone relational:

> *CC: But E, for you it feels like, only if you do something for people then they*
> *take an interest in you, and...if you don't have anything to do for them, then they go away?*
> *RE: Ja, then they don't know you. (Resident E)*

> *RN: And the people [care staff] don't really want to be here, but they do it*
> *anyway.*
> *CC: Does it feel like that to you, that they don't really want to be here?*
> *RN: [Another resident] said, "these people are only here for their money." But I*
> *don't know if it's really like that.*
> *CC: What do you think?*
> *RN: I can say they are for their money, and maybe they're here for us a bit too in*
> *some way. I wonder why. Do they care?*
> *CC: What do you think?*
> *RN: Maybe they care, hey. (Resident N)*

> *These days it's about money. I can't pretend it's not. (Nurse 7)*

> *It takes special nurses for ID work. Special people to work with ID...you can't come and work here just because you want a paycheque...it costs much more than that, but ja. (Nurse 11)*

> *CC: So for you it's about serving and caring?*
> *N13: Yes. (Nurse 13)*

As shown in Chapter 6, nurses have had objects thrown at them, been hit, and assaulted by residents, even sexually. Also for patients, care environments can seem neglected, unsafe, and unpredictable, requiring constant vigilance from its residents:

> *We don't feel taken care of – we as nurses. We don't feel protected at all. (Nurse 6)*

> *RJ:*   *Ja. I see it [patient-on-patient sexual abuse] every single day, and they want to know nothing.*
> *CC:*   *Who wants to know nothing?*
> *RJ:*   *The staff and the nurses. (Resident J)*

> *CC:*   *So, E, is there anyone that looks after you as nicely as you look after Sister V?*
> *RE:*   *Just my [biological] sister. (Resident E)*

> *RJ:*   *She [a resident] hit me with a mug last week and Friday. Then the doctor put stitches in for me.*
> *CC:*   *I can see you have stitches.*
> *RJ:*   *Hmm. You never know what they can do with you. You never know. (Resident J)*

7.3.1.1. Handling relational interaction with care: What about infantilisation and the unmaking of adults?

If care generates intersubjective spaces in which people who are never intact are constantly being made, dynamics of infantilisation must be addressed. A practice of blanket infantilisation of adult residents subsumed under the now customary term *kinders* (children) appeared ubiquitous across both care settings:

> *RJ:*   *Hmm. Before we had nice food like chops and "boerewors" [meat sausages]. Now...no. We don't get some of that anymore. We are actually, after all, just children, so we have to do like children (Ons is eintlik maar mos kinders, so ons moet maar soos kinders doen). (Resident J)*

> *RJ:*   *You must be dumb here. If you try and be clever, you'll walk into trouble. (Resident J)*

Perhaps unconsciously motivated as mothering, infantilising communication might serve as a disabling reminder of adults' limited autonomy as opposed to potential. Although the use of unambivalent and short sentences facilitate verbal interaction, communication as a vehicle for adult-making is easily undermined by scolding reprimands *("skel")*, or vocabulary and sentence construction more appropriate for young children:

> *RE:*   *Ja. I don't know how long I must still stay here. I want to go home for a change.*
> *Carer:* *What did I tell you? What did [your sister] tell you?*
> *RE:*   *I must stay another one weekend.*
> *Carer:* *Ja, maybe you are going this weekend. She was, after all, here two weeks ago.*
> *RE:*   *Ja.*
> *Carer:* *Then she said you must stay in for two weekends.*
> *RE:*   *I did stay two weekends. What time is she coming?*
> *Carer:* *Are you a little baby now? Why must you cry? You're a baby.*

213

Notwithstanding attempts at brightening up adult wards, child-oriented toys and decor, and non-private rooms, exemplify environmental infantilisation (Salari, 2006). Furthermore, although understandable from understaffed nurses' and vulnerable residents' safety point of view, confinement to rooms or passages limits opportunities for enriching interaction:

> *On ward C, sleeping and wakeful patients are locked into rooms. Patients with convulsive disorders sleep on mattresses on the floor so as to not fall far to the floor during a seizure. Some mill about in hallways between locked doors, while others sit on a floor in view from the nurses' station. One patient from ward B has been tied to a toilet for over an hour. It is winter, and the bathrooms are cold. (Field notes, 2013)*

Various forms of confinement – such as being tied to toilets for long periods of time – can impinge on psychological integrity since such care practices limit adult-making opportunities for protest, preference, and autonomy. Nurses remind themselves that residents may not appreciate behavioural antecedents or consequences, whilst formal training did not prepare them for the realities of intellectual disability care:

> *For years nobody wanted to work in Ward C. It was, after all, a dirty ward. Wet and dirty. Excrement on the walls and floors and so on. Now everyone wants to come and work here! (Nurse9)*

> *It was gross. (Nurse 8)*

> *Forty year old [patients] with the mental age of a three or five year old. (Nurse 4)*

> *Special children stuck in a phase...don't know what they're doing. (Nurse 1)*

> *Adults wearing nappies (Nurse 1)* [was a] *rude awakening. (Nurse 6)*

> *I didn't know there were these types of children. (Nurse 15)*

By a universalising group name, patients are referred to as "the children" or "my children" as nurses converse. By implication, adults with intellectual disability are habitually cast as children, remanded to a care relationship that negates developmental experiences of maturing and benefiting from being treated as adults with adult privileges:

> *If we think about clothes, hey, then they always request clothes for the adult children. (Nurse 7)*

> *RE:* *It's almost my birthday.*
> *CC:* *When is your birthday?*
> *RE:* *The X of July.*
> *CC:* *How old are you going to be?*
> *RE:* *I don't know. (Resident E)*

> *CC:* *But they kind of moved on, and you're still here.*
> *RJ:* *Hmm.*
> *CC:* *What do you think about that?*
> *RJ:* *It's weird.*

CC: Almost as if you stayed behind.
RJ: Exactly. It's the people that keep you stuck in this place. (Resident J)

RN: I don't know what's going to happen, because I'm trying so hard to do something in this life. (Resident N)

CC: But what was it like for you to be there [watching rugby] at Newlands?
RN: They [the adults] drank wine. I had a soft drink. Anyway. (Resident N)

Caring for adult residents with intellectual disability as eternally childlike may serve two functions. A nurse-resident bond may closely resemble one shared between mother-carer and child, with residents pulling from nurses an attachment essential for survival (Dodson & Zincavage, 2007). The attachment that residents form with one another, like Residents R and J2 had with Resident A, must also not be overlooked. Distress after his passing was felt by Nurse 5 and RJ2:

I grew attached quickly...I'm a mommy at work. (Nurse 1)

I came to love them, they are my children...this is your home, you look after the children, you are the mother. (Nurse 11)

These children are also my children. I am, after all, their caregiver. (Nurse 15)

We have to prepare them for the community, but when they go...I am very sad...I have to walk away. (Nurse 11)

The nurses grow very attached. (Nurse 8)

I couldn't function [after a resident's death]. He left a gap in the ward. (Nurse 5)

CC: Do you have friends here in Ward xyz?
RR: Resident A [name of resident].
CC: Where is A?
RR: Passed away.
CC: Oh R, A passed away. He was your friend.
RR: Yes.
CC: You miss him?
RR: Yes.
CC: Does it hurt your heart when you think of him?
RR: Yes.
CC: How long were you and A friends?
RR: Eleven years. (Resident R)

RJ2:   Buried A. Buried buried A. A! A buried. Where's A? A buried. In the coffin.
CC: In the coffin?
RJ2:   Where's A? Down in the ground!
CC: Down in the ground?
RJ2:   In the coffin.
CC: Somebody is in a coffin down in the ground.
RJ2:   Where's A now? Where's A? A is in the coffin. In the ground! It's A! (Resident RJ2)

215

Nurses describe Ainsworth's (1969, p. 2) "affectional tie" with residents in simulation of a parent-child bond. The tenet that attachment requires a desire for proximity that otherwise suffers distress is illustrated by both resident E and nurse participants:

RE: *We must watch out for them. Something can happen to that Sister V, oooooooo!*
CC: *You feel you must look out for Sister V.*
RE: *Hmm, I love her very much. (Resident E, session 4)*

RE: *Sister V is lying in hospital.*
CC: *How do you feel about that?*
RE: *Sad. I don't know if she's going to come back. (Resident E, session 7)*

CC: *May I ask, E, why do you have to take care of Sister V, watch over her?*
RE: *So that she doesn't become ill again.*
CC: *Oh, you are very protective of Sister V. You're scared something happens to her.*
RE: *I thought she wasn't going to make it.*
CC: *And you wondered what would become of you.*
RE: *Yes. (Resident E, session 8)*

RJ: *I like her, sister L. Good person. (Resident J)*

N15:   *I was away for two weeks after my father's death. They [the patients] screamed and clapped...one of them threw his hat!*
CC: *That was their way of saying they missed you. They are glad you're back?*
N15:   *Yes. (Nurse 15)*

The value of attachment as part of the human condition is not denied, but an even unconscious infantilising care dynamic might thwart treatment goals of ultimately discharging dignified adult residents into community care:

RE: *Auntie, how long must I still stay here?*
CC: *You're afraid of missing lunch?*
RE: *No, I'm asking how long I'm still going to stay here.*
CC: *You mean in [this hospital]?*
RE: *Yes, I'm asking how long I still have to stay here.*
CC: *Why do you ask?*
RE: *I want to get out of here. Auntie, how long must I still stay here? Auntie, I must get out of here. (Resident E, session 2)*

RE: *Auntie, how long must I still stay here?*
CC: *You would really like to live somewhere else.*
RE: *[A place] That is nice. Auntie, how long must I still stay here? (Resident E, session 5)*

RD: *I want to live somewhere with fewer people and more space. I miss my own space. (Resident D)*

RG: *I don't want to be in [Ward's name].*
CC: *Oh, I see. Ok. So you want to live somewhere other than Ward xyz?*
RG: *Nods. (Resident G)*

216

> RN: *I don't want to stay in this hospital. I won't stay here. You won't tell me that I have to –*
> *you're not my boss. That's how it starts. Then it gets worser and worser and worser. Then I*
> *hit him. Then it gets difficult. Then I want to assault people and so on when I get angry.*
> CC: *Like whom do you want to assault?*
> RN: *My dad and them. And afterwards I regret it. (Resident N)*

Not initiated consciously but now institutionally ubiquitous, infantilisation might also help nurses resolve anxiety provoking daily confrontations with realities of intellectual impairment. This care practice might assist nurses with maintaining esteem whilst facing life engulfing disability – residents are no longer adults with a tragic impairment, but less distressingly held in mind as "*special children stuck in a phase*" (Nurse 1). Having been a nurse for 30 years, Nurse 15 explains that this entrenched practice has been performed for at least the past 16 years:

> *People always spoke about the children. Then I wondered, "What children are these?" But it is*
> *actually grownups that they call children. They are, after all, retarded...with the brain of a two year*
> *old. (Nurse 15)*

Infantilising care is disabling – its practices may minimise adults' abilities and inhibit well-being, thereby decreasing opportunities for effective treatment. Involuntary exposure to age inappropriate environments coerces care dependant adults, some older than their carers, into acts of infantilisation. Albeit unintentionally, unawareness of this dynamic risks reproducing a power differential through condescending interactions. The term "*toebekkies*" (shut little mouths) (Nurse 7), for example, would denote patients who are unable to verbalise or vocalise, and when compared to verbally aggressive patients, easier to care for. Resident D, 79 years old, recalls being told to *"shut up"* on numerous occasions. Infantilising care for inescapably vulnerable adults casts them as eternally childlike and catastrophically dependent. It remands them to care environments that negate maturing experiences and disables adult-making care spaces into which they can shift from a childlike state to enjoy being treated as adults with adult privileges.

7.3.1.2. Handling relational interaction with care: What about how class, gender, and race are performed?

The first of the research sites is a 740 bed public hospital mandated with two services, separating itself into Psychiatric Services and Intellectual Disability Services (IDS). Further from the administration building and psychiatrists' offices, fenced off within hospital grounds, over half the patient population is split off from the 'psych side' and cared for on the 'IDS side'. From nurses' narratives, it appears that IDS is treated as a second class service:

N2:   *This is one hospital right? But in actual fact we are two hospitals. When it comes to overtime, this side of the hospital [IDS], we don't get overtime.*

CC: *How so?*

N2:   *The money that the manager is saving...that money is being used at the other side of the hospital for that staff overtime.*

N8:   *We [IDS] are the stepchildren. Psych gets everything, even when you sit with vetting and everything, when it comes to money and concerns. They [psych] get the bulk. We all know it is like that because they feel IDS is not important. The management. For years we've been talking about this. Management must change their attitude. They don't ever come here [to the intellectual disability wards]. They don't have insight into what is happening here.*

CC: *Do you think it's because they don't have or they don't want...to have insight?*

N8:   *I don't think they want to. So they cut themselves.*

CC: *Off?*

N8:   *Ja. That's my perception. But we can work on the psych side also!*

They don't treat psychiatry and IDS the same. We don't hear about these problems on psych side. (Nurse 6)

They treat IDS like a stepchild. We have to motivate harder to get things. It seems as if IDS, it seems as if we have to be satisfied with the scraps. Psych will always get better because those patients can speak and...they can complain. We must always wait longer to get certain things. One example, our food is not the same as Psych's food...we feel like the stepchild of the hospital. (Nurse 11)

Under the *apartheid* project's state sanctioned segregation the hospital was established in the 1980s to serve a certain catchment area. The flat, windswept sandlands of this part of Cape Town embodies a history of simulated communities organised into being after forced removals, prior to demolishing the Sixth Municipal District of Cape Town that had existed since 1867. Under the Group Areas Act of 1950, the resulting site was declared a Whites-only area on 11 February 1966, with forced removals commencing in 1968. By 1982, more than 60,000 people had been relocated to artificially knit together suburbs never meant to be, 25 kilometres away from their former homes. I do bear in mind that this intellectual disability service is currently located in a specific hospital with its own ruling relations. But where staffing norms are arbitrary at best and the wards symbolise purgatory for misbehaving nurses from the "*psych side*" (Nurse 13), disincentives and barriers to opting for employment out of free will in the hospital's intellectual disability service will be continually reproduced:

N13:   *There are jokes sometimes made by other nurses, that if you are sent to [IDS], it's a punishment.*

CC: *Really?*

N13:   *Ja.*

CC: *Why would they say that?*

N13:   *Before we had disposable diapers, nurses had to change and wash the cloth nappies.*

The second research site was formerly a military hospital complex during the First World War, later converted by the Provincial Authority in 1921 and sold to the Union Government for use as an institution for patients with intellectual disability. Formally opened as a rehabilitation and care facility under *apartheid*, the facility serviced predominantly White patients in the past. No longer the case, the second research site now functions as a specialist hospital for adults living with intellectual disability and psychiatric illness, and currently offers multi-disciplinary outpatient services as well as inpatient facilities. Both service a catchment area different from the aforementioned site, including Cape Town's "northern suburbs", the West Coast region, and an area that connects the Cape Flats and the city's "southern suburbs". On its wards built during the 1980s, there were very clear demarcated areas for White, Black, and Coloured nursing staff members. The wards had separate tea rooms for example – White nurses had their own tea room, whilst Black and Coloured nurses shared another (Personal communication, 1 June 2015). These demarcations have been discontinued, and the hospital staff consists of Black and Coloured mental health workers across all the professional disciplines.

Having worked at different hospitals in the Cape Town area during her 30 year career, Nurse 15 was aware that patients of different races were being treated differently under *apartheid*:

N15:   *Now I'm going to talk openly. The Whites got the best.*
CC: *Ja?*
N15:   *Do you remember? The Whites got the best. They always got [disposable] diapers.*
CC: *So the White patients...*
N15   *...always got [disposable] diapers. Like [research site 2] got [disposable] diapers, and hospital S got [disposable] diapers.*
CC: *Ja?*
N15:   *Not L [research site 1].*
CC: *So what you mean is, under apartheid the Coloured and Black patients, were made to wear towelling nappies.*
N15:   *...towelling...*
CC: *They didn't get the same treatment.*
N15:   *No, not the same.*
CC: *So during that time race determined the kind of diaper you got?*
N15:   *Yes.*

Although she was talking about the past, race, gender, class, and ableist practices still intersect with intellectual disability to problematise care on psychiatric intellectual disability wards in both research sites. At times obvious but more often disconcertingly covert, the ubiquitous performance of devaluation was striking not only in conversation with healthcare providers and patients, but also during participant observations. In spite of constitutionally

219

enshrined antidiscrimination laws, inequality seems to continue in the public healthcare settings this research is located in.

For the purposes of this discussion, *race* refers to "socially defined differences based on physical characteristics, culture, and historical domination and oppression, justified by entrenched beliefs" which can be accompanied by ethnicity (Acker, 2006, p. 444). In South Africa, inequalities surrounding race, class, and gender can hardly be separated from one another, and are linked to inequality in surrounding society, its politics, history, and culture (Acker, 2006; Glazer, 1991). As work processes that create and recreate inequalities become more subtle, they become more difficult to challenge and change. As Nurse 2, a Coloured male nurse, explains:

> *I have a lot of friends resigning. The new strategy of [this] hospital: the Blacks must be promoted, and the Coloureds must [participant waves hand in a sweeping motion]. I said: "Why don't we get a little bit coloured people here? Why every time an African person?" They start out, then they get used to the ward, then you have to speak to them every time: "Listen here, check-up on the patients. Why are you sleeping?" It's a constant problem. They put in a new staff nurse here, an African guy. He comes on duty to come sleep! (Nurse2)*

Although writing about inequalities within organisations may not be new, attempts at understanding these from an ethics of care perspective in a South African psychiatric intellectual disability setting might offer fresh ways of identifying race, gender, class, and disability inequality perpetuating "practices, processes, actions, and meanings" as loci for change (Acker, 2006, p. 443; Kekana et al., 2007). How these inequalities are enacted on hospital wards also serve to further complicate already difficult and at times even traumatogenic intellectual disability work (Corbett, Cottis, & Lloyd, 2012). Nurse 2 continues:

> *The people that failed the PN [Professional Nurse] interviews, they were placed in speciality, because they are Black. They put an African guy with me as a staff nurse. This guy is from Limpopo, he didn't know nothing. (Nurse 2)*

Care exchanged within an intersubjective and relational ethics of care frame sensitises us to racialised and gendered constructions of care participants' subjectivities (Tronto, 2010). Such a frame requires cultural and political tolerance regarding encounters with others not like us. Yet racialised experiences of South African political history still continue to affect care participants', like Nurse 2's, capacity to engage freely with language, age, race, culture, gender, (dis)ability, and class differences:

> *I have a European uncle. A White uncle. I was the leader of [a political party's] Mitchells Plain Youth. I know about [hospital property] being purchased and being sold. I reported this. They were*

clever...then they made a racism case against me. I allegedly said this one African guy is a da-...uh...is a kaffir. Racism remarks which I never said. Racism is immediate dismissal. You'll never work for government again. My one friend was dismissed last month for a false racism case because he's outspoken like me. Now he's suing the head of nursing. There's a "hit list" for people that are to be gotten rid of. People don't like you being honest. You will be victimised. (Nurse 2)

Intersubjectivity and relational ethical care would expect us to reflect on stereotyping and racism during care exchanges. But race has a history in South Africa which (re)creates and maintains a racialised gaze – it has made resident J, for example, into a hateful, offensive individual. Resident J is a 57 year old White male:

RJ: *(Whispers). The Black asses that are down there, the kaffirs, they are lazy!*
CC: *Why did you say it so softly?*
RJ: *Here are many kaffirs, bad! Black and lazy. I'm not talking about K that's a kaffir, I'm talking about the people that fucking work here. Ja, those are the people that are so lazy. (Resident J, session 3)*

RJ: *[R is] Coloured. He's a good guy. He believes in Jesus. They believe in god. He's not sly.*
CC: *So It's not because he's a Coloured person that he was sly, the other guy. He was sly in his heart?*
RJ: *He was of dark complexion. (Resident J, session 1)*

So Nurse 8 rightly explains that:

Our patients are racist! You know that? You can say it's not like that. It is like that! They don't want the Blacks on the ward. But you have to look at the organisational culture. You must balance staff allocation. Not too much of one race. Otherwise the patients tell you: "there's more of you, and more of you." Our own patients! So you must take that into consideration. But you must be careful also, because they'll say you said so. (Nurse 8)

The term *gender* in this discussion denotes "socially constructed differences between men and women and the beliefs and identities that support difference and inequality" (Acker, 2006, p. 444), for example, the "pride" (Nurse 7) with which wholly dependent adults are dressed, and the limits of gendered career options:

In the mornings, hey, that nurse takes pride in her patients. In the mornings, she puts all the buggies outside, hey. And if it's girls then she sees to it that they dress in pink. And for the boys she'll put them in blue. (Nurse 7)

We only knew about becoming a nurse, or a policeman if you're a boy, or a teacher. We didn't know about other careers. (Nurse 7)

Regarding gender issues contributing to nurses' stress as referenced in Chapter 6 (Stenfert Kroese et al., 2013), female nursing participants explain that clusters of male residents make them nervous given that aggressive residents are mostly male. Situations can rapidly escalate when uncontained residents disregard female nurses: *"...they won't listen to anything women say"* (Nurse 14). This does not seem unfounded, as Resident J, again, shows us:

> *RJ:*   *Women folk, huh-uh. They're not good here. (Yawns). They are bad. They are rude with the people. (Resident J, session 4)*

> *RJ:*   *Be weary of the women. Especially the Black ones, they can lie to you! (Resident J, session 13)*

Although nursing managerial ranks contain women, hands-on care work at both research sites is still primarily provided by women (Acker, 2006; Glazer, 1999; Tronto, 2010):

> *There should be two males and two females. The leader of the [ward nursing] team is normally a female. (Nurse 6)*

The ideal worker for many jobs, as Acker explains (2006), is a woman, particularly women who are compliant, and who will accept orders, low wages, and difficult working conditions (Hull, 2010; Tronto, 2010). During the 1970s and 1980s in South Africa under *apartheid*, a time during which inequality was legitimised by state sanction, Black and Coloured women had very limited options regarding career "choices" which were limited to secretarial work, social work, nursing, and teaching, as Nurse 7 explains:

> *Charlotte, we didn't have a choice. In our time we didn't have choices. We only knew about nursing and teaching. If your mother had money, you could become a teacher. I can't do anything else but nursing. I might have done something else. If I knew there were so many options. We didn't know about radiology or physiotherapy. There was just nursing, teaching. (Nurse 7)*

A particular paradox emerges around male nursing which sees males, in this case Nurses 2, 6, and 13, unconformingly cast into what can be viewed as a traditionally female role. But, as seen from female nursing narratives, when traditionally masculine characteristics of strength, aggressiveness, and competitiveness must be taken on (when fighting for patients or battling the system, for example) she no longer complies to a normative expectation of gender and caring:

> *I don't know why it is this way. I can't understand it because, honestly, we fight really hard for IDS. The entire institution makes me angry. We motivate and complain...we have to motivate harder to get things. After a lot of arguing and fighting, after how many years, they said we can now have disposable diapers. We complain because our patients cannot. We complain for our patients a lot. (Nurse 11)*

After such lengthy administrative *"battles"* (Nurse 14), female nurses are made to account for themselves or re-establish their arguably subordinate womanly role by doling out hugs, for example, as in the case of Nurse 8: *"Dr M [the male CEO] said to me: 'just come and let me just give you a hug'"* (Acker, 2006; West & Zimmerman, 1987). Women managers are almost expected to "work quietly to do the organisational housekeeping, to keep things running", and face "gendered contradictions when they attempt to use organisational power in actions similar to those of men" by violating "conventions of relative subordination to

222

men" when enacting power (Acker, 2006, p. 447; Holden & Littlewood, 1991; West & Zimmerman, 1987):

> *The nurse's voice is not always so important unless it's the doctor... if it's a nurse who sees there's a need then they won't jump to help you. (Nurse 14)*

Opportunities for equality do present themselves, but only if the female nurses function like men. Masculine stereotyped patterns of on-the-job behaviour at work might mean that women must make adaptations to expectations that interfere with family responsibilities: "*If I don't feel good at home, then I come to work*" (Nurse 9). But although men could traditionally dedicate themselves to their work and related responsibilities other than those required to earn a living, female and male nurses in this study carry the responsibilities for children or family demands in addition to earning a living. Nurses work long 12-hour shifts, and work is often put before self and family:

> *We're here from seven this morning till seven tonight...you get tired because we're working long hours. I try and separate family and work. (Nurse 6)*

> *It's not always easy. I'm then miserable towards my two children, which is not fair. I take it out on the two of them. You're not doing it intentionally, but it happens because you're only human. You try to be very strong at work, but you know when I go home again...I feel so sorry for my two children. At work I have to be there for other people, but I have to be there for my children also. So I get it from both sides! (Nurse 8)*

> *When you get home you don't really have time for your family, you just want to get in the bath and into bed. (Nurse 10)*

With staff shortages, a long-time complaint of the nursing participants in this study, nurses are expected to work as the hospital demands – shorthanded, overtime, or with little opportunity for leave and self-care:

> *They don't consider us overworked and overloaded. But when something happens, injuries, they ask like: 'where were the nurses'? (Nurse 6)*

> *Even when I'm on leave, I'm on the phone all the time! I did staff performance while I was in hospital! (Nurse 8)*

> *If I'm not here, then the nurses phone and ask: 'Where are you? Are you ill? We need you'! (Nurse 9)*

> *Sometimes it feels so overwhelming...like now I feel I need a leave. (Nurse 4)*

> *My manager cancelled my leave without telling me. (Nurse 2)*

> *[The residents] were running to me. "Are you on leave? Please don't go on leave again" ...that makes me see I'm wanted...it makes me feel good. (Nurse 11)*

223

Acker (2006) warns that gender and gender inequality tend to disappear in organisations or are seen as something that is beside the point of the organisation. Practices that generate gender inequality are sometimes so fleeting or so minor that they are difficult to see. Equal rights may be seen as protected in a constitution, warranting no need to consciously practice this in person. Inequality might have become so normalised that is becomes unrecognisable as a discourse separate from quality healthcare:

> RJ: *And that darkie nurse with the long hair, also my company.*
> CC: *What does "darkie nurse" mean?*
> RJ: *She's an African. They're all right with me, the African people. (Resident J, session 11)*

Given the legacy of segregation and inequity I might encounter as encapsulated on participating wards, I remained mindful of my embodiment as a White female researcher with a professional qualification, and the undue assumptions this could evoke.

7.3.1.3. Handling relational interaction with care: Issues in continuity of care

Systemic patient reporting at ward handover during 12-hourly shift changes is an important nursing communication event (Caruso, 2007; McGibbon et al., 2010). The complexity of providing medical and mental health care to patients living with intellectual impairment, coupled with care disabling institutional constraints, renders such person-making communication even more urgent (Tinney, 2008):

> *For the most part, shift changes involve swift departures. Staff greeted one another in passing, occasionally stopped for a quick chat unrelated to patients, and took their leave. These "flights" negated the exchange of patient information as a care interaction. Communication of patient information seldom occurred. I wonder about the silencing and withholding effect these not-mentioned patients' spaces have on a ward that is their whole world. Sinason's devoid of care speces...? (Field notes, 2013)*

One nurse manager explains: *"Tomorrow morning I'm here first thing. I need to get to the night people. Because they dodge you, man! The night people really need to jack-up their report writing"* (Nurse 8); whilst another must constantly discipline staff members that arrive late for morning shifts: *"she was disciplined for leaving point of duty [and] for coming late ... every morning coming late. It frustrates me, if you have to reprimand somebody every morning about being late, and there's no improvement. I got three people in to explain this to her, and she still doesn't understand"* (Nurse 9). Ideally, resident centred information is disseminated and nursing resources rotated during 12-hourly handovers with little disruption to ward life:

> RN: *Tonight I'll go to sleep early, because last night the pills were late again.*

CC: *Oh no. And how was that for you?*
RN: *I don't actually want to get pills late.*
CC: *What happens when you get pills late?*
RN: *Then I can't get up easily in the mornings. I have to go to bed early for the [computer] course. (Resident N)*

During one shift change, however, it was observed that a nightshift nurse shared pertinent information on each patient with the first day nurse to arrive. Without the exchange of such patient centred information, their personhoods are passed by as typical, mundane, irrelevant, ordinary, or not worth a spoken word. Adults in care cannot be brought to life from inanimate charts as feeling sad, despondent, suicidal, sleepy, excited, proud, independent, unwelcome, marooned, rejected, unhappy, grieving, shocked, or even useless. They cannot be anchored in time and place:

RN: *I am just fed-up. I don't have energy for life anymore. I feel like sleeping forever. Take a gun and get it over with. What do you think?*
CC: *Is that something I should report, that you want to go to sleep and not wake up again?*
RN: *For good?*
CC: *Hmm.*
RN: *Why? Do you want me dead?*
CC: *Do you want yourself dead?*
RN: *No. (Resident N)*

CC: *How are you doing today?*
RR: *Sleepy. (Resident R)*

RG: *I'm sad, man!*
CC: *You're sad?*
RG: *But it doesn't actually matter. (Resident G)*

RE: *Auntie must just get me dressed up nicely. My mommy said a surprise is waiting for me at home.*
CC: *You sound excited about tomorrow, and want to look pretty. (Resident E)*

RN: *I feel, you could say, marooned or rejected.*
CC: *Sjoe, that makes sense.*
RN: *I can't stay at home because they don't want me there. (Resident N)*

RJ: *I think I'm getting somewhere and doing my own thing. I'm beginning to become more independent on my own. (Resident J)*

CC: *How was it for you that things went well this weekend?*
RN: *No, I'm very happy. I'm proud of myself. (Resident N)*

RE: *Did auntie know my father died?*
CC: *I didn't know that, E.*
RE: *It was a real shock for me. (Resident E)*

RD: *Sorry I'm so useless. (Resident D)*

225

Yet patients existed anew on that morning to that nurse only, their stories not further relayed to arriving colleagues, and this is where the making of these patients ended. They live not a fluid past and present connected with care, but for 12 hours at a time, unmade and lost to others and themselves twice a day. Spending person-making time during shift changes could knit uninterrupted stories, mark patients' existences by reviving them with words, spare on-shift surprises, and perhaps foster a sense of ward-as-world cohesion. If documented, patient details could always be retrieved from files, but this would disqualify verbally animating the information. The significance of securing the patient as person, of marking this constantly made person in time and place by telling the story of the last 12 hours of his or her life, should be taken up during the care practice of ward handover.

It has been many years since Menzies Lyth (1960) suggested that nursing staff develop useful strategies for mediating stressful hospital environments, having conceptualised a "good" nurse as able and willing to transition between wards and hospitals with a certain amount of detachment. But participants narrate emotional exhaustion, depersonalisation, and system fatigue – the result of fighting to do good work in unworkable systems, extinguishing nurses' energy for the residents in their care:

> *You become fed-up, not feeling like complaining anymore. You hit a brick wall. Nobody notices your work. And we work very hard. We work hard, Charlotte. (Nurse 15)*

> *I love my job, although sometimes I feel so discouraged. You try to do good work with your patients, but the resources you need to do so...we don't get. The fact that there is nothing that I can do, I'll just do the little that I can. So you feel like you just gonna conform to this standard. Things have always been this way. I'll just zip my mouth and just do with little that we have. Just feel so discouraged. At the end of the day, I'm just wasting my time here. Nothing really happens here, and you don't go anywhere. For my own sake I must move. (Nurse 6)*

> *Most of us are burnt-out. Everyone wrote letters. They want to leave this ward. They fear burn-out. We get depression, high blood, and cholesterol. (Nurse 2)*

Menzies Lyth's (1960) suggested detachment from patients might serve to dispel carer anxiety; but perhaps also aids the illusion that nurses and the adults they care for do not become attached, even unconsciously, to one another. Undoubtedly, one should never underestimate the distress residents experience at the threatened loss of a much loved attachment figure as each shift change looms – a continuous attachment trauma in which the reappearance of the nurse for a next shift might not be held in mind:

> RJ: *It's quite nice people who work here, both shifts.*
> CC: *What's it like for you when the shifts change?*

226

> RJ: *Other people mustn't come here. Ooo, then it's going to be a mess. (Resident J)*
>
> RE: *Sister V is gone. On leave.*
> CC: *What do you think about that?*
> RE: *I'm sad. (Resident E)*
>
> RJ: *Today's nurses are nice to me. And they also look after us nicely.*
> CC: *So it feels to you as if they care.*
> RJ: *Yes, everyone cares for us. (Resident J)*

Although defensive detachment might keep seemingly painful affects and thoughts out of conscious awareness (McWilliams, 2011) by protecting nurses from the painful realities of living and working with intellectual disability, these could disable opportunities for relational care interactions during which one adult self is made, whilst another is made into an ethical carer.

7.3.1.4. Handling relational interaction with care: Scripted but unperformed daily activities

As an institutionalising text demarcating slots of care, wards have a set roster allocating daily activities. In public view, these regulate ward rhythm in pockets of time to reveal a familiar routine:

> *7:30 is the time allocated for "personal hygiene" (wash time). Meal times occur thrice, breakfast at 8:30, lunch at 12:00, and dinner at 17:00pm with leeway of about 30 minutes. Food often arrives late to the ward kitchen from a central distribution point. Between meals, slots are allocated to enrichment activities and leisure time. (Ward poster, field notes, 2013)*

The performance of personal hygiene as a care practice made it obvious that nursing staff were outnumbered by resident requirements:

> *Prof H said we're supposed to be seven staff members on duty every day. We must be four in the bathrooms. Today we are only three. (Nurse 2)*
>
> *I feel that a ward like this [with 22 patients] needs five nurses. That will be ideal. We are only three. One old nurse, me, and an agency nurse. Sometimes we are just two if we don't book somebody. (Nurse 6)*

I observed residents being gathered and herded into the bathroom, undressed where they stand, and divided into groups of equal size. These proceed along three stations where residents are washed, dried, and dressed in marked hospital clothing without individual choice as to preferred clothing:

> RE: *The staff must organise other pants for us. Sister said we bath only once a day, and then we put on our night clothes.*
> CC: *You have a right to new pants.*

> RE: *They gave jerseys this winter, now we have to wait for the new pants. These pants are now finished.*
> CC: *You showed me...*
> RE: *Hmm. We all wear the same.*
> CC: *What do think about that, everyone wearing the same?*
> RE: *Ooo, then I say to them: "You guys look prettier than me". (Resident E)*

Given that the ward of 23 residents had three nurses on duty, each station was commandeered by one nurse seeing to the needs of up to eight residents simultaneously. Care of nude and vulnerable human bodies had become non-private, undignified, systematic, and task orientated. Despite, or due to, being under such pressure to perform this care, "wash time" was completed effectively with no time spared for resident bodily autonomy whilst *"nurses feel like they're working in a factory"* (Nurse 9). Patients who are able to do so then assist nurses with tidying the bathroom:

Meal times offer further insight into ward life. Residents are herded to the dining room and allocated seats to prevent conflicts around pinched food, but without regard for where they would prefer to sit or time in which to choose. Plates of food are sequentially brought out to each resident, after which individual medications are administered:

> *On Ward A, patients use this time to interact with one another or with nurses. The sight resembles a surreal canteen or restaurant scene as individuals matter-of-factly converse over a meal, nodding in affirmation at something being said, or with elbows on the table if not gesticulating to emphasise a point. (Field notes, 2013)*

But once washing and taking meals have been performed, resident activities tend to cease despite scripted ward routine, becoming obscure and silent non-events:

> RN: *What I want to say, it's not easy living here.*
> CC: *I agree with you.*
> RN: *Food, clothes, sleeping, that's all. (Resident N)*
>
> *Everyday the same story: medication, eating, and washing. (Nurse 6)*
>
> CC: *So what is some of the things you can do here on this ward?*
> RJ: *You can do nothing. (Resident J)*

Engaging in supportive mental and physical activity outside of psychotherapy and physical or occupational therapy sessions aids self-determination and autonomy in individuals living with intellectual disability, provided they are supported in such endeavours (Barlto & Klein, 2011). Such support, however, is contingent on environmental factors present in patients' social settings (Nota, Ferrari, Soresi, & Wehmeyer, 2007). This investment falls on already

overstretched and outnumbered nurses who *"...do everybody's duties here"* (Nurse 6), disabled by staff shortages and unusually high staff to patient ratios, and who take consolation from what care they can give (McGibbon et al., 2010):

> *The activities we're supposed to be doing with them, we don't have much equipment. We need more of the things that we can use for the activities of the patients. Because sometimes, our patients, they get frustrated because of this environment. They can't go outside for a walk. We can take them outside, but how many staff will have to go with outside? Then we are not enough left in the ward. More staff, equipment for the patients, games and all those things. (Nurse 6)*
>
> *We don't have the amount of staff to sit with one patient. (Nurse 1)*
>
> *Sorry, I'm only doing my work. I'm not touching the grey area of nursing. Which is I have to do clerical, occupational therapy, and physiotherapy. I'm not doing that. (Nurse 2)*

Despite the relational significance of patient-nurse contact, however, attention to work routines amidst staff shortages can easily overlook the importance of care dynamics in institutional settings (Van Der Walt & Swartz, 1999). Amidst staff cuts leaving a single nurse on night duty per ward, every participant reported a shortage of nurses across the service which could render the exchange of quality care impossible: *"It became worse because the staff became less"* (Nurse 2); *"There's times when there's just one [nurse] on a shift"* (Nurse 1); or *"...with 30 patients ... and then we are only four people"* (Nurse 13). If one nurse is expected to care for seven or eight mobile adult psychiatric patients with intellectual disability, a sense that *"the system is failing"* (Nurse 8) gravely problematises ethical care demands, whilst Nurse 6 struggles to make sense of this long-standing staffing problem that still remains unaddressed:

> CC: How do you make sense of that?
> N6:   It doesn't make any sense. It doesn't make any sense to me. It doesn't make sense at all. I don't understand why nothing is being sorted out. (Nurse 6)
>
> CC: Sometimes decisions are made without talking to you guys first?
> N13:   That's it. Then things fall apart. (Nurse 13)

Further staffing issues include lack of support, nurses' safety concerns, work overload, covering for absent colleagues, lack of discipline, staff confrontations, professional jealousy, little cooperation, low staff morale, few male nurses, lack of training opportunities, and, as one operational manager explains, being undermined by colleagues:

> *My area manager is not very supportive towards me. Even...my e-mails, hey, she doesn't like sending me information. I don't know what's going on here, why she doesn't give me any information. But I'll get the information from other colleagues or operational managers. I ask: "what do you have on the e-mails that I don't know about? Send me everything that you get". Now I have to run around to find things out, where it could've been so easy to just open an e-mail and get the info. (Nurse 9)*

229

7.3.1.5. Handling relational interaction with care: Remote controlled care

If hierarchical organisational controls that impede changes toward ethics of care maintain the power of managers, the ways in which these controls are implemented warrant comment (Acker, 2006):

> *Managers are murderers. They kill all hopes and dreams. (Nurse 2)*

In terms of an intersubjective and relational conceptualisation of ethical care, the need for shifting loci of power becomes clear: ethical care is in principle aware of the power relations that can exist between enabled/disabling manager and disempowered nurse or patient, and implies equality and a balance of power among all of its participants. The perpetuation of unchecked power can continually recreate infantilised and dehumanised care participants. CCTV cameras are omnipresent on some adult inpatient wards, and care is distilled into constant surveillance:

> *Ward life is "locked-in", with residents separated into secured rooms, hallways, or communal areas to be easily observable at any time. Every space is under 24-hour nursing and management watch, and very little is left unobservable at any time. In moments when nurses are not tasked with physical patient care, CCTV enables remote supervision in lieu of personal interaction. (Field notes, 2013)*

But surveilled care deletes available relational care spaces and disables ethical care. The needs of the institution come into focus whilst those of residents' are obscured. Although this practice can be appreciated in light of medical management, remote controlled care risks amplifying invasive institutional omnipotence, depersonalising patient care, and eroding patient and staff autonomy. Nursing participants report that resident incidents are investigated as if nurses are at fault, and both nurses and residents feel surveilled by CCTV ward management (anecdotally, nurses tell of residents who interfere with cameras by tilting them away):

> *We have 20 cameras, busy recording us the whole day. You're being watched the whole time. You must answer for stuff that you don't know. (Nurse 2)*

Nursing managers must write statements on ward incidents even if not on duty at the time, and feel *"disciplined for other people's stupidity"* (Nurse 8), *"afgedruk"* (oppressed) (Nurse 9), and blamed for incidents despite being upset by them. Reports are subsequently discussed in their absence, and residents are scrutinised as witnesses:

> CC: *So what you're saying, there are consequences for assaulting someone here.*
> RJ: *Then we had to complete paperwork and all that jazz. (Resident J)*

230

In contrast to state-of-the-art surveillance equipment, requests logged to hospitals' information technology services, as with many made to maintenance, laundry, and catering services are not responded to with haste or urgency:

> *I had to struggle with Workshop to fix the windows. I had to log calls every day to get the ward cleaned, scrubbed, and thrown with acid. That really exhausted me to get the ward where it is now. (Nurse 9)*

> *Only when something happens do people take action. The patients don't have clothes. Patients must wear summer clothes in winter, not getting what they're supposed to get. Higher functioning [psych] patients can demand [winter clothing]...our patients can't. (Nurse 6)*

> RJ: *I don't know what is wrong in this place. We've reported it [set warm water temperature] how many times. The patients and staff said it won't work how many times. How's this place? Broken or working?*
> CC: *It feels to you that you could be treated better?*
> RJ: *Exactly. Because these things should have been fixed long ago. (Resident J)*

Furthermore, decisions about resident care are made remotely – in their absence without input or self-determined sense of control. Determinants of care take place elsewhere...

> RJ: *Ja, Charlotte. I'll get out of here.*
> CC: *How do you think that'll happen?*
> RJ: *They'll still talk about it.*
> CC: *And what do you think they'll talk about?*
> RJ: *About my behaviour and manners.*
> CC: *And what do you think they'll say about your behaviour and your manners?*
> RJ: *The nurses will talk. The staff will talk. (Yawns).*
> CC: *And what will they say?*
> RJ: *They'll say: 'no, let him go back, you might as well. He was nicely behaved and his manners were nice. He wasn't rude. (Resident J)*

> RJ: *So did you tell M what I said? But he didn't say something about what I said last week? So what did he say? (Resident J)*

Certainly, CCTV observation carries advantages: in cases of emergency for example, or as a means of continuous patient care that is only interrupted when nurses look away from a monitor. But perhaps we should not too swiftly opt for the advantages of remote surveillance without considering it a care practice that can potentially invade the privacy, freedom, and security of care participants' bodily and psychological integrity, and, in turn, create potential for reproducing instances of humiliation and disempowerment. Residents may be yearning for personal contact, and in considering limitations to such contact between care participants by practicing care via CCTV, Kittay (2009, 2011) reminds us to be wary of any care practices that could carry depersonalising and dehumanising risks to ethical care.

7.4.　　DISCUSSION: Caring intersubjectively and relationally about the people we make

Residents can be lonely, distressed, and insightfully aware of a traumatogenic loss of able-mindedness (see Sinason, 2010; as well as Tranvåg et al., 2013). An innate human need to relate is coupled with complex dependency care needs demanding specialised nursing care. Patients' want for comfort and interaction in support of their relational person-making may be limitless, but could be obscured by nurses' stress of sharing out their spatiotemporal proximity during each 12-hour shift (McGibbon et al., 2010; Tinney, 2008).

It is hard to bear in conscious mind that patients lost a life outside of wards that have become their homes – years of searching for family members on their behalf have proven fruitless, nobody calls, and the energy to arrange a new volunteer visitor programme is yet to be found. The ward becomes familialised, with nurses ascribed the roles of mothers and patients of siblings. Shift changes threaten the loss of attachment figures to the minds of adults who, in that moment, can only protest against the pain of loss with little memory that a beloved nurse returns for a next shift.

Intellectual disability care is not a mere performance or delivery of service, but includes relational responsibility for its exchange among care participants (Tronto, 2010). Care can be performed cognisant of how it will be internalised and affect the recipient, and the kind of person it makes as a result. Conditions for care are informed by our social, cultural, and ethical understandings of its worth (Kittay 2009, 2011; Kittay et al. 2005). Ethical care also depends on institutional ruling relations and the way hospital executives, as participants in care-making, choose to think about and plan for intellectual disability care. I am reminded of an earlier conversation with Nurse 8:

> N8:　　*We [IDS] are the stepchildren. Psych gets everything ... when it comes to money and concerns. We all know it is like that because they feel IDS is not important. The management. For years we've been talking about this. Management must change their attitude. They don't ever come here [to the intellectual disability wards]. They don't have insight into what is happening here ... I don't think they want to. (Nurse 8)*

Where differences in ability, gender, race, and class can create care disparities based on the societal evaluation and standing of these features, then care is deeply interwoven with societal power differentials. As a social individual with a certain history, each nurse was created in care relationships, with each interaction having contributed intersubjective and relational person-making value. Consequently, care exchanged with patients is an

232

amalgamation of nurses' internalised care experiences, to be received and internalised by patients in turn. Yet the phenomenon of caring is not solely the domain of nursing, but of human kind. From an intersubjective and relational perspective, we are all culpable in (re)producing patterns of care, and intellectual disability care is the product of all of us.

In my intersubjective research work on adult intellectual disability wards I was confronted with the myth of independence (Kittay, 2011; Kittay et al., 2005), and learnt that being human can be defined by what all humans are not. After many years of lifting patients and numerous back operations due to this, Nurse 8 explained how she became disabled herself, and found herself in need of a disabled parking disc: *"I need a disc, not that I'm that disabled. But I can't walk long distances. I sacrificed a whole life"*. The wards ask us to take cognisance of an inescapable universal human fragility so that we can face our future dependence with dignity, justice, and worth, secure in the protection against violence of moral, psychological, and physical abuse. The assumptions we hold subjectively, and the decisions we make on intellectual disability care today, will directly inform the care we will come to rely on in future as care dependents. By birth, injury, or insult, none of us are immune against the fragility of bone and brain, we are not in a state of permanent intactness, we are not of able mind and body permanence, and ultimately we are never independent. Relatively able-bodied for now (L. Swartz, 2010), we might ignorantly negate our culpability in contributing to a world that intellectually impaired individuals are disabled by daily. Yet every day, we are all creating the world that we will become disabled by.

Limited funding for intellectual disability care remains a compelling argument. But thinking about and practicing intellectual disability care ethically need not be dismissed for financial reasons. In learning from Goffman's (1961/1991) seminal work, ethical care neither infantilises nor depersonalises, nor does it contribute to the physical and psychological deterioration of its participants – it encourages dignity for all, promotes care participant well-being, fosters resident independence and confidence, and validates residents' adult status.

Still, the dilemma that well-intentioned yet harried nurses are cast into must be appreciated: task completion in service of patient bodily needs and economical requirements of the institution on the one hand; or exchanging ethical care in service of patients' individuality, dignity, autonomy, and integrity of person on the other. Although bodily care duties might be more easily met than multiple emotional needs of numerous patients by outnumbered nurses,

233

the attainment of either is precariously balanced in disabling care-making environments. In concurring with Tinney (2008, p. 204) during my observations of care on the wards, patients' requirements for both emotional and bodily care were "always greater than the capacity of [nurses] to meet it".

Notwithstanding the dedication of progressive psychiatric staff in service of intellectual disability, nurses absorb the spatiotemporal pressure that the constant availability of care to patients requires, long after clinical and managerial staff have left the premises (McGibbon et al., 2010). Efforts at reducing the powerlessness that intellectual disability nurses may feel lies in respect for their needs and requests, and in regard for their knowledge and skill (Stenfert Kroese et al., 2013). As Nurse 8 explains, *"I like to share my knowledge and skills. People always come to me for advice"*. But reducing powerlessness also depends on institutional ruling relations and the way hospital managers and executives, as participants in care-making, choose to think about and plan for intellectual disability care.

From experiencing ward life over the years and from its formal methodological observations captured in this research, it would seem that significant aspects of care in the lives of adult inpatients living with dual diagnoses – and those of their carers – may be lacking the kind of care that would be recognised as ethical. Perhaps care workshops offered as modules of in-service staff training at all levels and across all involved disciplines could be taken forward in future, and questions around prospective candidates' conceptions of care might be designed onto selection panels and into employment interviews.

And so, in light of the findings and discussion presented here, an attempt is made to conceptualise ethical care as relational and intersubjective: If ruling relations and practices, socio-political attitudes, and fiscal decisions stand in service of care that shapes and sustains a kind of self whose rights are respected; whose wishes and preferences are known and regarded; whose dignity is held above all else; whose powerlessness is reduced; whose value is built through relationships and pride in the smallest achievement of adversity overcome; whose emotional needs for comfort, reassurance, and psychological integrity are not inconsequential to bodily care; whose lives are witnessed, stories are heard, and memories held; and whose individuality and independence of personal choice trumps complacency in bulk custodial care, we might begin to delineate a quality of intellectually impaired life made

and maintained by ethical caring. Impediments to this kind of care are not-care making and not-ethical.

7.5.   CONCLUSION

Caregiving and receiving was studied as their exchange occurred on adult psychiatric intellectual disability wards where the basic needs of residents are being met: they are fed, they are washed, they sleep on a bed or mattress on the floor in case of a fall, and they are kept as safe as possible from injury. But even these basic care practices are yet to meet a conceptualisation of ethical care offered here.

Although care on the wards is both a patient right and necessity (Department of Health, 2007), the environment in which it is performed can be disabling. Nurses find themselves taking up the slack of laundry, cleaning, and kitchen duties, whilst providing both bodily and emotional patient care. Although nurses are grossly outnumbered by often difficult to care for patients, the imperative of meeting task oriented and documented Department of Health accreditation requirements can too easily eclipses patients' psychosocial wants (McGibbon et al., 2010).

Inexhaustible patient needs and nurses' skills in meeting these seem not to be commonly regarded with respect, nor are countless arguments for better training and more realistic staff-patient ratios taken seriously (Stenfert Kroese et al., 2013). A nurse may find him- or herself providing bodily care for up to eight patients, and supervise enrolled nurses and rotating students whilst attending to ward rounds, professional notes, and statistics that capture documentable work for future performance reviews.

Even routine tasks carry relational and intersubjective significance, and need not only stand in service of custodial, physical patient care (Tinney, 2008; Tronto, 2010). Relational conversations need not be withheld from individuals with intellectual impairment who struggle to reciprocate in conventional ways, or constrained by assumptions of a person's capacity to understand and respond. Relationally mindful communication was observed to initiate a wider range of conversational topics, with patients introducing spontaneous questions and comments in free and confident interactions as a result. Such person-making attention from caregivers affords adult residents a sense of meaning, that they are worth

carers' time, are significant and matter, and allow adult residents to share experiences and receive relational dignity-making care (Kittay, 2011; Tronto, 2010).

When medical and psychosocial needs compete for attention from embattled staff, it becomes complicated to argue that patient needs are being neglected. What Tinney (2008, p. 221) describes as "not care" was often the only care performed outside of bathrooms or bedrooms – the feeding of patients, wiping of mouths, adjustment of clothing, or tending to hair. This might not necessarily represent the care nurses wish they could provide, their competence to care, or pivotal role they play, but rather the difficult position they find themselves in regarding resources with which to do the actual caring: *"We have to make do. Cut up linen for nappies"* (Nurse 2). Intellectual disability care policy, design, implementation, evaluation processes, and ruling practices must be informed by their implications for carers who both perform care and need to feel cared about (McGibbon et al., 2010). Should we continue to neglect this, we run the risk of reproducing inadequate responses to patients' and nurses' ethical care requirements, with grave consequences for the kinds of care participants that are made as a result.

The implications of layering others' work on top of nurses' patient duties are seemingly seldom considered, highlighting an unspoken assumption that nurses will "take up the slack" or Nurse 2's *"grey area of nursing"* (McGibbon et al., 2010, p. 1376). This requires further research into resources and power for nurses who are left to deal with too many patients amidst Nurse 8's description of disabling ruling relations of care: *"...they feel IDS is not important. The management"*. Care practices can improve and shift in the direction of ethical care, but it is unfair to lay this responsibility on nurses alone. Perhaps Nurse 8's words are suggestive to all of us in that dependency care is important, and that we should perhaps change our attitudes toward it in light of our own inescapable future dependency.

I hope the observations and participant voices presented here give pause for reflection on all our parts. That they not only inform on ethical care literature but perhaps shift change toward its practice – in the words we choose to use, in the societal position we choose to (un)lock intellectual disability into, in decisions made around boardroom tables, in the performance of our duties and interactions with humans cast into intellectually impaired lives, in how we conduct ourselves as care participants, in the tone and pitch of the voices we use, and in the care institutions we create for intellectual impairment to be lived in and worked with.

Undoubtedly, there are many things I could not see or hear beyond my own subjectivity, things lost in my translation of wards into words. The observations left me with a fair measure of ambivalence – even understaffed care could be performed in relational spaces that, for now, are occupied by burnt-out, under-resourced, and outnumbered nurses without whom a hospital simply cannot function. Of course, this may not be the case at all, but I doubt other researchers with a similar brief would have witnessed significantly different care. Care travels beyond tending to bodily needs, and even their satisfaction can occur within its intersubjective and relational frame. To enable a shift away from disabling care environments and resultant disability, intellectual impairment care can be made economically and ethically.

CHAPTER EIGHT

Future research opportunities: The ethics of intersubjective and relational person-making, intellectual impairment citizenship, and a reclaiming of knowledge

Ours is a constitutional democracy that is designed to ensure that the voiceless are heard and that even those of us who would, given the choice, have preferred not to entertain the views of the marginalised or the powerless minorities, listen.
Chief Justice Mogoeng Mogoeng
(Tolsi, 2014, p. 1)

8.1.   INTRODUCTION

This chapter discusses possibilities for future research in the field of intellectual disability in South Africa, for example on citizenship and emancipatory research, and also touches on some of the limitations of this study. A main tenet of this discussion on further research is that socio-political thinking and decisions pertaining to resources for caring about intellectual impairment create, in turn, policy environments in which intellectual disability services will be delivered, as well as spaces for socio-political participation. By neglecting these care correlations, we perpetuate inadequate responses to intellectually impaired South Africans' assertions of personhood so closely tied to the rights, duties, requirements, and obligations of citizenship.

In response, this discussion reflects on Watermeyer's (2012) call for appropriate ways of representing South African intellectually impaired personhoods. It does so by drawing on intersubjectivity, and hopes to show how claims to traditional human rights, citizenship, knowledge, policy building, and care taking in making enabled or disabled kinds of persons could be re-explored in future intellectual disability research. We might then begin to co-create new cultural rules and subjective truths on intellectual impairment, ultimately authenticated in satisfactory socio-political lives (Ogden, 2003; Reeve, 2006b).

The discussion also responds to Kagee's (2014) call for professional and academic psychology to address the needs of South African society, specifically of citizens living with intellectual impairment against an arguably ableist socio-political background. To transform societal structures and attitudes toward marginalised individuals (Stein & Stein, 2007), we can no longer tolerate silences on ableism that must be approached with as much criticality as we afford racism and sexism. The onus for its resolution is on us, warranting critical engagement with oppressive socio-political structures we comply with, ableist policies and

practices we collude with (even if unconsciously), disabling assumptions and attitudes we hold, and circumscribed spaces made available for the expression of intellectually impaired personhoods.

Currently, most intellectual disability research comes from countries where many intellectually impaired individuals are not mired in poverty; and with greater government investment in intellectual impairment policy, practice, research, and care (McKenzie et al., 2013a; Stein & Stein, 2007). As in other policy and resource constrained countries in the global South, it would be inappropriate to transfer a system of thought that obscures the performance of intellectual impairment policy in South Africa or, at worst, perpetuates Eurocentric practice.

Furthermore, an exclusive appeal to a traditional human rights model against ableism can paralyse our thinking by focussing on protections we are entitled to rather than how to affect these entitlements. Despite having rights in law, South African intellectually impaired individuals' levels of socio-political participation remain limited due to rights implementation shortcomings, little political will, and a resultant lack of accountability toward these individuals (Cary, 2003; Stein & Stein, 2007). A relational and intersubjective ethics of care model might afford a fresh framework for considering intellectually impaired citizens' participation in determining policies – by means of inclusive and emancipatory research – that inform their lives.

In supporting the work of other disability researchers, a relational and intersubjective ethics of care approach highlights the importance of social participation, rejects the idea of gradation among humans, and echoes tenets from the traditional human rights and social models as well as from a disability human rights paradigm (Smith-Chandler & Swart, 2014; Stein & Stein, 2007). For reasons of the ethics of care model's universal appeal, this research purposefully did not refer to a disability ethics of care, or ethics of disability care approach. To operationalise claims to citizenship and *true expert* knowledge on intellectual impairment, emancipatory and inclusive approaches must be taken forward on important South African policy informing research.

8.1.1   Before we set off: some conceptual clarifications

There are different ways of thinking about intellectual impairment, and thoughts offered here are but some. As explained in the introductory chapter, there is also no "one kind" of intellectually impaired person (McDonaugh, 2008; Nakken & Vlaskamp, 2007). Some individuals can resist subordination, practise self-determination, participate autonomously as researchers or voters, and achieve their potential with little assistance; whilst others require support in such endeavours which need not, for this reason, be denied (Reeve, 2006a; Nonnemacher & Bambara, 2011; Shaw & Ogden, 2008; Stainton, 2005; Stein & Stein, 2007; Uys& Loots, 2008; Walker, 2013; Watson et al., 2013). Others with little independence may require full dependency care. But all people have intrinsic human worth regardless of necessary support levels, which are in turn contingent on enabling or disabling environmental factors.

In Chapter 1, it was mentioned that a distinction would be applied between impairment and disability as informed by a reading of the social model that views discriminatory attitudes toward impaired citizens as key obstacles to socio-political inclusion, and that locates disablement in difficult to navigate political and social environments (Goodley et al., 2012; Kelly, 2013; Stein & Stein, 2007). Introductory thoughts around the term ableism were also introduced, as were some on what the term care denotes. Care was further conceptualised as relational and intersubjective, something for us to invest our thinking in given that we will all, to some degree, become dependent on care during the course of our lives.

As for *citizenship,* this is about living as a full member of society with all the rights and duties this entails. It provides legal status, and confers a particular identity that speaks to the freedoms and obligations of belonging to a particular national space and place. Interwoven with citizenship are expressions and evaluations of civic virtue and social participation, both equally important measures of societal well-being and social capital (Yeung, Passmore, & Packer, 2008). Sadly, intellectually impaired individuals are often erroneously recognised as members of a homogenous group, "unfit" for citizenship or economic viability for neither suiting the liberal political model of being independent and autonomous; nor a materialist model of being economic instruments that make financially measureable contributions (Carey, 2009; Dowse, 2009; McDonaugh, 2008; Stein & Stein, 2007). Although intellectually impaired individuals might aspire to duties of citizenship, research, social involvement, social acceptance, living with dignity and respect, and pursuing ambitions, ableism can prevent

effective attainment of such participatory endeavours and obligations (Reeve, 2006a; Yeung et al., 2008).

8.2. DISCUSSION

8.2.1. Research into intellectual disability human rights is no longer enough

If the efficacy of laws depends on considerations beyond their mere existence, human rights approaches have failed to research and recognise the complexities of rights claims made by and on behalf of people who live with varying presentations of intellectual impairment (McKenzie, 2013a; McKenzie & Macleod, 2012a, 2012b; Stein & Stein, 2007; Young & Quibell, 2000). Intellectually impaired adults are morally demoted when referred to as children, yet are easily denied the enforceable rights bestowed on those they are likened to (Capri & Buckle, 2014; Kittay, 2009). This is disconcerting, since impaired individuals may be at risk due to lifelong dependence on caregivers; possible emotional and social insecurities; a relatively powerless, silent, and disabled position in society (Calitz, 2011; Reeve, 2006a); and perhaps little opportunity and ability to assert access to research and recourse without some form of assistance. There could easily exist an inverse relationship between extent of intellectual impairment and assumption of power in ableist societies – the more impairment one lives with, the less power one might be able to exert against bad care.

Ableist practices that exclude intellectually impaired individuals from research opportunities or from socio-political participation, or hinder access to appropriate services and good resources are as discriminating as racism and sexism, and similarly serious human rights violations (Kittay et al. 2005, Kittay 2009; Swartz et al., 2012, Tronto 2010). For the past 19 years, the Bill of Rights has enshrined for every South African the right to health care services, inherent human dignity, freedom and security of the person including bodily and psychological integrity, and the non-derogable right to equality. No person, nor the state, may unfairly discriminate directly or indirectly against anyone on grounds of disability (RSA, 1996). But the Bill of Rights should protect against the disablement of impairment, and could be changed to discrimination against anyone on grounds of *impairment*, since this alone "is not sufficient for disablement to occur. What disables people – what *makes* people disabled – is how society responds to the impairments" (own emphasis Swartz, 2010, p. 27-28).

We disable impaired individuals by designing research and shaping policy environments that confine options and choices, obstruct the right to a humane life, or restrict citizenship and

protest. An increasingly large fissure is seemingly expanding between intellectually impaired citizens and intentionally meaningful documents (like the *World Health Organization Quality of Life instrument for people with intellectual and physical disabilities*/WHOQOL-Dis and the Bill of Rights), that remains unfilled by operationalised rights claims. As a result, and evidenced later in the discussion, research agendas and planning documents continuously fail to address the specific needs of people with intellectual impairment (Stein & Stein, 2007). In a salient example of a disabling response by the state, and as mentioned previously, the 2001 South African National Census Survey found a 0.5% prevalence of intellectual disability but excluded individuals in institutional care, and the 2011 census fared no better (Adnams, 2010; SSA, 2014). These omissions render them invisible in the research and subsequent discourse of living as a South African with intellectual impairment. We might even ask why the inclusion of intellectually impaired individuals in any research sample that requires heterogeneous representation of the South African population *as a whole* is not happening yet (see Feldman, Bosett, Collet, &Burnham-Riosa, 2014).

A relational ethics of care model helps us understand our performance of care, research, policy, the kinds of people we make, and the kind of care we will come to rely on during the course of our lives. It draws attention to our relational culpability in determining the society we will become vulnerable in, research and policies that will enable or disable us, and our hand in making people we will come to depend on. By the same token, it confronts us with our contributions to the disablement of those who, for now, depend on us. It neither excludes nor discriminates, and applies to every human simply for being human. However, it does bring into focus the dynamics of divergent personhoods, produced in unique impairment experiences with other people and societal institutions. An intersubjective application of ethical care insists we relinquish the subjugating power imbalances in which we suspend intellectual impairment, of which "bestowed upon" research versus self-identified research agendas is but one example (Lynggaard, 2008; Stein & Stein, 2007). It allows us to disclose our helplessness, admit to our limited expertise in living with intellectual impairment, reflect on our own powerlessness, and interact with vulnerability without a need to hold power over another.

8.2.2.   An Ethics of Care Model: Relational and intersubjective citizen-making

In effecting social change, painful questions will be posed regarding the common humanity we share with individuals who might not satisfy our mistaken norms for sameness (Stein &

Stein, 2007). In shifting from what we believe we do not have in common, we might begin to share commonality in what we do not want: to be badly and inaccurately researched; or abused, hurt, violated, marginalised, disregarded, misrepresented, abandoned, forgotten, rendered helpless, excluded, mistreated, made incompetent, or exploited in our vulnerability in other ways. Kittay's (2001, 2011) myth of independence helps us see that intellectual impairment asks us to face our own fragile selves, and take cognisance of an inescapably universal human dependency so that we can face our own secure in the protection against disablement.

Why could it be possible to say that the only "good" intellectual disability research would be inclusive or emancipatory research? Because research results and subsequent policy making generates intersubjective spaces in which people who are never intact are constantly being made. These spaces should be created mindful of intellectually impaired individuals' internalisation of disenfranchising and dehumanising experiences during damaging relational interactions (Kittay, 2011; Tronto, 2010). We have to care that our subjectivities – and the research we pursue from these – are used by others as an external reality or representation of themselves to be internalised as a new part of, or addition to, their subjectivity, inner reality, and knowledge of a world that either celebrates and supports, or disavows and misrepresents intellectual impairment. Even whilst formulating research projects and social policy we are essentially creating our own and others' selves. In sharing intersubjectivity informed research and policy spaces we are making, and being made into, kinds of people who produce and sustain enabled or disabled others (Kelly, 2013; Kittay et al., 2005; Tinney, 2008).

Intersubjectively, and as we all do, intellectually impaired individuals gain knowledge of the world by using others' minds to learn about the world (Fonagy & Target, 2007). This implies that using others' research or oppressive minds to learn about oneself, becomes the self one knows to be. Perhaps Morris (2001) explains this better in quoting Nancy Mairs (1996, p. 103) that "[t]o know that one arouses dismay and fear and pity simply sickens the spirit of anyone, whether sound of limb and mind or not" (p. 11). With little recourse, the impaired person might rather internalise, or take into themselves, the oppression, hatred, and disgust for her own condition (Sinason 2010). Within the confines of an oppressed mind, little opportunity remains to pursue self-identified research questions, or the security associated with achieving citizenship. Moreover, there might be little resilience against damaging relational experiences of ableism, which could render intellectually impaired individuals

243

increasingly powerless in socio-political environments that advance subordination (see Tronto, 2010; also, beyond the scope of this argument, Social Identity Theory provides a sophisticated discussion of these dynamics – see Tajfel & Turner, 2004).

Within the intersubjective and relational ethics of care model as formulated and offered in earlier chapters, we can begin to restore intellectually impaired South Africans' research capabilities as socio-politically entitled and obligated persons – individuals who can delineate future turns in intellectual disability research, necessary conditions for person-making care, participation in the rights and corollary responsibilities of citizenship, and policy formulation. Where all research, policy making, and care is relational, and influences the kinds of persons made during its planning and practice, an application of our relational and intersubjective ethics of care model introduced in the previous chapter could respond to the above as follows: if our interactions with intellectual impairment and the messages we convey in research and policy formulations are person-making in an ethical way, opportunities for the pursual of autonomous research and citizenship might increase; as could emotional fortitude against damaging interactions. In turn, both these processes could contribute to a decrease of subjugation dynamics and subsequent resistance against subordination.

Intersubjectively, we all contribute to shaping research and socio-political spaces in which intellectual impairment is disavowed or acknowledged. Shifting our thinking about intellectual impairment might bring about shifts in research and policy spaces that can be occupied by, and produce, citizenship-making socio-political practices. From within egalitarian ethics of care practices, inadequate policy, lack of access to participation and citizenship, and inappropriate services could compound to motivate social movement that addresses systemic subordination and critiques dominant discourse (Tajfel & Turner, 2004). Perhaps it is time to support citizenship construction driven by intellectually impaired individuals' requirements for inclusion when formulating, monitoring, and implementing research agendas and subsequent policies that have bearing on their lives (Sidanius, Pratto, Van Laar, & Levin, 2004).

8.2.3. Claiming citizenship through expert research

By maintaining a "top-down ableist expert" colonisation of knowledge and policy that informs intellectually impaired lives, ableist practice reproduces subordination at the expense of intellectual impairment citizenship (Tideman, 2008). This precludes enabling "bottom-up

impaired experts", obscures internalised experiences of marginalisation, and quashes potential to inform appropriate research and policy in a meaningful way (Dukes & Sweeney, 2009). Omitting ableist research and policy from a list of omnipresent South African social problems disables issues of intellectual impairment (Kagee, 2014), limits opportunities for transformative interactions that secure intellectually impaired individuals as persons, and jeopardises their place in a country's history. Governmental Departments of Health, Education, and Labour; as well as legislatures, state institutions, and private sector oversight bodies have to take better care of intellectually impaired South Africans' potential and duty to inform policy through inclusive and emancipatory research than brief references made in the *National Mental Health Policy Framework and Strategic Plan 2013-2020* (RSA, 2013).

However, we must consider the relatively disempowered positions intellectually impaired individuals may inhabit from which to negotiate research and knowledge claims. Some compliance with systemic inequality, and even resistance to inclusive and emancipatory research and social change, must be afforded consideration. Sinason (2010) adds that it might be difficult for those who depend on others to show dissent, disapproval, or anger directly, especially when facing fear or threat of abandonment. Where severity of impairment increases dependency, fear of displeasing or angering a powerful caregiver can be emotionally painful and damaging – resistance is costly, and even defiant intellectually impaired individuals may be discouraged from separating and individuating as experts in research and care (Sinason 2010). Given this power disparity, any protest or "suggestions...[made]...about care are likely to be taken as resistance or obstruction" (Tronto, 2010, p. 165), met with retaliation, and may in turn reinforce a bestowed status of less than equal researchers and citizens.

Resonating with ways in which an egalitarian ethics of care model can relieve oppression and support intellectually impaired citizenship and expert research, we might apply Ndebele's (1972, p. 25) writing on Black Consciousness to

> believe that it is both good and right for [intellectually impaired individuals], so long deprived of human worth, to seek the freedom to give expression to [their] humanity; [we] must believe that it is both good and right for [them], so long degraded, to reassert [their] human dignity ... that it is good and right for all citizens of South Africa to share equally in the creation of the means of self-expression ... that a system that relegates humans to the status of feelingless things is ... wrong ... because it degrades man (in Biko [ed.] 1972; see also Watermeyer 2012).

One need not disavow intellectual impairment in order to claim one manner of research enquiry or citizenship more powerful or more "right" than another. Perhaps an intersubjective ethics of care approach might learn from Black Consciousness that by changing values assigned by those with power to attributes of subordinate groups, ableist comparisons begin to lose meaning. Thinking about intellectually impaired individuals intersubjectively attends to meaningful expert voices and contributions that, if taken up in credible research formulations and legitimate policy making, implementation, and monitoring processes, might serve to ameliorate psychological effects of lifelong demeaning internalisations.

The process of pursuing intellectually impaired citizenship could facilitate engaging with others who seek to change conditions that restrict socio-political freedoms; forming collaborative relationships by taking on required support to increase access to power and voice; and mobilising strengths and resources in order to develop political behaviour and meet obligations of citizenship. In this, claims to research agendas and citizenship are viewed as assertions of power, and in removing the oppressed mind from hands of oppressors, vital to mental health and socio-political functioning (Biko, 2004). A legitimate conceptualisation of such research and citizenship should be informed by the *true* experts who live with intellectual impairment.

To operationalise claims to citizenship, South African research with, or by, researchers as experts on living with intellectual impairment might take forward important policy informing studies on such topics as:
- Entitlement and access to voting – something that is being very poorly formulated in South Africa
    - (Hartley, 2013; Keeley, Redley, Holland, & Clare, 2008; Kjellberg & Hemmingsson, 2013; SAFMH, 2014; Morris 2001; Ndenze, 2013; Redley, 2008; RSA, 1998; Xingwana, 2011).
- Living as intellectually impaired citizens and societal contributors not only in South Africa, but also in the global South with examples from Thailand, Vietnam, Cambodia
    - (Bredemeier, Wagner, & Agranonik, 2014; Mercadante, Evans-Lacko, & Paula, 2009; Stein & Stein), Brazil, and India (BRICS partners).

- Living with intellectual impairment as member-citizens of BRICS countries – some, like China, with questionable Human Rights histories
    - (Cohen & Brown, 2012; Daley, Singhal, & Krishnamurthy, 2013; Dos Santos, Groth, & Machado, 2009; McVilly & Dalton, 2004; Stein & Stein, 2007).
- Citizenship training
    - (Bustard & Stewart, 2004; Bustard, Freestone, Hibbert, & Meakin, 2008).
- An intellectual impairment parliament
    - (Redley & Weinberg, 2007), addressing Kittay's (2009) finding of moral abuse when policies impacting individuals with intellectual impairment are "formulated on the basis of the denial of the moral personhood of individuals who do not have a place at the table where their fates may be decided" (2009, p.620).
- Participating on government advisory boards
    - (Frawley, 2008; Frawley & Bigby, 2011; Riddington, 2008, 2012).
- Employment initiatives
    - (Stein & Stein, 2007).
- Effective social participation, social entrepreneurship, advocacy, agency, and mastery
    - (Atkinson, 2004; Caldwell, Harris, & Renko, 2012; MacCann, 2008; Reeve, 2006a; Walmsley, 2004c).
- Service use and services to intellectually impaired individuals – especially in remote rural areas in South Africa
    - (Chenoweth & Clements, 2008; Stein & Stein, 2007; Heslop, Folkes, Rodgers, & Hillman, 2004).
- Intellectually impaired children as future service users
    - (Traustadottir, 2008).
- Positive cultural attitude change campaigns
    - (Stein & Stein, 2007).
- Residential living, independent living, and social inclusion
    - (Jackson & Irvine, 2013; McKenzie & Adnams, 2014; McKenzie et al., 2014a).
- Life phase transitions
    - (Atkinson, 2008).
- Social identity

- o (Field, 2004; Gilbert, Cochrane, & Greenwell, 2005; Hoogland &de Jong, 2004; Hughes, 2009; Loja, Costa, Hughes, & Menezes,2013).
- Sexuality and parenting
    - o (Hough, 2012; McKenzie, 2013b; Reinders, 2008).

8.2.4. Shifting claims to expertise and knowledge through inclusive and emancipatory research

As accentuated earlier in the research, Swartz and colleagues warned that "important voices have been marginalised in discourses on disability" (Swartz et al., 2012, p.952), whilst Sinason (2010, p.3) reminded us that "[w]hen there are people who cannot think, remember, speak, or write, it matters that others take up the scribe function". From this, opportunities can emerge for inclusive and emancipatory research to inform policy and "help shape a world that will accept [intellectually impaired individuals]", whilst also opening up spaces for addressing corollary commitments of citizenship (Kittay, 2009, p.611). If "the preferencing of the interests of vulnerable people and groups in ways that enable them to change the conditions of their vulnerability ... is ... [p]aramount to a human rights perspective" (London et al., 2012, p. 3), not documenting lived experiences of impairment and disability could further silence valuable opinions. The assumption that intellectually impaired adults lack the capacity to drive research, or to consent to or decline participation in research, negates inclusion and disengages claims on the time and thinking of able-bodied co-researchers (Kittay, 2009; Sinason, 2010).

As Clegg (2006) explains, knowledge on intellectual impairment solely owned by dominant discursive holders of scholarship "would not be expert knowledge ... only what other people had said. [Intellectually impaired individuals] would be disempowered by [such] expert knowledge: it is vital that they agree to say which, if any, [policy] ideas reflect their experiences, and reject those that do not" (p. 131). In terms of intersubjective power-sharing and collaboration as discussed in Chapter 4, shifting the locus of expertise might see intellectually impaired individuals becoming the experts on living with impairment and disability. It will be problematic if researchers or policy makers as knowledgeable "expert[s]" differ from the care receiver in what is needed ... have their own agendas in determining others' needs", or differ on the location of the expert, embodied voice of intellectual impairment (Tronto, 2010, p. 163). Not only does this presume knowledge on behalf of

intellectually impaired individuals, it moves individuals further away from their own experiences whilst personhoods are silenced.

Policy makers may not be fully attuned to intellectually impaired individuals' circumstances, but political will can remedy this and research priorities for intellectual disabilities can be set whilst keeping agency over research agendas in mind (Tomlinson et al., 2014). One way of informing policy in a significant and coherent way is by contributing inclusive and emancipatory research that would not only accurately identify and analyse the needs of intellectually impaired South Africans, but also offer ways of putting these into practice (Kagee, 2014).

In its own disclaimer, the *Twenty Year Review, South Africa, 1994-2014 Background Paper on Disability* is "written by officials in the Presidency and other government departments using inputs from literature reviews, commissioned research, government reviews and reports, and roundtable discussions with a range of stakeholders" (Van Der Byl, 2014, p. 2); but in reference to intellectually impaired South Africans, admits to "limited national strategies to address their needs and a low prioritisation of resources for persons with intellectual disabilities" (p. 32). Similarly, the *National Mental Health Policy Framework and Strategic Plan 2013-2020* commits to "[e]liminating stigma and discrimination based on mental disability and promoting the realisation of the United Nations Convention on the Rights of Persons with Disabilities", but little to no mention is made of how this commitment will be put into action (Government of South Africa, 2013, p.50). In these aforementioned fissures, intellectually impaired researchers – as contributors to literature reviews, commissioned research, government reviews and reports and roundtable discussions – could be included as expert holders of fresh knowledge who can inform, from a methodological and empirical base, necessary social and political change around intellectual impairment (Hamilton, Atkinson, & Walsh, 2008).

Located in inclusive research with intellectually impaired individuals as participants or co-researchers, or in emancipatory research where they drive research as principle researchers that select topics, set agendas, collect and analyse data, and publish results in accessible journals (here, South Africa lags very far behind especially the UK), opportunities arise for intellectually impaired individuals to inform and have power and control over studies, knowledge, and policy formulation that affect them directly (Barton, 2005; Garbutt, Tatersall,

Dunn,Boycott-Garnett,2010; Bigby, Frawley, & Ramcharan, 2014; Gilbert, 2004; Lee, Brownley, Hayes, Combes, & McClimens, 2004; McKenzie et al., 2013a; Strnadová&Cumming, 2014; Walmsley, 2001, 2004a, 2004b; WalmsleyHart, Davies, Still, & O'Byrne, 2014; Walmsley & Johnson, 2003). There exists an ever-expanding international body of co-created work – even toolkits – that has moved us past issues of *whether* intellectually impaired individuals can or may consent to participating in research, to resources on *how* consent, assent, and especially refusal processes should take place (Boxall & Ralph, 2009; Calveley, 2012; Cameron & Murphy, 2007; Daley et al., 2013; Elliott, 2008; Heslop & Jepson, 2008; Horner-Johnson & Lyman, 2008; Iacono, 2006; Krahn & Weaver, 2008; Feudtner & Brosco, 2011; Kidney & McDonald, 2014; McDonald & Kidney, 2012; McDonald & Patka, 2012; McDonald et al., 2009; Morgan, Cuskelly, & Moni, 2014; Ouellette-Kuntz, Cleaver, & Sarkar, 2008; Walker, 2013).

Inclusive research adds depth and strength to data; credits participant opinions, ideas, and insights; contributes to participant confidence and self-esteem; and most relevant to this discussion, involves intellectually impaired researchers in effecting socio-political change (Barton, 2005; Dye et al., 2004; Gilbert, 2004; Inglis & Cook, 2011; Stone & Priestly, 1996; Walmsley, 2001). Perhaps such research can shift us "towards a new focus on enabling justice which avoids amplifying unhelpful or dangerous beliefs" (Clegg, 2006, p. 140). Perhaps by breaking away from dominant discourse, we can help create counter-hegemonic knowledge claims by means of research *with* and *by* intellectually impaired individuals as true experts in the field of intellectual disability in South Africa.

One unexplored research area pertaining to care in institutional settings, for example, includes intellectually impaired individuals taking up roles in meetings and positions on committees as representatives of fellow residents; having suggestions around preferred choice of carers or medical professionals taken seriously; and participating in decision-making relating to intellectual impairment services, care, treatment, and resource distribution. Another relates to the absence of teaching on intellectual impairment and disability in clinical psychology professional training programmes. These programmes deliver interns to public psychiatric institutions with intellectual disability services rotations, where interns work with adult and child in- and outpatients, and their families. Moreover, a number of post-intern year-long community service posts are located in intellectual impairment areas, yet professional training programmes neglect this duty of care. Notwithstanding excellent and

rigorous training, delivering interns unfamiliar with intellectual impairment and disability seem contrary to competency regulations of the Professional Board for Psychology's rules for conduct pertaining specifically to psychology (HPCSA, 2004, p.2).

8.2.4.1. Inclusive research within intersubjective and relational ethics of care

By continuing to take "speaking for" positions, well-meaning researchers may unwittingly contribute to scientific silencing and further incapacitate already subdued voices. By co-creating or independently authoring texts on disability, expert intellectually impaired researchers could ensure that knowledge and policy environments are not dominated by non-expert able-bodied researchers, or by issues that are only important to non-expert professionals and politicians (French & Swain, 1997; Inglis & Cook, 2011; L. Swartz et al., 2012). "What is less clear, though", we are reminded, "is how we get to [these voices]" (L. Swartz et al., 2012, p.956). Apart from dyadic interviewing (Caldwell, 2014), Hollway and Jefferson's (2013) free association narrative interview (FANI) method, as introduced in Chapter 6, meets the objective of co-creating intersubjective knowledge with intellectually impaired individuals, foregrounds under-investigated contributions, and facilitates self-representative research environments. Such a research frame could shape spaces between people in which a spontaneous and co-created voice on living with intellectual impairment and disability can emerge (Moodley, 2007; S. Swartz, 2006).

To operationalise claims to knowledge, South African research with, or by, researchers as experts on living with intellectual impairment might take forward important policy informing studies on such topics as:

- Unemployment, especially with regards to its relationship with intellectual impairment in South Africa.
- Inclusive vocational training, as well as further education and training at a tertiary level, e.g., a citizenship course
  - (McKenzie et al., 2014a; O'Connor, 2004; Reitter, Karn-Vizeli, & Hess, 2009; Stein & Stein, 2007).
- Teaching intellectual impairment in professional training programmes – medicine, professional psychology, nursing, and social work for example; and employing intellectually impaired individuals as trainers and coaches
  - (Smith et al., 2008).

- Ownership of knowledge and commissioning of research
    - (Grant & Ramcharan, 2006; McClimens, 2010; McDonald, Keys, & Henry, 2008; Ramcharan & Grant, 2004).
- Care and health research agenda setting
    - (Cech, 2006; McKenzie et al., 2013b; Nierseet al., 2006; Tomlinson et al., 2014).
- Inclusive education
    - (McKenzie & Macleod, 2012a; McKenzie et al., 2013a; Ngwena & Pretorius, 2012).
- Collaboration with non-state actors
    - (Stein & Stein, 2007; Tilley, 2004).
- Future turns in participatory South African intellectual disability research or co-research
    - (Conder, Milner, & Mirfin-Veitch, 2011; Forrester-Joneset al., 2008; Janse van Vuuren, Boshoff, van Hove, &Struthers,2008; Johnson, 2008; McDonald, Kidney, & Patka, 2013; O'Brien & Curry, 2008; Read, 2008; Slevin, 2004; Walmsley 2004a, 2004b).
- Future turns in emancipatory South African intellectual disability research
    - (Hart, Spencer, & Buchanen, 2008; Marriott, Williams, & Townsley, 2008; McGrath, Kealy, & Johnson, 2009; Walmsley, 2014, Williams, England, Ponting, & Ford, 2008).

8.3.   LIMITATIONS OF THIS RESEARCH

Bearing the above in mind, the limitations of this research study have to be mentioned. In terms of the research with nurses who work with individuals living with psychiatric illness and intellectual disability, free association narrative interviews (FANI) allowed an unconstrained unfolding of perspectives on intellectual disability care. The capacity of the research to hold intellectual disability care ambiguities in its findings by not hypothesising on or demarcating participant responses is seen as an advantage. But the repercussions to generalisability cannot be denied, and participant narratives might have been subject to social desirability. Although the research study produced a variety of results and employed three different methods of data collection, it was limited in that data were collected from only two research sites in one province of South Africa. To address generalisability of results, future

research might expand on the work offered in this study by including more research sites in more provinces.

Moreover, participants were experienced nurses who mostly work day shifts. No data were gathered on psychiatric intellectual disability care experiences from nurses during night shifts. Not only can shift bias not be discounted, but the majority of nursing participants had years of psychiatric intellectual disability care experience. Although this is not a disadvantage, especially in light of the rich material that emerged, the possibly idealised experiences of newer nurses with less years of practice could not be included in the discussions. Although residents from two research sites were included as participants in the study, drawing nurse participants from a single psychiatric facility further impedes generalisability by excluding participant experiences from the second research site. Furthermore, the amount of formal observation time was limited to 45 hours across only three wards, and results may have been enriched if these participant observations were conducted over a longer period of time across several wards, including time spent on wards during night shifts.

Future research might aim to gauge the gratifying experiences of psychiatric intellectual disability nursing with more emphasis, and could take forward an exploration of how and why these experiences are possibly effective in moderating work stress. An additional aim of such research could be to investigate ways in which the positive experiences of psychiatric intellectual disability care could be amplified, whilst also developing intervention strategies that better inform nursing staff on effective ways of coping with the many demands of the care work.

Further research must be aimed at establishing the generalisability of findings that emerged from this study. Since it is believed that the findings presented here can encourage further research questions on working and living with intellectual disability in South Africa, many opportunities for research may be taken forward on topics that were only briefly introduced during this research. The area of mothering and infantilisation in intellectual disability care practices, for example, might be an interesting topic for future investigation; as would outcome studies of intersubjective therapeutic engagement. It might also be valuable to compare intellectual disability nurses' experiences of the work with those of professionals from other disciplines (e.g., clinical psychology, psychiatry, medicine, occupational therapy,

physiotherapy, social work, translating services – even housekeeping and kitchen staff); and with those of nursing staff in other fields. Although there are unique aspects to psychiatric intellectual disability nursing work, it is suspected that professionals from other disciplines in the field may share some, if not many, similar experiences of perhaps stigmatisation, marginalisation, system fatigue, and even depression.

Individuals with intellectual disability cannot read about themselves when written about by non-disabled experts-by-proxy, because abstracts of articles "about" intellectual disability remain inaccessible, let alone the articles. The study offered here, in its current form, is just as exclusionary and should be offered in a more accessible and inclusive format. Even this study effectively excludes individuals with intellectual disability from (dis)agreeing with its findings, while knowledge held about intellectual disability by the true experts in South Africa remains unpublished and therefore neither investigable by people living with intellectual disability, nor accessible by proxy experts. This not only excludes individuals with intellectual disability from academic participation, but also from having a voice on policies, legislation, issues, and campaigns that will affect them directly. If not driven by individuals with intellectual disability, then the expertise and opinion of individuals living with intellectual disability must, at the very least, be included during the development of research agendas and service priorities.

Finally, at the 21 May 2015 workshop where this paper was presented to Eva Kittay, Rosemarie Garland-Thomson asked a most important question: Now that we have this conceptualisation of an intersubjective and relational ethics of care, how are we going to implement it? Although I mentioned the need to operationalise human rights or policy documents, for example, her question highlighted the difficulty of implementing "good ideas". But the potential for research sparked by her question seems limitless...in talking with a colleague at the hospital where I work, we were even wondering how one could write this conceptualisation of care into practice protocols in collaboration with the adults we care for. I am very grateful to her – having been so invested in the thinking and writing of this work, the "doing" question, although hard to answer, can open many future research possibilities. This might also open avenues for research into the *completion of care*, something dependent not only on the receipt of care but on the recipient's acceptance thereof (Eva Kittay, Workshop Communication, 21 May 2015).

8.4.   CONCLUSION

In facing intellectual impairment, we are confronted "up close and personal with [our] own intolerance in quite an intense", even intolerable way (L. Swartz et al., 2012, p.954). But viewed through an intersubjective lens, differences between able-bodied and intellectually impaired individuals can be acknowledged and disarmed...differences that have in the past empowered some and subordinated others. The fantastically overwhelming and anxiety-provoking experience of having our own inevitable impairment reflected back tempts us into wishing it away, falsely believing that it will never happen to us. But, as protracted a process as it may be, it is happening as we speak – we must dare to think about it with the same courage intellectually impaired individuals have in living with *our* decisions and behaviour on a daily basis. Conditions for intellectual impairment to be cared about are informed by our understanding of its worth. Where differences in ability create value disparities based on the social standing of impairment, then caring about intellectual impairment is interwoven with the societal power differentials we help create (Kittay et al., 2005; Kittay, 2009). The question we must ask pertains to the kind of society and carers we want to create for ourselves for when, not if, we become increasingly dependent in *that* society on *those* carers.

To achieve citizenship with the rights and obligations this entails, we all require socio-political resources and opportunities to utilise those resources. In formulating inclusively researched social policy, resources and opportunities that exceed minimal levels must be provided – whether these are taken up or not remains the individual's autonomous choice (Stein & Stein, 2007). Intellectual impairment citizenship begins with respect for specific requests and needs, effective engagement with individual experiences and opinions, and recognition of a truer knowledge and expertise. Apart from societal power relations, such citizenship also depends on the ways in which policy makers, as participants in person-making, choose to research, think about, plan, and practice intellectual impairment care. Including impaired individuals as experts in research and policy formulation increases the likelihood that policies will more accurately reflect their social conditions, and have greater impact on their daily lives (Stein & Stein, 2007). This might also help ensure that policy implementation has the highest and most economical chances of success – be it in terms of social change, gains in psychological health, or future policy development (Kagee, 2014).

Inclusive and emancipatory research could inform on services delivered to many South Africans living with intellectual impairment, who are yet to benefit as full citizens from

255

transitions promised by alternative government over the last 21 years, and by a Bill of Rights over the last 19 (Kagee, 2014). It remains our task to facilitate conditions and opportunities in which expert voices on intellectual impairment can be raised. In relational and intersubjective research and care spaces experiences of impairment are no longer bestowed upon but voiced by *real* experts who live with intellectual impairment in a disabling world.

CHAPTER NINE
Concluding thoughts

This chapter offers some summative thoughts before the study is brought to its end. In writing about intellectual impairment and the ease with which disabling can ensue, I find myself returning to the same hope: that the topics and discussions offered here give pause for reflection on all our parts. And after having given this intersubjective disclosure much thought, I admit to feeling stupid during the process of writing this dissertation...the issues it attempted to grapple with are just so big. In facing these I felt out of my depth, scared, inept, stressed, incompetent, and unintelligent. Much like we could too easily make intellectually impaired individuals feel, I would imagine.

9.1.   From the last 26 years of research on intellectual disability in South Africa

By tracking authors on intellectual disability in South Africa through time, I became aware of historic turns in the research literature indicative of shifts in both study topics and nomenclature of what we currently term "intellectual disability". The Chapter 2 and 3 review of research questions over the past 26 years produced a number of observations: the shift from an overt, subjugating gaze through which intellectual disability work was titled and published in the past (for example a racialised gaze when considering the causes, by race, of moderate and severe intellectual disability in preschool children in Cape Town), to those authors who took risks in making early comments on this; the timings of first studied and reported salient South African cases were identified; one got a sense of how study topics shifted toward increasingly critical socio-political comment on different levels. From the period under review it also became possible to track authors that have contributed work to the field of intellectual disability in South Africa over time.

For more than two and a half decades, research on intellectual disability in South Africa has provided credible, crucial comment on the social activity and policy of government and nongovernmental organisations in the way(s) individuals with intellectual disability have been, and continue to be, engaged with. Although statistics are critical in holding government accountable for the well-being of intellectually disabled citizens, meaningful state generated, current data on intellectual disability in South Africa are exceptionally scarce. Moreover, intellectual disability contributes significantly to the global burden of disease with higher prevalence rates in African countries, but specialised intellectual disability health care

knowledge, training and service provision has lagged significantly behind that of other health areas in South Africa, resulting in a further marginalised sector with unmet or poorly met needs.

From the literature review we learned that intellectual disability aetiologies vary in range and can include prenatal, perinatal, and postnatal origins; maternal trauma in early pregnancy; genetic aetiologies invariably associated with intellectual disability; infectious illnesses; neurological deterioration due to metabolic conditions; the introduction of poisons or toxins; intra-uterine infection; maternal and/or placental disease; placental insufficiency; intra-uterine growth retardation; chromosomal anomalies; and aetiologies of unknown origin. As in many countries around the world, the association between postnatally acquired intellectual disability and social and environmental deprivation cannot be discounted in South Africa. Amongst other co-morbidities, intellectual disability can present with epilepsy and HIV/AIDS, which may both also be etiologically contributing factors.

Conclusively, HIV affects the growth and neurodevelopment of infected children as one contributor to intellectual disability aetiology. HIV infected children live with an eight-fold increased likelihood of severe developmental delay, including intellectual disability – but early initiation of ART might improve cognitive functioning in HIV infected infants. Mild, moderate, and severe intellectual disability with additional neurologic deficits were significantly more common among children with HIV and seizures when compared to children with HIV and no seizures; and features of developmental delay in children with seizures were documented twice as frequently as in children without. Although children infected with HIV who also live with epilepsy are at particular risk for the adverse effects of antiepileptic drugs, large studies in children living with both epilepsy and HIV remain lacking in the South African literature.

Most research on interventions for individuals living with Foetal Alcohol Spectrum Disorder(s) (FASD) and intellectual disability focused on school aged children, and the literature review in Chapters 2 and 3 found a need to develop interventions not only for children younger than school going age, but also for adolescents and adults. Research on interventions for individuals with FASD and intellectual disability transitioning into adulthood are just as critical since substance use problems, high risk sexual behaviour, and

illegal activities may emerge or worsen during developmental periods that are just as important as those of school going age.

In the early 1990s we were warned that operationalising the basic rights of all South African children – not only children with intellectual disability, but children with severe to profound intellectual disability – to be accommodated in inclusive school communities would remain a challenge. Schools for children with special educational needs remain in short supply and extremely so in rural areas, further highlighting the discrepancy between the scale of need and available intellectual disability resources in South Africa. A lack of implementing this commitment prevails and risks perpetuating separatism, despite political speeches and actions that appear outwardly committed to inclusive education. If constitutional rights to equal access are to be taken seriously, we require evidence that the education and health systems are adequately accommodating the needs of individuals living with intellectual disability, and also evidence of a significant commitment of state resources. In South Africa, children with intellectual disability who experience socioeconomic disadvantage may be particularly vulnerable due to cognitive impairment and limited capacity to garner necessary resources. The reciprocal exchange between individuals with intellectual disability and the South African socio-political and socio-economic environments can easily depress potential, since children living with intellectual disability in South Africa are more likely to have poor nutrition and live in socio-economically distressed areas known to predispose them to further developmental delay.

From Chapters 2 and 3 we also learned that the health care of persons with intellectual disability requires comprehensive management of often complex and long-term multi-system and multiply disabling conditions, including medical (such as epilepsy), psychiatric and behavioural disorders. The recognition of psychiatric illness in people with intellectual disability, or dual diagnosis, raises manifold difficulties as well as implications for allocation of service resources, and emphasises the need for specialist psychiatric treatment. This service need becomes more urgent if we consider that individuals with intellectual disability have a greater prevalence of both general and mental health problems than the general South African population. Questions around whether we can meet the requirements for the ethical exchange of such care were touched on in Chapter 7 of this study.

Furthermore, crimes of sexual violence are known to result in rather difficult court experiences for survivors, with disappointingly low conviction rates in South Africa, though in some respects South Africa has commendable programmes in this regard. These issues are compounded when the rape survivor lives with intellectual disability. Again, despite helpful research a lag in development or implementation of policies and plans to accommodate the intellectually disabled rape survivor has contributed to the severe shortage of services for people with intellectual disability in South Africa. Particular service delivery issues that emerged from the review in Chapters 2 and 3 include access to education, training, and health care; the provision of appropriate assistance and support; transitional spaces from care dependency to increased independence with care (such transitional progression might not only reduce social and economic exclusion, but also increase access to livelihood assets); income generation and poverty relief; and the importance of support to, and learning from, caregivers and families in both informal and formal care settings. Twenty years on, the seminal Bushbuckridge data are still used as a basis from which to advocate for the development of appropriate and integrated services for the best possible care of individuals living with intellectual disability in South Africa.

Of the many challenges facing persons with intellectual disability in South Africa, high prevalence, discrimination, and access to justice and education, all inextricably coupled with poor resource allocation, continue to confront us in the literature. There remains a severe shortage of services for people with intellectual disability in South Africa despite individuals who work very hard in this field of care. This demands not only examination by intellectually disabled and non-disabled researchers alike, but the time has surely come to insist on the implementation of 26 years' worth of credible, peer-reviewed research and recommendations. But amidst scores of references to insufficient or absent South African service infrastructure, identified throughout the reviewed literature as a major disablement to living with intellectual impairment, there have been some highlights that might offer examples to follow: like that of successfully connecting intellectually and physically disabled South Africans to primary health care practices at the Alexandra Health Centre, the work of Cape Mental Health, projects that assist individuals with intellectual disability to transition from a structured school environment into sustainable employment, tapping into indigenous and informal knowledge on and solutions to the complexities of intellectual disability care in under-resourced areas, and clinicians and researchers who invest years of hard effort into often progressive intellectual disability work.

From the literature reviews offered in Chapters 2 and 3, some gaps in the research on intellectual disability in South Africa could be identified and described in more detail in the chapter on future research (Chapter 8). Work that still needs to be taken forward includes topics of death and dying. During clinical interactions and assessments, elderly parents have expressed anxiety about what would happen to their adult children living with intellectual disability, or who would care for them, should these caregivers fall ill or after they pass. Preparing the person living with intellectual disability for their own or the death of a caregiver, or facilitating a therapeutic grieving process after the death, also still needs to be addressed in the South African literature.

Although individuals with intellectual disability – especially those living with dual diagnoses – are often described as problematic, dangerous, responsible for violent acts, and behaving in ways that are difficult to manage and contain to the point of requiring psychotropic medication, there is a paucity in published studies on psychologically informed interventions with especially adults living with intellectual disability in South Africa. Also, it would seem from the literature that the individual with intellectual disability must be treated and changed, as opposed to intervening in how individuals are interacted with. In a similar vein, there are few published South African studies on what it is like for individuals to live with intellectual disability, let alone with dual diagnosis in psychiatric settings, and very little on what it is like to care for individuals who live with intellectual disability or dual diagnoses. It is hoped that the research study offered here might have begun to bring attention to and address these paucities.

9.2.   Intellectual disability research with true experts

Chapter 4 brought to our awareness numerous criteria to be mindful of with regards to upholding ethicality when considering research with intellectually impaired participants. These include planning for prolonged processes of obtaining consent and assent, adapting information sheets and consent procedures appropriately whilst avoiding deprecating use of language, and assessing each potential participant's language skills in order to gauge individuals' levels of understanding the research project. Of further importance would be conceptualising and documenting consent as an ongoing process; and establishing ways of initiating, maintaining, and terminating the research relationship. Care workers' awareness of the research relationship also needs to be considered. Ultimately, the voluntary nature of

participation and the participant's right to make an autonomous decision about continuing or terminating his or her involvement is paramount.

Apart from the core ethical principles of anonymity, confidentiality, and informed consent, Kittay's (2009) "fundamental ethical precepts" of epistemic responsibility (know the subject), and epistemic modesty (know, and admit to, what you do not know) should also be considered. Intersubjective conceptualisations of research engagements allow and expect the reflective acknowledgement and tolerance of researchers' own ignorance and lack of knowledge. A disability research space will always, as Marzano (2007) informs, force researchers to come to terms with their own identity, to reflect on the nature of the social relations that they construct in the field, to consider the distribution of power within these, and to evaluate the legitimacy of their observations by engaging in peer reviewed, supervisory spaces.

9.3.   Approaching intellectual disability work within an intersubjective frame

By means of an intersubjective understanding of partners during both research and therapeutic interactions, Chapter 5 sensitised us to possibly (dis)abling constructions of subjectivity. In acknowledging the effect of marginalisation on intellectually impaired individuals' subjectivities and access to voice, intersubjective frames for intellectual disability work affords the opportunity to understand what resides unconsciously in able researcher/therapist and disabled participant/patient alike, to explore mutual defences, and to question perceptions and behaviour toward individuals who can too easily be othered or constructed as different (S. Swartz, 2007).

An expert voice on intellectual disability can emerge from egalitarian, intersubjective spaces created by two people. Equal parts of partners in research or therapy create S. Swartz's (2006) "third voice" (p.472), one that demands equality and a balance of power from which to emerge. New meanings of working and living with intellectual disability are created as one introjects, and in turn projects, subjectivity. As a result, neither partner in research or therapy remains unchanged. Understanding that we are never intact relates to the continual shifting states of enabledness, where being of able mind and body is actually "temporary for all of us, we get ill, we get injured, and...that othering process...the product of who we are is *always* relational" (own italics for emphasis – L. Swartz et al., 2012, p.957).

In facing intellectual impairment, and as mentioned by Marzano (2007) above, one can expect to be confronted "up close and personal with [one's] own intolerance in quite an intense", even intolerable way (L. Swartz et al., 2012, p.954). In thinking about such confrontations intersubjectively, embodied differences between enabled researcher and disabled participant can be acknowledged and disarmed...differences that have in the past empowered some in Chapters 2 and 3 as knowledgeable experts, and cast others as subaltern research subjects. It was the task of the researcher – as scribe of this study – to facilitate conditions in which the unconscious, co-created "analytic third" can co-develop and help raise an expert voice on intellectual impairment (Ogden, 1994, p.463; Sinason, 2010; S. Swartz, 2006).

9.4.　　What the nurses told us

In an attempt to elicit the voices in ways mentioned above by means of the free association narrative interview (FANI) method, it is hoped that intersubjective spaces between researcher and nursing participants enabled an emergence of fresh perspectives on psychiatric intellectual disability care in South Africa. Often undervalued in the mental health community, Chapter 6 showed that intellectual disability nurses hold valuable opinions on psychiatric intellectual disability care; that continuous rewarding-frustrating care interactions require an ability to tolerate ambivalences of intellectual disability work; and that nurses take what consolation their interventions can offer. Psychiatric intellectual disability nurses guard against physical and emotional exhaustion, but also against system fatigue – needing the system in which to do their work, but battling the same system *so that* they can do their work. The identified necessary resources requested for the sake of psychiatric intellectual disability patient care must be attributed managerial attention, gravitas, and budget – at the very least, equitable distribution of these. Should patient needs and intellectual disability nurses' efforts at meeting them remain marginalised, nursing migration might persist as well as one outcome of care incompatible with patient discharge into the community: the perpetual albeit unconscious infantilisation of adult intellectually disabled patients who should be referred to by a term more dignifying than "children" (*kinders*).

Ultimately, psychiatric intellectual disability nursing is a sub-specialty deserving of respect – although not yet in South Africa, it has been a recognised sub-specialty in other countries for many years. In an effort to address nurses' need to leave employment in search of professional opportunities outside of care resource and policy resource poor countries like

South Africa, nurses' training should attend to preparation for the realities of psychiatric intellectual disability work, whilst care institutions should seriously consider nurses' needs and coping resources for well-being and burnout prevention. Regarding ethical care for carers, nurses should have input in ways institutional controls above them are implemented, and be engaged with by employers in a non-exploitative and non-exclusionary way. It is hoped that Chapter 6 adequately operationalised the value of collaborative and intersubjectivity informed research, employing the FANI method in an attempt to remedy the subaltern position that living and working with intellectual disability can easily inhabit. As did 26 years of research on intellectual disability in South Africa reported on in Chapters 2 and 3, findings from the research with intellectual disability nurses also underscores the necessity of modifying institutional processes to better accommodate intellectual disability service providers' and recipients' needs, thereby improving service delivery and well-being outcomes in intellectual disability care participants.

9.5.   What the wards and residents told us

Care was studied in Chapter 7 as its exchanges occurred on adult psychiatric intellectual disability wards where, ostensibly, the basic needs of ward residents are being met. But even basic care practices are yet to meet a conceptualisation of ethical care as an ongoing intersubjective and relational human practice. Although the exchange of care on the wards is both a patient right and necessity, the environment in which it is performed can be disabling. Participant observations noted that nurses find themselves taking up the slack of laundry, cleaning, and kitchen duties, apart from providing bodily care to, and exchanging emotional care with, residents. Although nurses are grossly outnumbered by often difficult to care for patients, the imperative of meeting task oriented and documentable Department of Health accreditation requirements often eclipses patients' psychosocial needs.

Residents might be in need of inter-personal engagement, and relational conversations need not be withheld from individuals with intellectual impairment who struggle to reciprocate in conventional ways, or constrained by assumptions of a person's capacity to understand and respond. During data collection, relationally mindful communication from nurses was observed as initiating a wider range of conversational topics, with patients introducing spontaneous questions and comments in free and confident interactions as a result.

As we saw in Chapter 6, inexhaustible patient needs and nurses' skills in meeting these are not commonly regarded with respect, nor are countless arguments for better training and more realistic staff-patient ratios taken seriously. During the observations in Chapter 7, it was witnessed that one nurse might be providing bodily care for up to eight patients during a shift, and supervise enrolled nurses and rotating students whilst attending to ward rounds, professional notes, and statistics that capture documentable work for future performance reviews.

When medical and psychosocial needs compete for attention from embattled staff, it becomes complicated to argue that patient needs are being neglected. But if we do not advocate for ethical care conceptualised as intersubjective and relational – as person making – we run the risk of reproducing inadequate responses to patients' and nurses' ethical care requirements, with grave consequences for the kinds of care participants that are subsequently made. Care practices can improve and shift in the direction of ethical care, but it is unfair to lay this responsibility on nurses alone. In light of our own inescapable future dependency, perhaps we could all begin to shift the attitudes and assumptions we hold toward dependency care.

9.6.   We have our work cut out for us

When engaging in disability care of any kind, let alone intellectual disability care, the overwhelming experience of observing our own inevitable dependency might tempt us into denying that we will ever be touched by impairment. Perhaps we might find courage from the very individuals who live with the care created as a result of *our* decisions and behaviour. Conditions for intellectual impairment, or any dependency for that matter, to be cared about are informed by our understanding of its worth. By implication, do we not measure our own worth by the kind of care we not only make now, but would want to receive one day? The question pertains to the kind of society and carers we want to create for ourselves for when, not if, we become increasingly and inevitably dependent in *that* society on *those* carers.

And once dependent on care, how do we maintain our worth? What kind of citizenship would we hope to achieve? We all require socio-political resources and the ongoing, guaranteed opportunities and choices to utilise those resources. Intellectual impairment citizenship begins with respect for specific requests and needs, effective engagement with individual experiences and opinions, and recognition of an intellectually impaired individual's knowledge and expertise on intellectual disability. Such citizenship also depends on the ways

in which policy makers, as participants in person-making, choose to research, think about, plan, and practice intellectual impairment care. Including impaired individuals as experts in research and policy formulation increases the likelihood that policies will more accurately reflect their social conditions, and have greater impact on their daily lives. In resource constrained South Africa, this might also help ensure that policy implementation has the highest and most economical chances of success – be it in terms of social change, gains in psychological health, or future policy development.

In terms of sexual rights and health of South African individuals living with intellectual disability, even the right to be a parent, little has been published so far. The encouraging South African work that has been done over that past decade, hopefully gaining momentum, still lags behind the body of work from countries in the UK, for example. South African intellectual disability expertise remains located in non-disabled individuals, mostly at universities from which intellectually disabled individuals are still excluded, again as opposed to programmes in the UK.

Inclusive and emancipatory research could inform on services delivered to many South Africans living with intellectual impairment, and, for now at least, it remains our task to facilitate conditions and opportunities in which expert voices on intellectual impairment care can be raised. To enable a shift away from disabling environments and resultant disability, intellectual impairment care can be made economically and ethically. Changing our minds about intellectual disability and the exchange of care does not necessarily require exchanging money. In fact, changing our minds about intellectual disability does not have to cost a thing.

REFERENCES

Acker, J. (2006). Inequality regimes: Gender, class, and race in organisations. *Gender & Society, 20*(4), 441–464.

Adnams, C. M. (2010). Perspectives of intellectual disability in South Africa: Epidemiology, policy, services for children and adults. *Current Opinion in Psychiatry, 23*(5), 436–440. doi:10.1097/YCO.0b013e32833cfc2d.

Ainsworth, M. D. S. (1969). Object relations, dependency, and attachment: a theoretical review of the infant-mother relationship. *Child Development, 40,* 969–1025.

Alant, E. (1994). The use of bliss symbols as a first step into literacy with four children with Down Syndrome. *The South African Journal of Communication Disorders, 41*, 23–31.

Ali, A., Kock, E., Molteno, C., Mfiki, N., King, M., & Strydom, A. (2015). Ethnicity and self-reported experiences of stigma in adults with intellectual disability in Cape Town, South Africa. *Journal of Intellectual Disability Research*, *59*(6), 530–540.

Allan, A. (2011). *Law and Ethics in Psychology: An International Perspective.* Somerset West: Inter-Ed Publishers.

Altman, N. (2000). Black and white thinking: A psychoanalyst reconsiders race. *Psychoanalytic Dialogue, 10*(4), 589–605.

American Psychiatric Association. (2013). *Diagnostic and Statistical Manual of Mental Disorders, Fifth Edition.* Washington, DC: American Psychiatric Association.

Anderson, K. T. (2008). Intersubjectivity. In L. M. Given (Ed.), *The SAGE Encyclopaedia of Qualitative Research Methods* (pp. 467-468). Thousand Oaks: SAGE Publications. doi:10.4135/9781412963909.

Arnd-Caddigan, M. (2011). Toward a broader definition of evidence informed practice: Intersubjective evidence. *Families in Society, 92*(4)*,* 372–376.

Aron, L. (2006). Analytic impasse and the third: Clinical implications of intersubjectivity theory. *International Journal of Psychoanalysis, 87*(2)*,* 349–368.

Atkinson, D. (2004). Perspectives of people with intellectual disability (ID) as witnesses to change. *Journal of Intellectual Disability Research, 48,* 476.

Atkinson, D. (2008). "Getting a life": Key transitions in the lives of people with intellectual disabilities. *Journal of Intellectual & Developmental Disability, 33*(3)*,* 278–279.

Babbie, E., & Mouton, J. (2007). *The practice of social research.* Cape Town: Oxford University Press.

Banks, L. M., Zuurmond, M., Ferrand, R., & Kuper, H. (2015). The relationship between HIV and prevalence of disabilities in sub-Saharan Africa: systematic review (FA). *Tropical Medicine & International Health*, *20*(4), 411–429.

Barlto P.,& Klein P. J. (2011). Physical activity benefits and needs in adults with intellectual disabilities: Systematic review of the literature. *American Association in Intellectual and Developmental Disabilities, 116*(3), 220–232.

Barnes, C. (2012). Understanding the social model of disability: Past, present and future. In N. Watson, A. Roulstone, & C. Thomas (Eds.), *Routledge Handbook of Disability Studies* (pp. 12-29). London: Routledge.

Barton, L. (2005). Emancipatory research and disabled people: Some observations and questions. *Educational review*, *57*(3), 317–327.

Bateman, C. (2012). 'One size fits all' health policies crippling rural rehab - therapists. *South African Medical Journal, 102*(4), 200–208.

Beail, N., Warden, S., Morsley, K., & Newman, D. (2005). Naturalistic evaluation of the effectiveness of psychodynamic psychotherapy with adults with intellectual disabilities. *Journal of Applied Research in Intellectual Disabilities, 18*(3)*,* 245–251.

Behar, R. (1996). *The vulnerable observer: Anthropology that breaks your heart.* Boston: Beacon Press.

Beighton, P. (1990). Dyggve-Melchior-Clausen Syndrome. *Journal of Medical Genetics, 27*(8), 512–515.

Benjamin, J. (1990). Recognition and destruction: An outline of intersubjectivity. In S.A. Mitchell & L. Aron (1999) (Eds.), *Relational psychoanalysis: The emergence of a tradition* (pp. 181-210). London: The Analytic Press.

Berry, L., & Smit, A. D. V. (2011). Social assistance needs of children with chronic health conditions: A comparative study of international and South African eligibility assessment instruments. *Social Work in Public Health, 26*(7), 635–650. doi:10.1080/19371910903196484.

Bigby, C., Frawley, P., & Ramcharan, P. (2014). Conceptualizing inclusive research with people with intellectual disability. *Journal of Applied Research in Intellectual Disabilities*, *27*(1), 3–12.

Biko, B.S. (2004). *I write what I like.*Johannesburg: Picador Africa.

Bilgin, S.,& Gozum, S. (2009). Reducing burnout in mothers with an intellectually disabled child: an education programme. *Journal of Advanced Nursing, 65*(12)*,* 2552–5261.

Bless, C., Higson-Smith, C.,& Kagee, A. (2006).*Fundamentals of social research methods: An African perspective.* Cape Town: Juta.

Blumenthal, S., Lavender, T., & Hewson, S. (1998). Role clarity, perception of the organization and burnout amongst support workers in residential homes for people

with intellectual disability: a comparison between a National Health Service trust and a charitable company. *Journal of Intellectual Disability Research*, *42*(5), 409–417.

Bornman, J., & Alant, E. (1996). Nonspeaking children in schools for children with severe mental disabilities in the greater Pretoria area: Implications for speech-language therapists. *The South African Journal of Communication Disorders, 43*, 53–61.

Bornman, J., Nelson Bryen, D., Kershaw, P., & Ledwaba, G. (2011). Reducing the risk of being a victim of crime in South Africa: You can tell and be heard! *Augmentative and Alternative Communication, 27*(2), 117–130. doi:10.3109/07434618.2011.566696.

Boxall, K., & Ralph, S. (2009). Research ethics and the use of visual images in research with people with intellectual disability. *Journal of Intellectual and Developmental Disability*, *34*(1), 45–54.

Bredemeier, J., Wagner, G. P., Agranonik, M., Perez, T. S., & Fleck, M. P. (2014). The World Health Organization Quality of Life instrument for people with intellectual and physical disabilities (WHOQOL-Dis): Evidence of validity of the Brazilian version. *BMC Public Health*, *14*(1), 538.

Brown, D. S. O. (1991). HIV infection in persons with prior mental retardation.*AIDS Care*, *3*(2), 165–173. doi:10.1080/09540129108253059.

Brown, L. J., & Miller, M. (2002). The triadic intersubjective matrix in supervision: The use of disclosure to work through painful affects. *The International Journal of Psychoanalysis*, *83*(4), 811–823.

Brown, M., Duff, H., Karatzias, T., & Horsburgh, D. (2011). A review of the literature relating to psychological interventions and people with intellectual disabilities: Issues for research, policy, education and clinical practice. *Journal of Intellectual Disabilities*, *15*(1), 31–45.

Bryant, A. (2014). The grounded theory method. In Leavy, P. (Ed.), *The Oxford Handbook of Qualitative Research* (pp. 116-136). Oxford University Press: Oxford.

Bryman, A. (2012).*Social Research Methods, Fourth Edition.* New York: Oxford University Press.

Buccimazza, S., Molteno, C., & Dunne, T. (1999). Pre-school follow-up of a cohort of children with myelomeningocele in Cape Town, South Africa. *Annals of Tropical Paediatrics, 19*(3), 245–252. doi:10.1080/02724939992310.

Burman, E. (1997). Minding the gap: Positivism, psychology, and the politics of qualitative methods. *Journal of Social Issues*, *53*(4), 785–801.

Burnard, P. (2004). Writing a qualitative research report. *Accident and emergency nursing*, *12*(3), 176–181.

Bustard, S., Freestone, D., Hibbert, M., & Meakin, L. (2008). The impact of citizenship education for young people with intellectual disabilities. *Journal of Intellectual Disability Research*, *52*, 709.

Bustard, S., & Stewart, D. (2004). Citizenship education for pupils with special educational needs in schools in Nottingham, UK. *Journal of Intellectual Disability Research, 48,* 482.

Caldwell, K. (2014). Dyadic interviewing: a technique valuing interdependence in interviews with individuals with intellectual disabilities. *Qualitative Research, 14*(4), 488–507.

Caldwell, K., Harris, S. P., & Renko, M. (2012). The potential of social entrepreneurship: Conceptual tools for applying citizenship theory to policy and practice. *Intellectual and Developmental Disabilities*, *50*(6), 505–518.

Calitz, F. J. W. (2011). Psycho-legal challenges facing the mentally retarded rape victim. *South African Journal of Psychiatry, 17*(3), 66–72.

Calitz, F. J. W., van Rensburg, P. H. J. J., de Jager, P. P., Olander, M. L., Thomas, L., Venter, R., Wessels, G. A., Joubert, G. (2007). Psychiatric evaluation of intellectually disabled offenders referred to the Free State psychiatric complex, 1993-2003. *South African Journal of Psychiatry, 13*(4), 147–152.

Calveley, J. (2012). Including adults with intellectual disabilities who lack capacity to consent in research. *Nursing Ethics*, *19*(4), 558–567.

Cambray, J. (2002). Who's really there? Dreams and the analytic third.*Psychoanalytic Psychology*, *19*(4), 772.

Cameron, L., & Murphy, J. (2007). Obtaining consent to participate in research: the issues involved in including people with a range of learning and communication disabilities. *British Journal of Learning Disabilities*, *35*(2), 113–120.

Capri, C. (2014). On developing an intersubjective frame for intellectual disability work. *Disability and Rehabilitation*, *36*(5), 418–423.

Capri, C., & Buckle, C. (2015). 'We have to be Satisfied with the Scraps': South African Nurses' Experiences of Care on Adult Psychiatric Intellectual Disability Inpatient Wards. *Journal of Applied Research in Intellectual Disabilities*, *28*(3), 167–181.

Capri, C., & Coetzee, O. (2012). On the unethicality of disablism: Excluding intellectually impaired individuals from participating in research can be unethical. *African Journal of Disability*, *1*(1), 1–4.

Carey, A. C. (2003). Beyond the Medical Model: A reconsideration of 'feeblemindedness', citizenship, and eugenic restrictions. *Disability & Society*, *18*(4), 411–430.

Carr, A., O'Reilly, G., Walsh, P., & McEvoy, J. (2010). *The handbook of intellectual disability and clinical psychology practice.* Hove: Routledge.

272

Cartwright, J. D. (1992). Mental retardation – who cares? *South African Medical Journal, 81*(1), 3–4.

Cartwright, J. D., Jukes, C., Wilson, A., & Xaba, D. (1981). A survey of learning problems in Black primary school children. *South African Medical Journal, 59*(14), 488–490.

Cartwright, J. D., van Rijlaarsdam, A., Wagner, J., & Rothberg, A. D. (1988). Provision of services for mentally handicapped children in the Witwatersrand area. *South African Medical Journal, 73*(1), 26–28.

Cartwright, J., Nelson, M., & Fryns, J. P. (1991). Pre- and postnatal growth retardation – severe mental retardation – acral limb deficiencies with poorly keratinized nails. Another example of a distinct syndrome of inherited intrauterine dwarfism? *Genetic Counseling, 2*(3), 147–150.

Carulla, L.S., Reed, G.M., Vaez-Azizi, L.M., Cooper, S., Leal, R., Bertelli, M., . . . Saxena, S. (2011). Intellectual development disorders: Towards a new name, definition and framework for "mental retardation/intellectual disability" in ICD-11. *World Psychiatry, 10*(3)*,* 175–180.

Caruso, E. M. (2007). The evolution of nurse-to-nurse bedside report on a medical-surgical cardiology unit. *Medsurg Nursing*, *16*(1), 17.

Casper, M. J., & Talley, H. L. (2005). Preface Special Issue: Ethnography and Disability Studies. *Journal of Contemporary ethnography*, *34*(2), 115–120 doi:10.1177/0891241604272323.

Cech, B. N. (2006). A Bridge between research, empowerment and social care. *Journal of Applied Research in Intellectual Disabilities, 19*(3)*,* 260.

Charmaz, K.,& Henwood, K. (2008). Grounded theory. In C. Willig&W. Stainton-Rogers (Eds.), *The SAGE Handbook of Qualitative Research in Psychology* (pp. 240-260). SAGE Publications: Los Angeles.

Chenoweth, L. I., & Clements, N. M. (2008). Engagement in service delivery: services'
efforts to improve service user participation. *Journal of Intellectual Disability
Research, 52*(8/9), 702.

Chikte, U. M., Pochee, E., Rudolph, M. J., & Reinach, S. G. (1991). Evaluation of stannous
fluoride and chlorhexidine sprays on plaque and gingivitis in handicapped children.
Journal of Clinical Periodontology, 18(5), 281–286.

Child, C. (2013, July 29). Nursing in SA is in crisis. *The Times*. Retrieved from
http://www.timeslive.co.za/thetimes/2013/07/29/nursing-in-sa-is-in-
crisis?service=print

Christianson, A. L. (1997). Down Syndrome in Black South African infants and children –
clinical features and delayed diagnosis. *Ugeskrift for Laeger, 161*(29), 992–995.

Christianson, A. L., Chesler, N., & Kromberg, J. G. (1994). Fetal valproate syndrome:
Clinical and neuro-developmental features in two sibling pairs. *Developmental
Medicine and Child Neurology, 36*(4), 361–369.

Christianson, A. L., & Kromberg, J. G. R. (1996). Maternal non-recognition of Down
Syndrome in Black South African infants. *Clinical Genetics, 49*(3), 141–144.

Christianson, A. L., Stevenson, R. E., van der Meyden, C. H., Pelser, J., Theron, F. W., van
Rensburg, P. L., Chandler, M., & Schwartz, C. E. (1999). X linked severe mental
retardation, craniofacial dysmorphology, epilepsy, ophthalmoplegia, and cerebellar
atrophy in a large South African kindred is localised to Xq24-q27. *Journal of Medical
Genetics, 36*(10), 759–766.

Christianson, A. L., Zwane, M. E., Manga, P., Rosen, E., Venter, A., Downs, D., &
Kromberg, J. G. R. (2002). Children with intellectual disability in rural South Africa:
Prevalence and associated disability. *Journal of Intellectual Disability Research,
46*(2), 179–186. doi:10.1046/j.1365-2788.2002.00390.x.

274

Christianson, A. L., Zwane, M. E., Manga, R., Rosen, E., Venter, A., & Kromberg, J. G. R. (2000). Epilepsy in rural South African children – prevalence, associated disability and management. *South African Medical Journal, 90*(3), 262–266.

Chung, M. C., & Harding, C. (2009). Investigating Burnout and Psychological Well-Being of Staff Working with People with Intellectual Disabilities and Challenging Behaviour: The Role of Personality. *Journal of Applied Research in Intellectual Disabilities*, *22*(6), 549–560.

Clegg, J. (2006). Understanding intellectually disabled clients in clinical psychology. In D. Goodley&R. Lawthom (Eds.), *Disability & Psychology: Critical Introductions and Reflections* (pp. 123-140). Palgrave Macmillan: Basingstoke.

Coetzee, O. (2015). *Caregiving experiences of South African mothers of adults with intellectual disability who display aggression: Clinical case studies*(Unpublished doctoral dissertation). University of Cape Town, Cape Town.

Coetzee, S., & Cilliers, F. (2001) *Psychofortology: Explaining coping behaviour in organisations.* Retrieved from http://www.siop.org/tip/backissues/TipApr01/08Coetzee.aspx

Cohen, L., & Brown, R. I. (2012). Mapping Future Research in Disabilities–Research Initiatives in Intellectual Disabilities in India: Report of a National Interdisciplinary Meeting. *Journal of Policy and Practice in Intellectual Disabilities*, *9*(2), 151–155.

Conder, J., Milner, P., & Mirfin-Veitch, B. (2011). Reflections on a participatory project: The rewards and challenges for the lead researchers. *Journal of Intellectual and Developmental Disability*, *36*(1), 39–48.

Cooper, M. (2004). Towards a relationally-oriented approach to therapy: Empirical support and analysis. *British Journal of Guidance and Counselling, 32*(4)*,* 451–460.

Corbett, A., Cottis, T., & Lloyd, E. (2012). The survival and development of a traumatised clinic for psychotherapy for people with intellectual disabilities. In E. Hopper (Ed.), *Trauma and Organisations* (pp. 111-126). Karnac Books: London.

Cramm, J. M., Nieboer, A. P., Finkenflügel, H., & Lorenzo, T. (2013). Disabled youth in South Africa: Barriers to education. *International Journal on Disability and Human Development, 12*(1), 31–35. doi:10.1515/ijdhd-2012-0122.

Dada, S., Huguet, A., & Bornman, J. (2013). The iconicity of picture communication symbols for children with English additional language and mild intellectual disability. *AAC: Augmentative and Alternative Communication, 29*(4), 360–373. doi:10.3109/07434618.2013.849753.

Dagnan, D. (2008). Psychological and emotional health and well-being of people with intellectual disabilities. *Tizard Learning Disability Review*, *13*(1), 3–9.

Daley, T. C., Singhal, N., & Krishnamurthy, V. (2013). Ethical considerations in conducting research on autism spectrum disorders in low and middle income countries. *Journal of Autism and Developmental Disorders*, *43*(9), 2002–2014.

Davies, J. M., & Frawley, M. G. (1991). Dissociative processes and transference-countertransference paradigms in the psychoanalytically oriented treatment of adult survivors of childhood sexual abuse. In S. A. Mitchell & L. Aron (Eds.) (1999),*Relational psychoanalysis: The emergence of a tradition* (pp. 269-304). London: The Analytic Press.

Davis, L. J. (2006). *The disability studies reader*. New York: Routledge.

Dawood, N., Bhagwanjee, A., Govender, K., & Chohan, E. (2006). Knowledge, attitudes and sexual practices of adolescents with mild retardation, in relation HIV/AIDS. *African Journal of AIDS Research, 5*(1), 1–10.

De Beaudrap, P., Mac-Seing, M., & Pasquier, E. (2014). Disability and HIV: a systematic review and a meta-analysis of the risk of HIV infection among adults with disabilities in Sub-Saharan Africa. *AIDS Care*, *26*(12), 1467–1476.

De Beer, M., Kritzinger, A., & Zsilavcz, U. (2010). Young children with fetal alcohol spetrum disorder-communication profiles. *South African Journal of Communication Disorders*, *57*(1), 33.

De Vries, P. J., Venter, A., Jacklin, L., & Oliver, C. (2013). Behavioural phenotypes and neurodevelopmental disorders in Africa. *Journal of Intellectual Disability Research, 57*(9), 793–795. doi:10.1111/jir.12070.

Department of Education (DoE). (1999). *Consultative Paper No.1 on Special Education: Building an Inclusive Education and Training System, First Steps.* Pretoria: Government Printers.

Department of Education (DoE). (2001). *Education White Paper 6. Special Needs Education. Building an Inclusive Education and Training System.* Pretoria: LSEN Directorate.

Department of Education (DoE). (2010). *Guidelines for Full-service/Inclusive schools.* Pretoria: Department of Education.

Department of Health. (2007). *The Patients' Rights Charter.* Republic of South Africa. Retreived from http://www.doh.gov.za/docs/legislation/patientsright/chartere.html

Dercksen, M., Duran, M., Ijlst, L., Mienie, L. J., Reinecke, C. J., Ruiter, J. P. N., . . . Wanders, R. J. A. (2012). Clinical variability of isovaleric acidemia in a genetically homogeneous population. *Journal of Inherited Metabolic Disease, 35*(6), 1021–1029. doi:10.1007/s10545-012-9457-2.

DeVault, M. (2006).Introduction: What is institutional ethnography?*Social Problems, 53*(3), 294–298.

DeVault, M. (2013). Institutional Ethnography: A Feminist Sociology of Institutional Power. *Contemporary Sociology: A Journal of Reviews*, *42*(3), 332–340.

Devereux, J., Hastings, R., & Noone, S. (2009). Staff stress and burnout in intellectual disability services: Work stress theory and its application. *Journal of Applied Research in Intellectual Disabilities*, *22*(6), 561–573.

Devisch, R. (2006). A psychoanalytic revisiting of fieldwork and intercultural borderlinking. *Social analysis*, *50*(2), 121–147.

Dickman, B. J., & Roux, A. J. (2005). Complainants with learning disabilities in sexual abuse cases: A 10-year review of a psycho-legal project in Cape Town, South Africa. *British Journal of Learning Disabilities*, *33*(3), 138–144.

Disley, P., Hatton, C., & Dagnan, D. (2012). Inputs and outcomes: What do staff in services for people with intellectual disabilities perceive they bring to and receive from their work-based relationships? *Journal of Intellectual Disabilities*, *16*(4), 297–306.

Dodson, L., & Zincavage, R. M. (2007). "It's like a family" Caring labor, exploitation, and race in nursing homes. *Gender & Society*, *21*(6), 905–928.

Donald, K. A., Walker, K. G., Kilborn, T., Carrara, H., Langerak, N. G., Eley, B., & Wilmshurst, J. M. (2015). HIV Encephalopathy: pediatric case series description and insights from the clinic coalface. *AIDS Research and Therapy*, *12*(1), 1–10.

Donohue, D. K., Bornman, J., & Granlund, M. (2014). Examining the rights of children with intellectual disability in South Africa: Children's perspectives. *Journal of Intellectual and Developmental Disability, 39*(1), 55–64. doi:10.3109/13668250.2013.857769.

Dos Santos, F. H., Groth, S. M., & Machado, M. L. (2009). Autonomy markers in Brazilian adults with intellectual disabilities. *Journal of Policy and Practice in Intellectual Disabilities*, *6*(3), 212–218.

Dowse, L. (2009). 'Some people are never going to be able to do that'. Challenges for people with intellectual disability in the 21st century. *Disability & Society*, *24*(5), 571–584.

Dukes, E., & Sweeney, J. (2009). Recognising the value of involving service users with intellectual disability in healthcare planning. *Learning Disability Practice*, *12*(10), 33–37.

Dye, L., Hendy, S., Hare, D. J., & Burton, M. (2004). Capacity to consent to participate in research–a recontextualization. *British Journal of Learning Disabilities*, *32*(3), 144–150.

Education for All. (2005). *EFA Global Monitoring Report.* UNESCO: Paris.

Eiguer, A. (2007). The intersubjective links in perversion. *International Journal of Psychoanalysis, 88,* 1135–1152.

Elliott, D. (2008). Research ethics boards: Attitudes towards people with intellectual disabilities. *Journal of Intellectual Disability Research, 52,* 697.

Engelbrecht, P. (1993). A South African Perspective on Cognitive Control Therapy for Learning-Disabled Children. *School Psychology International*, *14*(2), 111–117.

Engelbrecht, P. (1996). Cognitive control therapy for South African children with learning difficulties. In P. Engelbrecht, S. Kriegler, & M. Booysen (Eds.), *Perspectives on Learning Disabilities: International Concerns and South African Realities* (pp. 199-206). *Pretoria: Van Schaik Publishers*.

Engelbrecht, P., Oswald, M., & Forlin, C. (2006). Promoting the implementation of inclusive education in primary schools in South Africa. *British Journal of Special Education*, *33*(3), 121–129.

Engelbrecht, P., Oswald, M., Swart, E., & Eloff, I. (2003). Including learners with intellectual disabilities: Stressful for teachers? *International Journal of Disability, Development and Education*, *50*(3), 293–308.

Erlich, H. S. (2003). Experience–What is it? *The International Journal of Psychoanalysis*, *84*(5), 1125–1147.

Eatough, V. & Smith, J.A. (2008). Interpretative phenomenological analysis. In C. Willig&W. Stainton-Rogers (Eds.), *The SAGE Handbook of Qualitative Research in Psychology* (pp. 179-194). SAGE Publications: Los Angeles.

Fanon F. O. (1961/2004).*The Wretched of the Earth.* Grove Press, New York.

Farrell, G. A., Shafiei, T., & Salmon, P. (2010). Facing up to 'challenging behaviour': a model for training in staff-client interaction. *Journal of Advanced Nursing*, *66*(7), 1644–1655.

Feldman, M. A., Bosett, J., Collet, C., & Burnham-Riosa, P. (2014). Where are persons with intellectual disabilities in medical research? A survey of published clinical trials. *Journal of Intellectual Disability Research*, *58*(9), 800–809.

Ferrinho, P., Robb, D., Cornielje, H., & Rex, G. (1993). Primary health care in support of community development. *World Health Forum, 14*(2), 158–162.

Feudtner, C., & Brosco, J. P. (2011). Do people with intellectual disability require special human subjects research protections? The interplay of history, ethics, and policy. *Developmental Disabilities Research Reviews*, *17*(1), 52–56.

Field, B. (2004). Prejudice, identity, and intellectual disability (ID). *Journal of Intellectual Disability Research, 48,* 476.

Fonagy P. (2001). Introduction to attachment theory. In R. D. Hack (Ed.), *Handbook of Attachment: Theory, research, and clinical applications* (pp. 1-18). New York: Guilford Press.

Fonagy P. & Target M. (2007). Playing with reality: IV – A theory of external reality rooted in intersubjectivity. *International Journal of Psychoanalysis,88,* 917–937.

Ford, S. (2013, September 24). Quarter of trusts seeking nurses overseas, claims RCN. *Nursing Times*. Retrieved from http://www.nursingtimes.net/nursing-practice/clinical-zones/management/quarter-of-trusts-seeking-nurses-overseas-claims-rcn/5063539.article

Ford, S.,& Stephenson, J. (2014, January 11). Year starts with multiple warnings of staff shortages. *Nursing Times*. Retrieved from http://www.nursingtimes.net/nursing-practice/clinical-zones/management/year-starts-with-multiple-warnings-of-staff-shortages/5066977.article

Forrester-Jones, R., Hastings, S., Palmer, A. P., Klein, A., Hewson, S., Jenkins, L. M., & Scott, E. (2008). Service user involvement: Does it leave people standing on the side-lines? *Journal of Intellectual Disability Research*, *52*(8-9), 702–702.

Frawley, P., & Bigby, C. (2011). Inclusion in political and public life: The experiences of people with intellectual disability on government disability advisory bodies in Australia. *Journal of Intellectual and Developmental Disability*, *36*(1), 27–38.

French, S., & Swain, J. (1997). Changing disability research: Participating and emancipatory research with disabled people. *Physiotherapy*, *83*(1), 26–32.

Friedman, S. L., Helm, D. T., & Woodman, A. C. (2012). Unique and universal barriers: hospice care for aging adults with intellectual disability. *American Journal on Intellectual and Developmental Disabilities*, *117*(6), 509–532.

Friez, M. J., Essop, F. B., Krause, A., Castiglia, L., Ragusa, A., Sossey-Alaoui, K., . . . Longshore, J. W. (2000). Evidence that a dodecamer duplication in the gene HOPA in Xq13 is not associated with mental retardation. *Human Genetics, 106*(1), 36–39.

Fujiura, G. T., Rutkowski-Kmitta, V., & Owen, R. (2010). Make measurable what is not so: National monitoring of the status of persons with intellectual disability. *Journal of Intellectual & Developmental Disability, 35*(4), 244–258. doi:10.3109/13668250.2010.519330.

Gagiano, C., Read, S., Thorpe, L., Eerdekens, M., & Van Hove, I. (2005). Short- and long-term efficacy and safety of risperidone in adults with disruptive behavior disorders. *Psychopharmacology, 179*(3), 629–636. doi:10.1007/s00213-004-2093-2 [doi].

Gara, N. M. (2007). *Effects of caring on mothers of intellectually disabled children in Alice, Eastern Cape, South Africa* (Doctoral dissertation). University of Cape Town, Cape Town.

Garbutt, R., Tattersall, J., Dunn, J., & Boycott-Garnett, R. (2010). Accessible article: involving people with learning disabilities in research. *British Journal of Learning Disabilities*, *38*(1), 21–34.

George, G., & Reardon, C. (2013). Preparing for export? Medical and nursing student migration intentions post-qualification in South Africa: original research.*African Primary Health Care and Family Medicine*, *5*(1), 1–9.

George, G., & Rhodes, B. (2012). Is there really a pot of gold at the end of the rainbow? Has the Occupational Specific Dispensation, as a mechanism to attract and retain health workers in South Africa, leveled the playing field? *BMC public health*, *12*(1), 613.

Gerhardt, J., Sweetnam, A., & Borton, L. (2000). The intersubjective turn in psychoanalysis: A comparison of contemporary theorists: Part 1: Jessica Benjamin. *Psychoanalytic Dialogues*, *10*(1), 5–42.

Giarelli, E., Clarke, D. L., Catching, C., & Ratcliffe, S. J. (2009). Developmental disabilities and behavioral problems among school children in the Western Cape of South Africa. *Research in Developmental Disabilities, 30*(6), 1297–1305. doi:10.1016/j.ridd.2009.05.006.

Gilbert, T. (2004). Involving people with learning disabilities in research: issues and possibilities. *Health &Social Care in the Community*, *12*(4), 298–308.

Gilbert, T., Cochrane, A., & Greenwell, S. (2005). Citizenship: Locating people with learning disabilities. *International Journal of Social Welfare*, *14*(4), 287–296.

Glazer, N.Y. (1991). "Between a rock and a hard place": Women's professional organisations in nursing and class, racial, and ethnic inequalities. *Gender & Society, 5*(3)*,* 351–372.

Goffman, E. (1961/1991). *Asylums: Essays on the social situation of mental patients and other inmates.* London: Penguin.

Goffman, E. (2006). Selections from *Stigma*. In L. J. Davis (Ed.), *The Disability Studies Reader, Second Edition* (pp. 131-140). New York: Routledge.

Goodley, D., Hughes, B.,& Davis L. (2012). Introducing disability and social theory. In D. Goodley, B. Hughes,& L. Davis (Eds.), *Disability and social theory: New developments and directions* (*pp.* 1-14). Palgrave Macmillan, New York.

Government of South Africa. (2013). *National Mental Health Policy Framework and Strategic Plan, 2013-2020*. Retrieved from http://www.health-e.org.za/wp-content/uploads/2014/10/National-Mental-Health-Policy-Framework-and-Strategic-Plan-2013-2020.pdf

Grant, G., & Ramcharan, P. (2006). A critique of standpoints on user involvement in research: Reflections on a national learning disability research programme. *Journal of Applied Research in Intellectual Disabilities, 19*(3)*,* 260.

Greeff, A. P., & Nolting, C. (2013). Resilience in families of children with developmental disabilities. *Families, Systems and Health, 31*(4), 396–405. doi:10.1037/a0035059.

Gregersen, N. (2006). Facial asymmetry with colon atresia. *Clinical Dysmorphology, 15*(1), 45–46. doi:10.1097/01.mcd.0000175604.03221.ad.

Griffin, C.,& Bengry-Howell, A. (2008). Ethnography. In C. Willig&W. Stainton-Rogers (Eds.), *The SAGE Handbook of Qualitative Research in Psychology* (pp. 15-31). SAGE Publications: Los Angeles.

Grisso, T.,& Applebaum, P.S. (1988). *Assessing competence to consent to treatment.* Oxford: Oxford University Press.

Gustafsson, C., Öjehagen, A., Hansson, L., Sandlund, M., Nyström, M., Glad, J., . . . Frederiksson, M. (2009). Effects of psychosocial interventions for people with intellectual disabilities and mental health problems: A survey of systematic reviews. *Research on Social Work Practice*, *19*(3), 281–290.

Haarburger, D., Renison, R., Meldau, S., Eastman, R., & van der Watt, G. (2013). Teenaged siblings with progressive neurocognitive disease. *Clinical Chemistry, 59*(8), 1160–1164. doi:10.1373/clinchem.2012.190710 [doi].

Hall, K. Q. (2011). *Feminist disability studies*. Bloomington: Indiana University Press.

Hamilton, C., Atkinson, D.,& Walsh, N. (2008). A story to tell.*Journal of Intellectual Disability Research, 52*, 697.

Hanass-Hancock, J. (2009). Disability and HIV/AIDS – a systematic review of literature on Africa. *Journal of the International AIDS Society*, *12*(1), 34.

Harden, A. (2010). Mixed-methods systematic reviews: Integrating quantitative and qualitative findings. *Focus Technical Brief, 25,* 1–8.

Harper, D. (2008). Clinical Psychology. In C. Willig&W. Stainton-Rogers (Eds.), *The SAGE Handbook of Qualitative Research in Psychology* (pp. 430-454). Los Angeles: SAGE Publications.

Harpur, P. (2009). Sexism and racism, why not ableism? Calling for a cultural shift in the approach to disability discrimination. *Alternative Law Journal*, *34*, 163–167.

Harrison, A.K. (2014). Ethnography. In P. Leavy (Ed.), *The Oxford Handbook of Qualitative Research* (pp. 223-253). Oxford University Press: Oxford.

Hart, C., Spencer, K., & Buchanen, I. (2008). A place for user-led research. *Journal of Intellectual Disability Research*, *52,* 698.

Hartley, W. (2013, September 16). *IEC rejects suggestions that mentally impaired be allowed to vote.* Business Day. Retrieved from http://www.bdlive.co.za/national/2013/09/16/iec-rejects-suggestions-that-mentally-impaired-be-allowed-to-vote

Hastings R.,& Horne S. (2004). Positive perceptions held by support staff in community mental retardation services. *American Journal of Mental Retardation, 109*(1), 53–62 doi:10.1352/0895-8017(2004)109<53:PPHBSS>2.0.CO;2.

Hatton C., Emerson E., Rivers M., Mason H., Mason L., Swarbrick R., . . . Alborz A. (1999). Factors associated with staff stress and work satisfaction in services for people with intellectual disability. *Journal of Intellectual Disability Research, 43*(4), 253–267.

Health Professions Council of South Africa/HPCSA. (2004). *Form 223: Professional Board for Psychology Rules of Conduct Pertaining Specifically to Psychology.*Retrieved from http://www.psyssa.com/documents/HPCSA%20Ethical%20Code%20of%20Professional%20Conduct.pdf

Heckmann, J. M., Carr, J. A., & Bell, N. (1995). Hereditary sensory and autonomic neuropathy with cataracts, mental retardation, and skin lesions: Five cases. *Neurology, 45*(7), 1405–1408.

Hemmings, C., Inwang, F., Gravestock, S., Diaz, Z., Lawson, L., & Walker, N. (2011). Treatment-resistant schizophrenia in intellectual disabilities: a case study. *Advances in Mental Health and Intellectual Disabilities*, *5*(2), 35–40.

Hemsley, B., Sigafoos, J., Balandin, S., Forbes, R., Taylor, C., Green, V. A., & Parmenter, T. (2001). Nursing the patient with severe communication impairment. *Journal of Advanced Nursing*, *35*(6), 827–835.

Henley, L. D. (1999). A home visit programme to teach medical students about children with special needs. *Medical Education, 33*(10), 749–752. doi:med471 [pii].

Heslop, P.,& Jepson, M. (2008). Negotiating consent to include people with intellectual disabilities in research. *Journal of Intellectual Disability Research, 52,* 698.

Heslop, P., Folkes, L., Rodgers, J., & Hillman, S. (2004). Service user action groups as co-researchers. *Journal of Intellectual Disability Research*, *48*, 512.

Holden, P.,& Littlewood, J. (1991). *Anthropology and Nursing*. Routledge: London.

Hollway W.,& Jefferson T. (2013). *Doing Qualitative Research Differently: A Psychosocial Approach*(2nd ed.). London: SAGE.

Hoogland, J., & de Jong, C. (2004). Concepts of citizenship. *Journal of Intellectual Disability Research*, *48*, 482.

Horner-Johnson, W., & Lyman, L. (2008). Strategies for ethically including people with intellectual disabilities in research studies. *Journal of Intellectual Disability Research*, *52,* 701.

Hough, R. E. (2012). Adult protection and 'intimate citizenship' for people with learning difficulties: empowering and protecting in light of the No Secrets review. *Disability & Society*, *27*(1), 131–144.

Hubbard, R. (2006). Abortion and disability: Who should and who should not inhabit the world? In L. J. Davis (Ed.), *The Disability Studies Reader, Second Edition* (pp. 93-104). New York: Routledge.

Hughes, B. (2009). Disability activisms: social model stalwarts and biological citizens. *Disability &Society*, *24*(6), 677–688.

Hull, E. (2010). International Migration, 'Domestic Struggles' and Status Aspiration among Nurses in South Africa. *Journal of Southern African Studies*, *36*(4), 851–867.

Human Rights Watch. (2015). *Complicit in exclusion: South Africa's failure to guarantee an inclusive education for children with disabilities*. Retrieved from http://www.hrw.org

Iacono, T. (2006). Ethical challenges and complexities of including people with intellectual disability as participants in research. *Journal of Intellectual and Developmental Disability*, *31*(3), 173–179.

Iacono, T., & Murray, V. (2003). Issues of informed consent in conducting medical research involving people with intellectual disability. *Journal of Applied Research in Intellectual Disabilities*, *16*(1), 41–51.

Ingham B., Riley J., Nevin H., Evans G.,& Gair, E. (2013). An initial evaluation of direct care staff resilience workshops in intellectual disabilities services. *Journal of Intellectual Disabilities, 17*(3), 214–222.

Inglis, P., & Cook, T. (2011). Ten top tips for effectively involving people with a learning disability in research. *Journal of Learning Disabilities and Offending Behaviour*, *2*(2), 98–104.

Jackson, R., & Irvine, H. (2013). The impact of ideology on provision of services for people with an intellectual disability. *International Journal of Developmental Disabilities*, *59*(1), 20–34.

Janse van Vuuren, E., Boshoff, T., van Hove, G., & Struthers, P. (2008). Are you looking for a co-researcher? Research involving people with intellectual disabilities. *Journal of Intellectual Disability Research*, *52,* 701.

Johnson, K. (2008). No longer researching about us without us. *Journal of Intellectual Disability Research*, 52, 698.

Johnson, R. B., Onwuegbuzie, A. J., Tucker, S. A., & Icenogle, M. L. (2014). Conducting Mixed Methods Research: Using Dialectical Pluralism and Social Psychological Strategies. In P. Leavy (Ed), *The Oxford Handbook of Qualitative Research* (pp. 557-580). Oxford: Oxford University Press.

Jones, R., & Donati, M. (2009). The therapeutic relationship in psychological therapy for individuals with learning disabilities: a review of existing literature.*Advances in Mental Health and Learning Disabilities*, *3*(1), 47–51.

Kagan, C., Burton, M., & Siddiquee, A. (2008). Action research. In C. Willig&W. Stainton-Rogers (Eds.), *The SAGE Handbook of Qualitative Research in Psychology* (pp. 32-53). SAGE Publications: Los Angeles.

Kagee, A. (2014). South African psychology after 20 years of democracy: criticality, social development, and relevance. *South African Journal of Psychology*, *44*(3), 350–363.

Katwan, E., Adnams, C., & London, L. (2011). Childhood behavioural and developmental disorders – association with maternal alcohol consumption in Cape Town, South Africa. S*outh African Medical Journal*, *101*(10), 724–727.

Keeley, H., Redley, M., Holland, A. J., & Clare, I. C. H. (2008). Participation in the 2005 general election by adults with intellectual disabilities. *Journal of Intellectual Disability Research*, *52*(3), 175–181.

Kekana, H. P. P., Du Rand, E. A., & Van Wyk, N. C. (2007). Job satisfaction of registered nurses in a community hospital in the Limpopo Province in South Africa. *Curationis*, *30*(2), 24–35.

Kelly, C. (2013). Building bridges with accessible care: Disability studies, feminist care scholarship, and beyond. *Hypatia*, *28*(4), 784–800.

Kidney, C. A., & McDonald, K. E. (2014). A toolkit for accessible and respectful engagement in research. *Disability & Society*, *29*(7), 1013–1030.

Kittay, E. F. (2001). When caring is just and justice is caring: Justice and mental retardation. *Public Culture*, *13*(3), 557–579.

Kittay, E. F. (2009). The personal is philosophical is political: A philosopher and mother of a cognitively disabled person sends notes from the battlefield. *Metaphilosophy*, *40*(3-4), 606–627.

Kittay, E. F. (2011). The ethics of care, dependence, and disability. *Ratio Juris, 24*(1), 49–58.

Kittay, E. F., Jennings, B., & Wasunna, A. A. (2005). Dependency, difference and the global ethic of longterm care. *Journal of Political Philosophy*, *13*(4), 443–469.

Kjellberg, A., & Hemmingsson, H. (2013). Citizenship and voting: Experiences of persons with intellectual disabilities in Sweden. *Journal of Policy and Practice in Intellectual Disabilities*, *10*(4), 326–333.

Kleintjes, S., Flisher, A. J., Fick, M., Railoun, A., Lund, C., Molteno, C., & Robertson, B. A. (2006). The prevalence of mental disorders among children, adolescents and adults in the Western Cape, South Africa. *South African Psychiatry Review, 9*(3), 157–160.

Knotter, M. H., Wissink, I. B., Moonen, X. M., Stams, G. J. J., & Jansen, G. J. (2013). Staff's attitudes and reactions towards aggressive behaviour of clients with intellectual disabilities: A multi-level study. *Research in Developmental Disabilities*, *34*(5), 1397–1407.

Kock, E., Molteno, C., Mfiki, N., Kidd, M., Ali, A., King, M., & Strydom, A. (2012). Cross-cultural validation of a measure of felt stigma in people with intellectual disabilities. *Journal of Applied Research in Intellectual Disabilities, 25*(1), 11–19. doi:10.1111/j.1468-3148.2011.00644.x.

Kozak, A., Kersten, M., Schillmöller, Z., & Nienhaus, A. (2013). Psychosocial work-related predictors and consequences of personal burnout among staff working with people with intellectual disabilities. *Research in Developmental Disabilities*, *34*(1), 102–115.

Krahn, G., & Weaver, A. (2008, August). Participatory action toolkit: A resource for researchers and people with disabilities. *Journal of Intellectual Disability Research, 52,* 701.

Kroese, B. S[Stenfert]., Rose, J., Heer, K., & O'Brien, A. (2013). Mental health services for adults with intellectual disabilities–what do service users and staff think of them? *Journal of Applied Research in Intellectual Disabilities*, *26*(1), 3–13.

Kromberg, J. G. R., Christianson, A. L., & Manga, P. (1997). Intellectual disability in rural Black children in the Bushbuckridge district of southern Africa. *Southern African Journal of Child and Adolescent Mental Health, 9*(4), 2–11.

Kromberg, J., Zwane, E., Manga, P., Venter, A., Rosen, E., & Christianson, A. (2008). Intellectual disability in the context of a South African population. *Journal of Policy and Practice in Intellectual Disabilities*, 5(2), 89–95. doi:10.1111/j.1741-1130.2008.00153.x.

Krueger, C., & Rosema, D. (2010). Risk factors for violence among long-term psychiatric in-patients: A comparison between violent and non-violent patients. *African Journal of Psychiatry, 13*(5), 366–375.

Kvalsvig, J., & Albonico, M. (2013). Effects of geohelminth infections on neurological development. *Handbook of Clinical Neurology, 114*, 369–379. Amsterdam: Elsevier. doi:10.1016/B978-0-444-53490-3.00029-7

Leary, P. M., Riordan, G., Schlegel, B., & Morris, S. (1999). Childhood secondary (symptomatic) epilepsy, seizure control, and intellectual handicap in a nontropical region of South Africa. *Epilepsia, 40*(8), 1110–1113. doi:10.1111/j.1528-1157.1999.tb00827.x.

Lebel, C., Mattson, S. N., Riley, E. P., Jones, K. L., Adnams, C. M., May, P. A., . . . Sowell, E. R. (2012). A longitudinal study of the long-term consequences of drinking during pregnancy: Heavy in utero alcohol exposure disrupts the normal processes of brain development. *Journal of Neuroscience, 32*(44), 15243–15251. doi:10.1523/JNEUROSCI.1161-12.2012.

Lee, D., Brownley, P., Hayes, S., Combes, H., & McClimens, A. (2004). Roundtable: Power sharing in intellectual disability (ID) research. *Journal of Intellectual Disability Research*, *48,* 512.

Leech, R., van Wyk, N. C., & Uys, C. J. (2007a). The management of infant developmental needs by community nurses. Part 1: Description of the responsibilities of community nurses with regard to the management of infant developmental needs. *Curationis, 30*(2), 91–103.

Leech, R., van Wyk, N. C., & Uys, C. J. (2007b). The management of infant developmental needs by community nurses. Part 2: The development of guidelines for the support of community nurses in the management of infant developmental needs. *Curationis, 30*(2), 104–112.

Levett, A. (2002). Problems of cultural imperialism in the study of child sexual abuse. In P. Reavy & S. Warner (Eds.),*New Feminist Stories of Child Sexual Abuse: Sexual Scripts and Dangerous Dialogue.* New York: Routledge.

Lewis, S., & Stenfert-Kroese, B. (2010). An investigation of nursing staff attitudes and emotional reactions towards patients with intellectual disability in a general hospital setting. *Journal of Applied Research in Intellectual Disabilities*, *23*(4), 355–365.

Lintern, S. (2013, February 19) NHS facing potential nurse workforce crisis, study warns. *Nursing Times*. Retrived from http://www.nursingtimes.net/nursing-practice/clinical-zones/management/nhs-facing-potential-nurse-workforce-crisis-study-warns/5055044.article

Loffstadt, H., Nichol, R. J., & de Klerk, B. (2006). A feral family on our doorstep. *South African Psychiatry Review, 9*(4), 231–234.

Loja, E., Costa, M. E., Hughes, B., & Menezes, I. (2013). Disability, embodiment and ableism: Stories of resistance. *Disability & Society*, *28*(2), 190–203.

London, L., Kagee, A., Moodley, K., & Swartz, L. (2012). Ethics, human rights and HIV vaccine trials in low-income settings. *Journal of Medical Ethics*, *38*(5), 286–293.

Lorenzo, T., & Cramm, J. M. (2012). Access to livelihood assets among youth with and without disabilities in South Africa: Implications for health professional education. *South African Medical Journal, 102*(6), 578–581.

Lowick, S., Sawry, S., & Meyers, T. (2012). Neurodevelopmental delay among HIV-infected preschool children receiving antiretroviral therapy and healthy preschool children in Soweto, South Africa. *Psychology, Health and Medicine, 17*(5), 599–610. doi:10.1080/13548506.2011.648201.

Lund, C., Kleintjes, S., Kakuma, R., Flisher, A. J., & MHaPP Research Programme Consortium. (2010). Public sector mental health systems in South Africa: inter-

provincial comparisons and policy implications. *Social psychiatry and psychiatric epidemiology*, *45*(3), 393–404.

Lynggaard, H. (2008). On learning from people with intellectual disabilities: Invoking reciprocity. *Journal of Intellectual Disability Research, 52,* 708.

MacCann, G. P. (2008). The positive effects of advocacy on the lives of people with intellectual disabilities. *Journal of Intellectual Disability Research, 52,* 708.

Madill, A., Jordan, A., & Shirley, C. (2000). Objectivity and reliability in qualitative analysis: Realist, contextualist and radical constructionist epistemologies. *British Journal of Psychology*, *91*(1), 1–20.

Mancillas, A. (2006). Recognizing and utilizing projective identification in brief psychodynamic therapy: A case example. *Clinical Social Work Journal*, *34*(3), 267–278.

Marais, P. J., Calitz, F. J. W., Pretorius, P. J., & Joubert, G. (2011). The demographic, clinical and forensic profile of offenders diagnosed with epilepsy referred to the Free State psychiatric complex observation unit in terms of section 77 and/or 78 of the criminal procedure act 51 of 1977. *South African Journal of Psychiatry, 17*(1), 16–22.

Marriott, A.M., Williams, V.,& Townlsey, R. (2008). Shaping our futures. *Journal of Intellectual Disability Research, 52,* 698.

Marzano, M. (2007). Informed consent, deception, and research freedom in qualitative research. *Qualitative Inquiry*, *13*(3), 417–436.

Marzi, A., Hautmann, G., & Maestro, S. (2006). Critical reflections on intersubjectivity in psychoanalysis. *International Journal of Psychoanalysis, 87,* 1297–1314.

Mascha, K. (2007). Staff morale in day care centres for adults with intellectual disabilities. *Journal of Applied Research in Intellectual Disabilities*, *20*(3), 191–199.

Maslach, C., Schaufeli, W. B., & Leiter, M. P. (2001). Job burnout. *Annual Review of Psychology*, *52*(1), 397–422.

Maulik, P. K., Mascarenhas, M. N., Mathers, C. D., Dua, T., & Saxena, S. (2011). Prevalence of intellectual disability: a meta-analysis of population-based studies. *Research in Developmental Disabilities, 32*(2), 419–436.

May, P. A., Blankenship, J., Marais, A. S., Gossage, J. P., Kalberg, W. O., Joubert, B., . . . Seedat, S. (2013). Maternal alcohol consumption producing fetal alcohol spectrum disorders (FASD): Quantity, frequency, and timing of drinking. *Drug and Alcohol Dependence, 133*(2), 502–512. doi:10.1016/j.drugalcdep.2013.07.013.

May, P. A., & Gossage, J. P. (2001). Estimating the prevalence of fetal alcohol syndrome: A summary. *Alcohol Research and Health*, *25*(3), 159–167.

McCabe, J. L., & Holmes, D. (2009). Reflexivity, critical qualitative research and emancipation: a Foucauldian perspective. *Journal of Advanced Nursing*, *65*(7), 1518–1526.

McClimens, A. (2010). These self-evident truths: Power and control in intellectual disability research. *Journal of Intellectual and Developmental Disability*, *35*(2), 64–65.

McDonald, K. E., Keys, C. B., & Henry, D. B. (2008). Gatekeepers of science: attitudes toward the research participation of adults with intellectual disability. *American Journal on Mental Retardation*, *113*(6), 466–478.

McDonald, K. E., & Kidney, C. A. (2012). What is right? Ethics in intellectual disabilities research. *Journal of Policy and Practice in Intellectual Disabilities*, *9*(1), 27–39.

McDonald, K. E., Kidney, C. A., Nelms, S. L., Parker, M. R., Kimmel, A., & Keys, C. B. (2009). Including adults with intellectual disabilities in research:

Scientists'perceptions of risks and protections. *Journal of Policy and Practice in Intellectual Disabilities*, *6*(4), 244–252.

McDonald, K. E., Kidney, C. A., & Patka, M. (2013). 'You need to let your voice be heard': research participants' views on research. *Journal of Intellectual Disability Research*, *57*(3), 216–225.

McDonald, K., & Patka, M. (2012). "There is no black or white": Scientific community views on ethics in intellectual and developmental disability research. *Journal of Policy and Practice in Intellectual Disabilities*, *9*(3), 206–214.

McDonaugh, P. (2008). Innocence economics and institutions: Changing the idea of idiocy in the 1840s. *Journal of Intellectual Disability Research, 52,* 706.

Mcfadden, P. (1994). Challenging biases against disability. *Southern Africa Political & Economic Monthly, 7*(10), 48–49.

McGibbon, E., Peter, E., & Gallop, R. (2010). An Institutional Ethnography of Nurses' Stress. *Qualitative Health Research, 20*(10)*,* 1353–1378.

McGrath, J., Kealy, M. & Johnson, K. (2009). Real lives in real places: Telling the stories of our work in the community in Ireland. *Journal of Intellectual Disability Research*, 52, 698.

McKenzie, J. A. (2013a). Models of intellectual disability: Towards a perspective of (poss)ability. *Journal of Intellectual Disability Research, 57*(4), 370–379. doi:10.1111/j.1365-2788.2012.01547.x.

McKenzie, J. A. (2013b). Disabled people in rural South Africa talk about sexuality. *Culture, Health &Sexuality*, *15*(3), 372–386.

McKenzie, J., & Adnams, C. A. (2014). South African adults with intellectual disability speak about residential options. *Journal of Applied Research in Intellectual Disabilities, 27*(4), 347–347.

McKenzie, J. A., & MacLeod, C. I. (2012a). The deployment of the medico-psychological gaze and disability expertise in relation to children with intellectual disability. *International Journal of Inclusive Education, 16*(10), 1083–1098. doi:10.1080/13603116.2010.540042.

McKenzie, J. A., & Macleod, C. I. (2012b). Rights discourses in relation to education of people with intellectual disability: towards an ethics of care that enables participation. *Disability & Society*, *27*(1), 15–29.

McKenzie, J. A., McConkey, R., & Adnams, C. (2013a). Intellectual disability in Africa: Implications for research and service development. *Disability and Rehabilitation, 35*(20), 1750–1755. doi:10.3109/09638288.2012.751461.

McKenzie, J., McConkey, R., & Adnams, C. (2013b). Health conditions and support needs of persons living in residential facilities for adults with intellectual disability in Western Cape province. *South African Medical Journal, 103*(7), 481–484. doi:10.7196/samj.6491 [doi].

McKenzie, J., McConkey, R., & Adnams, C. (2014a). Residential facilities for adults with intellectual disability in a developing country: A case study from South Africa. *Journal of Intellectual and Developmental Disability, 39*(1), 45–54. doi:10.3109/13668250.2013.865157.

McKenzie, J., McConkey, R., & Adnams, C. A. (2014b). Caring for adults with intellectual disability in South Africa: Family members' perspectives. *Journal of Applied Research in Intellectual Disabilities, 27*(4), 354–354.

McVilly, K. R., & Dalton, A. J. (2004). Roundtable: Ethics guidelines for multi-national research projects involving persons with intellectual disabilities (ID). *Journal of Intellectual Disability Research, 48,* 512.

McWilliams, N. (2011).*Psychoanalytic diagnosis: Understanding personality structure in the clinical process*(2nd ed.).Guilford Press, New York.

Mead, E. A., & Sarkar, D. K. (2014). Fetal alcohol spectrum disorders and their transmission through genetic and epigenetic mechanisms. *Frontiers in Genetics*, *5*, 1–10.

Meekosha, H. (2011). Decolonising disability: Thinking and acting globally.*Disability & Society*, *26*(6), 667–682.

Meel, B. (2009). Prevalence of HIV among victims of sexual assault who were mentally impaired children (5 to 18 years) in the Mthatha area of South Africa. *African Journal of Primary Health Care and Family Medicine, 1*(1), 3–5. doi:10.4102/phcfm.v1i1.5.

Mello, R. A. (2002). Collocation analysis: A method for conceptualizing and understanding narrative data. *Qualitative Research*, *2*(2), 231–243.

Menzies Lyth, I. (1960). Social systems as a defense against anxiety: An empirical study of the nursing service of a general hospital. *The Journal of Human Relations, 13,* 95–121.

Mercadante, M. T., Evans-Lacko, S., & Paula, C. S. (2009). Perspectives of intellectual disability in Latin American countries: epidemiology, policy, and services for children and adults. *Current Opinion in Psychiatry*, *22*(5), 469–474.

Mitchell D. (2000). Parallel stigma? Nurses and people with learning disabilities. *British Journal of Learning Disabilities* 28, 78–81.

Mitchell, S. A. (1998). Aggression and the endangered self. *Psychoanalytic Inquiry*, *18*(1), 21–30.

Mitchell, S. A. (2014). *Relationality: From attachment to intersubjectivity*. New York: Routledge.

Molteno, C., & Lachman, P. (1996). The aetiology of learning disability in preschool children with special reference to preventability. *Annals of Tropical Paediatrics, 16*(2), 141–148.

Molteno, C., Adnams, C., & Njenga, F. (2011). Sub-specialties in psychiatry in Africa - intellectual disability. *African Journal of Psychiatry, 14*(1), 1–3.

Molteno, C. D., Roux, A., Nelson, M. M., & Arens, L. J. (1990). Causes of mental handicap in Cape Town. *South African Medical Journal, 77*(2), 98–101.

Molteno, G., Molteno, C. D., Finchilescu, G., & Dawes, A. R. (2001). Behavioural and emotional problems in children with intellectual disability attending special schools in Cape Town, South Africa. *Journal of Intellectual Disability Research, 45*(6), 515–520. doi:368 [pii].

Moodley, R. (2005). Outside race, inside gender: A good enough "holding environment" in counselling and psychotherapy. *Counselling Psychology Quarterly*, *18*(4), 319–328.

Moodley, R. (2007). (Re) placing multiculturalism in counselling and psychotherapy. *British Journal of Guidance & Counselling*, *35*(1), 1–22.

Moore, S. W. (2008). Down syndrome and the enteric nervous system. *Pediatric Surgery International, 24*(8), 873–883. doi:10.1007/s00383-008-2188-7 [doi].

Morgan, M. F., Cuskelly, M., & Moni, K. B. (2014). Unanticipated ethical issues in a participatory research project with individuals with intellectual disability. *Disability & Society*, *29*(8), 1305–1318.

Morris, J. (2001). Impairment and disability: constructing an ethics of care that promotes human rights. *Hypatia*, *16*(4), 1–16.

Moss, S. J. (2009). Changes in coronary heart disease risk profile of adults with intellectual disabilities following a physical activity intervention. *Journal of Intellectual Disability Research, 53*(8), 735–744. doi:10.1111/j.1365-2788.2009.01187.x.

Muthukrishna, A. (1996**,** 8–13 July). The inclusion of children with Down's syndrome in to mainstream schools: A South African experience. *10th World Congress of the International Association for the Scientific Study of Intellectual Disabilities.* Helsinki, Finland.

Nakken, H., & Vlaskamp, C. (2007). A need for a taxonomy for profound intellectual and multiple disabilities. *Journal of Policy and Practice in Intellectual Disabilities*, *4*(2), 83–87.

Nash, E. S., & Navias, M. (1992). The therapeutic sterilisation of the mentally handicapped. Experience with the abortion and sterilisation act of 1975. *South African Medical Journal, 82*(6), 437–440.

National Association for the Dually Diagnosed (NADD) in association with the American Psychiatric Association (APA). (2007). *Diagnostic Manual-Intellectual Disability: A textbook of diagnosis of mental disorders in persons with intellectual disability.* New York: NADD Press.

Ndebele, N. (1972). Black Development. In B. S. Biko (Ed.), *Black Viewpoint* (pp. 13-32). Durban: SPRO-CAS Black Community Programmes.

Ndenze, B. (2013, September 17). *Prisoners will vote in 2014 elections.* iolnews. Retrieved from http://www.iol.co.za/news/crime-courts/prisoners-will-vote-in-2014-elections-1.1578772

299

Nel, L., van der Westhuyzen, C., & Uys, K. (2007). Introducing a school-to-work transition model for youth with disabilities in South Africa. *Work, 29*(1), 13–18.

Nel, N., Kempen, M., & Ruscheinski, A. (2011). Differentiated pedagogy as inclusive practice: The "Learn not to Burn" curriculum for learners with severe intellectual disabilities. *Education as Change*, *15*(2), 191–208.

Neser, P. S. J., Molteno, C. D., & Knight, G. J. (1989). Evaluation of preschool-children with Down'ssyndrome in CapeTown using the Griffiths Scale of Mental-Development. *Child Care Health and Development, 15*(4), 217–225. doi:10.1111/j.1365-2214.1989.tb00617.x.

Newman, D., Beail, N., & MacLean Jr., W.E. (2005). Analysis of assimilation during psychotherapy with people who have mental retardation. *American Journal on Mental Retardation, 110*(5)*,* 359–365.

Ngwena, C. G. (2013). Human right to inclusive education: exploring a double discourse of inclusive education using South Africa as a case study.*Netherlands Quarterly of Human Rights, 31*(4), 473–504.

Ngwena, C., & Pretorius, L. (2012). Substantive equality for disabled learners in state provision of basic education: a commentary on Western Cape Forum for Intellectual Disability v Government of the Republic of South Africa. *South African Journal on Human Rights*, *28*(1), 81–115.

Nierse, C., Abma, T., Haker, F., Broerse, J., Caron-Flinterman, F., Houdijk, N., & Widdershoven, G. (2006). Engaging people with intellectual disabilities in health research agenda setting. *Journal of Policy and Practice in Intellectual Disabilities*, *19*(3)*,* 260.

Njenga, F. (2009). Perspectives of intellectual disability in Africa: Epidemiology and policy services for children and adults. *Current Opinion in Psychiatry, 22*(5), 457–461. doi:10.1097/YCO.0b013e32832e63a1 [doi].

Nonnemacher, S. L., & Bambara, L. M. (2011). "I'm supposed to be in charge": Self-advocates' perspectives on their self-determination support needs.*Intellectual and Developmental Disabilities*, *49*(5), 327–340.

Noone, S. J., & Hastings, R. P. (2009). Building psychological resilience in support staff caring for people with intellectual disabilities Pilot evaluation of an acceptance-based intervention. *Journal of Intellectual Disabilities*, *13*(1), 43–53.

Norman, J. (2001). The psychoanalyst and the baby: A new look at work with infants. *The International Journal of Psychoanalysis*, *82*(1), 83–100.

Northway, R. (1997). Disability and oppression: some implications for nurses and nursing. *Journal of Advanced Nursing*, *26*(4), 736–743.

Nota, L., Ferrari, L., Soresi, S., & Wehmeyer, M. (2007). Self-determination, social abilities and the quality of life of people with intellectual disability.*Journal of Intellectual Disability Research*, *51*(11), 850–865.

Nussbaum, M. (2010). The capabilities of people with cognitive disabilities. In E.V. Kittay & L. Carlson (Eds.), *Cognitive disability and its challenge to moral philosophy* (pp. 75-95). Hoboken: Wiley-Blackwell.

O'Brien, P.,& Curry, P. (2008). All we want to say. *Journal of Intellectual Disability Research, 52,* 697.

Ochs, E., & Capps, L. (1996). Narrating the self. *Annual Review of Anthropology, 25,* 19–43.

O'Connor, A. (2004). Citizenship & advocacy for people with intellectual disabilities (ID): A university approach. *Journal of Intellectual Disability Research, 48,* 485.

Ogden T.H. (1994). The analytic third: Working with intersubjective clinical facts. In S.A. Mitchell & L. Aron (Eds.), *Relational psychoanalysis: The emergence of a tradition* (pp. 459-486). The Analytic Press, London.

Ogden T.H. (1999). The analytic third: An overview. In S.A. Mitchell & L. Aron (Eds.), *Relational psychoanalysis: The emergence of a tradition* (pp. 487-492). The Analytic Press, London.

Ogden, T. H. (2001). Re-minding the body. *American Journal of Psychotherapy*, *55*(1), 92–104.

Ogden, T. H. (2003). What's true and whose idea was it? *The International Journal of Psychoanalysis*, *84*(3), 593–606.

Oliner, M. M., & Bohleber, W. (2006). Intersubjectivity, recognition and the problem of the negative. *The International Journal of Psychoanalysis*, *87*(1), 259–262.

Olusanya, B. O. (2011). Priorities for early childhood development in low-income countries. *Journal of Developmental and Behavioral Pediatrics, 32*(6), 476–481. doi:10.1097/DBP.0b013e318221b8c5.

Op't Hof, J. (1983). Genetic services for patients with severe mental retardation. The South African situation. *South African Medical Journal, 63*(1), 8–13.

Op't Hof, J., Venter, P. A., Du Toit, J. L., Gericke, G. G., Dawson, B., Coetzee, D. J., . . . Reinecke, C. J. (1985). A multidisciplinary diagnostic/genetic study on the 105 patients with mental retardation of the E.S. le Grange School. *Journal of Mental Deficiency Research, 29*(1), 37–47.

Op't Hof, J., Venter, P. A., & Louw, M. (1991). Down's syndrome in South Africa - incidence, maternal age and utilisation of prenatal diagnosis. *South African Medical Journal, 79*(4), 213–216.

Ouellette-Kuntz, H., Cleaver, S., & Sarkar, A. (2008). Adults with intellectual disabilities in research: Declining participation rates. *Journal of Intellectual Disability Research, 52,* 697.

Paley, B., & O'Connor, M. J. (2011). Behavioral interventions for children and adolescents with fetal alcohol spectrum disorders. *Alcohol Research & Health, 34*(1), 64–73.

Parekh, A., & Jackson, C. (1997). Families of children with a mental handicap. In C. de la Rey, N. Duncan, T. Shefer, & A van Niekerk (Eds.), *Contemporary issues in human development: a South African focus* (pp. 38-53). Johannesburg: International Thompson Publishing.

Parker, I. (2005). *Qualitative psychology: Introducing radical research*. Berkshire: Open University Press.

PayScale South Africa. (2014). *Registered Nurse (RN) Average Salary.* Retrieved from http://www.payscale.com/research/ZA/Job=Registered_Nurse_(RN)/Salary

Petersen, E. M. (1986). Sanfilippo's syndrome type C - the first known case in South Africa. *South African Medical Journal, 69*(1), 63–68.

Petersen, I. (2004). Primary level psychological services in South Africa: Can a new psychological professional fill the gap? *Health Policy and Planning, 19*(1), 33–40.

Phasha, T. N. (2009). Responses to situations of sexual abuse involving teenagers with intellectual disability. *Sexuality and Disability, 27*(4), 187–203. doi:10.1007/s11195-009-9134-z.

Phasha, T. N. (2012). Sexual abuse of teenagers with intellectual disability: An examination of South African literature. *International Conference on Education & Educational Psychology, 69*, 1693–1699. doi:10.1016/j.sbspro.2012.12.116.

Phasha, T. N. (2013). Influences on under reporting of sexual abuse of teenagers with intellectual disability: Results and implications of a South African study. *Journal of Psychology in Africa*, *23*(4), 625–629.

Phasha, T. N., & Myaka, L. D. (2014). Sexuality and sexual abuse involving teenagers with intellectual disability: Community conceptions in a rural village of KwaZulu-Natal, South Africa. *Sexuality and Disability, 32*(2), 153–165. doi:10.1007/s11195-014-9344-x.

Phasha, T. N., & Nyokangi, D. (2012). School-based sexual violence among female learners with mild intellectual disability in South Africa. *Violence Against Women, 18*(3), 309–321. doi:10.1177/1077801212444578.

Phaswana, T. D., Van der Westhuizen, D., & Kruger, C. (2013). Clinical factors associated with rape victims' ability to testify in court: A records-based study of final psychiatric recommendation to court. *African Journal of Psychiatry, 16*(5), 343–348. doi:http://dx.doi.org/10.4314/ajpsy.v16i5.46

Pillay, A. L. (2008). An audit of competency assessments on court-referred rape survivors in South Africa. *Psychological Reports, 103*(3), 764–770. doi:10.2466/PR0.103.3.764-770.

Pillay, A. L. (2010). Intellectually disabled rape survivors' perceptions of morality and consequences of the crime. *Perceptual and Motor Skills, 110*(3), 1119–1124. doi:10.2466/02.07.13.15.16.PMS.110.C.1119-1124.

Pillay, A. L. (2012a). Intellectually disabled child and adolescent sexual violence survivors face greater challenges in the legal system. *Journal of Child and Adolescent Mental Health, 24*(2), iii–vi. doi:10.2989/17280583.2012.735498.

Pillay, A. L. (2012b). The rape survivor with an intellectual disability vs. the court. *South African Journal of Psychology, 42*(3), 312–322.

Pillay, A. L., & Kritzinger, A. M. (2008). Psycho-legal issues surrounding the rape of children and adolescents with mental retardation. *Journal of Child and Adolescent Mental Health*, *20*(2), 123–131.

Pillay, A. L., & Siyothula, E. B. (2011). Intellectual disability examinations and social context variables among patients of low socioeconomic status. *Perceptual and Motor Skills, 113*(2), 589–596. doi:10.2466/01.13.15.PMS.113.5.589-596.

Pillay, R. (2009). Retention strategies for professional nurses in South Africa. *Leadership in Health Services*, *22*(1), 39–57.

Potterton, J., Stewart, A., Cooper, P., & Becker, P. (2010). The effect of a basic home stimulation programme on the development of young children infected with HIV. *Developmental Medicine and Child Neurology, 52*(6), 547–551. doi:10.1111/j.1469-8749.2009.03534.x.

Power, D. J. (1977). A study of the prevalence of severe mental retardation among Coloured children in an urban community. *South African Medical Journal, 52*(1), 30–34.

Pretorius, C. (1984). The occupational therapist and the mentally handicapped child. *South African Journal of Occupational Therapy, 14*, 49–56.

Quinlan, E. (2009). The 'actualities' of knowledge work: an institutional ethnography of multi-disciplinary primary health care teams. *Sociology of Health & Illness*, *31*(5), 625–641.

Ramcharan, P. & Grant, G. (2004). Involving people with intellectual disability (ID) in commissioning research. *Journal of Intellectual Disability Research, 48,* 512.

Read, S. (2008). Focus groups with people with intellectual disabilities: Preparation and communication for involving people. *Journal of Intellectual Disability Research, 52,* 708.

Redley, M. (2008). Citizens with intellectual disability and the right to vote. *Journal of Intellectual Disability Research, 52,* 702.

305

Redley, M., & Weinberg, D. (2007). Learning disability and the limits of liberal citizenship: interactional impediments to political empowerment. *Sociology of Health &Illness*, *29*(5), 767–786.

Reeve, D. (2006a). Towards a psychology of disability: The emotional effects of living in a disabling society. In D. Goodley&R. Lawthom (Eds.), *Disability & Psychology: Critical Introductions & Reflections* (pp. 94-107). Palgrave: New York.

Reeve, D. (2006b). Oppression within the counselling room. *Counselling and Psychotherapy Research, 2,* 11–19.

Reeve, D. (2012). Psycho-emotional disablism: The missing link? In N. Watson, A. Roulstone, & C. Thomas (Eds.), *Routledge Handbook of Disability Studies* (pp. 78-92. London: Routledge.

Reinders, H. S. (2008). Persons with disabilities as parents: what is the problem? *Journal of Applied Research in Intellectual Disabilities*, *21*(4), 308–314.

Reinecke, C. J., Mienie, L. J., Hitzeroth, H. W., & Op't Hof, J. (1983). Screening for inborn errors of metabolism among mentally retarded patients. Outcome of a survey at the Witrand care and rehabilitation centre. *South African Medical Journal, 63*(1), 14–16.

Reitter, S., Karn-Vizelli, N., & Hess, I. (2009). Students with intellectual disabilities at university: A course in citizenship education. *Journal of Policy and Practice in Intellectual Disabilities*, 6, 144.

Renik, O., & Spillius, E. B. (2004). Psychoanalytic controversies: Intersubjectivity in psychoanalysis. *The International Journal of Psychoanalysis*, *85*(5), 1053–1064.

Republic of South Africa. (1974). *The Health Professions Act.* (Act No. 56 of 1974). Retrieved from http://www.hpcsa.co.za/Uploads/editor/UserFiles/downloads/legislations/regulations/mdb/regulations/scope_medical_science_2009.pdf

Republic of South Africa. (1988). Immorality Amendment Act (Act No. 2 of 1988), 25
February 1988. *Annual Review of Population Law,* 15, 123.

Republic of South Africa. (1996). *Constitution of the Republic of South Africa Act 108 of
1996: Chapter 2 – The Bill of Rights*. Retrieved from
http://www.gov.za/documents/constitution/1996/a108-96.pdf

Republic of South Africa. (1998).*Employment Equity Act 55 of 1998.*Retrieved from
http://bee.b1sa.co.za/docs/The%20Employment%20Equity%20Act%201998.pdf

Republic of South Africa. (2002). *Mental Health Care Act 17 of 2002.* Retrieved from
http://www.justice.gov.za/legislation/acts/2002-017_mentalhealthcare.pdf

Republic of South Africa. (2011). *"Towards Quality Care for Patients": National Core
Standards for Health Establishments in South Africa, Abridged Version.* Pretoria:
National Department of Health. Retrieved from
http://www.sarrahsouthafrica.org/LinkClick.aspx?fileticket=YnbSHfR8S6Q=

Reynolds, J., Wisaijohn, T., Pudpong, N., Watthayu, N., Dalliston, A., Suphanchaimat, R.,. . .
Sawaengdee, K. (2013). A literature review: the role of the private sector in the
production of nurses in India, Kenya, South Africa and Thailand. *Human Resources
for Health*, *11*(14), 10-1186.

Richardson, M. (1997). Addressing barriers: disabled rights and the implications for nursing
of the social construct of disability. *Journal of Advanced Nursing*,*25*(6), 1269–1275.

Riddington, C. J. (2008). How can adults with learning disabilities work effectively on
Learning Disability Partnership Boards? *Journal of Intellectual Disability
Research*, *52,* 702.

Riddington, C. (2012). Ten years of partnership. *Tizard Learning Disability Review*, *17*(1),
14–21.

Rispel, L. (2013, 25 July).*Quality of Patient Care and the Activities of Hospital Nursing Unit Managers in South Africa: A Paradox?* Theta Tau International's 24th International Nursing Research Congress. Prague, Czech Republic.

Roberts, T., Stephen, L. X. G., Fieggen, K., & Beighton, P. (2009). Wolf-Hirschhorn syndrome: Oro-dental manifestations and management. *Journal of Clinical Pediatric Dentistry, 34*(2), 173–176.

Robertson, J., Hatton, C., Emerson, E., & Yasamy, M. T. (2012). The identification of children with, or at significant risk of, intellectual disabilities in low-and middle-income countries: A Review. *Journal of Applied Research in Intellectual Disabilities*, *25*(2), 99–118.

Robinson, S. G. (2013). The relevancy of ethnography to nursing research.*Nursing Science Quarterly*, *26*(1), 14–19.

Roelofse, J. A., & van der Bijl, P. (1994). Propofol for sedation in a mentally retarded dental patient. *Anesthesia Progress, 41*(3), 81–82.

Rohleder, P., & Swartz, L. (2009). Providing sex education to persons with learning disabilities in the era of HIV/AIDS tensions between discourses of human rights and restriction. *Journal of Health Psychology, 14*(4), 601–610. doi:10.1177/1359105309103579.

Rose, J. (2011). How do staff psychological factors influence outcomes for people with developmental and intellectual disability in residential services? *Current Opinion in Psychiatry*, *24*(5), 403–407.

Rose, J., Mills, S., Silva, D., & Thompson, L. (2013). Client characteristics, organizational variables and burnout in care staff: The mediating role of fear of assault. *Research in Developmental Disabilities*, *34*(3), 940–947.

Rosenthal R.,& Rosnow,R. L. (2008). *Essentials of behavioral research: Methods and data analysis*(3rd ed.).McGraw-Hill: New York.

Roussotte, F. F., Sulik, K. K., Mattson, S. N., Riley, E. P., Jones, K. L., Adnams, C. M., . . . Sowell, E. R. (2012). Regional brain volume reductions relate to facial dysmorphology and neurocognitive function in fetal alcohol spectrum disorders. *Human Brain Mapping*, *33*(4), 920–937.

Royal College of Psychiatrists. (2001). *Diagnostic Criteria for Psychiatric Disorders for use with Adults with Learning Disabilities/Mental Retardation.* London: Gaskell.

Rubin, I. L., & Davis, M. (1986). Etiology of developmental disabilities in Soweto, South Africa. *American Journal of Public Health, 76*(9), 1112–1114.

Salari, S. M. (2006). Infantilization as elder mistreatment: evidence from five adult day centers. *Journal of Elder Abuse &Neglect*, *17*(4), 53–91.

Saloojee, G., Phohole, M., Saloojee, H., & IJsselmuiden, C. (2007). Unmet health, welfare and educational needs of disabled children in an impoverished South African peri-urban Township. *Child Care Health and Development, 33*(3), 230–235. doi:10.1111/j.1365-2214.2006.00645.x.

Samia, P., Petersen, R., Walker, K. G., Eley, B., & Wilmshurst, J. M. (2013). Prevalence of seizures in children infected with human immunodeficiency virus. *Journal of Child Neurology, 28*(3), 297–302. doi:10.1177/0883073812446161.

Sandy, P. T., Kgole, J. C., & Mavundla, T. R. (2013). Support needs of caregivers: Case studies in South Africa. *International Nursing Review, 60*(3), 344–350. doi:10.1111/inr.12022.

Saxton, M. (2006). Disability rights and selective abortion. In L. J. Davis (Ed.), *The Disability Studies Reader*(2nd ed., pp. 105-116). New York: Routledge.

Schoeman, C. J., Herbst, I., & Nienkemper, D. C. (1997). The effect of tuberculous meningitis on the cognitive and motor development of children. *South African Medical Journal, 87*(1), 70–72.

Schoub, B. D., Johnson, S., McAnerney, J. M., & Blackburn, N. K. (1993). Hepatitis B virus prevalence in two institutions for the mentally handicapped. *South African Medical Journal, 83*(9), 650–653.

Shabalala, N., & Jasson, A. (2011). PTSD symptoms in intellectually disabled victims of sexual assault. *South African Journal of Psychology, 41*(4), 424–436.

Shakespeare, T. (2006). The social model of disability. In L. J. Davis (Ed.), *The Disability Studies Reader*(2nd ed.,pp. 197-204). New York: Routledge.

Shaw, S., & Ogden, D. (2008). 'That's very good but I still can't read it': The production of accessible information for people with intellectual disabilities. *Journal of Intellectual Disability Research*, *52,* 706.

Shead, G. M., Potterton, J., & Stewart, A. (2010). Neurodevelopment and growth of institutionalized children with vertically transmitted human immunodeficiency virus. *Vulnerable Children and Youth Studies, 5*(1), 33–43. doi:10.1080/17450120903311582.

Shnier, M. H., Sims, F., & Zail, S. (1972). The Lesch-Nyhan syndrome. First case description in a South African family. *South African Medical Journal, 46*(28), 947–949.

Shulman, D. (1977). Homocystinuria in 2 South African negro siblings. *South African Medical Journal, 52*(3), 127–130.

Sidanius, J., Pratto, F., Van Laar, C.,& Levin, S. (2004). Social dominance theory: Its agenda and method. *Political Psychology, 25*, 845–880.

Siebold, C. (2011). What do patients want?: Personal disclosure and the intersubjective perspective. *Clinical Social Work Journal*, *39*(2), 151–160.

Simons, H. (2014). Case study research: In-depth understanding in context. In P. Leavy (Ed.), *The Oxford Handbook of Qualitative Research* (pp. 455-470). Oxford University Press: Oxford.

Sinason, V. (2010). *Mental handicap and the human condition: An analytic approach to intellectual disability.* London: Free Association Books.

Sinding C. (2010). Using institutional ethnography to understand the production of health care disparities. *Journal of Qualitative Health Research, 20*(12), 1656–1663.

Skirrow, P., & Hatton, C. (2007). 'Burnout'amongst direct care workers in services for adults with intellectual disabilities: a systematic review of research findings and initial normative data. *Journal of Applied Research in Intellectual Disabilities*, *20*(2), 131–144.

Sleigh, J. (1978). The therapeutic community for the mentally retarded. *Rehabilitation in South Africa, 22*(1), 29–33.

Slevin, E. (2004). New paradigm research: Potential benefits for those who leave the trodden path. *Journal of Intellectual Disability Research*, *48,* 512.

Slone, M., Durrheim, K., Kaminer, D., & Lachman, P. (1999). Issues in the identification of comorbidity of mental retardation and psychopathology in a multicultural context. *Social Psychiatry and Psychiatric Epidemiology, 34*(4), 190–194.

Slone, M., Durrheim, K., Lachman, P., & Kaminer, D. (1998). Association between the diagnosis of mental retardation and socioeconomic factors. *American Journal of Mental Retardation, 102*(6), 535–546.

Smith, L., Foley, P. F., & Chaney, M. P. (2008). Addressing classism, ableism, and heterosexism in counselor education. *Journal of Counseling & Development*, *86*(3), 303–309.

Smith-Chandler, N., & Swart, E. (2014). In their own voices methodological considerations in narrative disability research. *Qualitative Health Research*, *24*(3), 420–430.

Solomon, G. A. E., Jones, G., de Jong, G., & Marais, A. D. (2015). Biochemical and genetic diagnosis of Smith-Lemli-Opitz syndrome in South Africa. *South African Journal of Child Health*, *9*(1), 23–26.

South African Federation for Mental Health/SAFMH. (2014, August 1). *Fighting for the right to vote.*Retrieved from http://www.safmh.org.za

Springer, P., Swanevelder, S., van Toorn, R., van Rensburg, A. J., & Schoeman, J. (2009). Cerebral infarction and neurodevelopmental outcome in childhood tuberculous meningitis. *European Journal of Paediatric Neurology, 13*(4), 343–349. doi:10.1016/j.ejpn.2008.07.004 [doi].

Stainton, T. (2005). Empowerment and the architecture of rights based social policy. *Journal of Intellectual Disabilities*, *9*(4), 289–298.

Statistics South Africa (SSA). (2014). *Census 2011: Profile of persons with disabilities in South Africa.* Pretoria: Statistics South Africa.

Stein, M. A., & Stein, P. J. (2007). Beyond disability civil rights. *Hastings Law Journal*, *58*, 1203–1240.

Stilwell, B., Diallo, K., Zurn, P., Dal Poz, M. R., Adams, O.,& Buchan, J. (2003). Developing evidence-based ethical policies on the migration of health workers: conceptual and practical challenges. *Human Resources for Health,1*(1), 1–8.

Stilwell, B., Diallo, K., Zurn, P., Vujicic, M., Adams, O.,& Dal Poz, M. (2004). Migration of health-care workers from developing countries: strategic approaches to its management. *Bulletin of the World Health Organisation* 82, 595–600. Retrieved from http://www.scielosp.org/scielo.php?script=sci_arttext&pid=S0042-96862004000800009&lng=en&nrm=iso

Stolorow, R. (2011). From mind to world, from drive to affectivity: A phenomenological-contextualist psychoanalytic perspective. *Attachment: New Directions in Psychotherapy and Relational Psychoanalysis*, *5*(1), 1–14.

Stone, E.,& Priestly, M. (1996). Parasites, pawns and partners: Disability research and the role of non-disabled researchers. *The British Journal of Disability, 47*(4)*, 669–716.

Strandberg, G., & Jansson, L. (2003). Meaning of dependency on care as narrated by nurses. *Scandinavian Journal of Caring Sciences*, *17*(1), 84–91.

Strnadová, I., & Cumming, T. M. (2014). People with intellectual disabilities conducting research: New directions for inclusive research. *Journal of Applied Research in Intellectual Disabilities*, *27*(1), 1–2.

Strnadová, I., & Evans, D. (2008). Impact of ID on mothers of school-aged children: Different perceptions in New South Wales and the Czech Republic. *Paper Presented at the International Association for the Scientific Study of Intellectual and Developmental Disabilities.* Cape Town, South Africa.

Swartz L. (2010). *Able-Bodied: Scenes from a curious life*. Cape Town: Zebra Press.

Swartz, L. (2011). Race, gender and the impossibilities of care. *Medical Humanities*, *38*(1), 34–37.

Swartz, L., van der Merwe, A., Buckland, A., & McDougall, K. (2012). Producing boundary-breaking texts on disability issues: The personal politics of collaboration. *Disability and rehabilitation*, *34*(11), 951–958.

Swartz, S. (2005). Can the clinical subject speak? Some thoughts on subaltern psychology. *Theory & Psychology*, *15*(4), 505–525.

Swartz, S. (2006). The third voice: Writing case-notes. *Feminism & Psychology*, *16*(4), 427–444.

Swartz, S. (2007). The power to name: South African intersubjective psychoanalytic psychotherapy and the negotiation of racialized histories. *European Journal of Psychotherapy and Counselling*, *9*(2), 177–190.

Tajfel, H. & Turner, J.C. (2004). The social identity theory of intergroup behaviour. In J.T. Jost & J. Sidanius (Eds.), *Political Psychology* (pp. 276-293). New York: Psychology Press.

Tatar, M., & Bekerman, Z. (2002). The concept of culture in the contexts and practices of professional counselling: a constructivist perspective. *Counselling Psychology Quarterly*, *15*(4), 375–384.

Terblanche, E., & Boer, P.-H. (2013). The functional fitness capacity of adults with Down Syndrome in South Africa. *Journal of Intellectual Disability Research, 57*(9), 826–836. doi:10.1111/j.1365-2788.2012.01594.x.

Terre Blanche, M., Durrheim, K., & Painter, D. (Eds.). (2006). *Research in Practice*. Cape Town: University of Cape Town Press.

Thomas, C., & Rose, J. (2010). The relationship between reciprocity and the emotional and behavioural responses of staff. *Journal of Applied Research in Intellectual Disabilities*, *23*(2), 167–178.

Thompson, C. M., Puterman, A. S., Linley, L. L., Hann, F. M., van der Elst, C. W., Molteno, C. D., & Malan, A. F. (1997). The value of a scoring system for hypoxic ischaemic

encephalopathy in predicting neurodevelopmental outcome. *Acta Paediatrica, 86*(7), 757–761.

Thompson, L., & Rose, J. (2011). Does organizational climate impact upon burnout in staff who work with people with intellectual disabilities? A systematic review of the literature. *Journal of Intellectual Disabilities*, *15*(3), 177–193.

Thorne, S. E. (2014). Applied interpretive approaches. In P. Leavy (Ed.), *The Oxford Handbook of Qualitative Research* (pp. 99-115). Oxford University Press: Oxford.

Tideman, M. (2008). Resistance, identity of resistance and empowerment among people with intellectual disabilities. *Journal of Intellectual Disability Research, 52,* 709.

Tilley, E. (2004). The role of the voluntary sector in promoting rights of people with intellectual disabilities (ID). *Journal of Intellectual Disability Research, 48,* 476.

Tinney, J. (2008). Negotiating Boundaries and Roles Challenges Faced by the Nursing Home Ethnographer. *Journal of Contemporary Ethnography*, *37*(2), 202–225.

Tolsi, N. (2014, October 31 to November 6). Cameron and the caring state. *Mail & Guardian Law Report* (p. 3).

Tomlinson, M., Yasamy, M. T., Emerson, E., Officer, A., Richler, D., & Saxena, S. (2014). Setting global research priorities for developmental disabilities, including intellectual disabilities and autism. *Journal of Intellectual Disability Research*, *58*(12), 1121–1130.

Tranvåg, O., Petersen, K. A., & Nåden, D. (2013). Dignity-preserving dementia care: A metasynthesis. *Nursing Ethics*, *20*(8), 861–880.

Traustadottir, R. (2008). Voices of disabled children. *Journal of Intellectual Disability Research, 52,* 702.

Trevarthen, C., & Aitken, K. J. (2001). Infant intersubjectivity: Research, theory, and clinical applications. *Journal of Child Psychology and Psychiatry*,*42*(1), 3–48.

Tronto, J. C. (2010). Creating caring institutions: Politics, plurality, and purpose. *Ethics and Social Welfare*, *4*(2), 158–171.

Urban, M., Chersich, M. F., Fourie, L., Chetty, C., Olivier, L., & Viljoen, D. (2008). Fetal alcohol syndrome among grade 1 schoolchildren in Northern Cape province: Prevalence and risk factors. *South African Medical Journal, 98*(11), 877–882.

Uys, C. J. E., & Loots, J. (2008). South African youth with little functional speech tell their stories. *Journal of Intellectual Disability Research, 52,* 709.

Van der Bijl, P., & Roelofse, J. A. (1992). Propofol and midazolam for conscious sedation in a mentally retarded dental patient. *Anesthesia Progress, 39*(1-2), 36–37.

Van Der Byl, C. (2014). Twenty *Year Review South Africa 1994-2014. Background Paper: Disability.*Retrieved from http://accesstech.co.za/wp-content/uploads/2014/06/12%20Disability_20YR.pdf

Van der Linde, J., Swanepoel, D. W., Glascoe, F. P., Louw, E. M., & Vinck, B. (2015). Developmental screening in South Africa: comparing the national developmental checklist to a standardized tool. *African Health Sciences*, *15*(1), 188–196.

Van Der Merwe, J. V., & Roux, J. P. (1987). Sterilization of mentally retarded persons. *Obstetrical and Gynecological Survey, 42*(8), 489–493.

Van Der Walt, H., & Swartz, L. (1999). Isabel Menzies Lyth revisited institutional defences in public health nursing in South Africa during the 1990s.*Psychodynamic Counselling*, *5*(4), 483–495.

Van Heerden, C., & Kritzinger, A. (2008). Parental perceptions and practices of emergent literacy development in young children with Down's Syndrome: The development of

intervention guidelines. *The South African Journal of Communication Disorders, 55*, 37–48.

Van Toorn, R., & Schoeman, J. F. (2009). Encephalitis lethargica in 5 South African children. *European Journal of Paediatric Neurology, 13*(1), 41–46. oi:10.1016/j.ejpn.2008.02.008.

Van Toorn, R., Van Rensburg, P. J., Solomons, R., Ndondo, A. P., & Schoeman, J. F. (2012). Hemiconvulsion-hemiplegia-epilepsy syndrome in South African children: Insights from a retrospective case series. *European Journal of Paediatric Neurology, 16*(2), 142–148. doi:10.1016/j.ejpn.2011.06.009.

Vaslamatzis, G. (2011). Object-related and intersubjective processes in psychoanalysis: A twofold perspective. *International Forum of Psychoanalysis, 21*(3-4), 167–172.

Vassos, M. V., & Nankervis, K. L. (2012). Investigating the importance of various individual, interpersonal, organisational and demographic variables when predicting job burnout in disability support workers. *Research in Developmental Disabilities*, *33*(6), 1780–1791.

Vassos, M., Nankervis, K., Skerry, T., & Lante, K. (2013). Work engagement and job burnout within the disability support worker population. *Research in Developmental Disabilities*, *34*(11), 3884–3895.

Venter, A. (1997). Caregivers' expectations of services at Baragwanath hospital, Soweto and their understanding of the child's disability. *Developmental Medicine and Child Neurology, 39*(12), 815–820.

Venter, P. A., Gericke, G. S., Dawson, B., & Op't Hof, J. (1981). A marker X chromosome associated with nonspecific male mental retardation. The first South African cases. *South African Medical Journal, 60*(21), 807–811.

Venter, P. A., Op't Hof, J., & Coetzee, D. J. (1986). The Martin-Bell syndrome in South Africa. *American Journal of Medical Genetics, 23*(1-2), 597–610.

Viljoen, D. L. (1995). Porencephaly and transverse limb defects following severe maternal trauma in early pregnancy. *Clinical Dysmorphology, 4*(1), 75–78.

Viljoen, D. L., & Smart, R. (1993). Split-foot anomaly, microphthalmia, cleft-lip and cleft-palate, and mental retardation associated with a chromosome 6; 13 translocation. *Clinical Dysmorphology, 2*(3), 274–277.

Wagner, J. (1974). The placement of the mentally retarded child. *South African Medical Journal, 48*(10), 420–425.

Wahl, S., & Newmark, R. (2009). Die self-waargenome lewensgehalte van versorgingspersoneel by'n fasiliteit vir volwassenes met intellektuele gestremdheid. *Tydskrif vir Geesteswetenskappe*, *49*(2), 287–304.

Walker, E. M. (2013). Reflections on opportunities for people with profound intellectual and multiple disabilities to give informed consent to participate in research. *Journal of Policy and Practice in Intellectual Disabilities, 10,* 181.

Walmsley, J. (2001). Normalisation, emancipatory research and inclusive research in learning disability. *Disability & Society*, *16*(2), 187–205.

Walmsley, J. (2004a). Involving users with learning difficulties in health improvement: lessons from inclusive learning disability research. *Nursing Inquiry*, *11*(1), 54–64.

Walmsley, J. (2004b). Inclusive learning disability research: The (nondisabled) researcher's role. *British Journal of Learning Disabilities*, *32*(2), 65–71.

Walmsley, J. (2004c). Towards full citizenship, identity and people with intellectual disability (ID). *Journal of Intellectual Disability Research, 48,* 476.

Walmsley, J. (2014). Telling the History of Self-Advocacy: A Challenge for Inclusive Research. *Journal of Applied Research in Intellectual Disabilities*,*27*(1), 34–43.

Walmsley, J., Hart, C., Davies, I., Still, A., & O'Byrne, C. (2014). Telling the History of Self-Advocacy: A Challenge for Inclusive Research. *Journal of Applied Research in Intellectual Disabilities, 27*(1), 34–43.

Walmsley, J.,& Johnson, K. (2003). *Inclusive Research with People with Learning Disabilities: Past, Present, and Futures.* Jessica Kingsley Publishers: London.

Waska, R. (2007). Projective identification as an inescapable aspect of the therapeutic relationship. *Psychoanalytic Social Work*, *14*(2), 43–64.

Watermeyer, B. (2012). Is it possible to create a politically engaged, contextual psychology of disability? *Disability & Society*, *27*(2), 161–174.

Watson, J., Wilson, E., & Hagiliassis, N. (2013). Participation in decision making for people with severe-profound intellectual disabilities: What can it look like? *Journal of Policy and Practice in Intellectual Disabilities, 10,* 182.

Watson, N., Roulstone, A., & Thomas, C. (Eds.). (2012). *Routledge handbook of disability studies*. London: Routledge.

West, C., & Zimmerman, D. H. (1987). Doing gender. *Gender & Society*, *1*(2), 125–151.

Wildschut, A. & Mqolozana, T. (2008). Shortage of Nurses in South Africa: Relative or Absolute? In*A multiple source identification and verification of scarce and critical skills in the South African labour market.* Commissioned by the Department of Labour. HSRC, Pretoria.

Williams, V., England, M., Ponting, L., & Ford, K. (2008). Supporting researchers with intellectual disabilities. *Journal of Intellectual Disability Research, 52,* 698.

Wolbring, G. (2008). The politics of ableism. *Development*, *51*(2), 252–258.

World Bank. (2014). Total Population (in number of people): South Africa. Retrieved from
http://data.worldbank.org/indicator/SP.POP.TOTL

Xingwana, L. (2011). *Roundtable Two: Ensuring Effective and Full Participation in Political and Public Life (Article 29)*. Retrieved from
http://www.un.org/disabilities/documents/.../cosp4_statement_south_africa.doc

Yeates, N. (2010). The globalization of nurse migration: Policy issues and responses. *International Labour Review*, *149*(4), 423–440.

Yeung, P. H., Passmore, A. E., & Packer, T. L. (2008). Active citizens or passive recipients: how Australian young adults with cerebral palsy define citizenship. *Journal of Intellectual and Developmental Disability*, *33*(1), 65–75.

Yoo, J. H., Valdovinos, M. G., & Schroeder, S. R. (2012). The epidemiology of psychopathology in people with intellectual disability: A forty-year review. In R. M. Hodapp (Ed.), *International Review of Research in Developmental Disabilities*(Vol. 42,pp. 31-56). San Diego: Academic Press (Elsevier). doi:10.1016/B978-0-12-394284-5.00002-4.

Young, D. A., & Quibell, R. (2000). Why rights are never enough: Rights, intellectual disability and understanding. *Disability & Society*, *15*(5), 747–764.