Exploring the experiences of adults with intellectual disabilities in accessing health and healthcare in a small, rural, South African town.

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DECLARATION

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H. Gatley

Abstract

Background

In South Africa there is an ongoing emphasis placed on non-discrimination and the rights shared by all people, including those living with disabilities but despite this commitment, those with living with disabilities, and especially intellectual disabilities (ID), are often marginalised from accessing opportunities and resources.

In this research I provide a description of an understanding of health and the experiences of health services as told to me by a group of people with ID (PWID), to better understand their needs in creating health.

Purpose

To provide a description of the understanding of health and health care from the perspective of a group of adults with intellectual disability, contributing to the magnification of their voices within health-related research and service planning so eventually to benefit PWID more widely.

Methods

This is a qualitative, descriptive study that is heavily embedded within the context in which it takes place, a residential facility. In this study, I have framed my enquiries from an emancipatory perspective and used the lens of occupation to understand the participants' experiences through the social model of disability.

After extensive care was taken with the gathering of consent, data generation was performed through interviews with 14 participants. The transcribed interviews were analysed using thematic analysis, while three interviews were also analysed according to narrative analysis.

Findings

The overarching themes that emerged from the data generated within this research were conceptualised into a model to show the multidimensional interaction of the participation in health-creating behaviours along a spectrum of agency and dependence, embedded within a social context. Several health-creating behaviours were highlighted and described. The participants' experiences of interaction with health care services were also examined and discussed in terms of the interplay of trust, empowerment and power. Finally, three of the participant interviews were isolated and two narrative elements each were examined and described.

Conclusions

PWID have many contributions to make to a better understanding of the lived experience of health for themselves and others. The idea of interdependency of society can provide a basis to create more positive attitudes towards PWID and so free their voices to be better heard. People with and without disabilities live within contexts that affect their ability to exercise their personal potential and it is important to examine these influences before deciding to situate limitations that are experienced, within the individual. This interaction is especially stark in PWID.

Keywords

Health

Participation

Intellectual disability

Emancipatory

Agency

Ethics of Care

Opsomming

Agtergrond

In Suid-Afrika word daar 'n deurlopende klem geplaas op nie-diskriminasie en die menseregte wat deur alle mense gedeel word; Hierdie sluit diegene in wat met gestremdhede in ons gemeenskap saamleef. Maar ten spyte van hierdie houding, word diegene wat met gestremdhede, en veral intellektuele gestremdhede (IG), dikwels gemarginaliseer en ontneem van geleenthede en hulpbronne.

My navorsing bied 'n beskrywing van ‘n groep individue met intellektuele gestremdhede, hul begrip van gesondheid en hul ervaringe van gesondheidsdienste soos aan my meegedeel. My doel, hiermee is om hul behoeftes in verband met gesondheidskepping beter te verstaan.

Doel

Om 'n beskrywing van die begrip van gesondheid en gesondheidsorg uit die perspektief van 'n groep van volwassenes met intellektuele gestremdheid te verskaf. Daardeur wil ek graag bydra tot die versterking van hul stem binne gesondheidsverwante navorsing en gesondheidsdiens beplanning, om uiteindelik mense met intellektuele gestremdhede, in die algemeen, te baat.

Metodes

Dit is 'n kwalitatiewe, beskrywende studie wat ingewortel is binne die konteks waarin dit plaasvind: 'n residensiële fasiliteit vir dié met gestremdhede. In

hierdie studie het ek my navrae uit 'n bevryding perspektief gestel. Ek probeer, deur die oogpunt van arbeid te gebruik, om die deelnemers se ervarings deur die sosiale model van gestremdheid te verstaan.
Na uiterste sorg geneem is met die insameling van toestemming, is data geskep deur onderhoude met 14 deelnemers uit te voer. Die transkripsie van die onderhoude is geanaliseer deur gebruik te maak van tematiese analise, terwyl drie onderhoude ook ontleed is deur 'n narratiewe analise te gebruik.

Bevindinge

Die oorbruggende temas wat na vore gekom het uit die data is gekontekstualiseer binne 'n model. Deur hierdie model te gebruik word die multidimensionele interaksie van die deelname in gesondheidskepping, (binne 'n spektrum tussen hulpverlening en afhanklikheid), in 'n sosiale konteks, te beskryf. 'n Aantal tipes gesondheidsskepping-gedrag word beklemtoon en beskryf. Die deelnemers se ervaringinge van interaksies met die gesondheidsorgdienste is ook ondersoek en bespreek in terme van die wisselwerking tussen vertroue, bemagtiging en mag. Uiteindelik is drie van die deelnemers se onderhoude geïsoleer en word twee narratiewe elk ondersoek en beskryf.

Gevolgtrekkinge

Mense met intellektuele gestremdhede het ‘n baie bydrae om te maak, met betrekking tot 'n beter begrip van die ervaringe van gesondheid vir hulself en ander. Die konsep dat die samelewing interafhanklikheid is, kan 'n basis

verskaf om ‘n meer positiewe houdings teenoor mense met intellektuele gestremdhede te hê en daardeur hul stem te bevry en beter gehoor word. Mense, met en sonder gestremdhede, woon binne kontekste wat hul vermoëns beïnvloed om hul persoonlike potensiaal uit te leef. Dit is belangrik om hierdie invloede te ondersoek voordat mens besluit om beperkings te stel op wat die individu binne hom/haarself ervaar. Hierdie interaksie is veral ooglopend in mense met intellektuele gestremdhede.

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To my literature search assistants, thank you Mom (again) and Margaret Clay Bowen for helping with the sometimes-soul-destroying task of finding duplicates in a sea of literature.

And now finally ‘to Him who is able to do far more abundantly than all we ask or think, according to the power at work within us.’ (Eph 3v20; ESV) it is for Your glory.

Contents

List of figures and tables

Abbreviations/acronyms

ADL – Activities of Daily Living

HIV/AIDS – Human Immunodeficiency Virus/Acquired Immune deficiency Syndrome

ID – Intellectual Disability

ICF – International Classification of Functioning, Disability and Health

LMIC – Low and Middle-income countries

PEO Model – Person-Environment-Occupation Model

PWD – People with Disabilities

PWID – People with Intellectual Disabilities/Disability

PWoID – People without Intellectual disability

SSA – Statistics South Africa

SA - South Africa

UNCRPD – United Nations Convention on the Rights of People with Disabilities

WHO – World Health Organisation

Definition of Terms

Disability: “Disability is a complex interaction of biological, psychological, cultural and socio-political factors, which cannot be extricated except with imprecision” and results in experience of restricted participation (Shakespeare, 2014, pg.26). In this study I have used the word disability rather than differentiating between impairment and disability as I am primarily concerned with the lived experience of a group of people. Multiple influencing factors are relevant to that experience, rendering the dichotomy unnecessary.

Intellectual Disability: Disability that includes the lived experience of cognitive impairment and limitations in adaptive functioning. Multiple terms are used across different countries, but I have used intellectual disability. This is a widely used term.

Participation: “Involvement in a life situation” (World Health Organisation, 2002, pg.10)

Agency: “The ability of an individual to act intentionally and in a manner that directly or indirectly influences current and/or future outcomes” (Landes & Settersten Jr, 2019, pg.1). This takes place “through interactions with (….) social worlds and within (….) relationships” (Landes & Settersten Jr, 2019, pg.4)

Occupation: “Groups of self-directed, functional tasks and activities in which a person engages over the lifespan” (Law et al., 1996, pg.16)

Occupational Performance: “a dynamic experience of a person engaged in purposeful activities and tasks within an environment” (Law et al., 1996, pg. 16)

Occupational engagement: The act of taking part in or performing occupations.

Health: In this research I sought to understand health from the perspective of the participants, without adopting an *a priori* definition. My understanding shifted from the planning through to the conclusion of this research. By the conclusion of this study, I used the terms health and wellbeing (see the definition below) interchangeably. For further discussion on health see chapters 5 and 6.

Wellbeing: “a state of contentment – or harmony – with one’s: physical/mental health; emotional/spiritual health; personal and economic security; self-worth; sense of belonging; opportunities for self-determination; opportunities to engage in meaningful and purposeful occupational; sense of hope” (Hammell & Iwama, 2012, pg.387)

Spirituality: A transpersonal “connection to a reality beyond the human condition with the ability to positively transform lives” (Griffith et al., 2007, pg.88): often but not always connected to a religious belief system. In this study, religious beliefs formed a significant part of spirituality of the participants.

Chapter 1: Introduction

1.1. Introduction

In South Africa (SA), there is an emphasis placed on non-discrimination and the rights shared by all people. SA was quick to sign on to the United Nations Conventions on the Rights of Persons with Disabilities (UNCRPD) (The United Nations, 2006) but despite this commitment, people with disabilities, and especially intellectual disabilities (ID), are still often marginalised from accessing opportunities and resources (Capri et al., 2018; Kromberg et al., 2008; Ouellette-Kuntz, 2005).

The wide socio-economic gaps within SA society and a lack of adequate resources mean that people must compete fiercely for their chance to access services, including healthcare. For people with ID (PWID), who are often dependent on others to find health-creating opportunities with which to engage, this phenomenon is a marked reality.

When planning and enacting health services, the needs of those who will be making use of the services should be considered. It is a concern that PWID may be marginalised to the point that their voices concerning healthcare are not heard resulting in their service needs being assumed rather than investigated.

In this thesis I provide a description of health and the experiences of health services as told to me by a group of PWID, to better understand their needs as participants in health creation. In conducting this research project, I made use of an emancipatory approach, maintaining the view of the participants as central, and thus attempting to produce a co-created work of maximum benefit to them. I also interpreted the participants' stories of health creation through the lens of occupation, which allows for greater understanding of the dynamics surrounding active participation of the group within their own journeys. An occupational lens also naturally includes the assumption that there is a constant dynamic interplay between the person, their context, and the occupation (action). This is congruent with the social model of disability, which also formed part of the basis for the study.

1.2. Background

1.2.1. ID and Health

PWID can be found and form part of the health-seeking population in all countries. ID as a diagnosis can refer to many different conditions and as such PWID do not form a homogenous group, though they may experience certain commonalities regarding health challenges. PWID are in need of access to both general healthcare and specialist (e.g. mental health) healthcare services, but face a potential disadvantage in their access to such services compared to those without ID (Ali et al., 2015; Ali et al., 2013; Dinsmore, 2012; Ervin et al., 2014; Gibbons et al., 2016; Iacono & Davis, 2003; Mileviciute & Hartley, 2015;

Webber et al., 2010). Unfortunately, along with a disadvantage in access to health care, people with disabilities in general and with ID in particular also tend to experience a higher prevalence of health difficulties, a greater chance of delayed diagnosis and treatment and a greater chance of preventable death than in the general population (Ali et al., 2013). Considering the twin disparity of poorer health and poorer access to services experienced by many PWID, it is important for them to be represented within a body of research, which informs the planning and implementation of health services.

1.2.2. Intellectual Disability in SA

In SA there is little specific information regarding the prevalence of ID, although various surveys have been conducted (Adnams, 2010). The SA Census of 2011 (Statistics SA, 2014) found that 4,2% of people reported some form of cognitive disability ranging between mild and severe although this is considerably higher than the rate of 1.1% found in the National Disability Survey in 1999 (Adnams, 2010).

It is estimated that the prevalence of ID globally is between 1% and 3% (Maulik et al., 2011). Much of the historical data relating to prevalence rates has been gathered in high-income countries however, and it has been shown that the prevalence of ID is higher in LMIC, in adolescent and child populations and in peri-urban or urban slum areas (Maulik et al., 2011). From this it can be assumed that SA is likely to fall within or above this estimated prevalence range due to the high proportion of young people in the population, and large areas peri-urban and urban slums as well as widespread poverty (Statistics SA, 2012). It was found by Maulik and collegues (2011) that in studies conducted in LMIC, informal testing was generally used to identify PWID and these tests were often not specific to ID, which could account for some of the difference in prevalence rates found. The lack of specificity could mean either an over or under count but is likely to have resulted in an overestimation of numbers of PWID due to the inclusion of people with other cognitive difficulties. Overall, prevalence rates of ID in SA are difficult to know because of a number of barriers (Kromberg et al., 2008) but there is a high burden of preventable causes that contribute to the prevalence of cognitive disabilities, which further makes the prevalence of ID likely to be higher than other countries.

Very little is known about the experiences of adults living with ID in SA, or indeed, on the African continent. An exception is the recent work of Capri (2014) in the Western Cape, but as Capri herself notes, her work is something of an outlier within the field.

1.2.3. Institutionalised living for PWID in SA

With poor data on the lives of PWID available in SA, it is difficult to know much about those living in institutionalised settings. However, it is a relevant topic of investigation in SA following the widely publicised recent incidents of neglect and abuse within certain organisations (Capri & Swartz, 2018). We do not know enough about the services available to PWID in SA but despite the government's commitment to addressing the service needs of people with disabilities within community settings, change has been slow and many barriers remain (Republic of South Africa Department of Social Development, 2008).

While the vast majority of PWID in SA can be assumed to live in relatively impoverished community settings (Statistics SA, 2014) in line with the socio-economics of the country, this study is set within a group home. Institutions such as this one are relatively rare in SA and are largely privately funded although they may receive government subsidies. SA shows an increasingly large wealth gap, and the subgroup of people who can afford a place in a well-resourced, non-governmental residential facility, such as the one in which this study took place, are generally drawn from the small proportion of the population who are wealthiest. PWID however generally form part of the most vulnerable and excluded members of society within SA (Adnams, 2010). This pattern also means that this home and those like it in SA tend to be far more culturally, racially, and socio-economically homogenous and privileged in terms of access to resources, than the general population of the country. It is important to note that this study takes place in a setting that is unlikely to be representative of the general experience of those with ID across the country and in community settings.

1.2.4. Protectionist view of PWID

It has generally been the view of researchers and professionals that it is necessary to protect people who are considered vulnerable, and for a long time, research has excluded PWID for various reasons, including concern about the ethics of placing vulnerable groups under any kind of pressure (Capri & Coetzee, 2012). With the rise of a more emancipatory approach towards research, however, it has been suggested that the exclusion of the perspective of PWID themselves in research could be considered a human rights and ethical violation (Capri & Coetzee, 2012). PWID have a right, to be consulted and have their opinions heard on their own needs and experiences.

1.3. Positioning the researcher

I was employed as an occupational therapist at the institution where this study took place. I worked at the home from December 2013 to March 2019. After working at the institution for two and a half years and having found that, although I learnt something new every day, my learnings never outstripped my questions, I decided to study further. This thesis is the product of those studies.

Because I was an employee of the organisation at which I conducted this research, my pre-existing role and relationship with the participants is an inextricable part of the fabric of this research. It was important to consider the ethical implications of my position at the home, and this is expanded on in Chapter 3. Furthermore, my background as an occupational therapist is also critical to understand as a launchpad from which I began to listen to the voices of the participants.

In a country with the diversity of SA, it is usually culture and language that form some of the most important factors for a researcher to consider when examining data. In the case of this study, however, it is my state as a non-disabled researcher, occupational therapist, and member of staff with a position of authority that form the most relevant factors for consideration. Regarding culture, as a staff member of the same organisation that was home to the participants, we shared the micro-culture of that community. While I do not claim to be as much a part of the fabric of that community as the participants themselves, nor that I can assume an automatic understanding of their perspectives, as part of the home staff, I did have some insight into the workings, assumptions and interactions that form part of the study findings.

1.4. Research Outline

1.4.1. Problem Statement

PWID are known to experience generally poorer health than those without ID and to have more difficulty accessing resources and services. Although the patient perspective has become an increasingly important component of health planning, current knowledge regarding the experiences of PWID is relatively scarce and in SA is almost non-existent.

1.4.2. Purpose

To provide a description of the understanding of health and health care from the perspective of a group of adults with intellectual disability, to contribute to the magnification of their voices within health-related research and service planning, and so eventually to benefit PWID more widely.

1.4.3. Aim

This study's primary aim is to explore the perceptions of a particular group of adults with ID regarding their own health. The secondary aim is to explore the experiences of these adults with ID in accessing health services.

1.4.4. Research question

How do adults with intellectual disability in a small, rural, SA town understand their own health and what is their experience of contact with health care services?

1.4.5. Objectives

- To gain an understanding of the meaning of health from the perspective of adults with ID
- To identify a view of health service needs of PWID from the perspective of this group of participants
- To examine barriers and facilitators to autonomy for these adults with ID in engaging with health services and health-related activities.

1.4.6. Study Features

This is a qualitative study that explores and describes the perspective of adults with ID about their health and health care. In this study, I have framed my enquiries from an emancipatory perspective and used the lens of occupation to understand the participants' experiences, through the social model of disability. In the next chapter I will further discuss these theoretical underpinnings, as well as how I have integrated and applied them to this piece of research.

Chapter 2 Theoretical Framework

2.1. Introduction

In this study, it was clear that the context in which it was to take place would be of great significance in both the enactment of study procedures and interpretation of data. For this reason, using a frame of reference that takes account of social context was important. In this study I have chosen to make use of and integrate concepts from three different pieces of theory. I adopted an emancipatory approach to the research but also used an occupational lens when interpreting the data, through both the emphasis on occupations and the use of the Person-Environment-Occupation (PEO) model (Law et al., 1996). I further, assumed a version of the social model of disability as a base of understanding of disability. In this chapter I will take time to unpack each of these theories and then describe the interaction of the theories as a point of understanding for this study.

2.2. Social model of disability

The social model of disability emerged in the 1970s when disability advocates became increasingly frustrated with an approach to disability that placed the need for adaptation or improvement on the individuals with disability rather than the barriers that they faced within their own communities and society at large.

This raised the importance of differentiating between impairment, as something existing within a specific person and disability as a function of the interaction between a person with an impairment and their environment (Oliver, 2013).

The underlying basis of the social model of disability is that disability cannot be understood as residing within the individual but rather in the barriers, whether cultural, political or physical, that people face in order to access life spaces and occupations within the world around them (Levitt, 2017; Oliver, 2013; Owens, 2015; Shakespeare, 2014). An obvious example of such a barrier is a person making use of a wheelchair but faced with stairs to enter their place of work. In this example few people would argue the replacement of the stairs with a ramp would presumably allow that person to enter the building and so take their place as an active and contributing member of the workforce. As in this example, the model's focus on the removal of barriers, rather than correcting the individual, has been invaluable in the lives of people with disabilities, especially where pervasive disadvantages have and do still exist (Levitt, 2017). Few lived experiences are as simple as the example above, however, and it is at times impractical to attempt to define all experiences of disability in terms of external factors.

The social model of disability has become a generally accepted viewpoint in the field of disability studies over the years, emerging as a replacement for the medical model, and yet there are many criticisms as to its practicality and application (Levitt, 2017). There is some variation on opinion as to the usefulness of the social model and the need for it to be reimagined (Oliver, 2013; Shakespeare, 2014). There is also a risk by adopting the social model, theorists may turn people with disabilities into objects being acted on and irrelevant to their stories, rather than players in their own lives (Owens, 2015; Shakespeare, 2014). It must further be considered that people with disabilities are not a homogenous group and as Owens says, “[d]efining impairment and disability in terms of their consequences may exclude people with cognitive impairment” specifically by not taking into account the distinctive barriers faced by this group when compared to those with physical disabilities (2015, p. 388).

In this study where lived experiences of PWID are the subject up for examination, it would be equally unhelpful to either deny the contribution of external factors to the creation of disability, or to confine influence to them alone. For this reason a version of the social model of disability is taken as the basis for this study, in which disability can be understood as a complex interaction of multiple factors, including those both internal and external to the individual (Shakespeare, 2014). This more complex view of disability is akin to that underpinnings the International Classification of Functioning, Disability and Health (ICF) as developed by the World Health Organisation (WHO) (Palmer & Harley, 2012). In this study the societal and other external barriers are recognised for PWID, the differences between PWID and their interactions with and experiences of society and their broader environment are also acknowledged

By incorporating an occupational lens, as explained in 2.4., with the social model, I further was able to consider both internal and external factors in the lived experience of PWID in this study. Following on from the social model, this study has been framed using an emancipatory approach, which I will explain in section 2.3.

2.3. Emancipatory Approach

The emancipatory approach to disability research also originally arose out of the disability movement (strongly influenced by feminist politics) as a way to take into account and mitigate the dynamics of power within knowledge creation (Barton, 2005; French & Swain, 1997; Noel, 2006). Like the social model, this approach sets its focus on societal issues affecting people, such as deprivation, oppression, and discrimination, rather than the remediation of difficulties arising within the individual.

As the goal of the emancipatory approach is to create space and empower those who have been marginalised to engage with knowledge creation, such research needs to be focused on the generation of knowledge that is of value to those who have been disadvantaged and excluded (Danieli & Woodhams, 2005; Noel, 2006). Emancipatory research with people with disabilities does not only require their participation, but also their directional control over the research process (French & Swain, 1997). This is a challenge to conducting research with PWID, especially considering the complicated power dynamic in which the researcher holds the training and knowledge that allows for research to be conducted.

Many different theorists and critics have written about emancipatory research with PWD. A number of these authors have also acknowledged the sometimes impractical nature of holding too tightly to the ideas of the approach, but there are a few factors that are required to make research emancipatory in nature (Barton, 2005; Danieli & Woodhams, 2005; French & Swain, 1997; Noel, 2006). These are noted below.

1. Emancipatory research needs to acknowledge and seek to understand the influence of societal or external factors that act to maintain the marginalisation of vulnerable people (Noel, 2006).
2. Emancipatory research requires the participation of the vulnerable group in question wherever possible (Barton, 2005).
3. Emancipatory research must be of benefit to the vulnerable group, in the relevance of the knowledge generated and in the promotion of self-emancipation rather than simply paternalistic solutions (Noel, 2006).

Insofar as possible I did attempt to hold to the emancipatory principles during this study, in the process of gaining permission to conduct the research, the process of consent and in the presentation of findings sometimes far removed from my expectations. These details are shown in chapters 4 and 5.
Finally, it is evident in that it is the perspectives of PWID that forms the primary point of examination for this research.

From these explanations it can be seen how the social model can be thought to form part of the base of understanding for emancipatory research (Danieli &

Woodhams, 2005), but for this study I have also sought to integrate a third lens, the occupational perspective.

2.4. Occupational Perspective

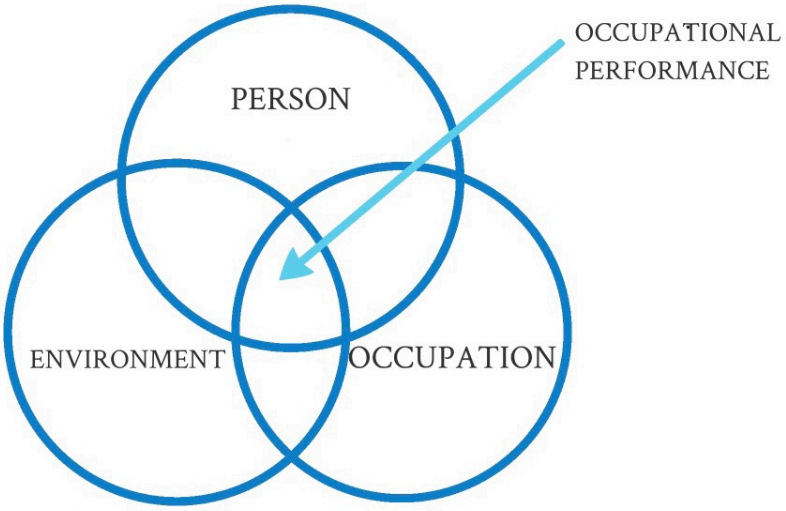
The occupational perspective arises from the fields of Occupational Science and Occupational Therapy but in fact with perhaps some differences in language the perspective has been used across many other disciplines (Wilcock, 2007). I will give some background about the perspective here before explaining the application to this study using the Person-Environment-Occupation (PEO) model.

According to Njelesani and colleagues (2014) the occupational perspective can be considered 'a way of looking at or thinking about human doing' (pg. 233). As such this perspective inherently considers the active participation of the person or persons who are the subject of the consideration to be a critical factor to understand. There can also be some confusion when using the word occupation as being specific to employment and other income generating actions but for this perspective all aspects of human doing or action are considered as worthwhile areas of consideration for study (Njelesani et al., 2014). With regard to how occupations and health relate to each other, although further research is warranted it is generally accepted when using the occupational perspective that occupations can be an important vehicle for affecting health (Njelesani et al., 2014; Wilcock, 2007). Considering this the perspective that I have used in this study is one that considers the actions of the participants regarding their own health as particularly noteworthy, and this will be reflected in the findings in Chapter 5.

I am making use of the PEO model as a basis for integrating all the theoretical foundations into a unified vision and specifically for the application of the occupational perspective. This model allows for a simple and helpful way of understanding the lived experiences of people within their complexity. It is represented in Figure 1 below.

Figure 1

Person-Environment-Occupation Model



Model developed by Law et al., (1996), from Rudin, 2013.

In this model, the person is an individual containing all the complexities and dynamics that that implies, the environment is the broad context in which this person exists, and the occupation is that which the person does (Law et al., 1996). The three components can be seen as overlapping and interacting with each other to produce a greater or lesser fit between the components. This place of meeting is where occupational performance or engagement occurs (Law et al., 1996). Njelesani et al. (2013) suggest a critical occupational approach that "considers occupation to be a site of knowledge production" (p. 211). This view allows for a greater dynamism in the examination of occupations and the context in which they occur by considering their interaction. The occupational perspective has long held to the importance of the environment in the lives of individuals (as seen in the PEO) and over time has moved from an interactional to a transactional understanding of this relationship (Law et al., 1996) in which the components rather than just interacting with each other are considered to act upon each other. An occupational perspective using the PEO model, therefore, allows for easy integration with the other two theoretical bases as I have explained them above for this study.

It is a core assumption of the critical occupational perspective that engagement in occupations can have an effect on wellbeing or health, but also that wellbeing cannot simply be achieved by creating change within the individual (Hammell & Iwama, 2012). In order for wellbeing to be enhanced, the external barriers within their environments also need to be addressed (Hammell & Iwama, 2012). As Hammel asserts, the intention of the focus on occupation is not simply one that seeks to create engagement for engagement's sake, but that through occupational engagement, health can be created (Hammell & Beagan, 2017).

This study is primarily concerned with the health of adults with intellectual disability, and in adopting the occupational perspective I have a lens with which to examine health but also health creation through the actions, choices or environmental influences that form part of the participants' experiences of health.

The social model of disability and the emancipatory approach to research can and have both been criticised for dismissing the individual factors that influence the lives of people with disabilities, in favor of focusing on the external barriers that they face (Barton, 2005; Danieli & Woodhams, 2005; French & Swain, 1997). It is possible that the occupational perspective, which flows naturally out of a person-centered ideology, could be accused of the opposite, that it focuses on the individual to the risk of exclusion of outside factors (Hammell & Beagan, 2017), but with the use of the PEO model the consideration of context is ensured.

2.5. Study assumptions

The three theory bases which I have explained above each contain several inherent assumptions. Below I have represented the most pertinent of these in a table for ease of comparison. It is important to note that Table 1 does not represent an exhaustive list, but merely those assumptions which were most relevant to this piece of research.

Table 1

Assumptions of the research

Assumption	Source
A power discrepancy exists between groups within society that needs to be mitigated	Emancipatory approach
Knowledge is co-created rather than dependent on the researcher	Emancipatory approach
Disability is not located exclusively within the person but also in their context.	Emancipatory Approach Social Model of Disability PEO Model
The lived experience of disability is a complex transactional relationship between the person, their environment, and their actions.	Social Model of Disability Occupational Perspective PEO Model
PWID should have the opportunity to actively participate, voice their views on their own lives and effect change	Emancipatory approach Occupational Perspective Social Model of Disability
Health creation can occur through occupational engagement.	Occupational Perspective

2.6. Conclusion

In this chapter I have briefly explained the theoretical basis for this research study. I have adopted and integrated three pieces of theory to frame the study.

Although the social model of disability can be considered a prerequisite for emancipatory research, this view is not universal (Levitt, 2017). The social model has also been criticised for being impractical and so it was important for me to explain the tempered understanding of its use in this research.

In keeping with the disability movement slogan the last few decades, ‘nothing about us without us’, the use of the emancipatory approach to research in this study was an obvious choice (Noel, 2006; Owens, 2015). The emancipatory approach’s focus on creating opportunities for self-liberation from environmental sources of oppression however, has come under a similar criticism as the social model for ignoring the personal in its understanding of the lived experience (Barton, 2005). While considering the external factors affecting marginalised and vulnerable groups is vital, to consider these factors in isolation is to make the person affected by them irrelevant and to deny their agency (Shakespeare, 2014).

For this reason, I have also included an occupational perspective as the lens through which to understand the findings of this research. The occupational perspective provides an approach to better emphasis the role of the person to act on and within their environment through occupation as a space in which both research based and general knowledge can be created (Njelesani et al., 2013). The occupational perspective also acknowledges a link between occupation and health and wellbeing, which is vital to this research (Hammell & Beagan, 2017; Hammell & Iwama, 2012).

In this study I have taken three theoretical perspectives and applied them all with the belief that the congruency between them provides a balanced and complex understanding of the health experience of this group of PWID in context. In the next chapter I will review some of the existing literature that has considered the experiences of PWID and their health.

Chapter 3: Literature Review

3.1 Introduction

Despite the increasing interest in disability-related research over time, there are still many gaps in our global knowledge and understanding of the experience of living with a disability and how to create the best possible opportunities for the creation of health and wellbeing for people for whom it is a daily experience. In the case of PWID, gaps in understanding are even more glaring. As McClintock et al., (2018) point out, although all people with disabilities experience health disadvantages, these are often worse for PWID.

In 2011 the WHO published a World Disability Report that reiterated the disadvantages faced by all people around the world living with disabilities, but especially those living in low and middle income countries (LMIC) such as SA (WHO, 2011). Despite the ratification of documents such as the UNCRPD (The United Nations, 2006), which are aimed at defending and upholding the rights of PWID, the inequity that they face in the realm of health is still pervasive.

In this chapter I will be setting out a summary of the relevant literature on understanding health for PWID. I will begin by looking at literature about health in general and how health is understood. Secondly, I will expand on the topic of ID under the headings of Health of PWID, Health Services and PWID, Health of PWID in SA and finally PWID and institutionalised care. In the third part of this chapter, I will be looking at the inclusion of PWID in health-related research regarding issues of participation, consent and contribution. Finally, in the fourth part I will briefly expand on the issues of social and occupational justice as they pertain to the health of PWID.

3.2 Health

According to the WHO “health is a complete state of physical, mental and social wellbeing and not merely the absence of disease or infirmity” (WHO, 2006, p. 1). While at first glance the inclusion of a social aspect of health in this definition creates the impression of an open and non-exclusive version of health, it is in fact confining in its specificity. The idea of a complete state of health and absence of disease and infirmity automatically excludes those with disabilities and in fact, according to Huber (2011) most people, from claiming health. Bostan et al., (2014), point out that self-reported health has become a commonly used measure for health reports, but it is difficult to create accurate comparisons because of the wide possibilities of understanding health according to individual values. They suggest the use of qualitative studies to create a better understanding of the specific parameters of self-reported health. Likewise Stucki and Bickenbach (2019) posit that the lived experience of health must be investigated rather than biological health alone, but there is a large challenge in doing that because they are by definition embedded within context. It has been suggested that perhaps it is time to consider new ways to assess health according to quality of life (QoL) rather than simply biology (Clark, Pett, Cardell, Guo, & Johnson, 2017), in order to better influence policy and affect outcomes (Rand & Malley, 2017). Attempts to find a different assessment of overall health and to develop new screening tools for health in PWID are aimed at correcting any inequity experienced (Bakker-van Gijssel, Lucassen, Hartman, Assendelft, & van Schrojenstein Lantman de Valk, 2018).

3.3 Intellectual disability

3.3.1 Health and ID

It is widely acknowledged that PWID face a disadvantage compared to those without ID in their experience of health and wellness. Despite the presence of different health systems and cultures across the world, the gap between the health and health-related QoL experience of PWID and people without intellectual disability (PWoID) seems universal (Ali et al., 2013; Booth, 2011; Brehmer-Rinderer, Zigrovic, Naue, & Weber, 2013; Emerson, Hatton, Baines, & Robertson, 2016; Hughes-McCormack, Rydzewska, Henderson, MacIntyre, Rintoul, & Cooper, 2018; Ouellette-Kuntz, 2005; Simões & Santos, 2016). Compared to PWoID, PWID experience higher rates of chronic disease (Reichard, Stolzle, & Fox, 2011), lower rates of mental health (Axmon, Ahlström, Persson, & Eberhard, 2019; Cooper, Smiley, Morrison, Williamson, & Allan, 2007; Hatton, Emerson, Robertson, & Baines, 2017; Hermans & Evenhuis, 2012; Stinton, Tomlinson, & Estes, 2012), poorer oral health (Blaizot, Hamel, Folliguet, Herve, Meningaud, & Trentesaux, 2017; Brehmer-Rinderer et al., 2013), higher rates of secondary health concerns (Brehmer-Rinderer et al., 2013; Koritsas & Iacono, 2011; Perez, Ball, Wagner, Clare, Holland, & Redley, 2015), higher rates of falls recorded at a younger age than PWoID (Ho, Bulsara, Patman, Downs, Bulsara, & Hill, 2019), a greater chance of delayed diagnosis and treatment and a greater chance of preventable death (Ali et al., 2013) and more physical health difficulties (van Timmeren, van der Putten, van Schrojenstein-Lantman de Valk, van der Schans, & Waninge, 2016). The secondary conditions experienced can cause significant limitations for PWID (Koritsas & Iacono, 2011) for example epilepsy, which is common in this group of people, and can be difficult to manage (Mengoni, Gates, Parkes, Wellsted, Barton, Ring, Khoo, Menji-Patel, Friedli, Zia, & Durand, 2016). Added to this it is easy for symptoms in PWID to be missed or incorrectly attributed to behavioural problems and dementia (Bowers, Webber, & Bigby, 2014; Webber, Bowers, & Bigby, 2016). Turk, Khattran, Kerry, Corney, and Painter (2012) found that PWID reported significantly more pain and health concerns than their carers reported on their behalf. It has been pointed out that many symptoms of poor health experienced by PWID can be attributed to disadvantages in living conditions rather than diagnoses associated with disability (Emerson et al., 2016; Hatton et al., 2017). Since PWID often experience poor living conditions this further adds to a difficulty of recording of health.

With the improvement of the life expectancy of people generally, that of PWID has also increased. This brings with it the difficulty of research and policy adequately keeping pace with the changing health needs of elderly PWID (Innes, McCabe, & Watchman, 2012; Kåhlin, Kjellberg, Nord, & Hagberg, 2015). As PWID age they experience poorer health (Cocks, Thomson, Thoresen, & Parsons, 2018) and an increased need for hospice care (Finkelstein, Tenenbaum, & Bachner, 2019; Friedman, Helm, & Woodman, 2012). It is important for those people caring for elderly PWID to have intricate knowledge in order to cater for the complex needs of those for whom they are caring (Northway, Holland-hart, & Jenkins, 2017) as they become more dependent on their carers (Johansson, Björne, Runesson, & Ahlström, 2017). For example, as PWID age they are exposed to a higher number of adverse life events such as loss, that are associated with depression and anxiety (Hermans & Evenhuis, 2012). Older PWID have a need for a health understanding that is specific to their stage of life, as with other life stages (Oakes, Milroy, & Hickerson, 2019).

PWID are often expected to be uninformed about and unable to manage their own health, but there is evidence that indicates that PWID can understand and should be given health information in an appropriate form (Bollard, 2017; Caton, Chadwick, Chapman, Turnbull, Mitchell, & Stansfield, 2012). In order to better facilitate the inclusion of PWID in the management of their own health, there is a need for adapted, targeted information resources (Cardol, Rijken, & van Schrojenstein Lantman-de Valk, 2012; Dysch, Chung, & Fox, 2012; Geukes, Bruland, & Latteck, 2018) and skilled staff in order to support their health choices (Ferguson, Jarret, & Terras, 2010; Krahn & Fox, 2014; Mckenzie, Mirfin-Veitch, Conder, & Brandford, 2017) and assist in self-monitoring and motivation (Bossink, van der Putten, & Vlaskamp, 2017; Mitchell, Stalker, Matthews, Mutrie, Melling, McConnachie, Murray, & Melville, 2018; Sundblom, Bergström, & Ellinder, 2015; Taliaferro & Hammond, 2016; Whitehead, Trip, Hale, & Conder, 2016). Collings et al. (2019) found that trust in the relationship between the PWID and the person supporting their health choices was important.

Understanding the health of PWID is not a simple endeavour. For PWID the close presence of family and paid carers in their lives has to be considered and these carers must be included in any consideration of health outcomes and interventions (Krahn & Fox, 2014). On occasion however it is possible for the carer of a PWID to become a hindrance to the improvement of health either because of a need or more training (Kroese, Rose, Heer, & O’Brien, 2013) or a well-meaning but problematic choice, such as the instinct to protect from distress or the use of food as a behavioural reward (Cartwright, Reid, Hammersley, Blackburn, & Glover, 2015; Flynn, Hulbert-Williams, Hulbert-Williams, & Bramwell, 2016). When considering the social context of PWID what ultimately matters however is that it is considered, and that PWID are allowed to participate in their communities, as this has a positive impact on health outcomes (Simões & Santos, 2016). Exclusion from meaningful occupations and community engagement is associated with poorer health (Bollard, Mcleod, & Dolan, 2018).

Far more is known about the views and experiences of carers than PWID with regard to health (Tomlinson & Hewitt, 2018; Venville, Sawyer, Long, Edwards, & Sawyer, 2015). Ultimately there is still too much that is unknown about the health and health needs of PWID (Matson & Shoemaker, 2011; Venville et al., 2015; Wheeler, Wylie, Villagomez, Bishop, & Raspa, 2019), but the understanding of accurate information about ID is essential for proper planning of health services (Hughes-McCormack et al., 2018).

3.3.2. Health Services and ID

In two systematic reviews examining literature related to health care and rehabilitation for people with disabilities in LMIC, it was found that there is generally very poor data available to understand the experience of people with disabilities (PWD) in these countries (Bright & Kuper, 2018; Bright, Wallace, & Kuper, 2018). Despite this lack of information, a few things are known. It was found that there is generally poor access to rehabilitation for mental health care users, including PWID (Bright et al., 2018) and although it was shown that PWD in LMIC make more use of health care services than those without disabilities. It is unclear if this is because of greater needs or good access, as not enough information is available (Bright & Kuper, 2018). Given what is known about the access that PWID have to health care in the Global North however, it is safe to assume that there are significant barriers to access in LMIC as well (Ouellette-Kuntz, 2005; van Schrojenstein Lantman de Valk, 2005; World Health Organization, 2007).

As is the case with health, from data in the Global North, it is widely documented that PWID experience a disadvantage when it comes to their access to health services (Ali et al., 2013; Dinsmore, 2012; Ervin, Hennan, Merrick, & Morad, 2014; Gibbons, Owen, & Heller, 2016; Iacono & Davis, 2003; Mileviciute & Hartley, 2015; Ouellette-Kuntz, 2005; Webber, Bowers, & Bigby, 2010).

Suggestions have been made to explain the presence of this disparity including poor staff attitudes (Dinsmore, 2012), lack of adequately trained staff (Webber et al., 2010), difficulties with communication (Gibbons et al., 2016; Webber et al., 2010), lack of appropriate equipment (Iacono & Davis, 2003) and a lack of flexibility in order to accommodate specific disabilities (Dinsmore, 2012; Iacono & Davis, 2003; Webber et al., 2010).

Despite evidence to indicate that health screening and checks for early detection of chronic disease can have benefits, and the known high rate of chronic disease for PWID, such checks are often not offered (Arana-Chicas, Kioumarsi, Carroll-Scott, Massey, Klassen & Yudell, 2019; Martin, Roy, & Wells, 1997; Reichard, Stolze, & Fox, 2011). In one study it was found that the reason for this incongruence between need and service was the view of service providers that the relatively small number of PWID meant that changes to their practice that may better accommodate PWID were not a priority as the burden of so many health issues were viewed as more important and so took precedence (Selick, Durbin, Casson, Lee, & Lunsky, 2018). In another study, general practitioners doubted the benefit and need for health screening for PWID (McConkey, Taggart, & Kane, 2015). Sadly it is often the case that even with known risks, screenings are ignored with the potential consequence of preventable death (Strnadová & Evans, 2015). As in all aspects of health with PWID there is complexity however, as Chapman, Lacey, & Jervis (2018) point out that even when available, the uptake of health checks can be low and variable and Macdonald, Morrison, Melville, Baltzer, MacArthur, & Cooper

(2018) iterates that checks are of greater benefit when the health professional knows the PWID being screened.

Staff members and health professionals can have a major impact on the experience of a PWID when accessing health services. Staff attitudes were found to be an important factor in the experience of health care for PWID (Bradbury-Jones, Rattray, Jones, & MacGillivray, 2013; Whittle, Fisher, Reppermund, & Trollor, 2019). A number of studies made the recommendation that staff need better support through training, access to information, communication skills, profession specific information and decision-making tools in dealing with PWID (Bradbury-Jones et al., 2013; Daaleman, 2016; Fredheim, Haavet, Danbolt, Kjønsberg, & Lien, 2013; Hemm, Dagnan, & Meyer, 2015; Iacono, Bigby, Unsworth, Douglas, & Fitzpatrick, 2014; Lennox, Van Driel, & van Dooren, 2015; Macdonald et al., 2018; Moores, Lidster, Boyd, Archer, Kates, & Stobbe, 2015; Prokup, Andridge, Havercamp, & Yang, 2017; Roberts, Townsend, Morris, Rushbrooke, Greenhill, Whitehead, Matthews, & Golding, 2013; Weise, Pollack, Britt, & Trollor, 2017). PWID can experience stigma from health professionals themselves (Pelleboer-Gunnink, Van Oorsouw, Van Weeghel, & Embregts, 2017) and medical students express feeling anxious and unprepared to work with PWID (Ryan & Scior, 2016). Researchers have also noted that during hospitalization there is a tendency for the hospital staff to place a great deal of reliance on the carers of PWID for day to day requirements such as feeding, dressing, bathing, toileting and simple communication (Ali et al., 2013; Dinsmore, 2012; Gibbons et al., 2016; Iacono et al., 2014). This places a heavy burden on the shoulders of carers to continue providing full-time care within hospital settings, often around the clock, and can constitute an abdication of responsibility by the hospital staff.

With regard to the health service needs of PWID, there is a need for areas of specialised care in order to better serve the needs of PWID (Chaplin, 2004; Cleary & Doody, 2016; Sinai, Werner, & Stawski, 2013) as it can be considered a specialist area of knowledge (Ervin et al., 2014). Despite this however there is cost attached to specialist care, and adults with ID can already in many cases be considered costly service users, so care needs to be improved in order to reduce the burden placed on the system (Ruiz, Giuriceo, Caldwell, Snyder, & Putnam, 2019). The decentralisation of healthcare means that PWID need to access services at the level of primary care (Rose, Kent, & Rose, 2012). This is also true for SA where the emphasis on service delivery has been moved to the primary setting in recent years (Maillacheruvu & Mcduff, 2014).

Cost can be another barrier to accessing health care. Iezzoni, Frakt, & Pizer (2011) found that in the USA, PWD generally were more likely to have no health insurance and were also far more likely to encounter difficulty in accessing care even than uninsured PWoD (29,5% to 6,6%). In this study it was found that rates were different for different disabilities, with PWID experiencing some of the worst rates of difficulty in access. This is again relevant to the SA context were poverty remains high and many people with disabilities live in poverty (Statistics SA, 2014).

Several further studies described patterns in the use of health services by PWID. Benevides, Carretta, Graves, & Sikka (2020) found that PWID and autism made more use of emergency services than those with only autism, but another study found that there was a poor understanding of the complex needs of PWID accessing emergency care and communication was a barrier to care (Heutmekers, Naaldenberg, Frankena, Smits, Leusink, Assendelft, & van Schrojenstein Lantman de Valk, 2016). Chaplin (2011) reported that when seeking in hospital-based mental health care, PWID experienced inconsistencies in the care received and delayed discharge, which can be bettered when professionals adopt a positive approach towards the care of PWID. Corbett (2011) argues that in the psychotherapeutic realm, PWID have been excluded from taking part.

Aging adults with ID have a higher need for healthcare services than those without ID (Hsu, Lin, Chiang, Chang, & Tung, 2012; Robinson, Dauenhauer, Bishop, & Baxter, 2012) and in order to accommodate these needs, planning should be done to better address this population's health (McCarron, Cleary, & McCallion, 2017). There is a need for targeted health systems and service pathways to accommodate aging PWID and those with dementia (Chapman et al., 2018; Ruiz et al., 2019). Better planned and organized services help to improve QoL for elderly PWID. An eleven-year study conducted in Sweden noted that although young PWID used healthcare services more than PWoID, this trend was reversed in older adults, suggesting that there are possible further unidentified barriers to older PWID in accessing health services (Sandberg, Ahlström, Axmon, & Kristensson, 2016).

Overall there are still gaps in evidence for planning and monitoring of health care of PWID across the life span (Määttä Määttä, Tervo-Määttä, Taanila, Kaski, & Iivanainen, 2011). The health care needs of PWID are complex and require cooperation between sectors. It has been suggested that in lower resourced settings where information is scarce, existing guidelines from other settings can be used as a starting point for planning services to be adapted for contextual differences (Coetzee, Swartz, Capri, & Adnams, 2019).

3.3.3. Intellectual disability in SA

There is some literature that speaks to the conditions of life of PWID living on the continent of Africa. This information, while helpful considering the little evidence that we have about ID in Africa, must be considered in the light of the size and diversity of the continent (Njenga, 2009). In general it is accepted that PWID in Africa experience poorer access to many aspects of life including work (McKenzie, McConkey, & Adnams, 2013). As a diagnosis, ID is often viewed unfavourably and as a burden on people and families (Njenga, 2009). This is not markedly different from attitudes in SA, according to a report released by Special Olympics (Bardon, Siperstein, & Parker, 2005). The report noted that, despite many people in SA reporting knowing a PWID, people consistently underestimated their abilities and believed in the idea of specialised work and schooling spaces rather than full inclusion.

In SA, access to the health system is biased along historical, spatial, economic and racial lines largely by virtue of the historical segregation of apartheid (Neely & Ponshunmugam, 2019). There is a decided shortage of resources in general and increasingly the country is losing skilled workers such as nurses to the economic opportunities offered abroad (Capri & Buckle, 2015). Specialised services for PWID are limited and tend to be concentrated in large centres, leaving outlying rural areas with poor access to services (Adnams, 2010; Vergunst, Swartz, Mji, Maclachlan, & Mannan, 2015). When PWID do access services, the staff face difficulties of a lack of communication skills, training and overstretched time (Malapela, Mfidi, Sibanda, & Thupayagale-Tshweneagae, 2017). It was also found that student nurses were nervous when faced with PWID but felt that exposure to working with PWID increased their confidence and also facilitated personal growth (Janse van Rensburg, Poggenpoel, & Myburgh, 2012). This supports the assertion by Shakespeare and Kleine (2013) that contact with PWD is a more effective form of education that attending lectures about PWD.

As in other countries SA needs a collaborative, intersectoral approach to the care of PWID and mental health care in general (Skeen, Kleintjes, Lund, Petersen, Bhana, Flisher, & The Mental Health and Poverty Research Programme Consortium, 2010). When attempting to access primary health care, PWID in SA often meet with barriers, being sent to specialist services which require travel expense and time to access (Capri et al., 2018). There are a number of barriers for PWID in SA to inclusion despite having their rights enshrined in the law and in the UNCRPD (The United Nations, 2006). According to Lund, Kleintjes, Cambell-Hall, Mjadu, Petersen, Bhana, Kakuma, Mlanjeni, Bird, Drew, Faydi, Funk, Green, Omar, & Flisher (2008) ID is heavily marginalised in SA, even within the domain of mental health.

In SA most PWID live in communities and with their families but the SA Mental Health Care Act (The Republic Of SA, 2002) does allow for institutionalised care. Sadly this act does not specify strict standards for that care (Capri & Swartz, 2018b). For the PWID in SA who live in residential facilities, despite the care received from the institution, access to relevant healthcare is not guaranteed (Mckenzie et al., 2013). Residential facilities also tend to be expensive, at least partly self-funded and largely also exhibit the same racial divisions that are present in other aspects of SA life (Mckenzie & Mcconkey, 2016). One of the difficulties of residential facilities is that they tend to be short on resources, and staff are overworked (Conradie, Erwee, Serfontein, Calitz, & Joubert, 2010) and tend to be more custodial than supportive of full inclusion (Capri & Swartz, 2018b).

3.3.4. ID and institutionalised care

For a number of years, around the world there has been a move towards deinstitutionalised care for PWID, but the transition is not complete, with many countries still having residential care for those with disabilities (Hallrup, 2012; Marlow & Walker, 2015; Pallisera, Vilá, Fullana, Díaz-Garolera, Puyalto, & Valls, 2018). There are a number of reasons why a family may hand over care of their loved one to an institution, such as the burden and impact of care on the family, or conversely the desire to give that person an opportunity to experience life out of home (Nankervis, Rosewarne, & Vassos, 2011).

The decision for PWID to move into a residential facility is one that can have an emotional impact, as families can feel a sense of guilt or failure as they have been unable to provide care (Nankervis et al., 2011) and as one Swedish study found, residents can feel there is a meaningless monotony to their lives in institutionalised care (Hallrup, 2012).

Residential institutions around the world are not all run based on the same set of beliefs or assumptions, and the attitudes and care given have a large impact on the experience of life inside (Gjermestad, Luteberget, Midjo, & Witsø, 2017). Svanelov, Wallén, Enarsson, and Stier (2019) found in their study that for PWID in institutions, the experience of meaningful participation requires opportunities to engage in work-related tasks and social interactions. It is important in these facilities for the creation of participation to take an active stance as passivity toward participation will almost always allow for reverting to a state of exclusion (Hallrup, Kumlien, & Carlson, 2019) as living in a group setting is not a guarantee of inclusion (Burghardt, 2015; Giesbers, Hendriks, Jahoda, Hastings, & Embregts, 2019). In Spain, facility managers spoke of part of their role being the education of others who they felt underestimated the abilities of PWID under their care (Pallisera et al., 2018). Another barrier to participation for those living in residential institutions is the divergent views of staff members on the topic (Talman, Wilder, Stier, & Gustafsson, 2019). In light of this, it becomes important to listen to the voices of those living in residential institutions. Byhlin & Käcker (2018) found that PWID were concerned about being treated as adults and individuals who could have voice in the decisions affecting their own lives. The creation and maintenance of social networks have also been found to be very important to the wellbeing of PWID living in institutional care (White & Mackenzie, 2015). PWID are ultimately individuals who have their own views on the lives that they would choose to live given the opportunity and independence is not valued as paramount for all (Hamilton, Mesa, Hayward, Price, & Bright, 2017) but a personalised approach to their care is. Unfortunately it is an extremely difficult feat of coordination to see to meeting the needs of a number of different people within a facility and therefore, the services or care offered to residents tends to be standardised rather than personalised (Dahm, Georgiou, Balandin, Hill, & Hemsley, 2019).

Health promotion is important as a part of the fabric of residential care but for it to be effective it needs to be approached as an integrated effort between the PWID, the institution and external researchers (Wahlström, Bergström, & Marttila, 2014). Health promotion can however be labour intensive and it is difficult for some organisations to sustain a health promotion focus through staff, unless their policies and procedures are reworked to support such efforts (O’Leary, Taggart, & Cousins, 2018).

A few studies have examined the changes in the health of people when moving from an institutional setting to a community-based setting. Marlow and Walker (2015) did not find a significant change in the biological health of PWID following such a move, but they did find that the incidences of challenging behaviour were reduced. Likewise, Griffith Hutchinson and Hastings (2013) found that challenging behaviours declined and attributed this to the movement away from an imbalance of power, poor staff attitude and the stress of group living. When PWID in these studies were moved from institutional care to community-based care they tend to experience an improvement in their QoL (Mccarron et al., 2019; Sines, Hogard, & Ellis, 2012) as well as better community participation, although it is not to say that such a move automatically removes all barriers to inclusion (Sheth et al., 2019). It is worth noting that most of these studies indicating the benefit of community living for PWID, presuppose the existence of adequate community-based services which is not guaranteed in many places. Much of the research available on the institutionalised care of PWID comes out of high-income countries. In SA a survey of family carers found that as a group they felt committed to the care of their relatives, but the community structures and support to allow for the care were largely missing, leading to a very high burden on the family (Mckenzie & Mcconkey, 2016).

3.4. Intellectual disability in research

Despite the large amounts of research available on the health disparities faced by PWID, there are still large gaps in our knowledge on the wider health needs of this group (McCarthy & O’Hara, 2011). ID is complex in its nature and yet there is a dearth of information on many topics (Lunsky, Lake, Balogh, Weiss, & Morris, 2013;).

Historically PWID have often been viewed as a single homogeneous group of people and so research that investigated the nuances of their health and health needs is inadequate. There is a risk that in conducting research on topics relevant to ID one can begin to view the PWID in terms of diagnosis rather than their personhood (Watchman, 2016) and so create an ableism in the research journey (Campbell, 2019) but with good planning this can be countered.

Although some research has been conducted into the health needs and service use of PWID, far less research exists exploring the perspectives and experience of these people in accessing the services. PWID can contribute and participate in research in a meaningful way when the research well planned and adequate support is provided (Tyrer et al., 2017).

3.4.1 Participation of PWID

It has increasingly been acknowledged by health researchers that the voices of health care users should be included within the body of health knowledge (Soni, Hall, Doulton, & Bowie, 2014) and so their perspectives have become a more important focus of research in recent years (Fujiura, 2012). In fact Fujiura (2012) notes that self-reported health has become recognized in the USA as a key health outcome. Despite this, the inclusion of the perspective of those living with ID in research has been slower (Lennox et al., 2005) as the research community has primarily relied on information gathered from family members and carers (Gibbons et al., 2016).

PWID have been excluded from participation in research for various reasons. Dowse (2009) points out that the traditional goal of research with PWID has been to correct or measure the disability rather than to understand the lived experience, an approach that can have a disabling effect on the research participants. Inclusive research is time-consuming and difficult, but it is necessary for PWID to be empowered to voice their opinions (Salmon, Barry, & Hutchins, 2018). Historically PWID have also been excluded from research in an attempt to protect them from undue pressure or stress (McDonald & Keys, 2008). PWID have also long been considered unable to adequately express themselves and therefore meaningfully contribute to a body of knowledge (Gibbons et al., 2016). This exclusion due to belief of incapacity has often been accepted without a true empirical foundation for its necessity (Feudtner & Brosco, 2011).

With the increase of a more emancipatory approach in recent times, it has been suggested that the exclusion of the perspective of PWID in research could be considered an ethical violation (Capri & Coetzee, 2012). To exclude an entire group of people from research is not only discriminatory but results in gaps in information and knowledge that have an impact on health care planning (Calveley, 2012). PWID are an already marginalised group in society and so where historically accepted practices are indiscriminately held onto, they will have little chance of finding space for their voices to be heard (Capri & Swartz, 2018a). Mietola, Miettinen and Vehmas (2017) however argue that sometimes it is the good intentions of emancipatory research itself that can create exclusion through insistence on the enforcement of participation beyond that capacity of those with more severe disabilities.

Feldman, Bosett, Collet and Burnham-Riosa (2014) examined studies on the inclusion of PWID and found that of their sample, 90% of trials were designed in such a way as to automatically exclude PWID, and only 2% included this group in their sample with the other 8% having excluded PWID by chance. Study designs and methodologies need to be re-examined and adjusted in order to allow for better inclusive research (Beighton, DeWilde, Victor, Cook, Carey, Manners, Hosking, & Harris 2019; Cleaver, Ouellette-Kuntz, & Sakar, 2010). A number of options are available to make research more inclusive, with PWID taking an advisory, leading or controlling role in the research, with a strong background of self-advocacy (Bigby, Frawley, & Ramcharan, 2014).
There are a number of options and theoretical bases from which to choose when planning inclusive research (Jen-yi, Krishnasamy, & Der-Thanq, 2015; McDonald & Stack, 2016). Inclusive research may be time-consuming and challenging but it is possible with PWID (Salmon et al., 2018) although while the goal is to widen the spectrum of voices in the research field, it can be very difficult to provide training for PWID in inclusive research without colonising their voices with those that are already more dominant (Nind, Chapman, Seale, & Tilley, 2016).

The participation of PWID in research is important and valuable in order to give voice and challenge attitudes towards disability (McDonald & Keys, 2008), build a stronger knowledge base on ID (Beighton et al., 2019) and open a socially valuable opportunity for the PWID included in the research (Soni et al., 2014). By considering more carefully the details of how people with different abilities and disabilities are able to participate in research such as this greater richness of co-created knowledge can be achieved (Mietola et al., 2017).

3.4.2 Capacity to consent

A belief in the incapacity of PWID to consent to research has been a major barrier to inclusive research, and the instinct to provide protection from exploitation is a good one (Goldsmith & Skirton, 2015). The capacity to consent is not a simply understood or identified concept and in fact may change moment by moment through the research process (Jepson, 2015). There are methods that can be used in order to allow PWID to take part in research more easily, such as making use of gatekeepers (Goldsmith & Skirton, 2015). PWID are often underestimated in their ability to understand and answer questions (Stancliffe, Tichá, Larson, Hewitt, & Nord, 2014). Calveley (2012) makes the suggestion that even in the cases of participants with severe and profound ID, a judgment can be made on balance of their best interests by others, as their participation can in itself empower them to effect change on interventions and procedures that ultimately affect their lives. Mietola et al. (2017) argues that in the case where research aims can be justified as ethical, even people with profound ID who cannot easily consent should be included. In order to approach the difficult space of inclusive research, researchers need to apply understanding and reflexivity on the assumptions that inform beliefs on disability and capacity (Jepson, 2015).

PWID can be excluded from participation in research trials either actively, through the choice of exclusion criteria, or passively by the unintentional planning of inaccessible procedures. Exclusion of PWID is however not always based on the research plan itself but sometimes in the ethical approval process. As such even with adapted research procedures, PWID are under- represented in research (Hamilton, Ingham, Mckinnon, Parr, Tam, & Le, 2017).

Tools to decide on a person's capacity to consent can never be used exclusively, but can guide judgment, as the ability to consent is dependent on personal and individual factors influencing understanding, remembering and communicating (Wong, & Breheny, 2018). Where it is tempting to simply exclude PWID due to the complexity of gaining consent, they should rather be supported in order to make decisions for themselves (Devi, 2013) through adapted ways of sharing information and simplified explanations where necessary (Wong & Breheny, 2018).

3.4.3. Contribution of PWID to research

A number of studies have been conducted in various countries to explore the perspectives of PWID about health and have yielded rich and valuable information (Ali et al., 2013; Gibbons et al., 2016; Llewellyn, McConnell, & Bye, 1998). These studies are however limited in their size and scope as well as their generalizability across contexts. In the United Kingdom, Ali et al. (2013) noted that although participants were generally satisfied with their access to health services, many had experienced distress in hospital stays. In a similar study by Gibbons et al. (2016) within managed care, they found that participants were similarly satisfied with their health and access to services. They also found that the participants placed a high degree of importance on spirituality as a part of health. These two studies conducted within the same country provide examples of how research that acknowledges the potential contributions of PWID to research can add to existing knowledge and a holistic understanding of health. Inclusive research can therefore contribute to a more robust and holistic knowledge base (Frankena, Naaldenberg, Cardol, Linehan, & van Schrojenstein Lantman-de Valk, 2015). It is important therefore for there to be a shift in research, to a paradigm of inclusion and participation allowing participants with ID a voice within the research which concerns them (Dowse, 2009).

There are a few instances where it is easy to see how the inclusion of the voices of PWID could contribute new and more complete knowledge to research findings. It is known that much of the planned care that already exists does not adequately meet the needs of PWID and so it follows that hearing them in research would provide valuable information in planning services (Abbott & McConkey, 2006; McDonald, Kidney, & Patka, 2013; Reichard et al., 2011) as well as helping to created more equitable care (Ryan & Scior, 2016) and advocating for better policy and legislation into the future (Johnson, Minogue, & Hopklins, 2014). It is not enough to assume that the views of professionals and staff will yield all the necessary information (McDonald et al., 2013), and it is therefore important to look at inclusion in both qualitative and quantitative research (McVilly, Stancliffe, Parmenter, & Burton-Smith, 2006).

Research has shown that PWID place value on the opportunity to take part in and contribute to research (Puyalto, Pallisera, Fullana, & Vilà, 2016), particularly when it involves working with a trusted individual (Lewis et al., 2016). Likewise, non-disabled researchers expressed a belief that the depth of research was better when PWID were included (Puyalto et al., 2016). The social care sector is one sector that has the potential to greatly benefit from the richness added by doing research with PWID (Gilbert, 2004) and who, as a group tend to believe that this is beneficial, although some people expressed concern that the effort required to conduct research with PWID would outweigh the benefits derived from it (Hall, Durand, & Mengoni, 2017).

There are difficulties in conducting inclusive research, and so having PWID advise researchers is paramount (O'Brien, Mcconkey, & García-Iriarte, 2014). It may also be important to allow for some flexibility and adjustment in the research procedures (Hall et al., 2017; O'Brien et al., 2014). It has been common that where co-researchers with ID have been included in the procedures, their views are still either absent or only reported selectively (Strnadová & Walmsley, 2018). There is also a need to address gaps in research such as end-of-life research with PWID (Savage, Moro, Boyden, Brown, & Kavanaugh, 2015) and the lack of inclusion of PWID in level 1 and 2 intervention trials, as the efficacy of an intervention for PWID cannot be investigated without including PWID in the sample (Oliver, Piachaud, Done, Regan, Cooray, & Tyrer, 2002). Once research has been conducted, there is also a need to examine the process of dissemination in order to make it more accessible to PWID (Corby, Taggart, & Cousins, 2015).

In SA there has been little in the way of attempts to include the voices of PWID in research or policy making. However, as Capri and Coetzee (2012) point out, in SA principles of equal rights and non-discrimination are universal in their application to citizens, including those with ID.

3.5. Occupational and social justice and the rights of PWID

It is generally understood that the concept of social justice places its focus on society and the forces that shape people and relationships through society, while occupational justice expands this concept to include occupational rights (this refers to occupation in the sense of the occupational lens in section 2.4. and not occupational rights that refer to the right to work or employment) (Durocher, Gibson, & Rappolt, 2014). The World Federation of Occupational Therapy (WFOT), in their position paper on human rights, make the point that people by virtue of their humanity have the right to occupational opportunity, based on the assumption that engagement in occupations can improve wellbeing (Hocking, Townsend, & Mace, 2019). By forming part of human wellbeing, occupational opportunity and engagement become integral to human rights (Hammell & Iwama, 2012).

Occupational justice also recognizes the political and economic factors that influence the opportunities that people have to engage fully within their contexts (Channon, 2014). Likewise, social justice is influenced by external factors, sometimes even those forces that originate beyond the nation state (Cutajar & Adjoe, 2016). Hammell (2017) points out that occupation itself can be social and that collective doing is vital to wellbeing, meaning that the occupational and social cannot be teased apart from each other. It has been argued that occupational and social justice are indistinguishable from each other (Durocher et al., 2014) and for the purposes of this discussion and the lives of PWID that are affected, while they may focus on rights from slightly different angles, their impact is collective.

The rights of PWID are enshrined in the UNCRPD (The United Nations, 2006) as well as the Constitution of SA (The Republic Of SA, 1996). Despite this commitment to the rights of PWID, these are not always realized and exclusion of PWID is common (Scior, 2011). For example, in reports submitted to the UN Committee on the Rights of Persons with Disabilities, a number of European countries barely included people living with ID, suggesting that even within the field of disability those with ID experience marginalisation (Brehmer-Rinderer et al., 2013). Chan (2016) has suggested that in Australia, the increasing importance placed on occupational health and safety has led to practices limiting the freedoms of PWID, as society has come to view them more in terms of risk than of personhood. In SA the point has been made that PWID seem to live under a second apartheid through exclusion (Foskett, 2014).

Memari and Hafizi (2015) suggest that the consideration of ID from the point of view of human rights could lead to better inclusion for PWID through the influence of public policy, which they point out has already begun to change in some places. McConkey (2019) however, expresses skeptism about the potential for true change for PWID, not just because of stigma but also because of dependency. He posits that there is an underlying belief in society that to be deserving of rights, you should be able to care for yourself and that even should the world prioritise the correction of history for PWID, change would be extremely difficult.

The rights of PWID can be and are infringed on in many ways: through separation from occupational opportunities (Hammell & Beagan, 2017), cultural influences (Memari & Hafizi, 2015), institutional policies that place value on efficiency over self-determination (Johnson & Bagatell, 2017), poor attitudes to inclusion, and barriers within the built environment (Sherman & Sherman, 2013). Meanwhile, PWID have their own ideas and preferences, which are hampered by the infringement of their social and occupational rights (Devi, 2013).

While it is true that research claiming to reflect the values of the UNCRPD is increasing, little is still known about the impact of the document (Steinert, Steinert, Flammer, & Jaeger, 2016). Further research is needed to understand this, although the understanding of inequities does not on its own translate to the reduction of complex barriers (Naaldenberg, Banks, Lennox, Ouellette-Kunz, Meijer, & van Schrojenstein Lantman-de Valk, 2015).

3.6. Summary of Chapter 3

In this chapter, existing literature has been explored to better understand several concepts. While many relevant papers were available, the majority come out of concentrated areas situated in the global North, and better geographical representation is needed (Chaplin, 2011). Research is also heavily influenced by power dynamics within society generally and research specifically and this means that, until better inclusivity is achieved, available information and even assumptions about and attitudes towards disability are framed by the understandings and values of the powerful (McDonald & Keys, 2008). This exploration of literature forms the starting point for the current study.

Chapter 4 Methodology:

In this chapter I describe how and why I planned this research as I did, as well as the deviations from the plan in some instances. I will be giving special attention in this section to explaining my ethical reasoning, as well as how both I and the research, were situated within the organisation in which the study was conducted. For this research I made use of a qualitative, descriptive design.

4.1 Setting:

This piece of research was conducted within a residential facility for adults with ID. An explanation of the setting will be essential to the understanding of this research.

I collected the data from a group of residents living within a non-governmental organisation, residential facility in a rural SA town. Going forward I will refer to the facility as a home, because it is considered as such by those who live there and is referred to as such in the data. It is situated at the edge of the town on what was once a farm. The home was established a number of decades ago in for children and adults but, in response to legislative changes, it now caters exclusively to adults. There are still several residents at the home who first entered as children, but most have moved in as adults.

The home consists of three main residential units, which cater for varying levels of support needs. Each of the three main units operates under the supervision of a housemother. Most of the residents have families who supply extra resources to them such as cell phones, computers, and internet access but this is individualised and dependent on the residents and their families'.

Also available at the home are a medical unit with professional nurses, an occupational workshop in which the residents work on weekdays, sports and fitness coaching and Sunday chapel services. The term occupational workshop is used in the facility but simply refers to work as the main activity of the workshop. At the time of conducting this research I was the occupational therapist at the home and head of the occupational workshop, and responsible for developing and managing the programs for residents within this department. I resigned from this post some months after having collected the data but have aimed to maintain a good working relationship with the home. My position in relation to the research and residents will be more fully explored within the section on ethical considerations.

I was employed at the home for 5 years, and during that time I made some changes that may have impacted on this study. The most significant of these was the establishment of a residents' committee. This committee began with the intention of creating a space for the residents to air their concerns and views to staff without judgment or concern for retribution or discipline. The residents were also encouraged to voice their ideas and suggestions for changes to the schedules, activities, or events to be planned. The committee was formed with volunteers from the residents. For all areas of the home's operations to have a voice within the group we encouraged residents from each section to join. At the start, the aim was for the group to meet once a month for 6 months - although sometimes the meetings were held up to six weeks apart - at which time those who chose to step down could and new members who wished to volunteer could do so. The members of this committee were also tasked with gathering any comments or concerns that might have been raised by a non-committee member and representing these to the committee for discussion. This forum allowed residents opportunities to practice the skills involved in advocating for their own viewpoints. The forum was also formed to allow residents to grow in confidence when expressing their views and to allow them space to develop their creativity and use of choice in an institutional setting. I chose to draw all the participants of this study from those who had participated in the committee for at least one full six-month term. This will be further explained later in the sections on recruitment and ethics.

I would like to note at this point that although the home in which this study took place is one that aims to provide high standards of care as well as space for individuality and choice where possible, as within any institution, there are inherent barriers to residents enjoying the relative freedom of people living in communities. For example, within an institutional setting it is necessary for the safety of the group to maintain certain standards of behaviour that may be stricter than those held in a family home. Mealtimes and menus need to be set and are rarely deviated from, and general activity scheduling is designed around convenience to the greatest number of people, as well as staff working times, without variation for individual preferences or needs. These factors not only affect the view that the residents have of their world but also their participation in that world.

At this point I shall explain some of the home's operating structures as well as the procedures and referrals generally followed with regard to the medical needs of the residents. Within this home structure at the time of the research, each department operated separately, with their own head and their own capacity to make changes to plans and procedures over which they had control. All department heads would then report to the general manager on a weekly basis. It is at this point that much of the interdepartmental co-ordination and cooperation would occur. This structure made it possible for me, as one of the department heads, to conduct this research within the facility. Because the medical department was responsible for all health-related needs during working hours and the house mothers after hours, I was able to ask questions regarding the health of the residents without the pressure of participants feeling that should they have negative responses, they would be insulting me personally.

The system of referral for any health-related concern would work as follows: Should the resident be in the unit and either feel sick or get injured they would report this to the housemother on duty, who would draw their personal medical files. With their files they would then be sent to the medical department to await assessment by one of the nursing sisters. The nursing sisters would examine the resident and either administer treatment and instructions, or in the case of serious emergencies take the resident to the emergency department of the nearest hospital. The nurses would also give instructions as to recovery needs such as rest or dietary changes. Should illness or injury strike while the resident was in the occupational workshop, the resident would return to the unit to approach their housemother for their file and then attend the medical department. I have explained this procedure to show that, although I was both a head of department and the only therapist on staff - and as such did take part in discussions with other staff members regarding the wellbeing of the residents - I was not part of the referral chain for most general health concerns.

There were a handful of residents with whom I formed a therapeutic interpersonal relationship during specific interventions, but these residents were excluded from recruitment to the study. After I had started applying for ethical clearance for this study, I also began rolling out a sexuality education program at the home. This was started with specific residents who were identified for this intervention and these residents were also excluded from recruitment due to the deeply personal nature of some of our previous discussions. One potential for conflict between my role as a therapist and that of a researcher in a prospective sense. What I mean by this is that once I had started recruitment and data generation, the potential existed for one of the participants to be identified by the team as needing my therapeutic intervention. Fortunately, this did not happen.

With this background understanding of the setting, I now move on to talking about the procedures that I followed while conducting this study.

4.2. Study Procedure:

I first approached the general manager of the home for consent. I then also spoke to the residents committee at one of their meetings and asked if any of them, as representatives of the resident body, had objections to my conducting of the research at the home. Neither the manager nor the residents' committee raised any objections and so I then proceeded to apply for ethical approval through Stellenbosch University. The Stellenbosch University Research Ethics Committee (REC): Humanities granted approval, under the project number REC-2018-6557 (see Appendix A). Once I had received these permissions and approval, I began to recruit participants to the study.

4.2.1. Participant Recruitment and consent

I planned the recruitment procedure for participants in this study with an awareness of the vulnerability of the population. Although I will be outlining the procedures of the study within this section they are inextricably intertwined with the ethical considerations and will therefore be touched on again within that section.

The participants in this study were drawn from the group of residents living in the home at the time of the study. The home catered for over 100 live-in residents and a handful of day-residents, aged between 20 and 76 years. All the residents can communicate in English although a small percentage speak either IsiZulu or Afrikaans as their first language.

For this study, purposive sampling was used. I selected a short list of participants by making use of the in-depth personal knowledge I and my colleagues at the facility had to exclude residents who were unlikely to understand the explanation and implications of their participation and therefore unable to give informed assent. I began with a list of 31 potential participants and asked for feedback from the medical department and housemothers regarding the suitability of the residents for the study. These staff members helped to exclude residents who would not have been suitable due to various reasons such as, illness or anxiety, as well as residents who would be unlikely to engage with the data generation procedures.

After receiving these recommendations, I took all the information to the general manager to discuss his impressions of the potential participants and consider any specific concerns he had regarding the list. I eliminated four names from the list for reasons such as a concern that participation in the study may cause undue distress, and a concern that the participant would not understand well enough to give informed assent.

The sample goal was to have 5 participants from each of the 3 residential units, totalling 15 participants in all. This sample size was chosen, to allow for a richness of data even if some participants were to choose to leave the study at some point during the process. Drawing participants from each of the 3 housing units allowed a representative sample of experiences of people with different functional capacities and service needs. A sample size of 15 is comparable to other similar studies such as the 12 interviews conducted by Dinsmore (2012) in their study and the 7 interviews used in a study conducted by Gajewska and Trigg (2016). The sample size of 15 was chosen as a starting point but the study plan was left open to allow for changes such as snowballing should it be seen that data saturation had not been reached.

At this point I would like to make a small note regarding my use of the terms consent and assent. The consent that I obtained from the legal guardian of each participant was necessary as the participants are all considered legal minors. It was also important when working with a vulnerable population such as PWID that those responsible for their care be consulted when attempting to involve them in a research process. Having said this, the participants of this study are also all adults and so deserved the opportunity to agree to their participation for themselves from an ethical point of view and in terms of the emancipatory approach aimed at in this study.

Table 2

Participant Details

NAME *	**GENDER**	**AGE****	**RESIDENTIAL UNIT*****
Jason	Male	50-60years	1
Adam	Male	40-50years	1
Caryn	Female	70-80years	1
Tarryn	Female	30-40years	2

Andrea	Female	30-40years	1
Chloe	Female	50-60years	3
Natalie	Female	50-60years	3
Wendy	Female	40-50years	3
Richard	Male	40-50years	2
Amanda	Female	20-30years	2
Carl	Male	30-40years	2
Robert	Male	50-60years	3
Daniel	Male	40-50years	3
Patricia	Female	20-30years	3

** All names are psuedonyms to protect the participants identities.*

*** Ages have been given as a range to provide demographic details while protecting the participants identities as they come from a closed community.*

**** Each of the three residential units was allocated a number to show the distribution of participants across the units. Unit 1 caters to those with the highest care needs, Unit 2 caters to those with the lowest care needs and Unit 3 is a mid-level unit in terms of level of care and houses residents with a variety of needs.*

Table 2 gives an overview of the participants who finally took part in the study. As can be seen the distribution of gender was fairly even with 6 men and 8 women participating. Similarly, the distribution of participants over residential units was relatively even, with four participants from each of Units 1 and 2 and six from Unit 3 taking part. As Unit 3 is in fact significantly larger than the other two units I did not feel that it was necessary to even out these numbers further. The ages of participants ranged from their twenties to their seventies with seven of fourteen participants falling between the ages of thirty and fifty years. These participants make up a relatively diverse group in terms of personal and social circumstances. Below are some further details regarding the study participants to give a better idea of their lived experiences.

- All the participants had lived at the home for over 10years with the longest stay being over 30years.
- All but 2 of the participants were in regular contact with their families which included the occasional visit to their family or excursion to the local community for a day.
- Of the 2 who were not close to their family members one only had family overseas and the other had no family at all.
- Before coming to be a resident at this facility 1 of the participants had been employed and lived alone for a time.
- 9 of the participants had also at some point taken part in competitive sport where they had travelled within South Africa and on occasion internationally to compete. Some of this travel occurred staff and residents from the home and for a small number certain trip included a parent of family member as well.

I applied several criteria in the selection of participants for recruitment to this study. They are outlined in table 3 below.

Only live-in residents and not day residents were considered. This was done largely partly for convenience due to weekend availability of the participants, but also as this allowed for a similar contextual understanding to be applied across all the data that was gathered. The second and third criteria for inclusion were that the participants had to be able to understand and engage with the study process and to give informed assent. I did consider using a screening tool to eliminate possible participants who did not fall within the mild to moderate spectrum of intellectual disability, but I rejected the idea for two reasons. First, because the pool of potential participants is a small, closed population and I was very familiar with the people within that group. Second, the participants were being selected for their ability to engage in the research rather than for category of disability. I judged that my knowledge of the participants as well as the assistance of the other staff members would give a better indication of candidates' potential for participation than most screening tools would. I am aware of the potential bias in this method of recruitment which is another reason to have included the opinions of several people not connected to the study to get other perspectives on candidates for participation.

Table 3

Inclusion and exclusion criteria for participants

Inclusion Criteria	**Exclusion criteria**
Live-in residents of the facility	Day residents of the facility
Able to understand and engage with the study process	Unable to understand the study process
Able to give informed assent	Unable to assent to participation in the study

Able to communicate verbally in any SA language	Unable to communicate verbally
No history of direct therapeutic relationship with me	History of a direct therapeutic relationship with me
Previous participation in the Resident Representatives Committee	No previous participation in the Resident Representatives Committee

Residents who were unable to communicate in spoken language were excluded due to the difficulty of facilitating interviews with them and due the difficulty is obtaining assent. I had originally planned to limit language to English but, chose to also include participants who speak in other SAn languages. In the end there were 3 participants recruited who were first language non-English speakers. They were offered the option of taking part in English or their own home languages and all chose to use English with a few translated words through the conversation. 2 of these participants were Afrikaans speakers and the last one was isiZulu. As I can communicate in Afrikaans and have reasonable isiZulu understanding there was no barrier to their inclusion although a translator could have been provided should one have been needed.

The next criterion was that the participant did not have a pre-existing direct therapeutic relationship with me. At times while working at the facility I have needed to work more closely with specific residents. These residents were excluded to avoid any abuse of the therapeutic trust. This issue was also expanded on in the previous section 4.1 on the setting.

Finally, participants had to have previously taken part in the Residents' Representatives Committee for one term of 6 months. This committee was also explained in section 4.1. Free expression and choice of participation were two of the hallmarks of the residents committee which I also hoped would allow the recruits to refuse participation more easily in this study should they so wish. This recruitment criterion was included as a precaution to add a further layer of protection for possible participants. By doing this, the participant group became a somewhat self-selecting one, but I believe t the ethical value of this criterion was enough to offset the possible concern of data quality arising from this.

Once I had a short-list of 27 possible participants, I began contacting the guardians of these people for consent to recruit their family member to participation in the study. I contacted 18 families over several weeks with requests for consent to approach their family members and received 16 positive responses. The two families who were excluded at this point were both unreachable despite multiple attempts to contact them.

The 16 positive family consent forms were received over a period of roughly 3 months. I asked the prospective participants to each attend a group information session in which I explained the study procedure and expectations for participants to them. These groups consisted of 3-4 people each and were held outside of normal workshop activities to help mitigate the power discrepancy between the participants and me as the head of department. They were given the opportunity to ask any questions that they had. Most of the questions were about the reason for me conducting the study, as well as the timeline of the study. As pointed out by Nind (2008) it is not only capacity to give consent that is important but the possession of relevant information, which can at times be neglected when dealing with PWID. For this reason, I endeavoured to make sure that the information session answered all questions that were put forward by potential participants. The participants were not asked to give assent at this session but were allowed time to consider their willingness to participate. They were also given copies of the information sheets and assent forms that can be seen in Appendix C. I held these information sessions at the beginning of the week to allow time for the participants to think, and to approach me with questions. During the intervening days I did not approach the candidates to avoid putting any undue pressure on them, but I was available to them when they had questions themselves.

After a minimum of three days, I approached each of the prospective participants again to ask whether they would be willing to participate in the study. I provided this break because from my observations, many of the residents readily agree to requests under pressure that they may have chosen to decline given enough time to consider. The information sessions were conducted in small groups to allow for the candidates to hear each other's questions and to avoid feeling singled out. The confirmation of participation, however, was asked individually to allow for any questions that a candidate may have been embarrassed to ask and to prevent any peer pressure to consent. At this stage, 15 candidates said that they wished to participate and one declined. at this stage I felt that the refusal showed that the measures that I had taken to prevent candidates' feeling coerced had worked. The participants were still not asked at this stage to sign assent forms as I wanted to make sure that they had every opportunity to express any objections that they may have had before they committed. Once the participants had agreed to an interview, I set a meeting time with them on a weekend according to their preferences.

The interviews took place after normal working hours in the home's boardroom. This room is generally used for training of caregivers and staff and board meetings. I chose this space as it is comfortable and private and forms no part of the workshop activities over which I had control. There is also neutrality to the space that I hoped would assist in creating a more relaxed atmosphere than if I were to make use of one of the offices. On one of the weekends in which I conducted interviews it was cold and raining. This did make the use of the board room difficult as two of the participants mobilised by wheelchair and the wheelchair access route to the board room covers ground that gets extremely muddy when it rains. I was sure to check with the participants regarding their comfort when trying to get to our interview venue and they were both happy to continue.

4.2.2. Developing the interview guide

My initial data generation took place as semi-structured interviews, for which I developed an interview guide (See Appendix E). I planned to adjust the interview guide slightly following the initial interviews if I had identified problems with the questions, but this was not necessary. The only change that was made was that we spent far more time discussing the questions about general health than those about health services, which I did not expect. This will be discussed further in the section on results.

To develop the interview guide, I requested the assistance of a resident who was not on my short-list for possible study participants. This resident is also a person living with ID and I asked her to check the questions I had written for clarity and use of language for easy comprehension. She offered some suggestions to me, and I checked with her whether she felt the terms that I had used were easily understood. Once she and I were both happy, I finalized the interview guide.

I chose this resident to assist me because she has previously attended training in self-advocacy skills and the rights of people with disabilities and as such has a good understanding of the need for PWID to voice their own experiences. She was however not included as a participant because she had never been a member of the resident committee, which I had included as an inclusion criterion.

4.2.3. Data Generation

Once I had spoken to the participants and set a date and time for our interview, I arrived early to set up our interview space. I brought refreshments of hot and cold drinks and some snacks, which I offered to each participant during their interview time. At the allotted time I fetched each resident from their units and accompanied them to the interview room where I asked them to choose where they would be most comfortable sitting, before offering them refreshments. It was only at this time that I gathered assent from each participant, and I did this by going through each question on the assent form and allowing the participants to ask their own questions. Although I did ask those who could, to sign their names to the assent forms, I was very aware that many of them were only able to read very simple sentences and so I made sure my recording device was turned on for the giving of assent. In addition to this procedure of gathering assent, each of the residents had the option to withdraw from the study at any stage and I made sure to repeat this to them at the start of the interview. Given that there have been concerns about PWID being over-compliant when consulted on a range of issues, even where participants gave assent (Cameron & Murphy, 2006), I kept alert to any signs based on my clinical experience and familiarity with the potential participants as to whether they had truly assented. In one case, once we had started talking, I felt that the participant had not truly understood the purpose of our conversation and should therefore be excluded. I then switched off the recording device and continued to have tea and an informal chat with them. I did this to prevent the participant from feeling disappointed or affronted in any way by having the time cut short. The interview was then excluded from the study. Had I believed that there was any likely harm or undue distress being caused to one of the participants, I would have concluded the interview and excluded them from the study as well, but this did not occur. One of the methods I used to ascertain whether true informed assent had been obtained was to ask the participants to share their understanding of what would happen during the study and what would be expected of them.

I had budgeted for each interview to take close to 60 minutes with breaks to allow the participants to continue engaging without becoming too tired; however, most interviews only lasted between 20 and 40 minutes. One hour is a long time to hold an interview for this group, but I was pleased to have budgeted the time in this way as it allowed for an unhurried and conversational interview with each participant. In my experience, many PWID become anxious when they feel that they are being pressured to rush and my budgeting of time allowed me to feel unhurried as well as protected the quality of data from the influence of my fatigue.

I held the interviews on Saturdays and Sundays over a period of 4 months. I had planned to conduct the interviews over a shorter period but due to delays in obtaining consent the time was extended. This allowed me more time to reflect between interviews. I also made sure not to hold more than three interviews on the same day in order to avoid becoming fatigued myself and thereby missing important cues and opportunities.

During the interviews I made use of prompts such as visual images to aid interaction and accessibility of the questions for the participants. For example, pictures of various objects and people associated with health were used to aid in prompting responses to questions (See Appendix E). I did not ask my resident assistant to check these images for me before conducting the interviews, which was an oversight as they were sometimes more distracting than helpful although some participants made effective use of them.

It is important to note that should any participant have become extremely distressed in relation to their participation in the study that the services of a psychologist would have been made available to them at my expense as they are not available within the facility as part of the standard services. The participants and their families were informed of this fact in their information sessions and packs respectively.

4.2.4. Data Management

Once the interviews were complete, I had 14 total interviews and decided that this number was adequate to start analysing. I initially began trying to transcribe the interviews myself time was a concern and as such I decided, to hire transcription services. I began by dividing the interviews into those which were easily audible, and sent those out first, and those that were difficult to understand. Several the participants for this study were unclear in their speech and so I was aware that those interviews would be difficult to transcribe. I found a transcriber who is also an experienced occupational therapist as I felt that she would more easily understand the second batch of interviews. Once I received the transcribed interviews back, I went through each one myself to check the accuracy of the transcriptions. I had to make many corrections to the interviews where unclear speech was evident, but the others required almost no adjustment.

For the protection of the participants, I allocated pseudonyms to each one in the transcribed interviews. Only I have access to the information necessary to match pseudonyms to specific participants and this information has been kept on password-protected devices only. All data from the interviews was recorded and then transcribed to written form. The recording devices were stored in a locked cupboard in my office at work and now at home, and the data has been stored on a password-protected computer. Data has also been kept on a back-up hard drive, which has been stored in a locked cupboard and is password protected. Files that were shared for transcription have been deleted from shared space.

4.2.5. Data Analysis

The data have been analysed primarily using thematic analysis, however I have also endeavoured to explore some of the narratives within three of the interviews. The combination of thematic and narrative analysis allows the results to reflect cross-sectional themes common to participants' experiences while also preserving the integrity of individual participants' stories. I began with thematic analysis, however I came to see that there may have been merit in first exploring the narratives and then extending this analysis to look at common themes across all the interviews. This may have allowed me to more effectively use the stories to frame my understanding of emergent themes. Nevertheless, I found a great richness in data through this process.

For the thematic analysis I made use of the work of Braun and Clarke (2006) who suggest a 6-step process for analysing data according to themes. These steps are first to become familiar with the data, secondly to form some initial codes to use in analysis, and thirdly to begin find themes. Once initial themes have been found in the data they suggest that they are then reviewed before being renamed and clarified as needed (steps 4 and 5) so that the final step of reporting on the data can be completed.

In order to conduct narrative analysis on 3 of the interviews in this study I considered the writing of Wong and Breheny (2018) who point out that the use of stories in research need to be considered in how they relate to the research question but should also be done once an overall understanding of the data has been achieved. As such once completing the thematic analysis as mentioned I re-examined the data for specific stories that would reflect not only personal experiences of specific participants but also shared some of the underlying commonalities between participants. In this way I was able to reflect findings on both a personal and social level of narrative analysis in these participants' stories (Wong & Breheny, 2018).

I had planned in my protocol to have three interviews independently coded to help minimise bias in my analysis. Once I had the interviews, I found that this was difficult to enact due to the very contextually embedded nature of the data. It would have been very difficult for a person unfamiliar with the context and the idiosyncrasies of the speech within the closed community of the home to code the data in the same way that I as part of the community was able to. To avoid over-interpretation on my part however I did still seek advice and peer debriefing at various points from Dr. Kate Sherry, to whom I had initially intended to give the task of interview coding. Dr Sherry is also an occupational therapist, who has completed her PhD through the School of Public Health and Family Medicine at the University of Cape Town.

I made use of the NVivo 12 software package to aid me in data management and analysis.

Once initial themes were identified in the data, I held 2 focus groups with half of the participants in each group. The purpose of these groups was to provide data validation by allowing the participants to hear and give feedback on the themes, which I had crystalised out of their interviews. These groups were held on a Sunday at the home. These focus groups also took place one month after I had resigned from my position. I hoped that this change in my role would have also allowed participants to speak to anything that they may have felt unable to before. I did present my initial findings for clarification and received generally positive feedback. During these groups the participants expressed agreement with the themes that I had identified and many asked if it would be possible to do something similar again in the future. I explained that this study would be over and thanked them for their help. Sadly, two of the participants were unable to participate in the focus groups as they were away from the home at the time.

4.2.6. Dissemination

The focus groups that were used for data validation also formed the first stage of feedback for the participants, where they heard the report of emerging themes from the analysis of the data.

Once the study has been finalized, the organisation will be offered a further feedback session in which the results of the study will be presented to participants. The organisation will also be offered similar information sessions should they choose for staff, families, and management.

Feedback to the guardians will also take the form of a written summary (Appendix G) of the general findings and recommendations of the study. This is because not all the guardians will be able to attend a presentation due to them living across the country and in some cases, abroad.

The results of this study will further be disseminated through this written dissertation, submitted to Stellenbosch University, and journal articles that will be written and submitted for publishing in academic journals in the coming year.

4.3. Ethical Considerations

Although some ethical considerations have been addressed in the methods section, I would like to expand on the ethical considerations in the following section.

4.3.1. Informed Consent:

For informed consent to be obtained it is required that the participant understands and can make a voluntary decision regarding their participation (Iacono & Murray, 2003). As noted in the methods section, informed consent or assent was obtained from management, guardians, and individual participants. The management and guardians acted as gatekeepers in the consent process (Goldsmith & Skirton, 2015). At each stage of the study, participants were given the option of withdrawing from the research.

During the interview process I watched the residents for signs of discomfort and anxiety. Should such signs have arisen I would have concluded the interview and provided relevant support.

It was a concern that the residents may have felt that they had no choice but to consent to participate in the research both due to my position of authority in the organisation and due to a sense of loyalty to me (Irvine, 2010). This was addressed in the information sessions explained above, as well as through the inclusion of other members of the team during recruitment. The other team members were not directly involved in recruitment but were able to help me exclude those who they believed would struggle to give assent and were also made aware of my research activities. I then made the potential participants aware that other staff members knew of the research and should they have felt uncomfortable saying no to me they could seek the help of another staff member. I was thus able to open other potential avenues for the possible participants to seek support as they felt they needed. I also was cognisant of this possibility of participants feeling compelled in my drawing up of the initial short-list. Every effort was made to assure the participants of their freedom to choose to decline the invitation to participate. It was for this reason that I also decided to include residents who had experience expressing their views, ideas, and desires within the residents' committee forum. These residents by virtue of their engagement in this forum were more likely to be able to deny assent should they have chosen to do so.

All these steps were included in the planning of this study for the obtaining of consent to be an on-going process, which is important when researching with PWID (Cameron & Murphy, 2006). Cameron and Murphy (2006) also point out that there are measures that can be taken during consent to allow greater opportunity for those who may otherwise be excluded to take part in the research process. Measures that they suggest which were included in this study are allowing extra time for decision making, providing multiple and ongoing explanations and clarification, the involvement of people who know the participants well to provide guidance and an ongoing relationship between the researcher and participants to assist in overcoming communication barriers.

4.3.2. Reflexivity in researcher role

It is traditionally accepted that a researcher should not have a pre-existing relationship with the participants of the study. In this study, however a long-term and well-established relationship already existed.

As head of the occupational workshop, I held a position of power in my relationship with all the potential participants in this study. It was a concern that they might feel compelled to share or might have felt afraid to share their thoughts with me. My position and familiarity with the individuals could however also be an advantage. The residents of the home were more able to be relaxed while talking to me than they may have been to a stranger. Due to my involvement in the Residents' Committee, the residents who formed the pool of potential participants were all used to expressing their concerns and opinions to me within that forum. So, although I held a position of authority within the facility the nature of my relationship with the residents included engagement in some collaborative spaces as well. My knowledge of them was also used to assist in gauging signs of distress during the data generation process. As someone who is familiar with them I was more likely to be able to understand and respond to their opinion. I found this to be true for a number or the participants who tended to express themselves in fragmentary sentences and gestures that I would have been unable to understand had they not been known to me. In this way my role and history with the participants was an advantage in understanding.

I conducted the interviews and focus groups with the participants in a section of the home over which I had no authority and outside of normal operating hours of the occupational workshop. This was done to mitigate the power imbalance between us.

There were several considerations to be made regarding role overlap in this study and arguments could be made for both advantages and disadvantages of my familiarity with the possible participants. Where possible problems were identified regarding this difficulty and precautions were taken in the planning of the study. Despite concerns, there was no actual conflict of interest in the conducting of this research. I summarise the issues in Table 4.

Table 4

Advantages and Disadvantages of pre-existing researcher relationship

Disadvantages	**Advantages**
Blurring of roles between researcher & staff member	Personal knowledge allows me to intervene in the case of distress
Possible compromise to the reliability of data due to desire to please out of loyalty or response to authority	Training and experience as an occupational therapist valuable in data generation method
Personal knowledge of participants could lead to bias or over-interpretation of data	Familiarity could allow participants to speak more freely due to a preexisting level of trust and allow a greater depth of understanding and exploration in analysis

4.3.3. Benefit to Participants

It is important that the process and information gathered in this research has some benefit to the participants and the group from which they were drawn. This is especially true due to the emancipatory approach utilised in this study (Noel, 2016). Although there was no immediate benefit to participants, there is the strong possibility that participants were able to derive benefit from the therapeutic space of the interviews as evidenced by repeated requests for me to embark on this process again in the future. The opportunity to share one's thoughts, views and stories can also be an enjoyable experience.

More importantly, however, it is my intention that the participants benefit from the use of the results of the study. The results of this study will not only be published for the use of others but can with hope be used to improve the residents' experiences of health within the setting of the organisation. The recommendations drawn from the views of the participants will be offered to management and staff for use to improve the services offered.

4.3.4. Information Sharing

Now that the results of the study have been analysed and written up, the information will be shared wherever possible to be of benefit to the residents and the organisation. Within the context of a closed community such as a group home however, confidentiality can be a real cause for concern and as such anonymity has been carefully respected with regard to individuals and their specific comments. Where quotes were used in writing of the results, any information that can identify the speaker has been excluded. As can be seen in Table 1, pseudonyms have been used and other demographic data has been either excluded or reported in more general terms as in the case of age.

4.3.5. Summary of Ethical Considerations

In this section on ethical considerations, I have outlined some of the concerns that were a part of this study and how I dealt with them. Every effort was made to maintain the highest standard of ethics possible without creating barriers that would unfairly exclude participants from the study.

4.3.6. A Note on Data

As noted in earlier in this chapter, there are various factors of concern around communication when working with a population such as adults with ID. These difficulties can arise from simple speech difficulties or a lack of vocabulary, as well as larger structural factors such as social roles and interpersonal dynamics. As with all people, in this population, a great amount of meaning is unspoken, and seemingly simple statements can be heavy with assumptions. In the data gathered in this study there were a few participants with idiosyncrasies of speech that could be difficult to understand. My preexisting relationship with the participants of this study, however, allowed me to understand and interpret the data in a way that an outsider could not have done. This was critical to the eventual outcome of my research and my understanding of what I have learnt through this process, but it would be irresponsible for me not to acknowledge that my own beliefs and assumptions also form part of this piece of work. In the process of conducting qualitative research, especially research that is participatory in nature, knowledge is a co-construction of the role players in the research space but in this instance, I was not only a part of the research space but also part of the context in which the research was set. This means that I could not have separated myself from the descriptions and interpretations of this research however much I tried, and so rather than try, I have instead attempted to use my observations and assumptions to enrich the results of this study. I have tried to be explicit in my inclusion of my own thoughts and reflections through my presentation of the data and made extensive use of clarifying questions and statements during the interviews as well. The use of reflexivity throughout the process of conducting, analysing and writing up of this research content was important in order to identify my own possible biases (McCabe & Holmes, 2009).

In a few cases, during interviews, I was told stories with which I was already familiar and so on occasion did not ask for background information where it was important for the narrative. This can at times be seen in the fragmentary nature of some of the narratives that were shared with me and so in these cases, where necessary and ethically possible I will be explicit in my observations and understandings. As the interviews were aimed at being conversational in nature it would have seemed odd to ask participants to explicitly state each unspoken detail of which they knew I was already aware. I did however make use of many clarifying questions aimed at checking the accuracy of my understanding. In the extracts included in the next chapter these may at times seem like leading questions but are aimed at checking my understanding rather than leading the participants to a response.

Furthermore, I have made the choice not to paraphrase the participants responses in my reporting. I have preserved the original language to demonstrate the need for integration of my observations and reflections into the writing and interpretation of the findings but also to clearly demonstrate the division between the voices of the participants and my own ideas. I felt that this was important in keeping with the emancipatory approach underpinning this research.

4.4. Summary of Chapter 4

In this chapter I began by describing the setting in which this research takes place and showed that this understanding is critical to the understanding of the research. I have outlined the process followed in planning and conducting this research and have also pointed out some potential ethical pitfalls that I identified and my response to those issues. With the background understanding of how this research was planned and conducted I will now talk about the findings.

Chapter 5 - Findings

5.1. Introduction

In this chapter I outline the findings and reflections that emerged from the data collected in this research study. In keeping with the primary and secondary aims of the study, I present the findings in multiple parts. Part 1 will deal with the primary aim, to explore participants' perceptions and experience of their own health, while Part 2 will look at the secondary aim addressing participants' experiences of accessing and interacting with healthcare services and healthcare professionals.

Part 3 is a presentation of three interviews analysed through a narrative framework, looking at what can be learnt from the personal stories within the data.

All findings are presented discursively along with my own reflections and understanding. As pointed out in the earlier chapters my position as a part of the context in which this study took place allowed me an understanding of the interviews that included a depth not available to a more independent researcher. I acknowledge that with this method, there is a level of assumption and potential over interpretation inherent, but I believe that the benefits of my position in the study context and the understanding attached to those makes this method of reporting appropriate in this case.

5.2. Creating Health

5.2.1. Introduction

In attempting to understand participants' views of health and the meaning attached to being healthy, I began to conceptualise the interaction of a few key themes that emerged from the interviews and attempted to create a visual representation of this interaction. An image of this can be seen below in Figure 2.

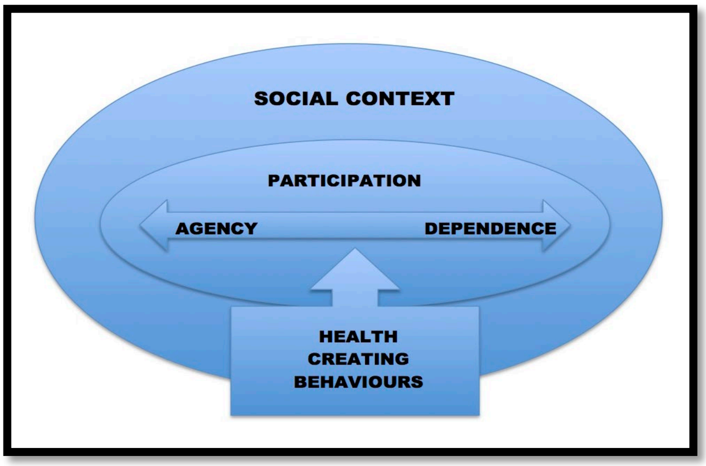
I will begin this section by giving a brief overview of this image and the interaction of the concepts depicted within it. I would also like at this point, to give some broad strokes of the meaning of being a healthy person from the participants' points of view. Finally, I will then expand on each of the key themes in the diagram, those being Participation, Agency versus Dependence, Health Creating Behaviours and Social Context, and explore more fully how they were depicted within the data. Figure 2 emerged as I anaysed the data rather than forming the framework with which I analysed it but for the purposes of reporting it lends a useful structure to understanding the findings and so I have chosen to begin with it.

5.2.2. Explaining the Model[1]

As can be seen in Figure 2, all the actions taken or performed in the creation of health are deeply embedded within a social context. This is particularly important for the participants of this study who not only are part of a specific closed community but also by virtue of their disability are often excluded from expanding or changing the social context in which they find themselves.

Figure 2

Conceptualising Health Creation



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[1] Although this is not a fully developed model, I have used the term in describing Figure 2 for ease of expression only.

I have also visualised all health-creating behaviours as existing on a spectrum of agency and dependence. These behaviours each take place through participation of the person within a social context, and as such behaviours cannot be seen as static along this spectrum but rather shift up and down depending on changes within the context and the person engaging in them. These changes could be anything from the presence or absence of specific people to organisational policy changes that lead to adjustments in accepted norms of behaviour within the social context. This conceptualisation is informed through the occupational lens as described earlier in chapter 2.

Each of the components of this model is depicted as occupying the same space because although I will be describing them each separately in the rest of this section, they are all in a constant state of interaction and influence on and by each other. There can be no real division when understanding the different components that formed part of the description of creating health that emerged from the data. Keeping in mind the concepts represented in Figure 2, I will now give an overview of what the participants of this study described health to look like.

5.3. Part 1 - Being a Healthy Person

When asking participants to describe what it would mean for them to be healthy, as well as whether they saw themselves as such, I found that although the expected responses of healthy eating, exercise and hygiene did feature, many of them described health in terms of a general feeling of wellness rather than being attached to a lack or presence of disability, illness, treatment or even independence. The participants also saw health as important to participation and engagement in their lives rather than a goal in and of itself. This will be shown more fully in the data in section 5.3.3.

Participants were asked what it meant to them to be a healthy person. Many described the experience of health as a sense of wellness.
Amanda, described being healthy in the following way:

> Amanda: Your spirits are high. You enjoy your life to the fullest. Ja[2], that's all I can say, to the fullest'.

In this response, the participant describes health in subjective terms of not only enjoyment but also the achievement of an ultimate level of satisfaction with life. Robert, another participant described being healthy almost exclusively in terms of a feeling or sense of wellbeing.

> Robert: It makes me feel nice inside.

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[2] Many of the participants make use of the Afrikaans word, 'Ja' for yes as is common to most SAs. It has been written as spoken to reflect the true speech of the participants.

When asking the question 'what does health look like?' some participants found that a description of a lack of health was easier to make. I had the following interaction with Andrea while discussing the importance of being healthy:

> Andrea: To be healthy is very important. You have to be very healthy.
>
> Interviewer: Ja. Why do you have to be healthy? Why do you think it's important?
>
> Andrea: To not feel, oooh, to not hide away, if you know what I mean.

Andrea described the opposite of being healthy as 'hiding away', which conjures the image of disengagement from occupations or activities and people. I find this image of disengagement to be poignant in the light of our presence in a closed community that is quite literally walled off from the world outside, ostensibly for the protection of those who live inside.

On reflection, I recognise that I carry an internal conflict between seeing the need for supportive and protective community environments such as this home for vulnerable people and the sense that these communities are in their nature limiting to those same people. This is a tension that I carried with me through all the interviews in this study[3].

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[3] As an occupational therapist my customary lens is one of activity and a goal of autonomy, but this value was not always held by the participants.

While the examples above show health to be slightly abstract, there were some participants who described their view of health in terms of concrete factors within their lives. The quote below is an example of this.

> Caryn: Well, I have my own things I want to mention, like the things which are most important to me in life, especially physical exercise like exercises on the spot. Health foods, foods which keep you healthy. And also, family. You know, my family means a lot to me, and also close friends connected to the family especially.

In this response although Caryn lists several concrete factors that she sees as being part of her view of a healthy life, we can see that she is still speaking to the concept of engagement being necessary for health. Caryn has not only listed physical factors that are important in her health but social factors as well. She points out that her family and friends are very important to her health and so this engagement for health occurs on multiple levels.

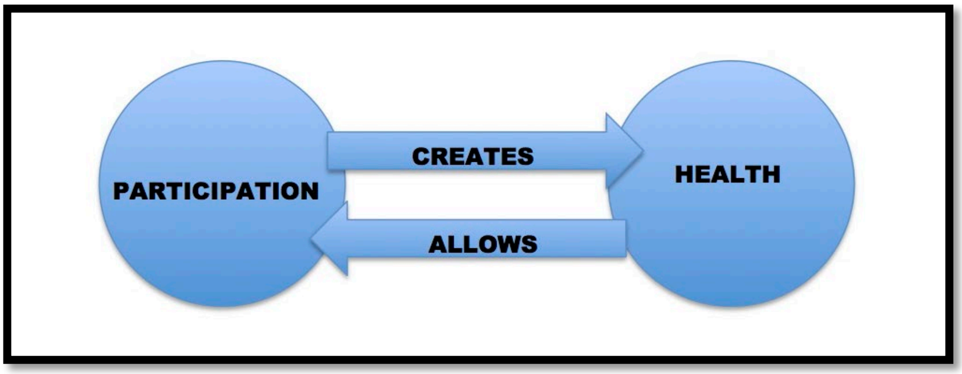
The idea of creating health being a process of active engagement in various levels of life brings us to the first component of our conceptualization of creating health: participation.

5.3.1. Participation

Although in my explanations of findings I have created a divide between a description of what health looks like and participation as a component of health creation, in many of the interviews, participation emerged as almost synonymous with health. It appeared through the interviews that there is to the participants a cyclical relationship between participation and health which I will show.

Figure 3

Participation and Health



This relationship is represented in Figure 3 where, while health is created through participation, being healthy also allows for participation in life. In this way, participation can be seen as both a contributor to and consequence of health. Participation as a concept also exists on multiple levels. One can participate in simple activities of daily living (ADL)[4] such as setting the table but in so doing it is possible to then also be participating in the social environment by contribution to collective activities such as mealtimes. In this way

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[4] ADL and self-care are sometimes used interchangeably. I am using ADL in this instance to refer to a wider range of necessary daily tasks than simply bathing, dressing, toileting etc. such as setting the table for a meal.

participation can be considered to refer to not only simple activity engagement but in a more abstract sense of belonging to a group or community.

Richard, a participant who had experienced some health difficulties, spoke of wanting to be healthy to be able to do things, as well as the act of working to help others as a way of becoming healthier:

> Richard: I want to be stronger and then I can do things. If I want to do things I am happy about it. I am happy to do this, I'm happy to do this and if people ask me to do things I do it for them. That's what I want to do and it's more important to ask. If you want you must just ask them what you want to do. That's more important.

Here Richard expressed not only his desire to be able to do more (when he gets healthy) but also his willingness to do work. In expressing his desire and willingness to participate in various tasks Richard also made the point of emphasising repeatedly the importance of activity participation within his relationships with others, thereby demonstrating the importance of the social context.

Likewise, Tarryn spoke of the importance she placed on participation in sports activities for health creation.

> Tarryn: Healthy get to do some sports too. Sports or swimming keep me busy.

> Interviewer: So, sports and swimming keep you busy as well. Is that good?
>
> Tarryn: Yes, it is good for me………Keep me busy and healthy, ja.

Tarryn makes the point that it is not only the physical benefits of sports that contribute to health but the act of taking part in activities as well.

Whether it is the participation in fitness, family, friendships, work or any other aspect of life, it was clear through the participants' interviews that being actively engaged is critical for the creation of health. The idea of active engagement then begs the examination of the next part of the Figure 1 model to begin to understand the role of agency and dependence in health creation.

5.3.2. Agency versus Dependence

As I conducted these interviews, I found that the questions of who is responsible for and who should be responsible for creating it were a constant refrain in my head. I had expected to find either a frustration among the participants that their agency was being robbed from them given the institutional context of their lives, or a sense of resigned reliance on the rules and governance of staff in the institution such that they had stopped considering alternatives. What I found however was far more nuanced than this and frustratingly far more difficult to understand and describe.

I asked participants about their experiences of being prevented from acting on their own choices for health creating behaviours and received several different perspectives on this question leading me to understand the dynamic between agency and dependence as a spectrum (Figure 3).

During one exchange in my interview with Jason he demonstrated this complexity in his response to my questions.

> Interviewer: Is there something that you feel like you need?
>
> Jason: Hmm, I need vitamins.
>
> Interviewer: Then how do you get what you need? Is there a way you can get what you need?
>
> Jason: Ask [the doctor][5]. He gives all the residents tablets.

And then he continued:

> Interviewer: So, Jason, do you feel like you can get the help that you need if something goes wrong?
>
> Jason: No. I'm stressed about that.
>
> Interviewer: How come?
>
> Jason: I was walking to the workshop one morning on my own and they said, would you like some help? I said, yes, please. And they helped me. I was feeling a bit dizzy that day.

---

[5] Where individuals (staff, family or other people) were referred to by name, I have replaced their names with their role.

> Interviewer: So, you did get help that day.
>
> Jason: I did get help, ja. I called for help.
>
> Interviewer: But it worries you that you can't get it, that maybe one day you will need help that you can't get? Is there any way that you can think of or anything that we could change or anything that someone could do to help you not have that stress? Can you think of anything to take away that worry for you?
>
> Jason: Can you get tablets for stress?
>
> Interviewer: You can. I'm thinking of the worry. You say you worry that one-day you won't be able to get the help you need. Is there anything that you can think of that would help that worry to go away and be less?
>
> Jason: No.

I find this piece of conversation fascinating when examined for the tension between agency and dependence. In the first part Jason states that he can access what he needs from the doctor. There is no real sense of pause in this response and yet in the second part he begins by expressing concern about not being able to get help when he needs it. In my reflection on this shift, I wonder if his initial response is the knee-jerk of an answer that he knows to be 'correct' but in conversation that answer gives way to an underlying concern that is always there. After expressing worry, Jason went on to share an incident in which he was ill and did receive the assistance that he needed and yet this is not followed by a sense of reassurance that his needs would always be met in the future.

Holding this tension in the conversation I went on to prompt Jason for possible solutions to his worry. His response to trying to find a solution to reduce the source of his worry is ‘no’. There is a sense of powerlessness in that response, which is uncomfortable. I recognise that my sense of discomfort however could reflect the value that I place on independence, but he is also expressing distress which he cannot see a way out of.

In her interview Natalie expressed no concern over the possibility of not receiving help when it was needed.

> Interviewer: Imagine you go back after we are done here and you go rest and you don’t feel so well or maybe you fall and hurt yourself, and you need to get help. How do you get help? What will you do?
> Natalie: I will ask the night staff and they will phone up the medical sisters and they will come and see to you…….. they will come and give you a tablet

Natalie’s view of the help that she has access to, is not only that someone will come and assist her when needed but that they will be able to solve the problem. Richard presented a scenario where he would provide the needed solution himself. In talking about avoiding stress to help create health I asked him what he would do in a case where a solution was not immediately available. He responded:

> Richard: I get someone to make me happy.

> Interviewer: Ok. How do you do that?
>
> Richard: You go the other person and say right, come and sit with me and calm me down. All the other… ja… that's more important. Sit together and talk about it. We will sit together and communicating with that person to just be happy and cheerful.

At first reading his response of getting someone to make him happy could appear heavy with a dependence on another for a sense of wellbeing, however, he paints a picture of action-taking to find solutions to stress through the seeking of connectedness. Once again, the nuanced interaction of agency and dependence is evident in this response.

Carl adds another dynamic to the idea of being dependent on those around one as he expressed both the need of cooperation with others in the building of a healthy life and the frustration of not being able to make them see his perspective and needs.

> Carl: Okay I say to a person, 'Let's say don't tell me what I cannot do' and if I wanted to be alone or with someone else, they mustn't say any unkind things. Like yeah, that I had a few arguments and people is not trying to make me to understand where I am coming from because I'm trying to open out myself[6] and try to make them understand what I am trying to say about them. They are not giving me a solid answer because

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[6] Carl is referring to conflicts that he has experienced with other residents and his attempts to connect with them following this.

> I'm trying to open out to them, and they are not being honest to me……….. trying to open out to say what I am doing wrong and they are not trying to open out to anyone, they are trying to be mean or what but I try to get to the truth and be honest to those people, but they don't want to.

The frustration of other people is a big part of life in a group home setting as privacy and solitude can be difficult to find, and yet in her response to my questioning Patricia demonstrated some of the advantages of community living. When asked where she goes for help:

> Patricia: I go to medical[7].
> Interviewer: Do you feel safe, and you've got everything you need?
> Patricia: I've got family here like housemothers and carers. That's why people be nice and helping, carers and housemothers keep my not well and upset………. me happy cause of got my family and family this home like the carers and housemothers. Not residents. Residents not staff.

Patricia points out that by living in a group home she has gained an extended family on which to depend in the form of members of staff. She does however make a point of excluding her fellow residents from this designation. As I think about this it occurs to me that there is once again another layer to the ideas of agency and dependence in this response. In her exclusion of the resident body as being a potential source of support in creating health is she revealing her

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[7] Medical refers to the nurses employed in the home.

view of her own ability to be the creator of her own good health? I feel that the answer to that question must at least in part be yes.

In this section on agency versus dependence I have explored some of the complications and complexities of these concepts in health creation. It has been made clear through the voices of the participants that there is not an easy and clear state that can be pointed to along this spectrum but rather a multilayered and perpetually mobile interaction of factors that allow for agency or necessitate dependence at different times, in different ways and through different actions.

5.3.3. Health Creating Behaviours

The participants identified several behaviours that could be performed in the creation of health. I have grouped some of these health-creating behaviors under the general heading of 'Taking care of yourself' to give more attention to those behaviours that emerged as the stronger categories and sub-categories. These are reducing stress, being a friend and talking to God and I will discuss each one in the following section.

5.3.3.1 Taking Care of Yourself

The task of looking after oneself is one that involves several components such as healthy eating, keeping fit and active, hygiene and cleanliness, getting rest and stimulating the mind. Along with these positive behaviours though, the need to avoid harmful behaviours was also identified by the participants. In this part I would like to take a brief look at these components as expressed by the participants.

- Healthy eating

Healthy eating was something that most of the participants referred to as an important component of keeping healthy. In some instances their comments were connected to weight loss or maintenance specifically but at times their comments were simply about moderation of eating habits.

Interestingly, there were several comments where participants expressed eating principles as conditional. By this I mean that some comments referred to treats on special occasions or even the exclusion of certain foods only on condition of the inclusion of others. Although healthy eating can be seen as a basic and standard aspect of keeping healthy, the participants were able to express some nuance in their views on the topic.
In this comment Andrea refers to the connection between healthy eating and physical fitness.

> Andrea: To keep fit you must eat the right food. And when you eat too much…you must cut down on bread. Can you understand that?

Carl, demonstrates that he seeks balance in his eating habits but also refers to keeping his 'tummy' healthy, showing the importance of food choices for general wellness rather than just weight control.

> Carl: And also I do like bread and stuff but I have to make sure to only have, if its soup its okay to have bread with it. But if it's like stir-fry or… mixed with the bread then it like too much starch. We can't like mix stir fry and bread because [housemother] used to say you can't have too much of stir fry and bread because that don't go together. So I want to stay having more good things in my body and leave the bread to … like in the mornings and at supper not when it's mixed with rice and that. That is how I like to make my tummy to be healthy and that.

Patricia refers to taking fruit when it comes around. She is referring to the end of meals when a box of fruit is sent around the dining hall and each person can choose whether to take a piece or not.

> Patricia: Only eat fruits like bananas, apples or oranges and if the fruit round then have[8] to eat. And drink more water [to be] healthy

Here Patricia demonstrated a belief in the need to make positive food choices rather than only to limit negative ones or volume. This is also notable because of the demonstration of agency in Patricia making her own choice about food.

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[8] In this quote Patricia uses the term 'have to' which is an idiosyncrasy of her speech that she uses to express a good choice or desired outcome.

Healthy eating was a very strong theme across interviews and although it seems simple there is some detail to the responses of the participants from which to learn.

- Keeping fit and active

In the interviews a few participants referred to keeping active as another important part of taking care of oneself. In this section activity refers to not only the idea of physical activity for fitness purposes, such as swimming or running, but also engagement in a wide array of areas such as work and leisure.

Andrea: You must jog. You must get up early and jog with some friends

In the above example Andrea demonstrates that there can be a social component to these activities while reflecting the need for physical activity. Keeping active can also speak to values of living within a community. The next two comments value is placed on activity over perceived laziness or disengagement.

Interviewer: So, when you were feeling so irritated, how did you deal with that?

> Amanda: Ag[9], just sat in front of the TV and hope it went away. But one shouldn't do that, one should go and do something, like read a book or something.

Carl voiced something similar:

> Carl: Good because I like to work hard. Work hard is good for me and make sure I don't get lazy and that because I know some people do. I am not going to point out anyone because they know who they are that sit and watch the others work and not helping us to do it.

Amanda speaks of the tension between the urge to sit and avoid a difficult situation versus the knowledge that it is better for her to be more active. Carl expressed a related sentiment in placing value on hard work and expressing some frustration with those who do not do what they should. Both Amanda and Carl see being active, in some fashion, as a part of leading a healthy life.

Despite the shared belief that being active and productive is part of a healthy lifestyle there was also a need for balance that was expressed by some participants. This can be seen in the comment by Natalie below:

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[9] 'Ag' is a SA expression that can depict various emotions such as annoyance, resignation, or empathy. In this sentence 'ag' gives the impression of the futility of the action that she is describing.

> Natalie: The work helps me to (stay healthy). Sometimes you get tired of working you have worked hard, and they say you have done enough work and you can go relax on your bed.

It is easy to see that the need for fitness and a productive use of time is considered by this group of participants to be valuable and important to leading a healthy life.

- Hygiene and Cleanliness

Another commonly referred to component of taking care of yourself is the need for general hygiene and cleanliness.

Richard pointed this out in one exchange during his interview.

> Richard: Well if you look after yourself that means you can bath on your own, you can dress yourself. You can put your own dirty things in the basket and things like that and hang up your own towels and brush my own hair. I can do everything myself and pack my clothes away. That's how it goes.
> Interviewer: And those things help you to stay healthy?
> Richard: Yes, and also the most important thing if you look after yourself that means you've got to keep yourself neat every day. That is more important.

In this interchange Richard makes the observation that looking after yourself and staying clean is not simply about the body but extends to the cleanliness of your surroundings by putting dirty items away where they should be.

In her interview, Natalie indicated that in her view cleanliness and hygiene are critical to health rather than just one equal component. When asked if she was a healthy person her response was:

> Natalie: Yes, they say my body is clean. The caregivers say my body is clean. I am a clean person.

She makes it clear that she is reporting the caregivers' opinion on her cleanliness but then follows it with an emphatic statement that reflects this opinion.

In an extension of Richard's view that cleanliness should extend to the environment, Chloe expresses her preference for a living in an open and wholesome place.

> Interviewer: And what was it like in [there][10]?
>
> Chloe: I feel it's cramped, like closed in.
>
> Interviewer: Do you know why it felt like that?
>
> Chloe: I don't know, I felt like there's not much air in the place.

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[10] The name of another organisation has been replaced here for reasons of confidentiality.

> Interviewer: Do you feel like that still sometimes?
>
> Chloe: Not here. It’s open. I never get so much sick like when I used to be down there. I think it’s the climate. It was closed in.
>
> Interviewer: The weather? When you say closed in, do you mean there were lots of people too close to you? Is that what you mean?
>
> Chloe: Not closed with people, it’s just the whole. The buildings. The place is like closed and you can’t walk anywhere else.

Chloe here expresses that there is a sense of a health promoting environment.

Many participants spoke to le need for general hygiene and cleanliness as a part of creating health but this was also extended to an expression of need for a health-supporting environment.

- Getting Rest

Rest is generally acknowledged by most people as vital for health and wellbeing. The participants in this study reiterated this belief.

Carl pointed out the need for him to perform relaxing activities on the weekend to provide a balance to the workload of the week.

> Carl: Relax but no to sleep. Maybe I might play games on my tablet or watch DVDs because I don’t want to walk in the cold air because it’s not good……..[I need rest], because on Monday, Tuesdays and Wednesdays I’m always…. busy.

Likewise, Natalie expressed her need to go and rest after completing work tasks to recover.

> Natalie: I sleep on my own in my room and I just say to the residents I am going to go have a rest and they go to their own rooms and have a rest too.

Rest is reflected I these quotes as a necessary balance to the activity that is a normal part of life such that rest becomes in itself a health creating activity. There is intentionality in the way these participants describe their rest.

- Stimulating the Mind

The need to keep one’s mind active and sharp emerged as valuable to a few the participants in the interviews. Jason, Richard, and Andrea demonstrate this in the following quotes.

> Interviewer: How do you keep your mind healthy?
> Jason: Reading books, reading Christian books from the library.

Jason had not considered the need to keep his mind healthy until our conversation but quickly recognised that it was something he did anyway through reading books.

Richard spoke about learning as a part of maintaining a healthy mind in this quote.

> Richard: Healthy means to myself you get on with other people and healthy is all about if someone says okay… When people go and study and things that's how you learn about things and you go and do all the things that you can do.

Perhaps the clearest view of keeping the mind healthy, however, came from Andrea when she said:

> Andrea: You have to keep your mind thinking, like what you're doing, you know.

These participants recognised the need for and ongoing effort to maintain a healthy mind as part of creating overall health.

- Avoid the Bad Stuff

Up to this point the components that have been described as part of the behaviours that contribute to Taking Care of yourself have all required the addition of a health-giving factor, but several participants also pointed out the need to avoid harmful behaviours such as smoking, drinking, and overeating. The views expressed by the participants on these harmful behaviours often took the form of absolutes such as this dictate from Jason.

> Jason: You're not allowed to smoke. You're not allowed to drink alcohol.[11]

Tarryn expressed concern that her boyfriend should not gain any weight and lamented his avoidance of listening to her instructions on the matter.

> Tarryn: Not listen. Watch his weight.
>
> Interviewer: He's watching his weight? Is he worried about it or are you worried about it?
>
> Tarryn: No my honey[12] don't put on a weight.[13]

Despite there being a previous section on healthy eating, I have included this here because of the way that Tarryn has expressed the thought as a need to avoid gaining weight rather than the need to actively eat healthy to either lose weight or become healthier.

- Summary

There are many factors included under the heading of Taking Care of Yourself in this section. I have done this to report the health creating behaviours

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[11] In this quote, Jason expresses these statements as rules. This is a common way of expressing beliefs for the residents at this facility, particularly those beliefs that were picked up as part of a framework of good or correct 'choices' early on.

[12] In the home the term "my honey" is used to refer to their significant other.

[13] Tarryn's concern here is expressed as an instruction rather than an assertion that her boyfriend must not gain weight. Tarryn commonly expresses herself in this way.

highlighted by the participants as minor categories with clarity. These positive and negative aspects of health creation are all valuable.

5.3.3.2. Being a friend

The importance of having friendships was raised repeatedly by several participants and so emerged as a theme in our discussions of health creation. I have named this section 'being a friend' to reflect the engagement of the participants in the receiving and performing of acts of friendship making. There is a sense of 'doing' in the way the participants describe the importance of their relationships, not as something that they simply have but as something in which they participate. Although this section is called 'being a friend' I have also included family relationships in it.

In her interview Chloe described to me the sense of loneliness that she felt due to a lack of close relationships. She said:

> Chloe: I feel like I get tired. Sometimes I feel lonely and there's nobody to talk to and stuff, then I go for a walk.

In her description, Chloe shows that it is not just the proximity of people but the connection with them that is important. This was also evident in the following interaction with Jason:

> Interviewer: So do you have people in your life now still who help you?

> Jason: Hmm, Caryn.
>
> Interviewer: How does she help you?
>
> Jason: She helps me not to eat too fast and that.
>
> Interviewer: So she gives you advice.
>
> Jason: Hmm.
>
> Interviewer: And how does that make you feel to have someone helping you like that?
>
> Jason: Happy. And I get on well with Caryn, talking.

Jason mentions that Caryn helps him by advising him not to eat too fast. This is a piece of advice that I know is given out by staff members and taught as a part of life and self-care skills within the home. Jason went on to explain why he felt his interactions with Caryn aided his state of health.

> Interviewer: So when you say healthier, how do you mean you are healthier now? What's different about it[14]?.....
>
> Jason: There's someone with me.
>
> Interviewer: So you don't feel so alone?
>
> Jason: No. When he[15] went, very alone when he passed away. They told me and I was so upset about it.

Jason expressed the difference he felt between a time when he had lost a friend and after he had gained a new friend. It seems that for Jason the value if

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[14] The 'it' here is the making of a new friend.

[15] The name of Jason's friend was removed for confidentiality.

Caryn's advice regarding his eating is not in what she says as much as that she cares enough about his wellbeing to say it.

Although the participants did point out the value that they placed in having friends to provide support to them, many of them also expressed the importance of being a source of support for others as a part of creating health within their own lives. Richard explained how part of his reasoning for wanting to be strong and healthy was so that he was more able to help others.

> Richard: I want to be stronger and then I can do things. If I want to do things I am happy about it. …….I'm happy to do this and if people ask me to do things I do it for them. That's what I want to do and it's more important to ask.

When asked about being healthy, Tarryn likewise spoke about how helping her family made her feel healthier.

> Tarryn: I gonna help to help babysitting next week.
> Interviewer: You're gonna babysit next week? ………..
> Tarryn: Ja, my nieces.
> Interviewer: And does that help you to feel healthy and strong?
> Tarryn: Yes

From Richard and Tarryn's comments it seems that it is not just about being healthy to help others but the act of helping others is health-creating. There is sense of belonging that is gained from helping others. Tarryn finds place and purpose in her family by helping with babysitting.

However, it was expressed, it was clear that relationships with other people are viewed as vital to health, which reflects to the model in Figure 1 that shows all health creation occurring within a social context. From this section on being a friend however we can see that not only is the context important to behaviour but that relational acts in themselves can be health-creating behaviours.

5.3.3.3. Being Spiritual

Another theme that emerged from the data was one of spirituality as a part of health creation. In the home in which I conducted this research, the overarching belief system for the residents is a Christian one. This can be seen in a few comments but does not necessarily mean that the learning cannot be helpful for those who ascribe to other belief systems.

Different aspects of value in spirituality were identified. Engagement in spiritual practices creates connection to something greater than oneself but also to other people.

> Robert: I like going out to church because it’s quite nice to talk to other people.

Robert expresses that being able to connect with a spiritual community is meaningful and health giving for him. Richard speaks of turning to God for assistance in helping him to improve his health and relationships. Prayer for him is about speaking to a God who will provide comfort and assistance.

> Richard: I've been to church with my parents. That means we prays to God that my God with you and be healthy today and healthy you to sing to God and helps you to think what you pray for and that is why we can communicate if that you can pass the message onto the next person and say come, I want to sit with you and talk to you and that's how your life goes. And be with that person to guide them and say right, if you have sadness you communicate of be happy for your own life, and that's how it goes. If you can't let this go you gotta sit and talk about it. If that person gets on with you and you can be happy[16]. And that's what I'm exactly doing.

Richard seems here to be expressing the value of his spiritual beliefs as a basis for other relationships and other aspects of his life. Like all other parts of health that have been discussed, spirituality is linked through participation and social context and the complexities of the humans engaging in it to all other aspects of health. Amanda put it like this in her interview:

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[16] This statement of Richards refers to the sharing of his beliefs and the passing on of those beliefs to others so that they can have a similar experience.

> Interviewer: ……..you're not just talking about keeping your body healthy, you're talking about everything together.
>
> Amanda: Spirits, faith, and belief, I think.

5.3.3.4. Reducing Stress

One of the major themes that emerged from the data was the need to manage stress as a part of health creation. In almost all the references made by the participants to stress, community living emerged as both a source of and antidote to stress. Interpersonal conflict and the difficulty of managing social dynamics was vital to the experience of living with and trying to reduce stress. As Amanda put it:

> Amanda: Stress ain't good for health.

Patricia adopted the approach of avoidance to avoid stress. She repeatedly expressed exasperation with what she felt was continual and unnecessary fighting in the home:

> Patricia: Well because people, don't get me involved. Say something. I won't get me involved and then one person says don't people say get residents involved. I not say anything – I be quiet and walk away.

And then:

> Patricia: I don’t get me stressed. I don’t get me in trouble.
>
> Interviewer: You don’t like being stressed?
>
> Patricia: I don’t like I don’t get me stressed.

There is an odd irony to the idea that to provide a protective environment for PWID they are exposed to higher levels of interpersonal conflict and the stress associated with it as a side effect of the created community.

Natalie spoke of aiding others to feel calmer.

> Interviewer: How do you manage to keep yourself so relaxed?
>
> Natalie: By helping others to do their chores and that.

And Richard identified communication as key in helping to avert stressful situations but also spoke of relying on his spiritual beliefs as a source for stress management.

> Richard: That’s my point. You sit together, what I am saying for love its more important to sit with a person and get on with them. You must be happy; you must be healthy and not get on with anger but to sit with them and calm them. That’s more important for life to get on with each other that you’re communicating with that person and not communicating with that person to be angry with that one. I am not like that because I’ve been to church with my parents. That means we prays to God that my God with you and be healthy today and healthy you to sing to God and

> helps you to think what you pray for and that is why we can communicate if that you can pass the message onto the next person and say come I want to sit with you and talk to you and that's how your life goes.

Both Natalie and Richard demonstrated in their responses to stress how being with people and building strong relationships can be part of the management of stress.

Finally, Amanda also spoke of the need to manage stress and specifically referred to the effect that stress can have on the management of medical conditions such as epilepsy.

> Amanda: Ja, I mean, there are ways to deal with it I find. There's breathing. There's meditation. There's yoga. Personally, I prefer the meditation, but I get a bit worried when I sit in my room here and then I get disturbed. But I try and do that when I need it.

Even in this comment Amanda's attempts to reduce her stress are affected by the presence of the people around her. There is no way to separate health creation from relationships with other people, which leads on to the next section on social context.

5.3.4. Social Context

The social context in Figure 1, is the space in which all health creation occurs. Within this space each behaviour is influenced by and embedded within the social realities but in the data, it also became clear that being a part of and actor within the social fabric was valuable to the participants as part of health creation.

All the participants in this study pointed out in their interviews the value of being with and engaging with other people. The idea of connectedness to others was something that arose repeatedly in interviews, whether those others are friends, family, or the greater community. In some instances, participants described other activities, such as those contributing to physical (playing sports) or spiritual (attending church) wellbeing, as being of as much value for their provision of opportunities for social interaction as for their benefits to the physical or spiritual aspects of health. Social connections were described by the participants as being important as a component of health as well as being a source of support for success in other aspects of health creation such as eating well and exercising. It also emerged as important to several participants for them to provide rather than just receive support within these social relationships. When asked how it made him feel, Jason described in this exchange how important he found having a friend with whom to spend time is to his health.

> Jason: Happy. And I get on well with [her], talking. When she was in that unit and come back, I would keep going to bed like 7 o’ clock to midnight……… Because I didn’t have somebody to talk to, like when [my other friend] was here.

> Interviewer: And so now, what do you do?
>
> Jason: We have our tea, sometimes half past seven, sometimes at eight o'clock we have tea, and then I'm talking until half past eight or quarter to nine. Then I go to watch the news.
>
> Interviewer: And do you feel that you are healthier now because of that?
>
> Jason: Yes

In this excerpt, Jason is describing the changes in his wellbeing following the gaining of a neighbour with whom he could engage as compared to a time when he had lost a friend and so did not have that companionship. He talks about how his activity routine was affected by having a person to talk to. Likewise Robert points out the value of social interaction as part of a fitness related activity.

> Robert: I won't mind to join that bicycle place because I enjoy riding bicycles. It also keeps you involved with other people who do cycling, and I don't mind doing that.

A great deal of importance was placed by some participants on having people around for support and encouragement that contributed to their sense of health and their ability to engage in activities that added to their health.

When asked about which people help him to stay healthy Robert described this act of affection, hugging, as a health giving act for the sense of wellbeing that it creates in him.

> Robert: He helps me a lot because I like to give him a hug…… I like to give [people] a nice morning hug. It makes me feel nice inside and I like that.

Conversely Chloe described a lack of wellbeing associated with not having strong relationships. She said:

> Chloe: I feel like I get tired. Sometimes I feel lonely and there's nobody to talk to and stuff, then I go for a walk.

Another important aspect of having a part in community is the support that can be gained. This emerged particularly strongly in connection with support from family both current and historical. Carl talked about his parents as being important players in his health journey because of the principles and habits they taught him, as well as their ongoing support and encouragement.

> Carl: I got this from my mother because she was the one that used to say to me less eating and more going out there and doing active things and going out and seeing other people. Because that is good for me.
> …….. and also my Dad too. Same thing because they don't want me to doing work and be more active like doing other things like keeping my body stronger and that….

As in the previous excerpt the next quote shows the value of family support when dealing with a period of ill health. When being asked about a particularly difficult time of illness Amanda made this poignant statement regarding her family:

> Amanda: And I don’t know how my mum and dad have stuck with me through thick and thin, honestly, but I’m grateful to them very much, the whole family.

Amanda sees her family as having played an important part in her recovery and sees the value of having their support.

Some participants also placed great value on being a support or source of help to others. This can be seen in the following two participant responses.

> Interviewer: What are the things you need in your life to be healthy?
>
> Robert: I like to help people.

And:

> Interviewer: Do you want to help other people to get healthy?
>
> Patricia: I want them be healthy and myself.

In these comments they appear to have a view of community in which assistance is given back and forward between people. The common sense emerged that assisting others is of as much value as receiving assistance from others in the creation of ones’ health.

5.3.5. Summary of Part 1

In Part 1 of the results, I have described a view of what is involved in the creation of health from the participants. From the data I have described the creation of health as, active, communal, spiritual, existing on a spectrum of dependence and agency and embedded within a social context.

5.4. Part 2: Health Service

In this section I will look at the interaction of the participants with various health services and their reported experiences. In examining this data, I will report findings in a discursive manner to facilitate better engagement with the participants' stories.

5.4.1. Trust, Empowerment and Power

There is an inherent power dynamic in the provision of health services between the health professional and the patient[17] not unlike the dynamic between researcher and research participant. It is a dynamic that runs largely along lines of expertise. In research there is an obvious irony in the idea of expertise as the researcher (supposedly the expert) is engaging in the process with the express purpose to learn from the participant. This irony is however reflected

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[17] The collective term patient has been used here to include, client and any other terms used to refer to a health care user. The term patient highlights the dynamic of power between the health care provider and health care user and although is used less in literature, is still widely used in daily practice.

in the health professional –patient dynamic as well, in that while the health professional may be the expert in health conditions the patient is the expert in his or her own lived experience.

During the generation of data in this study this tension was very evident in the responses of the participants. I found myself feeling frustrated with both the sense that some participants seemed to feel unheard by the health providers and the sense that other participants seemed happy to cede control of their own health journeys to those providers. Although frustrating for me, this lack of clarity reflects the dynamic nature of the provider-patient relationship within health services. Where is the line between trust and dependence, power, and empowerment?

One of the first barriers to be overcome in the provider-patient relationship is communication. This is reflected in Caryn's comments.

> Caryn: You see, sometimes I feel people think I'm just putting it on or I'm just pretending. I'm just not being quite honest or something. At first I think they don't really perhaps believe it.

Here Caryn talks of feeling like those who can help her do not believe her. She went on to say:

> Caryn: At least people like her[18], her feelings, or about people or the news or about herself, she can express everything exactly as it is. But I find I leave lots of things out and find it difficult to express all sorts of things.

There is a sense in Caryn's comments that she feels that the responsibility for any communication failure lies at least partly in her inability to adequately explain rather than the provider needing to better understand.

Jason expressed a similar concern with communication during his interview, but in his comments, he did not seem to feel the responsibility though they reflect a similar powerlessness.

> Interviewer: So you are on tablets now and you say they keep changing.
> …….. Does it bother you that you don't know what they're for?
> Jason: It bothers me that I don't know what they're for…………
> I go to Dr #[19] and, often when I get out there, they talk to the nurses[20].
> Interviewer: And not to you?
> Jason: Not to me, no.

In Jason's description of his appointment he is cut out of the conversation that takes place about him. He is unhappy with this dynamic but remains

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[18] The name of another resident has been replaced with a pronoun in order to protect anonymity.

[19] I have removed the doctor's name for reasons of confidentiality.

[20] The nurses referred to here are the nurses that work at the home and go with the residents to offsite and onsite medical appointments.

disempowered enough in the situation not to be able demand his inclusion. Jason also described a stay that he had in hospital when he felt well looked after.

> Interviewer: And what was it like to be in hospital?
>
> Jason: Relaxing…………….
>
> Interviewer: So why did you enjoy being in hospital? Because not everyone likes it.
>
> Jason: They've got nice nurses.
>
> Interviewer: What did the nurses do that was nice?
>
> Jason: They come and check your sugar every time. They come and take your blood pressure. They come and take your cholesterol every time.
>
> Interviewer: So they were…
>
> Jason: On the ball.

Jason does not make a point out the importance of him receiving explanations from the professionals but there is an assumption that he was engaged with to some degree while his vital signs were taken and other investigations conducted. These interactions did not include the explanation of medical information but remained a part of the process rather than an observer. This is echoed in Andrea's description of her hospital stay.

> Andrea: I went to hospital, I don't know when was it. The hospital was big, one of those big hospitals. I was very, very frightened when I went

> into the front of the door….The nurses and the doctors were so kind to me. …They looked after me so kindly.

When comparing the two descriptions from Jason and one from Andrea it occurs to me that it is not necessarily the information that is shared but the recognition of them as a stakeholders in their own health that makes the difference in the experiences. The inconsistency within Jason's experiences has left him with an ongoing insecurity about future interactions with health care providers. He expressed this insecurity in his interview:

> Interviewer: So Jason, do you feel like you can get the help that you need if something goes wrong?
> Jason: No. I'm stressed about that.

Jason carries a concern for his future health but for a number of the participants, this seems to be relatively easy. When asked about accessing health services Adam simply said the following:

> Adam: I went to the doctor before. He helped me.

Caryn however described a more dynamic interaction.

> Caryn: Well, also, when you go to the doctor, especially a good one, it's important for you to keep on listening to what he tells you and doing what he tells you to do. That's vital I think.

In thinking about the participants' responses to questions about their experiences of accessing health services it struck me that by and large I found the concepts of power, empowerment, and trust far more difficult to reconcile than the participants themselves.

From these interviews is that there is a certain universality to the experience of seeking out help from someone else about something as personal as your health. Amanda describes her feelings about the experience.

> Amanda: Well, you walk into the doctor's room, la-la-la. See all the magazines, they are out of date and whatever. And then you sit and you wait. Then you get into the room and [he] talks to you…basically, I feel very nervous……..But I feel also very grateful that he's helping me……….
>
> Interviewer: And how does it help you? How does it make you feel when you get that explanation?
>
> Amanda: Honestly, I can't find the words for that either, but I also feel grateful and happy about what they say. Because remember, it's my health we're talking about………Not anyone else's.

In part 2 of this chapter I have presented a tension that I was aware of through the interviews. I found the stories that the participants shared fascinating in their variety and in their detail. Throughout, I found myself asking these questions: where is the line between trust for professional knowledge and disempowerment? How does one become empowered and who can shift the power dynamics of health provision? Having no answers to these questions myself, there is however insight to be gained through the examination of the experiences expressed by these participants into the dynamics present for PWID when accessing health care. In this section I have highlighted aspects of the participants' experiences with health care services through the lens of the trust, empowerment and power dynamics of the health provider-patient relationship.

5.5. Part 3: Stories of Health

In Part 3 I have selected three interviews to be explored as narratives. In these interviews I have looked for and highlighted some of the unspoken layers of the stories that I was told to better understand the lived experience of health for these participants. I have chosen two narrative threads per interview to illustrate noteworthy health-related aspects of the stories, but the richness of these stories could have allowed for far more exploration had there been space within this dissertation. I will describe the interviews in the present tense in order to better illustrate the non-verbal details of these interactions.

5.5.1 Wendy's Story

5.5.1.1. Choice and responsibility

Wendy is anxious as she comes in for the interview. Her anxiety seems to reside in anticipation and eagerness rather than fear, however. She seems excited but concerned that she will not have the answers that I need or want. I try to reassure Wendy that there really are no right answers and that I am there to learn. Being the first interview, in the back of my mind I hold my expectation of the simple, concrete answers that I anticipate to my questions.

I have pondered and cannot come up with a better set of terms to use other than being healthy, well and strong, so we proceed with my hopes that these terms suffice. We settle down and begin.

Wendy is bouncing in her seat and wants to know about my studies. She wants to understand what her answers will be contributing to and is very concerned with my success. At the time I thought nothing of this interaction past her general curiosity and my need to make my explanations as clear as possible for the effective gaining of assent but in reading back over the interaction I think about the topics of interdependence and social context and wonder: is this interview a health creating behaviour?

I begin the interview by pointing out the other snacks available to Wendy and then the following exchange ensues:

> Wendy: Uh can I leave that?

> Interviewer: You don't have to... you...you... I've put a different selection there so you can choose what you want, ok?
>
> Wendy: I like this [pointing to snack].
>
> Interviewer: You can take one of each or none or whatever you want. OK
>
> Wendy: Ok, uh, Helen, I got taught you and thing when you and you're over…… cause my eyes tend to be bigger than my stomach. (*Wendy is gesturing with her hands as she tries to explain her concern over the snacks.)*

At this point I still have not asked a question, but when offered some food choices, Wendy feels the need to clarify what freedom of choice she has. I did not notice this at the time. As I read and listen back over the interviews however, I see that later she talks about making good food choices to be healthy. Wendy says[21]:

> Wendy: I think you let yourself down when you do those things [make poor health choices] …. And even if somebody offers you, ok… you can't say no. Sometimes I say no. And like for my sister is coming end of this month and sometimes she spoils me …. and she buys sometimes popcorn and stuff and like a packet of chips and then we have that watching the movie.

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[21] Where it makes more sense for the narrative discussion, I have left portions of the conversation out of the quotations to achieve better clarity and flow. I have been careful to maintain the meaning of the quoted portions and keep or explain the context where that is important.

> And then I help…… her to clean the house cleaner, so I do work for her when she comes home.
>
> …… It's just seeing other people, eat what they eat, like a salad, ja it actually does help you. And even, like we get a salad every day, here too. ……Sometimes I won't take a salad, or I take very little, like last night I just had, what we had for supper, pasta, and I didn't take any bread. I do sometimes but when I'm hungry like on this morning I had, um, two slices of bread, and maybe lunch if it's something I don't like, I take very little.

Wendy sees herself as carrying some responsibility for her own choices and health. As she talks about letting yourself down but how do I understand that responsibility in the light of her question as to whether she had permission not to eat the interview snacks. Wendy articulates the feeling that she cannot say no when offered something, but this does not seem to diminish her sense of responsibility for herself. She later in the interview says with a sigh:

> Wendy: Okay, I don't eat enough vegetables.

There is resignation in this statement. I feel a familiar frustration as I ponder the idea of agency and choice within an institution. I can hear the voice of many of my colleagues as Wendy talks about limiting bread and choosing salad, but I consider if in our well-meaning effort to empower the residents to be healthy we have added a burden of responsibility to their shoulders without giving them the power to make themselves successful.

Wendy mentions how she takes encouragement from others around her, but she also later talks about how food is dished up for her at the home and tuck[22] is portioned out to prevent overindulgence:

> Wendy: They dish up the food and stuff and we also do. Like the salads and like, I don't know, oh they make tea for us so …. not so much sugar[23] but for everybody. And also, when we get tuck, we don't get a lot, but we get just enough. Ja like a small, you don't have to have a whole big one; to finish all your tuck, you just have a like a small little portion.

These stories highlight to me a fine line between cognitive impairment and contextual disablement.

5.5.1.2. Health creation is social

Throughout her interview Wendy brings up the people who are part of her life. She clearly values her relationships highly. There is eagerness in the way she talks about others.

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[22] Families often bring treat foods and leave then at the home for the residents. These are placed in a locked cupboard and portioned out on evenings when the housemother is on duty.

[23] At teatime a large container is made for all the residents with milk and sugar. Usually only those residents who have been allocated dietary requirements are made their own individual cups and taste alone is not catered for. This is however dependent on the units, as the smaller units can cater to individuals.

When asked about how living in a group home affects her health, Wendy answers without hesitation.

> Wendy: Everybody I think just tries to be healthy, but nobody has stopped us.
>
> Interviewer: So, do you feel like being in the home means that your health is looked after?
>
> Wendy: Ja, it does.
>
> Interviewer: ok. And, um, is that because of yourself or other people mainly?
>
> Wendy: Myself and other people as well so its half, fifty fifty……. Or you could say a hundred percent both ways

Wendy doesn’t see health creation as an independent act but describes it has made up of one whole of her own effort and another whole of the efforts of others. The way that she describes health here indicates, the inclusion of other people from within her social context is not just an addition to creating health but a requirement. On reflection I recognise the competing reactions within me. On one hand, I am impressed and agree with Wendy: we are all part of a collective and need each other and yet on the other hand, the part of me that values independence wants to deny that what Wendy has said could apply to me.

During the interview, Wendy talks often about her family, and it is clear how she values and misses them. Wendy talks about both the positive and negative influences that family can have on one by using examples from her own family. She tells a story of one family member influencing another to get drunk and while she notes that alcohol can damage a person's body, she appears more bothered by how it damaged her family relationships. Wendy describes spending time with her family member as if the alcohol is another person within the social space.

> Wendy: It was like me and her and her with her vodka and brandy and coke and spirits.

Wendy goes on to talk about how people can help one another to make healthier choices as well. Referring to another family member she says:

> Wendy: And he's gone so healthy now that I want to go more healthier.

As Wendy talks, I get the impression that it is not just that she needs other people to create a healthy life, but a desire to share her journey with those around her. Wendy describes a time when she visited a psychologist and the value that she gained from telling someone about her experiences:

> Wendy: It was actually, you know, there were so many things that I never spoke to my dad, or my mom and it just spilt out. Like your cup overflows, everything I told the therapist.

In her story she had felt that there were many things that she needed to talk through. Wendy describes how she learnt the value of sharing during that time, and that she has cultivated a few different supportive relationships since then.

> Wendy: not [only] talking to a therapist helps. It is even talking to like maybe [my friend] or the other staff or my teacher [24] or the housemothers. That helps as well.

Through her interview, Wendy paints a picture of cooperative health creation, where the social context in which she has lived cannot be separated from her health journey. She recognises that she cannot live a healthy life without the involvement of others and tries to make an effort to seek out the assistance that she needs when she needs it. It would be easy to dismiss Wendy's experiences as being irrelevant to those of us who do not live in an institution but as I think about how Wendy's observations could apply to my life and the lives of those around me, I have to question that dismissal. While the setting in which Wendy lives may make her dependence on others more obvious, I am hard pressed to think of an example of any person walking a journey of health creation without support of some kind.

5.5.2. Robert's Story

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[24] Teacher refers to the workshop assistant in charge of the section in which Wendy works.

Robert is calm and collected as we begin our interview. He has a quiet dignity to him. As we sit, he starts telling me about the changes that have been made to the home over the years and I am reminded of a wise elder presiding over the telling of the community histories. Robert sits back in his chair and rests his hands on the chair arms. I feel as if he is taking ownership of this space and his place in the world. While Robert talks, I start to see a tension between the image he presents and the current of loss in so much that he shares. Robert shares with me stories of the things that he values, past and present, and the two that stand out to me are his desire for space and spiritual growth.

5.5.2.1. Space for health: "I don't want to get squashed in. I want to be out."

As we chat, and I ask Robert about living a healthy life, he tells me about some of his favourite memories, many of which involve being outside in nature. He describes going to the beach with his mother.

> Robert: Ja, it's got a nice view. You go to the beach and watch the people. That's what I used to do with my mum, watched the people surfing and yachting. I like that. It makes you nice…it feels nice.

He mentions walking outside and cycling as some of his chosen methods of exercise.

> Robert: I take part with [the coach], the other[25] residents, walking out on the streets.

And,

> Robert: I won't mind to join that bicycle place[26] because I enjoy riding bicycles. It also keeps you involved with other people who do cycling, and I don't mind doing that.

As Robert mentions his enjoyments, I find myself feeling increasingly frustrated for him and yet he continues to exhibit an unruffled calm. Finally, we have a short interaction about exercising in the home's gym.

> Robert: I like doing gyming. I like doing that. Because the gym room is over there somewhere, up top there. (*Robert points off in the direction of one of the other buildings.)*
>
> Interviewer: Do you go there?
>
> Robert: I can't go because it's all locked up…

I realise that I have an image in my head of a man seeking out space and being confronted with locked doors, whether they are the locked doors surrounding the home or those keeping the gym equipment safe. This is an uncomfortable image for me and yet I look at Robert and see him just as relaxed as ever. I ask him:

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[25] I have referred to a specified group of residents as other here to preserve anonymity.

[26] This refers to a mountain bike club that has a space across the road from the front entrance of the home.

> Interviewer: Can you tell me; how does it affect you? How does it make you feel if there's stuff like that that you maybe want to do, but you can't do?
>
> Robert: It feels fine.
>
> Interviewer: So, it doesn't bother you that you can't do those things?
>
> Robert: No.

Robert has achieved an acceptance of his situation that I find difficult and yet am impressed by it. I consider that perhaps this is a symptom of years of living in an institution where choice is limited and so discontent serves very little purpose, but Robert also talks about the ways he finds space in his life now such as going for walks and running errands that keep him out of the workshops. I wonder if I am reacting to seeing how institutionalisation has narrowed his options and his hopes or if in fact, he has found an acceptance to which we could all strive. After all, many people face narrowed options and hopes in the face of barriers other than institutional walls.

I find myself humbled by Robert's attitude but cannot quite shake the image of him standing on top of a mountain, feet planted, taking in the view of his surroundings as in his description below.

> Robert: One thing that has helped me a lot, it's that I go to my dad's farm and me and my dad climbed the mountain together, watching the whole view of that part where you stand on a…it's like a head. Me and

> my dad was standing on top of that mountain, and you look all over the whole countryside.

5.5.2.2. Spiritual growth

As Robert speaks there is another thing that he brings up repeatedly. For Robert health is not just a physical or mental or even social journey but spiritual as well.

> Robert: Yes. I like to learn more a Christian life.

Robert displays passion when he talks about this faith and while he talks about moving closer to God he also talks about ways that it works out in his community. For Robert his spiritual health is also about contributing and growing through service to others:

> Robert: Because I like to preach in the chapel as a minister. I don't mind doing that.
>
> Interviewer: So that's something you want to do. Is that something you have done?
>
> Robert: I've been doing it for a few times.
>
> Interviewer: You have done it.
>
> Robert: Hmm.
>
> Interviewer: That's special.

> Robert: And all the other residents and the caregivers, they like me to take the chapel service. I don't mind doing that.

Robert gets excited when he talks about preaching for the other residents but then as if just remembering, goes on to tell me about other remembrances:

> Robert: When I used to go out with my [friend's] mum, we went and visited somebody in an old age home, the people there. When I see them, it makes me crying a bit…When I see them, I was just thinking about something there. Some of them can't walk, some of them can't talk. I like to go up to them and say, be at peace because you have good people to look after you. That's what I like to do, you know, go to the hospitals or things like that.
>
> …I just like to help them. That's what I like doing, go and see the people in hospital. I like to go up to them and pray for them. That's how I feel about that.

There is lightness as he talks about going and praying for others in hospital and I am aware of the link to what many other participants have revealed to me about the importance of helping others in their health journey. For Robert the act of caring for the sick is health-creating. There is an interdependence between him and those he seeks to serve, and I am impressed by his desire to do more than accept ministerial input. Robert sees a need for movement within his journey in spiritual health. He wants to go out to others and grow in contribution to the group.

Robert finishes his interview after sharing many interesting stories and I am left with a bit of the calm that he brought into the research space.

5.5.3. Amanda's Story – The experience of personhood.

Amanda arrives for her interview having read through the information sheet that I left with her. She comes across as confident and outspoken and does not appear nervous to be interviewed. Despite this impression though there is a quality to all her movement of coiled energy, as if she is containing anxiety. Amanda taps her fingers, tips her head this way and that and blinks often. This is her normal state and I find myself picking up on her energy and we are talking to each other at speed.

5.5.3.1. Being a burden

As we start, Amanda gives her view of health as a holistic one. She says that when you are healthy "you enjoy your life to the fullest".

She then goes on to tell me about some of her recent experiences of seeking treatment for ill health and the difficulties involved. Thinking that I may get some good information, I ask her about her recent doctor visits, and she describes being grateful for their explanations.

She goes on to point out the importance of her having knowledge of her own health and I'm struck that her gratitude is not necessarily one that comes from a position of subservience but there is a sense of empowerment in her getting the input that she requires from the doctor.

Continuing her thought, Amanda goes on to talk about her family:

> Amanda: And I don't know how my mum and dad have stuck with me through thick and thin, honestly, but I'm grateful to them very much, the whole family.

This statement makes me wonder: does Amanda carry the sense that she is a burden to those around her? I think back to some of the other interviews that I have done and that sense I got of the participants putting forth effort to mitigate the weight that they place on their families.

I called this short section of Amanda's story 'Being a burden' to reflect my knee jerk reaction to some of what she said and because of the individualistic instinct so often seen in society that any dependence for assistance is burdensome to others. Although there may have been times that Amanda felt like a burden, it did not reflect in her narrative as the dominant state of her relationship with her family or others. I felt that the section title would also reflect my own musings regarding my assumptions and whether perhaps in my intention for an emancipatory approach to this data, I was denying Amanda and other participants' experiences of the normal and healthy human experiences of interdependence.

5.5.3.2. People as the source and solution for stress.

Amanda continues to sit in a state of leashed energy through the whole interview. As we speak, she tells me about some of the stressors in her life and her coping strategies. Very quickly a pattern emerges that living with large groups of people is difficult and a big source of stress. Amanda talks about the difficulties that she can identify in the home and expresses frustration that not everyone seems ready to help others. She is happy to have an interview to attend:

> Amanda: And it was nice to get out because everyone is just fighting and fighting……..It could be also the end of the year, but it's happened all the way.
>
> Interviewer: Does it make you feel tired? You look tired as you're saying it.
>
> Amanda: Hmm. Because even on a weekend they fight. And it's like, guys, stop it, it's the weekend. There's no workshop. And then I'm going to blow a gasket and then it's going to go in the file. Meantime, it's not my problem.

The way Amanda describes the challenges of living in a group home has a relentlessness to it. She tells me about people seeking her out for help but laments that they do not seem to put forth effort themselves:

> Amanda: Sit on their big, fat arses all day watching TV. I don't mind the ones who can't do much, but the ones that can just sit on their big, fat arse. And then they come to you …………….
>
> Interviewer: So, they're asking you for help.
>
> Amanda: Ja, but too much help[27] can get very annoying. They must also pull their backs.

And she goes on to explain to me why she retreats to her room at times.

> Amanda: Just to keep everyone out, like the house, because I seem to be the guinea pig where everyone wants to come to you.

Amanda expresses a frustration at not being able to escape the constant intrusion of the other residents in the home and yet she tells me how much she values her friends. As I am trying to get her to give me information about her experiences with health professionals, Amanda is telling me who she sees as a true source of support for herself.

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[27] Here Amanda is referring to others asking for her help with tasks including 'house' duties (e.g., table setting or cleaning) that are performed by residents on a rotational basis.

> Interviewer: So, as I say, we've mentioned some people who might help to keep you healthy….. So, there are different people who could be there to help with health, people like nurses, people like doctors, people like dentists, you know, there are different…
>
> Amanda: And friends.
>
> Interviewer: Psychologists, therapists. Ja, all these different people.
>
> Amanda: Friends is a big one.

Despite my stubborn questioning, Amanda maintains her friends at the top of the list of people who help her stay healthy and whom she seeks out when she is stressed. And so, in her experience, the people who form part of her life within the communal living space are both a source of and solution to her experiences of stress.

Amanda goes on to describe the many tools that she uses to help herself cope with stress many of which include taking time for herself to meditate or read or listen to music. I am impressed with her self-awareness, and it strikes me that what she is talking about is management of stress in the truest sense of the word.

When I ask Amanda, who has helped her to find all these strategies to respond to her stress, she tells me.

> Amanda: Technology. Technology and apps.

> Interviewer: So, have people helped you? Or have you gone out to look for something?
>
> Amanda: I've gone and done, but mum and my sister have [helped].

Once again Amanda demonstrates working together with others towards solutions for life but there is a great sense of agency in her response that while she may have had help her answer is, 'I've gone and done'.

As Amanda told me about her experiences, I was first struck by the relentlessness of stressors that she must deal with in her life and then later with the levelheadedness with which she has tried to find management strategies that work for her within the context in which she finds herself.

5.6. Summary of Chapter 5

In chapter 5 I have given an overview of the overarching themes that emerged from the data generated within this research. I began by framing the findings according to a pictorial model (Figure 1) to show the multidimensional interaction of the participation in health creating behaviours along a spectrum of agency and dependence, embedded within a social context, of the study participants. I identified many health-creating behaviours but highlighted those that emerged as the strongest themes. In part 2 I discussed the interplay of trust, empowerment, and power in the experiences of PWID accessing health care services. These dynamics are present in most interactions with health services but can be of great effect when PWID seek out health services. Finally, in part 3 I took three of the participant interviews and isolated two narrative elements per interview that were notable and, in some way, reflected the themes and ideas that emerged in the first two parts. In the next chapter I will be expanding on and discussing elements of these findings in the context of relevant literature.

Chapter 6: Discussion

6.1. Introduction

Although the findings of this study created many opportunities for discussion about several topics, the two critical questions that I aimed to answer with this study will be examined here in the context of other research.

I will begin by looking briefly at an understanding of health from the data and other literature. I will then similarly examine the issues raised by the participants around the experiences of accessing health services.

Finally, I will consider some of the limitations of this study and how they should be considered when making use of the results.

6.2. Towards a holistic understanding of health

According to participants in this study, health can be considered a sense of wellbeing, and encompasses several aspects of life including the social, the emotional, the physical and the environmental. These findings are in keeping with other studies and theorists. Hammell, (2017) points out that wellbeing incorporates looking after oneself and belonging or connection to culture, family, nature, and spirituality, which is precisely how the participants in this study described health. Likewise, Scott, Foley, Bourke, Leonard, and Girdler, (2014) described the meaning of wellbeing as consisting of relationships and community participation. Close relationships with others, whether with friends, family or caregivers are extremely important to PWID (Sullivan, Bowden, McKenzie, & Quayle, 2016), which was reflected in the findings of this study through the emphasis the participants placed on relationships. The findings also reflect not only the importance of gaining but of giving support within relationships.

In this study, participants reflected the idea of interdependence in health creation by talking not only about how the people around them helped them, but also about the value of their role in helping others. Despite the value that they expressed feeling in the idea of contributing to the lives of others, and though some participants spoke to their need for the support of others, not one participant expressed that they felt that they were in any way necessary to the wellbeing of others. Perhaps considering this discussion, rather than thinking of independence and dependence it would be better to think about life and the creation of health as the process of doing occupations together. “The concept of co-occupation, for example, offers a unique, alternative perspective to shift discussion away from the dichotomy of dependence and independence toward new possibilities of interdependence” (Channon, 2014, p. 454).

WHO defines health promotion as “the process of enabling people to increase control over and improve their health” which as Thibeault and Hébert, (1997, p. 272) point out, encompasses the idea of social integration as it by definition requires the interaction of at least two people or one person with an environment. In Sweden a study regarding the quality of life of PWID found that it was linked to a sense of control, recognition, belonging and choice (Umb-Carlsson & Lindstedt, 2011). If this is considered in the context of health, then it further reflects the findings of this study as it conceptualised health existing on a spectrum from the individual (agency) to the collective (dependence). Health is a complex concept, and it has often been considered a state to be attained (sometimes for ease of measurement). What can be learnt from the PWID in this study, is that it could more accurately be thought of as a process with many contributing factors. Health can be considered to exist in several domains of life and experience and so as Yerxa (2009) puts it, health cannot be measured as an object. Understanding health in a holistic sense as a product of active participation, within a context, to produce a lived experience helps us to move away from the view of PWID as somehow deficient and so unable to maintain an equal part in health creation. Under this paradigm of health all people, are situated within their own lived experience of health along with the internal and external factors. Their experience of health is thus created by the interaction of these factors rather than by any societal or other expectation that may be imposed on that individual.

It strikes me that though we inherently know that health is contextual and transactive as demonstrated in the findings of this study, we do not always reflect this in service planning or resource distribution. The next section considers more directly the experience of the participants in their interactions with health care services.

6.3. The experience of health services

In this section I will highlight aspects of the participants' experiences with health care services through the lens of the trust, empowerment and power dynamics of the health provider-patient relationship. It is also worth acknowledging, however, that these issues can be considered as learning opportunities within the broader context of residential care and intentional communities where similar dynamics may exist between residents and staff members who may or may not be health professionals themselves.

It was noted by some participants in this study that while they were generally grateful for the care received from health professionals, they experienced distress at being excluded from information and decision making regarding their own health. Feldman, Owen, Andrews, Tahir, Barber, and Griffiths (2015) note that PWID should be afforded the opportunity to be trained in the understanding and management of their own health and when good information and training is available there is strong evidence to suggest that some PWID can understand and manage their own health with greater success. In a study conducted by Williams and Porter (2017) PWID preferred to seek assistance from professionals who could assist them in building confidence in their own ability to make decisions, listen to the wider issues of concern to them and to help plan and articulate the steps involved in making health decisions. In this study a few of the participants expressed frustration at not being included in discussion and decision making regarding their own health. It has been suggested that staff or carers should assist PWID to make choices but more information is needed about how best to support their autonomy in decision making (Williams & Porter, 2017) and carers often require further training to increase their competence in working with PWID (Kroese et al., 2013). The further training to facilitate a shift in understanding of ID needs to extend to health professionals who work with PWID as well. For example, Crotty and Doody (2016) point out that improved cultural awareness can have a positive effect on the understanding of ID and provision of care from professionals.

6.4. Limitations of Study

There are several limitations that need to be considered when making use of this research study but my position within the context of the study poses some significant considerations. As an employee of the organisation, and someone with preexisting relationships with all the participants I was able to obtain a depth of information that would be difficult to replicate under different circumstances. Although there is benefit to this the significant risk existed for my interpretation of the participants' responses to have been influenced by my own biases and expectations.

Furthermore, the communication difficulties of some participants and the lack of clarity in some of the data compound the possibility of over-interpretation. While I made every effort to guard against this, it is nonetheless a significant consideration. In the positioning of this work within the spectrum of inclusive, emancipatory research the inclusion of co-researchers with ID in more than just an advisory role on the interview guide, would have been good. This might have helped to mitigate some biases of which I as the researcher may have been unaware.

The sample size for this research was small and the exclusion of those who were unable to communicate or consent verbally, while practical, means that the data may not be representative of the whole group of residents at the facility and important information could therefore have been missed.

The context in which this study was conducted is a small and specific one that is not representative of the demographics of SA either socio-economically or culturally. As such the results of this study provide a snapshot into a specific group of people and cannot be assumed to be a true representation of the experiences of most PWID in SA although it does contribute to filling in some of the gaps of our understanding on this topic.

Despite the limitations inherent in this study, it has provided some valuable and worthwhile insights into the lives of a group of PWID in SA.

6.5. Conclusion

In this research study I sought to understand a view of health as expressed by a group of PWID. The view of health that emerged was one of a process of active and contextualised engagement with health creating behaviours.

I have looked at health as a social, transactional, and contextualised state of being and an experience of wellness. I have considered that disability, under this paradigm, becomes not an arbiter disallowing the creation of health but simply another factor that influences and is in turn influenced by the person’s state of being in the process of health creation. There is dynamic interaction between the person and context in this concept of health where each part acts on the other. People with and without disabilities live within contexts that affect their ability to exercise their personal potential and it is important to examine these influences before deciding to situate limitations that are experienced, within the individual. PWID have many contributions to make to a better understanding of the lived experience of health for themselves and others.

The findings of this research reflect ideas from many other pieces of literature while also adding further detail and nuance to the understanding of the experiences of PWID in South Africa.

6.6. Contribution to literature

Considering the extreme lack of research involving PWID in SA, this study contributes by filling a small part of that space. Very little is known about the lives of PWID in SA and so this research can be considered and based on which to expand that understanding.

6.7. Recommendations for Further study

As stated, before, there are large gaps in the current knowledge that is available regarding PWID around the world but especially in the global south. As such the suggestions that could be made for further study are immense and so I will mention only a few that are most relevant.

It would be useful to repeat this study or one similar across other contexts within SA. This could include community-based settings, as well as the inclusion of people from a wider variety of cultural and racial groups within SA.

This study was also limited in scope and so further study of health and ID in different settings would be useful. This could include mixed methods to better understand the impact of context on health-creation as well as the perspectives of health professionals and carers as well as PWID to further explore the discrepancies that may be present in those opinions.

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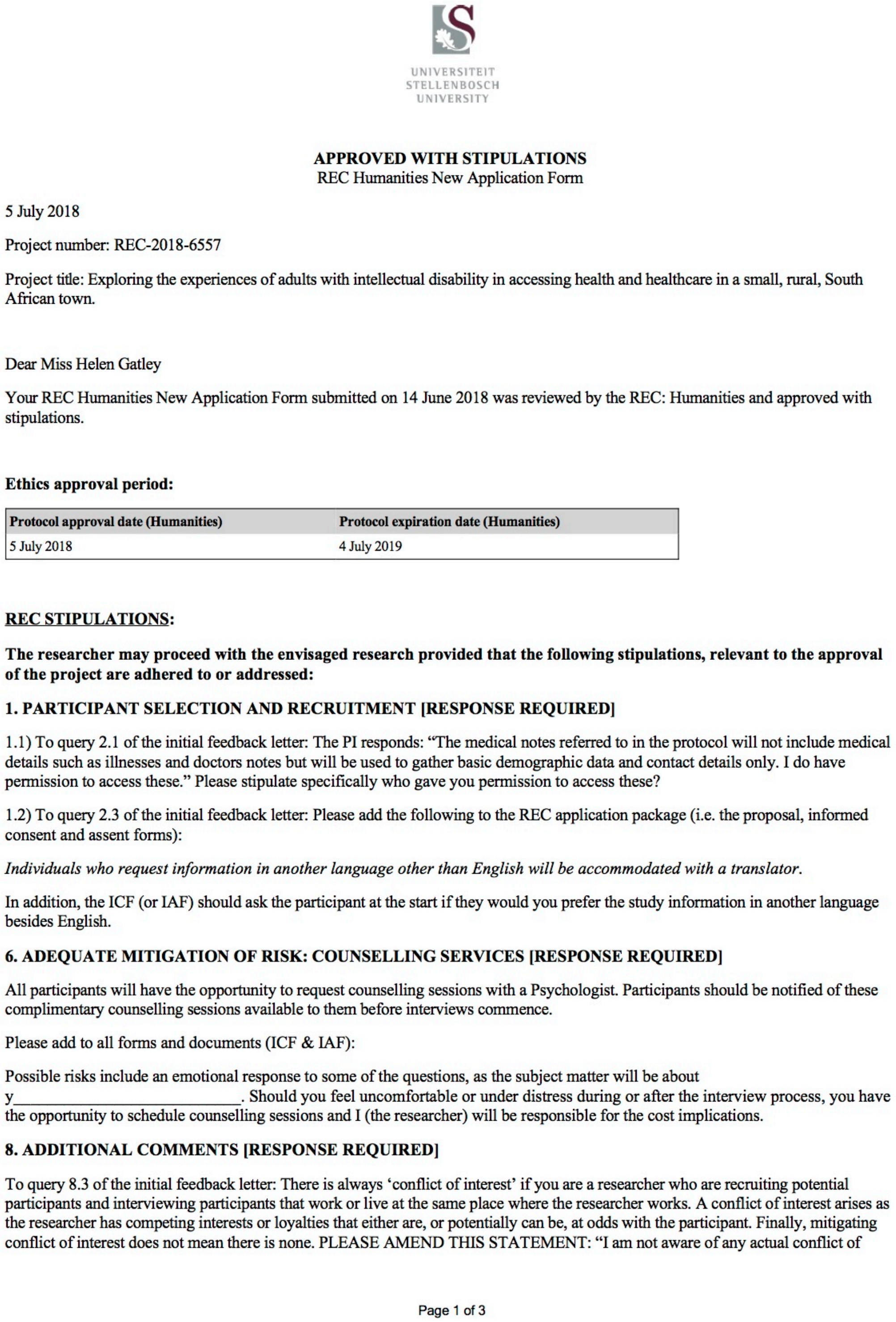
Appendix A: Ethical Clearance: Stellenbosch University



UNIVERSITEIT
STELLENBOSCH
UNIVERSITY

APPROVED WITH STIPULATIONS
REC Humanities New Application Form

5 July 2018

Project number: REC-2018-6557

Project title: Exploring the experiences of adults with intellectual disability in accessing health and healthcare in a small, rural, South African town.

Dear Miss Helen Gatley

Your REC Humanities New Application Form submitted on 14 June 2018 was reviewed by the REC: Humanities and approved with stipulations.

Ethics approval period:

Protocol approval date (Humanities)	Protocol expiration date (Humanities)
5 July 2018	4 July 2019

REC STIPULATIONS:

The researcher may proceed with the envisaged research provided that the following stipulations, relevant to the approval of the project are adhered to or addressed:

1. PARTICIPANT SELECTION AND RECRUITMENT [RESPONSE REQUIRED]

1.1) To query 2.1 of the initial feedback letter: The PI responds: “The medical notes referred to in the protocol will not include medical details such as illnesses and doctors notes but will be used to gather basic demographic data and contact details only. I do have permission to access these.” Please stipulate specifically who gave you permission to access these?

1.2) To query 2.3 of the initial feedback letter: Please add the following to the REC application package (i.e. the proposal, informed consent and assent forms):

Individuals who request information in another language other than English will be accommodated with a translator.

In addition, the ICF (or IAF) should ask the participant at the start if they would you prefer the study information in another language besides English.

6. ADEQUATE MITIGATION OF RISK: COUNSELLING SERVICES [RESPONSE REQUIRED]

All participants will have the opportunity to request counselling sessions with a Psychologist. Participants should be notified of these complimentary counselling sessions available to them before interviews commence.

Please add to all forms and documents (ICF & IAF):

Possible risks include an emotional response to some of the questions, as the subject matter will be about y___________________________. Should you feel uncomfortable or under distress during or after the interview process, you have the opportunity to schedule counselling sessions and I (the researcher) will be responsible for the cost implications.

8. ADDITIONAL COMMENTS [RESPONSE REQUIRED]

To query 8.3 of the initial feedback letter: There is always ‘conflict of interest’ if you are a researcher who are recruiting potential participants and interviewing participants that work or live at the same place where the researcher works. A conflict of interest arises as the researcher has competing interests or loyalties that either are, or potentially can be, at odds with the participant. Finally, mitigating conflict of interest does not mean there is none. PLEASE AMEND THIS STATEMENT: “I am not aware of any actual conflict of

Page 1 of 3

interest in proceeding with this study."

HOW TO RESPOND:

Some of these stipulations may require your response. Where a response is required, you must respond to the REC within **six (6)** months of the date of this letter. Your approval would expire automatically should your response not be received by the REC within 6 months of the date of this letter.

Your response (and all changes requested) must be done directly on the electronic application form on the Infonetica system: https://applyethics.sun.ac.za/Project/Index/6876

Where revision to supporting documents is required, please ensure that you replace all outdated documents on your application form with the revised versions. Please respond to the stipulations in a separate cover letter titled **"Response to REC stipulations"** and attach the cover letter in the section **Additional Information and Documents**.

Please take note of the General Investigator Responsibilities attached to this letter. You may commence with your research after complying fully with these guidelines.

If the researcher deviates in any way from the proposal approved by the REC: Humanities, the researcher must notify the REC of these changes.

Please use your SU project number (6557) on any documents or correspondence with the REC concerning your project.

Please note that the REC has the prerogative and authority to ask further questions, seek additional information, require further modifications, or monitor the conduct of your research and the consent process.

FOR CONTINUATION OF PROJECTS AFTER REC APPROVAL PERIOD

Please note that a progress report should be submitted to the Research Ethics Committee: Humanities before the approval period has expired if a continuation of ethics approval is required. The Committee will then consider the continuation of the project for a further year (if necessary)

Included Documents:

Document Type	File Name	Date	Version
Proof of permission	Signed letter of permission from Sunfield	06/03/2018	1
Informed Consent Form	Participant Informed Assent form	06/06/2018	2
Data collection tool	Interview guide	06/06/2018	2
Research Protocol/Proposal	Ethics proposal6June2018	06/06/2018	2
Informed Consent Form	Parental Informed Consent Form	06/06/2018	2
Default	Letter of Changes for Ethics	14/06/2018	1

If you have any questions or need further help, please contact the REC office at cgraham@sun.ac.za.

Sincerely,

Clarissa Graham

REC Coordinator: Research Ethics Committee: Human Research (Humanities)

National Health Research Ethics Committee (NHREC) registration number: REC-050411-032.
The Research Ethics Committee: Humanities complies with the SA National Health Act No.61 2003 as it pertains to health research. In addition, this committee abides by the ethical norms and principles for research established by the Declaration of Helsinki (2013) and the Department of Health Guidelines for Ethical Research: Principles Structures and Processes (2nd Ed.) 2015. Annually a number of projects may be selected randomly for an external audit.

Appendix B: Study Approval: Organisation

Sunfield Home
Howick
for intellectually impaired adults
main road howick, po box 82, howick, kwazulu natal
tel: 033 3302094, fax: 033 3303084, email: residents@netfocus.co.za

6 March 2018

To Whom it may concern

This letter serves to confirm that Helen Gatley, currently a student at Stellenbosch University, completeing a Mphil in Public Mental Health, has been granted permission to recruit participants for her masters study from within the residents of Sunfield Home Howick. Participation in this study will be voluntary on the part of the residents.

This permission is granted in order that data collection may be started at such a time as ethical approval has been received from the Research Ethics Council of the University.

Thank you

Cliff Freeman

General Manager at Sunfield Home Howick

company incorporated under section 21 reg.no.1996/003869 npo no.013/221. pbo no 18/11/13/2902

Appendix C: Information and Consent form for families

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STELLENBOSCH UNIVERSITY

PARENT/LEGAL GUARDIAN CONSENT FOR A PERSON WITH INTELLECTUAL DISABILTY TO PARTICIPATE IN RESEARCH

‘Exploring the experiences of adults with ID in accessing health and health care in a small, rural, South African town: A qualitative study.’

Please note that if you would prefer this information in a language other than English then it will be made available to you in your language of choice.

I would like to invite your family member/ward to take part in a study conducted by me, Helen Gatley and supervised by Professor Leslie Swartz, from the Department of Psychology at Stellenbosch University.

I would like to speak to a group of adults with intellectual disability about their health and experiences of health care services. I would like to speak to your family member/ward because he/she is an adult with ID who lives at Sunfield

Home Howick and is able to communicate clearly. He/she has also been selected, as he/she is able to communicate if he/she does not wish to participate in the study.

1. PURPOSE OF THE STUDY

As health professionals and researchers, we know very little about the experiences and views of PWID on their health and health care. Although there have been some studies in other countries, in South Africa we know almost nothing about this issue. In healthcare the opinions of the patient or service user is also becoming more and more important in order to improve and adapt service delivery but generally PWID have been left out of adding their views. In this study I hope to gather information from adults with intellectual disability in order to use it as a start to understanding how their health needs can be better catered for.

2. WHAT WILL BE ASKED OF MY FAMILY MEMBER/WARD?

Before interviews are started your family member/ward will be asked to attend an information session where they will be given all the information about the study and will be asked to think about their willingness to participate. They will not be asked to agree straight away but will be given a few days to think about it before deciding. Should they agree to be part of the study they will go on to take part in an interview.

Your family member/ward will participate in one interview with me.

During this interview he/she will be asked to answer questions that about their health and how they keep themselves healthy. He/she will also be asked to relay any stories or experiences that they may have had regarding their health or accessing health services. He/she will be asked to speak about how they feel about these experiences and how they feel about their health in general.

If your family member/ward does not wish to answer any of the questions during the interview, he/she may say so and I will move on to the next question. The interview will take place in the boardroom at Sunfield Home Howick and no one else but me will be present unless the participant asks for someone else to be there.

Following the completion of all the interviews, I will ask the participants to take part in one focus group each. These focus groups will take the form of a discussion with between 6 and 10 participants. I will guide the discussions. During these focus groups I will begin by making the participants feel comfortable. I will then give them some feedback about the common themes that I have found in the interviews. I will ask them to give me their thoughts and opinions on how accurate these themes are and how well I have understood their experiences. This discussion will take place in a group, as I will be checking the accuracy of the information that applies to all or most of the participants. I will not share any individual or personal details or stories during these group sessions.

The information will be recorded but will be kept confidential, and no people other than me, Prof. Leslie Swartz and my co-researcher Dr Kate Sherry will have access to the information documented during the interviews or focus groups. The recordings will be kept locked up in my possession and deleted after the interviews have been accurately transcribed onto a password-protected computer and back-up disc.

Overall I am asking your family member/ward to participate in one information session, one interview and one focus group. The interview, which will take about 1 hour of her/his time, will be conducted at the home over a weekend. A few weeks following the interview there will be a focus group that will also take about 1 hour. All together I am asking for about 2 and a half hours of their time.

Basic demographic data will also be accessed from records at Sunfield Home Howick. This data will consist of age, gender and primary diagnosis. These details along with the interview records will be ascribed to a pseudonym to protect the participant's identity and then kept protected in the same manner as the rest of the data.

All information and contact sessions will be made available and conducted in the language of choice for the participant.

3. POSSIBLE RISKS AND DISCOMFORTS

Possible risks may include an emotional response to some of the questions, as the subject matter will be about experiences of health and health services. It is possible that your family member/ward may feel uncomfortable or under distress during or after the interview process. Should the participant feel this way the scheduling of external counseling sessions will be made available with me (the researcher) being responsible for the cost implications. It is important to know that the participant also has the option to refuse to answer any question that they do not want to. He/she also does not have to give me any reason for deciding not to participate.

In addition to this, I will be watching for signs of distress and may bring the interview to a close should I see any reason for concern.

4. POSSIBLE BENEFITS TO THE PARTICIPANT OR TO THE SOCIETY

There is no immediate benefit to participants although there is the strong possibility that participants may feel some emotional benefit from the opportunity to speak freely in the interviews. The opportunity to share one's thoughts views and stories can be an enjoyable experience.

Secondly the participants will benefit from the use of the results of the study. The results of this study will not only be published for the use of others but I will also be using any information I can to improve the participants' experiences of health within the setting of this facility. I will make use of the recommendations that they give me in the interviews to improve the services offered wherever I can.

5. PAYMENT FOR PARTICIPATION

Your family member/ward will not be paid for taking part in this research but he/she will be given refreshments to enjoy at the time of their interview and focus group. Once all the information has been gathered then I will be taking all the participants out for a milkshake, as a group to thank them for their time.

6. PROTECTION OF YOUR AND YOUR FAMILY MEMBER/WARD'S INFORMATION, CONFIDENTIALITY AND IDENTITY

It is likely that people will ask questions about the research that is being conducted. It is important for you to know that if your family member/ward participates I will not be sharing information about them outside of the research team. The information that is gathered will be kept safe under lock and key as well as on password-protected devices only.

When recording the results I will assign a pseudonym to each participant and use that name to identify each participant. Only I will know what each participant's pseudonym is and that information will be locked away. When writing up the research findings I will exclude any information or quotations that could be used to identify your family member/ward.

During the focus group I will ask all the participants to keep the contents of the discussions confidential. It is important to note, however that I cannot guarantee that other participants will not share information with those outside of the group. I will not, however, be asking any in-depth personal questions during the focus groups, merely checking the validity of my information, so this risk will be less.

All electronic and paper copies of consent forms and transcribed interviews will be kept for a period of 5 years before being destroyed.

7. PARTICIPATION AND WITHDRAWAL

You do not have to agree that your family member/ward can talk to me. You can choose to say no and any services that they receive at Sunfield Home Howick will not change or be affected by your refusal in any way. I know that decisions involving loved ones can be difficult but you may ask as many questions as you would like and I will take the time to answer them. You do not have to decide immediately. You can take time to think about it and let me know once you have decided.

You may choose not to have your family member/ward participate in this study and your family member/ward does not have to take part in this research if she/he does not wish to do so. Your family member/ward will not suffer any discrimination or adverse consequences from choosing not to participate in this study. It is also possible at any time in the study process for you or your family member/ward to withdraw without any negative consequences. Your family member/ ward may also refuse to answer specific questions and still remain in the study. Should your family member or ward choose to withdraw from the study the data which they have provided up to that point will be excluded and all recordings deleted accordingly.

8. SHARING OF RESEARCH FINDINGS

The information that is gathered in this study is ultimately intended for the improvement of health and services for PWID and so it will be shared with various people.

Information will first be shared with the people who participated in the study. Following this feedback will be given to the guardians/families of the participants and the management of the residential facility. After this information will be shared with the rest of the staff and residents of the facility.

The results of this study will also be shared through a written thesis, which will be submitted to Stellenbosch University, and journal articles that will be written for publication.

9. RESEARCHERS' CONTACT INFORMATION

If you have any questions you may ask them now or later, even after the study has started. If you wish to ask questions later, you may contact me at helengatleyot@gmail.com or on 0728976249.

This proposal has been reviewed and approved by the Stellenbosch University Research Ethics Committee (REC): Humanities, which is a committee whose task it is to make sure that research participants are protected from harm. If you wish to find about more about the REC, Aden Williams (Administrative

Assistant: REC: Humanities), 021-8089185. The project number study is REC-2018-6557.

10. RIGHTS OF RESEARCH PARTICIPANTS

Your family member/ward may withdraw their consent at any time and discontinue participation without penalty. Neither you nor your family member/ward are waiving any legal claims, rights or remedies because of your participation in this research study. If you have questions regarding your or your family member/ward's rights as a research participant, contact Ms. Maléne Fouché [mfouche@sun.ac.za; 021 808 4622] at the Division for Research Development.

DECLARATION OF CONSENT BY THE PARENT/ LEGAL GUARDIAN OF THE PARTICIPANT

As the parent/legal guardian of the participant I confirm that:

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

By signing below, I ________________________________ (name of parent/guardian) agree that the researcher may approach my family member/ward to take part in this research study, as conducted by Helen Gatley.

____ ______________________

Signature of Parent/Legal Guardian **Date**

DECLARATION BY THE PRINCIPAL INVESTIGATOR

As the **principal investigator,** I hereby declare that the information contained in this document has been thoroughly explained to the parent/legal guardian. I also declare that the parent/legal guardian was encouraged and given ample time to ask any questions.

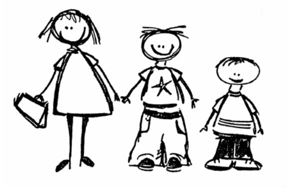
____ ______________________

Signature of Principal Investigator **Date**

Appendix D: Information and Assent form for participants

	STELLENBOSCH UNIVERSITY

ASSENT FORM



WOULD YOU LIKE THIS FORM IN A DIFFERENT LANGUAGE?

IF YOU WANT TO SPEAK ANOTHER LANGUAGE THEN THAT IS OK. YOU CAN CHOOSE ANY LANGUAGE THAT IS BEST FOR YOU.

TITLE OF THE RESEARCH PROJECT: What do people with intellectual disabilty think and feel about being healthy and staying healthy?

RESEARCHERS' NAME: Helen Gatley

RESEARCHER'S CONTACT NUMBER: 033-330 2094

What is RESEARCH?

Research is something we do to find **NEW KNOWLEDGE** about the way things (and people) work. We use research projects or studies to help us find out more about children, teenagers and adults and the things that affect their lives, their schools, their families and their health. We do this to try and make the world a better place!

What is this research project all about?

For this research that I am doing I want to speak to adults with intellectual disability and I want to learn more about how these people feel about health and being healthy. I also want to know about what it feels like for people with intellectual disability to visit places like clinics and hospitals and to visit people like doctors and nurses, therapists and psychologists.

Why have I been invited to take part in this research project?

I have asked for your help with study for a few reasons.

First of all you are an adult with intellectual disability and you live at Sunfield Home Howick.

Secondly you are someone who will be able to understand and answer my questions.

Thirdly you are someone who I think will be able to tell me if you do not want to be part of this research.

Who is doing the research?

I will be doing the research myself. I already work here at Sunfield Home Howick so you know me but I am working with Stellenbosch University in the Western Cape.

I am doing this research because I would like to know more about the questions that I will ask but also so that I can get a Master's Degree at the end.

What will happen to me in this study?

During this study I will first ask you to spend some time with me as you are now, listening to me talk about the study and thinking about if you would be happy to be part of it. After a few days if you decide that you are happy to be part of this study and answer some questions then I will ask you to spend more time with me one weekend or evening. We will go to the boardroom and we will talk for about 1 hour. I will ask you questions and give you a chance to answer.

After I have met with you and everyone else I need to, I will ask everyone to meet with me again but in a group. There will be too many people to all meet together so I will meet with half the people at one time and half at another time. At this meeting I will tell you what I have learnt from everyone and ask you and the others if you think that I understand what you told me and if I am correct. I will not tell the others anything that you told me about yourself. I will only ask about things that most people said were the same and check if I have understood nicely.

Both times that we get together to talk I will record everything that is said. This is only so that I can remember everything. Once I have listened to the recording and written down everything that we said I will delete those recordings. No one else will listen to them but there are 2 people who are helping me who may read what you have said. These people will not know your real name though. The two people helping me will be Prof. Leslie Swartz and Dr Kate Sherry.

Can anything bad happen to me?

There is nothing dangerous in this research for you but it can feel a bit scary sometimes to talk about yourself to another person. Sometimes I also might ask questions that you do not like or make you feel stressed. You are allowed to say that you don't want to answer something. If you feel very uncomfortable you might want to go and talk to someone else about how you feel, like a psychologist or a counselor. You will be able to do this and your family will not have to worry about paying because I will.

Can anything good happen to me?

Sometimes it feels good to talk to someone and have him or her listen to you, which I will try to do well. This might happen to you.

At the end of the research I will take all the answers from all the people and put them together. I will use these answers to try and make things better where I can. There will probably be problems that I can't fix though.

Will anyone know I am in the study?

Your family will know that you are in the study because I have to ask them if they are happy for me to ask you questions.

Staff and residents at the home will know that you are in the study because they will see you going to meet with me but they will not know what you said in our meeting because I will keep that information safe.

Who can I talk to about the study?

If you want to ask questions about the study you can talk to your family or me.

What if I do not want to do this?

If you do not want to do this research then you can say no and you will not be forced. You are allowed to say no even if your family have said yes. You will not get into trouble if you say no. If you say yes to doing this research but later decide that you do not want to take part, then you are allowed to stop at any time. If you do decide to stop part way through the study then I will make sure that I do not keep any of the recording of the times you have talked to me and I will not write about anything that you have said.

Do you understand this research study and are you willing to take part in it?

☐ YES ☐ NO

Has the researcher answered all your questions?

☐ YES ☐ NO

Do you understand that you can STOP being in the study at any time?

☐ YES ☐ NO

____________________________ ________________________

Signature of Participant Date

Appendix E: Interview Guide

Exploring the experiences of adults with ID in accessing health and health care in a small, rural, South African town: A qualitative study - Interview Guide

Introduction:

Thank you for coming to talk to me today. I hope you are feeling relaxed and rested. Please remember that if you feel stressed at any time then you can tell me and we can take a break or if you want, we can stop this talk at any time. You can also tell me if there is any question that you don't want to answer or talk about and we can carry on with something else. Is that ok for you? Are you happy for us to start?

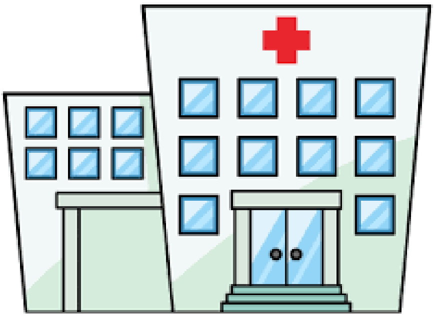
Questions	**Follow up questions and prompts**
I want to start by talking about what it means to be healthy. Can you tell me about what it means to you to be healthy in your life?	• Look at these pictures. Do any of them help you

Is there anything that you do to keep yourself healthy and can you tell me about the things that you do?	• You can use the pictures to help you if you want.
How does it feel when you do things to help yourself to keep healthy?	• How does it feel when you can't do the things that you want to keep yourself healthy? • Are there things or people in your life that help you to keep yourself healthy? • Are there things or people in your life that stop you from keeping yourself healthy and what can you do about them?
We talked about people that might help you to stay healthy before. I want to talk about that again. This could be doctors, nurses, dentist, therapists, psychologists and other people like that. Can you remember a story of a time when you saw or visited a person that to help you and can you tell me the story?	• How did it make you feel when that happened? • What did you say/do then? • When this was all over did you feel better or not? • Were there things in this story that you can think of that made it a good/bad experience for you? What were those things?

You have told me one story of when you visited a ______(doctor or clinic or dentist etc.). Do you have any other stories that were good or bad that you would like to tell me?	• Was there a time when you felt like it was very difficult for you to go to the ……(doctor, clinic etc.)? • Was there a time when going to the …….. (doctor, clinic etc.) was really good for you? • What made it good?
What sort of things or people do you think you need to keep yourself healthy and can you get to those things or people when you need them?	• What happens if you think you need to see a……. (doctor, therapist, dentist etc.)? What do you do? •
Do you have any more things about your health that you would like to tell me about?	

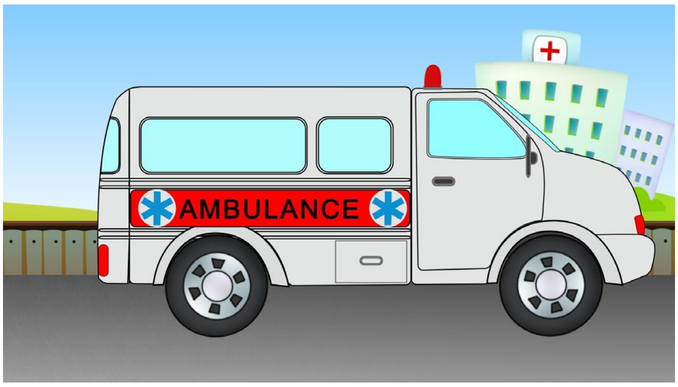
Conclusion:

Thank you for coming here and talking to me today. I'm so thankful for everything that you shared with me. Remember that if you feel stressed or confused at any time about this study that we are part of you can come and ask me.




MARTIN


Medical Clinic
classroomclipart.com


AMBULANCE

Appendix F: Literature Review Search Strategy

In order to examine the literature related to adults with intellectual disability's experience of health I searched the databases listed below in October 2019. Initially I included a thirty-year period from 1989 – 2019 but due to the nature of the search terms far too many articles were found to practically sort through. Following this I limited the time period to 2011-2019 because of the release of the WHO World Disability Report in 2011.

Due to differences in the databases, the search string had to be adjusted for Science Direct, SCOPUS and Google Scholar. The adjustments can be found below.

Databases searched:

Pubmed, Web of Science, ERIC, PsychInfo, Academic Search Premier, Science Direct, SCOPUS, Google Scholar

Limiters

Limiter	**Options Selected**
Peer-reviewed	Yes
Date Limit	2011 -2019
Abstracts available	Yes

Language	English
Age of subjects	Adults only

Search Query

Key Word Category	**Synonyms and Related Terms**
Experience	(experience* OR “lived experience*’)
Intellectual Disability	(‘intellectual disabilit*’ OR ‘mental retard*’ OR ‘intellectual developmental disorder’ OR idiocy OR ‘mental deficien*’ OR ‘general learning disabilit*’ OR ‘Downs syndrome’ OR ‘fragile X syndrome’ OR ‘developmental disabilit*’ OR ‘Cri-du-Chat Syndrome’ OR ‘De Lange Syndrome’ OR ‘X-Linked’ OR ‘Prader-Willi Syndrome’ OR ‘Rubinstein-Taybi Syndrome’ OR ‘Trisomy 13 Syndrome’ OR ‘WAGR Syndrome’ OR ‘Williams Syndrome’
Health	(Health OR well-being OR ‘well being’ OR wellness OR ‘health care’ OR ‘health services’)

Database	**Adjusted search string**
Science Direct	Experience AND ADULT AND (“intellectual disabilit” OR “mental retard” OR “intellectual developmental disorder” OR “mental deficien”) AND (Health OR well-being OR Healthcare)
SCOPUS	(experience* OR "Lived experience*") AND adult* AND ("intellectual disabilit*" OR "mental retard*" OR "intellectual developmental disorder" OR idiocy OR "mental deficien*" OR "general learning disabilit*" OR "Downs syndrome" OR "fragile X syndrome" OR "developmental disabilit*" OR "Cri-du-Chat Syndrome" OR "De Lange Syndrome" OR "X-Linked" OR "Prader-Willi Syndrome" OR "Rubinstein-Taybi Syndrome" OR "Trisomy 13 Syndrome" OR "WAGR Syndrome" OR "Williams Syndrome") AND (health OR well-being OR "well being" OR wellness OR "health care" OR "health services") AND (LIMIT-TO (PUBYEAR , 2020) OR LIMIT-TO (PUBYEAR , 2019) OR LIMIT-TO (PUBYEAR , 2018) OR LIMIT-TO (PUBYEAR , 2017) OR LIMIT-TO (PUBYEAR , 2016) OR LIMIT-TO (PUBYEAR , 2015) OR LIMIT-

	TO (PUBYEAR , 2014) OR LIMIT-TO (PUBYEAR , 2013) OR LIMIT-TO (PUBYEAR , 2012) OR LIMIT-TO (PUBYEAR , 2011)) AND (EXCLUDE (SUBJAREA , "BIOC") OR EXCLUDE (SUBJAREA , "PHAR") OR EXCLUDE (SUBJAREA , "AGRI") OR EXCLUDE (SUBJAREA , "COMP") OR EXCLUDE (SUBJAREA , "BUSI") OR EXCLUDE (SUBJAREA , "ENGI") OR EXCLUDE (SUBJAREA , "ENVI") OR EXCLUDE (SUBJAREA , "ECON") OR EXCLUDE (SUBJAREA , "CHEM") OR EXCLUDE (SUBJAREA , "MATH") OR EXCLUDE (SUBJAREA , "CENG") OR EXCLUDE (SUBJAREA , "VETE") OR EXCLUDE (SUBJAREA , "PHYS") OR EXCLUDE (SUBJAREA , "DECI") OR EXCLUDE (SUBJAREA , "EART") OR EXCLUDE (SUBJAREA , "MATE") OR EXCLUDE (SUBJAREA , "ENER")) AND (LIMIT-TO (DOCTYPE , "ar") OR LIMIT-TO (DOCTYPE , "re") OR LIMIT-TO (DOCTYPE , "cp")) AND (LIMIT-TO (EXACTKEYWORD , "Review") OR LIMIT-TO (EXACTKEYWORD , "Intellectual Disability") OR LIMIT-TO (EXACTKEYWORD , "Intellectual Impairment") OR LIMIT-TO (EXACTKEYWORD , "Autism Spectrum Disorder") OR LIMIT-TO (EXACTKEYWORD , "Cognition") OR LIMIT-TO (EXACTKEYWORD , "Down Syndrome") OR LIMIT-

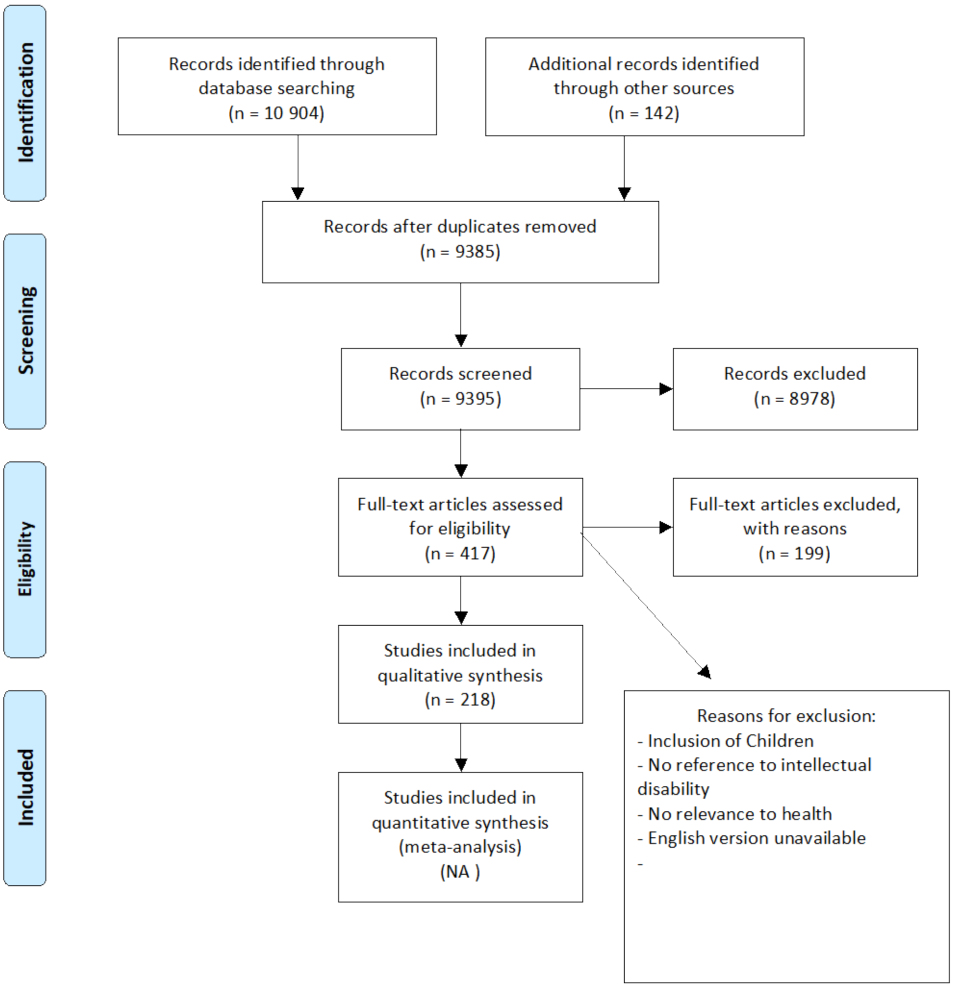
	TO (EXACTKEYWORD , "Developmental Disabilities") OR LIMIT-TO (EXACTKEYWORD , "Developmental Disorder") OR LIMIT-TO (EXACTKEYWORD , "Disabled Persons") OR LIMIT-TO (EXACTKEYWORD , "Mental Disorders") OR LIMIT-TO (EXACTKEYWORD , "Disabled Person") OR LIMIT-TO (EXACTKEYWORD , "Cognitive Defect") OR LIMIT-TO (EXACTKEYWORD , "Intellectual Disabilities")) AND (EXCLUDE (EXACTKEYWORD , "Child") OR EXCLUDE (EXACTKEYWORD , "Adolescent") OR EXCLUDE (EXACTKEYWORD , "Preschool Child") OR EXCLUDE (EXACTKEYWORD , "Child, Preschool") OR EXCLUDE (EXACTKEYWORD , "Nonhuman") OR EXCLUDE (EXACTKEYWORD , "Infant") OR EXCLUDE (EXACTKEYWORD , "School Child") OR EXCLUDE (EXACTKEYWORD , "Infant, Newborn") OR EXCLUDE (EXACTKEYWORD , "Newborn") OR EXCLUDE (EXACTKEYWORD , "Animal") OR EXCLUDE (EXACTKEYWORD , "Child Development") OR EXCLUDE (EXACTKEYWORD , "Children")) AND (EXCLUDE (DOCTYPE , "re") OR EXCLUDE (DOCTYPE , "cp"))

Google Scholar	health AND experience AND adults AND (disability intellectual OR retard OR mental OR cognitive OR developmental) AND (-child -OR -children -OR –adolescents)

When eliminating articles as per the Prisma diagram (2009) in Appendix G, where articles were not available through the Stellenbosch University or University of Cape Town libraries I excluded them, except in the case of obvious relevance and importance to the study, in which case I purchased them from the publishers.

Appendix G: Prisma Diagram for literature inclusion

PRISMA 2009 Flow Diagram



From: Moher D, Liberati A, Tetzlaff J, Altman DG, The PRISMA Group (2009). *Preferred Reporting Items for Systematic Reviews and Meta-Analyses:* The PRISMA Statement. PLoS Med 6(6): e1000097. doi:10.1371/journal.pmed1000097

For more information, visit www.prisma-statement.org.

Appendix H - Summary of Study Results for Dissemination to participants and their families

Exploring the experiences of adults with intellectual disabilities in accessing health and healthcare in a small, rural, South African town.

Procedure

- I first approached the general manager of the home for consent. I then also spoke to the residents committee at one of their meetings and asked if any of them, as representatives of the resident body, had objections to my conducting of the research at the home. I then proceeded to apply for ethical approval through Stellenbosch University, which was granted.
- For this study, I began with a short list of 31 potential participants and asked for feedback from the medical department, housemothers, and general manager regarding the suitability of the residents for the study after which I eliminated four names from the list.
- I contacted 18 families over several weeks with requests for consent to approach their family members and received 16 positive responses in time.
- I approached each of the prospective participants to ask whether they would be willing to participate in the study. 15 candidates said that they wished to participate and one declined.

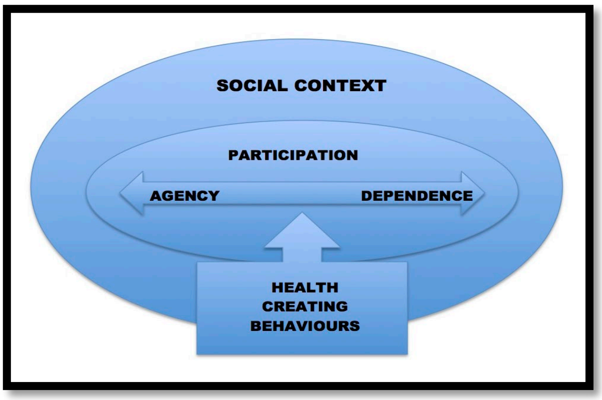
- The interviews took place after normal working hours in the home's boardroom.
- My initial data generation took place as semi-structured interviews, for which I developed an interview guide with the assistance of another resident.
- In one case, once we had started talking, I felt that the participant had not truly understood the purpose of our conversation and so I switched off the recording device and excluded the interview from the research.
- Once the interviews were complete, I had 14 total interviews and decided that this number was adequate for my study.
- For the protection of the participants, I allocated pseudonyms to each one in the transcribed interviews.
- Once initial themes were identified in the data, I held 2 focus groups with half of the participants in each group. The purpose of these groups was to provide data validation by allowing the participants to hear and give feedback on the themes, which I had crystalised out of their interviews. Sadly, two of the participants were unable to participate in the focus groups as they were away from the home, traveling with family at the time.

Ethical Considerations

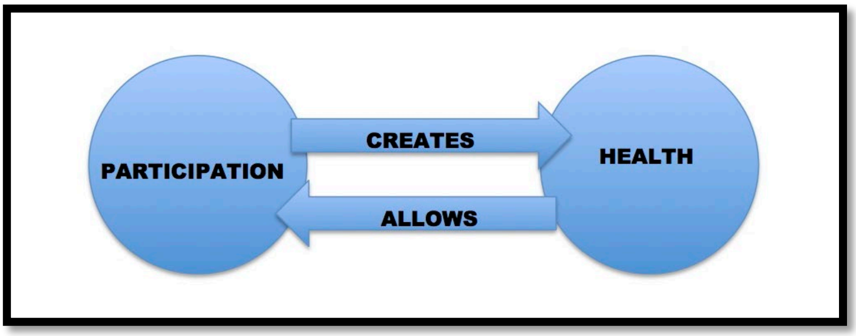
The two biggest areas of concern for me in planning this research were the process of obtaining consent and the possible blurring of my roles as therapist and researcher. Every effort was made to maintain the highest standard of ethics possible without creating barriers that would unfairly exclude participants from the study.

Findings

- All the actions taken or performed in the creation of health are deeply embedded within a social context. This is particularly important for the participants of this study who are part of a specific closed community also also by virtue of their disability are often excluded from expanding or changing the social context in which they find themselves.
- I have imagined all health creating behaviours as existing on a spectrum of agency to dependency. These behaviours each take place through participation of the person within a social context, and as such behaviours cannot be seen as static along this spectrum but rather shift up and down depending on changes within the context and the person engaging in them. These changes could be anything from the presence or absence of specific people to organisational policy changes that lead to adjustments in accepted norms of behaviour within the social context.



- When asking participants to describe what it would mean for them to be healthy, as well as whether they saw themselves as such, I found that although the expected responses of healthy eating, exercise and hygiene did feature, many of them described health in terms of a general feeling of wellness rather than being attached to a lack or presence of disability, illness, treatment or even independence.
- The participants also saw health as important as a means to participation and engagement in their lives rather than a goal in and of itself.
- Although in my explanations of findings I have created a divide between a description of what health looks like and participation as a component of health creation, in many of the interviews participation emerged as almost synonymous with health.
- The cyclical relationship between participation and health is represented in the image below.
- While health is created through participation, being healthy also allows for participation in life. In this way participation can be seen as both a contributor to and consequence of health.



- I had expected to find either; a frustration among the participants at their lack of agency and self-determination given the institutional context of their lives; or a sense of accepted reliance on the rules and governance of staff in the institution such that they had stopped seeing that there may be another way to live. What I found however was far more nuanced.
- The participants identified several behaviours that could be performed in the creation of health. I have grouped some of these health-creating behaviors under the general heading of taking care of yourself with the others being are reducing stress, being a friend and talking to God.
- The task of looking after oneself is one that involves a few components such as healthy eating, keeping fit and active, hygiene and cleanliness, getting rest and stimulating the mind. Along with these positive behaviours though, the need to avoid harmful behaviours was also identified by the participants.
- The social context is the space in which all health creation occurs. Within this space each health creating behaviour is influenced by and embedding within the social realities.
- The idea of connectedness to others was something that arose repeatedly in interviews, whether those others are friends, family or the greater community.
- There is an inherent power dynamic in the provision of health services between the health professional and the patient that runs largely along lines of expertise.

- One of the first barriers to be overcome in the provider-patient relationship is communication.
- Inconsistency in health service experiences can cause an ongoing insecurity about future interactions with health care providers.
- Spiritual growth and well-being is an important component of health
- Several participants expressed the sense that they felt that they are a burden to those around them which caused distress
- There was a sense from a few participants that they experienced a constant stress from living in a group setting. The teaching of stress management techniques could therefore be useful to them.