



“Life’s About Choices”: Exploring the everyday occupational choices of young adults with intellectual disability in a community context in South Africa.

Submitted in partial fulfilment of Masters of Philosophy in Intellectual Disability

Cole Goldberg

GLDNIC006

colegoldberg.ot@gmail.com

University of Cape Town, Faculty of Health Science

Department of Psychiatry and Mental Health

Research Supervisor: Professor Sharon Kleintjes

Co-supervisor: Professor Colleen Adhams

Date: 24 October 2019

The copyright of this thesis vests in the author. No quotation from it or information derived from it is to be published without full acknowledgement of the source. The thesis is to be used for private study or non-commercial research purposes only.

Published by the University of Cape Town (UCT) in terms of the non-exclusive license granted to UCT by the author.

Plagiarism Declaration

Plagiarism Declaration

I know that plagiarism is wrong. Plagiarism is to use another's work and pretend that it is one's own.

I have used the American Psychological Association 5th convention for citation and referencing. Each contribution to, and quotation in, this thesis from the work(s) of other people has been attributed and has been cited and referenced.

This thesis is my own work.

This thesis has been submitted to Turnitin and I confirm that my supervisor has seen my report and any concerns revealed by such have been resolved with my supervisor.

I have not allowed, and will not allow, anyone to copy my work with the intention of passing it off as his or her own work.

Name: Cole Goldberg

Student number: GLDNIC006

Signature:

Signed by candidate

Date: 24 October 2019

Acknowledgements:

I am exceptionally grateful to all those who have helped and supported me throughout this Master's journey.

To Professor Colleen Adnams: Thank you for seeing the potential in me and selecting me as your final student for this programme. Thank you for helping me develop the foundations for my journey in this field of intellectual disability.

To Professor Sharon Kleintjes: Thank you for the motivation, guidance and support throughout this process. Thank you for your wisdom, patience, understanding, late nights, long weekends, encouragement, and for pushing me further than I thought I could go.

To Vera Grover, and her scholarship from the Western Cape Forum for Intellectual Disability, thank you for funding my studies, and making this research possible.

To the participants from The Living Link: Thank you for giving up your time, for the effort, and for talking to me and trusting me to sharing your experiences. Your voices are important, and I value that you allowed me the opportunity to listen.

To my family and friends, thank you for supporting me through this process and, particularly to my mom who always taught me from a young age, that in truth "life really is all about choices."

"And all we have, in the end, are the choices we make." – Naomi Alderman, Disobedience

Abstract

Background: It is well documented in the literature in the intellectual disability field that choice people with intellectual disabilities is limited. The human need to experience and inform everyday life choices, and the limited opportunities to do so, results in a contemporary health and human rights issue. Research Question: This study aims to explore what informs the everyday occupational choices made by young adults with intellectual and developmental disabilities in a community based setting in South Africa. Method: Qualitative interviews and a focus group were held with six young adults, who were recruited through a local non-profit training organisation. Results: Respondents identified (1) being different, (2) having limited choices, (3) accepting and staying small or (4) challenging and growing up, were the four core themes that arose from the interviews. Conclusion: It became evident that everyday occupational choices are co-constructed in context, where factors that were identified are consistent with those from the international literature which show that people with intellectual disabilities are widely stigmatised and prohibited from choice making, for several reasons, both intrapersonal and contextual. Implications: This study highlights the influence and importance of raising awareness and consciousness in society so that counter-hegemonic practices can promote occupational and social justice and change attitudes to ensure that people with disabilities have the choice to engage in balanced, meaningful occupations.

Table of Contents

PLAGIARISM DECLARATION	2
ACKNOWLEDGEMENTS:	3
ABSTRACT	4
DEFINITION OF TERMS:	7
LIST OF FIGURES:	8
LIST OF TABLES:	8
CHAPTER ONE	9
INTRODUCTION	9
CHAPTER TWO: LITERATURE REVIEW	26
CHAPTER THREE: METHOD OF INQUIRY	43
3.1 RESEARCH DESIGN:	43
3.2 STUDY SETTING:	44
3.3 THE RESEARCHER:	45
3.4 STUDY POPULATION AND SAMPLING:	46
3.5 DATA COLLECTION	47
3.6 DATA MANAGEMENT	50
3.7 DATA ANALYSIS	50
3.8 SPECIAL CONSIDERATIONS	52
3.9 ENSURING RESEARCH RIGOR	53
3.9.1 CREDIBILITY	53
3.9.2 DEPENDABILITY	54
3.9.3 TRANSFERABILITY	54
3.9.4 CONFIRMABILITY	55
3.10 ETHICAL CONSIDERATIONS	55
3.10.1. AUTONOMY	55
3.10.2. BENEFICENCE	56
3.10.3. NON- MALEFICENCE	56
3.10.4. CONFIDENTIALITY	56
3.10.5. JUSTICE	57
CHAPTER FOUR: RESULTS	58
CHAPTER FIVE: DISCUSSION	74
CONCLUSION	89

REFERENCES	91
APPENDIX 1: INFORMATION SHEET / ADVERT	98
APPENDIX 2: INFORMED CONSENT	99
APPENDIX 3: VIGNETTES	101
APPENDIX 4: QUESTION SCHEDULE	102
APPENDIX 5: CODING FRAME	103

Definition of Terms:

- Choice: The outcome of the process of choosing or choice making. Merriam-Webster (2019) illustrate the value placed on choice by also explaining it as the “best part or the best one”. This is the act of picking between a number of possibilities.
- Choice Making: The act, opportunity or power of choosing (Merriam-Webster, 2019)
- Intellectual Disability: Intellectual disability is defined as having impairments of general mental abilities that impact adaptive functioning, affected by the interaction between persons with impairments and attitudinal and environmental barriers that hinders their full and effective participation in society on an equal basis with others, (American Psychiatric Association, 2013; United Nations, 2006).
- Occupation: All the things that people need, want or have to do, on a daily basis both ordinary and extraordinary (Motimele & Peters (2017)
- Occupational Choice: Refers to the occupational science construct which involves the selection of occupations, as co-constructed through an individual, group and community’s transactional relationship with their context (Galvaan, 2015).
- Social Model: The social model is a model or way of thinking that identifies environmental and contextual barriers that contribute to the exclusion of people with disabilities from society. This model recognizes persons with disabilities as equal citizens with full political, social, economic and human rights (United Nations, 2006). Instead of looking at disability within a person, the social model looks at the external factors that disable them.

List of Figures:

Figure 1: Selection process for inclusion of studies

Figure 1: "Knapsack of The Lack of Privilege": A model created to illustrate the study findings in young adults with intellectual disability

List of Tables:

Table 1: Characteristics and Findings of Included Studies

Chapter One

Introduction

This section will provide an overview of disability in the context of South Africa, current literature on how everyday occupational choices have been negotiated for young adults with intellectual disability and discuss concepts from occupational choice frameworks. This will inform the conceptual framework that will be used in this study to generate insights into what informs everyday occupational choices, and the barriers and enablers found by a group of young adults with intellectual disability across multiple community contexts in Cape Town, South Africa. This chapter will also outline the research question, aims, and objectives of this study.

Background to the Study:

1.1 Disability in the South African Context

Before 1994, in South Africa, the Apartheid government considered disability as a matter of social welfare and a medical concern and used what is known as the "medical model" (Parliament of the Republic of South Africa, 2015). This perspective views impairments of a person's body or mind as the source of their disability and offers medical treatment aimed at curing and returning the person to "normal functioning" (Parliament of the Republic of South Africa, 2015). The term "medical model" was coined in the early 1970s (Laing, 1971 as cited in Sarto-Jackson, 2018), and is used to explain the assumptions and understanding of disease and disability. The medical model relies heavily on labels and diagnoses (Byrne, Happell, Reid-Searl, 2016)

The model does not consider contextual factors which include, the role that barrier-free environmental access can make to the independence and human dignity of persons with disabilities; nor did it consider the human, social, political and economic rights of persons with disabilities, the rights to full inclusion and integration into society as well as the abilities of

people with disabilities (Republic of South Africa, 2015). This model perpetuated the marginalization and exclusion of people with disabilities within the South African context. Both internationally and nationally there was a need for a shift in thinking around disability, and so the national socio-political context enabled the country to adopt and integrate the global changes that were happening to look towards health reform, improving the health care service, particularly in terms of access and affordability. (Republic of South Africa, 2015; Du Plessis, 2013, Byrne et al, 2016).

The African National Congress (ANC) came to power in South Africa in 1994, as the first democratically elected government, and on the 8th of May 1996, the first democratically elected president, President Nelson Mandela, endorsed the South African Constitution, the first legislation to promote equity and justice among all South African citizens (Howell, Chalklen, & Alberts, 2006). This new constitution was important because it extended basic human rights to all citizens for the first time in South Africa's history, outlawing unfair discrimination against any person, a success for people with disabilities (Howell et al, 2006). The Constitution's recognition that disabled people are discriminated against because of their impairments, meant that disability would be an important consideration in new legislation and policy that make up South Africa's legal and policy framework (Howell et al, 2006).

The White Paper on an Integrated National Disability Strategy (INDS) (Parliament of the Republic of South Africa, 1997), was informed by the United Nations Standard Rules for the Equalization of Opportunities for Persons with Disabilities and the 1992, Disability Rights Charter which was developed by Disabled People South Africa (DPSA), which is a national disabled people's organisation comprised of various representative organizations of persons with disabilities. Unlike the medical model, the INDS applies a "social model" to address disability (Parliament of the Republic of South Africa, 2015; Retief & Lesosa, 2018).

The social model was inspired by the activism of the British disability movement in the 1960s and 1970s in response to the medical model and the limitations thereof (Retief & Letsosa, 2018; Levitt, 2017). According to the social model: disability is ultimately a socially constructed

phenomenon (Retief & Letsosa, 2018; Levitt, 2017, Woods, 2017) with implications for the socio-political and economic inclusion - or exclusion of people with disabilities in mainstream society.

A social model addresses the impact that barriers have on the full participation, inclusion, and acceptance of persons with disabilities as part of mainstream society. While the social model does not deny the reality of a person's 'impairments', it focuses on the abilities of persons with disabilities, recognizing persons with disabilities as equal citizens with full political, social, economic and human rights (Parliament of the Republic of South Africa, 2015; Du Plessis, 2013).

Social model theorists have responded to critiques by pointing out that they do not deny the impact of illness or the role of health professionals, but rather identify the difference between a person's illness/impairments and their disability (Retief & Letsosa, 2018). The social model acknowledges and emphasizes barriers in the environment (eg physical and attitudinal) which disable the person, highlighting the need for broader systemic and attitude changes in society; as well as the provision of accessible services and activities; and the mainstreaming of disability to ensure full inclusion of persons with disabilities as equals (Parliament of the Republic of South Africa, 2015, Retief & Letsosa, 2018, Du Plessis, 2013). However, while the social model is used ideologically to advocate for marginalised groups, it does have significant limitations (Du Plessis, 2013). Polarising the medical and social models is not constructive, as both have limitations - considering how disability in itself is highly complex.

Du Plessis (2013) highlighted some of the critiques of the social model, for example, some may use the model to the extreme whereby the personal characteristics are not considered at all, as well as a perspective which may consider too wide of a scope of the causes of disability. Despite the critiques, she does acknowledge that this model adequately captures a rights-based framework that is useful when addressing human rights concerns of people with disabilities (Du Plessis, 2013).

South Africa has ratified the United Nations Convention on the Rights of Persons with Disabilities (UNCRPD) (United Nations, 2006), committing the country to respect and implement the rights of persons with disabilities as documented in the various articles of the convention. Despite its inclusive, emancipatory legislative and policy framework, it has been noted that South Africa is still one of the most unequal countries in the world, socially and economically (Sulla & Zikhali, 2018). This is crucial as disabled South Africans are collectively “amongst the nation’s poorest, even within a country characterized broadly by atrocious levels of economic inequality” (Swartz & Watermeyer, 2006. p.1). Within this context, disability, poverty, gender, and race are intimately linked (Emmett, 2006). Human rights are underpinned by equality and dignity, but people with disabilities have historically been discriminated against and marginalized, resulting in an ongoing struggle for their rights.

The rationale for the choice of the social model in this study is in how it underpins a human rights ethos. The South African disability movement adopted the social model of disability, applying a human rights and development approach, a means of advocating for the rights of people with disabilities (Du Plessis, 2013). The choice of a social model to underpin this study is that the tenets of the social model suggest that we should be confronting disabling societies, challenging the relationships between service users and service providers, addressing social exclusion and isolation and valuing the lived experience and expertise of people who live with a disabling condition (Byng & Duchan, 2005).

1.2 Intellectual Disability: Definitions and Terminology

The term 'intellectual disability' has developed from a long line of stigmatizing terms or labels used for this condition. These conceptions have changed and shifted over time, as ideas of social justice, and society has changed (Clegg & Bigby, 2017). Multiple terms are currently in use, including: intellectual disability, learning disability, intellectual and developmental disorders. There has been an ongoing search to find the best possible terminology and to eliminate stigmas and stereotypes. The co-presence and blending of the medical model and social models of disability are evident in the different definitions and terms which are currently being used. The term 'intellectual disability' has been derived from blends of the social and medical model, using the best attributes of each. Intellectual and Developmental Disabilities (IDD) is a collective term for intellectual and or developmental disabilities, where 'intellectual disability' is one of the many developmental disabilities.

1.2.1 Terminology

Historically, terms such as 'idiots', 'fools', 'arrested development', 'imbeciles', 'mental deficiency' and 'morons' were used in South African legislation to describe people with intellectual disability (Fisch, 2011; Girimaji & Pradeep, 2018; Reynolds, Zupanick & Dombeck, 2018). For example, in the International Classification of Diseases (ICD) 6, which is a World Health Organisation diagnostic coding system for medical conditions, the condition was named 'mental deficiency' and was used with terminology such as 'borderline', 'imbecility,' 'idiocy' in the description (Girimaji & Pradeep, 2018). The term 'Mental Retardation' was introduced into the ICD-8 and has been retained in subsequent revisions (Girimaji & Pradeep, 2018)

The ICD 11, which was launched in June 2018 and which was tabled at the World Health Assembly in May 2019 for acceptance by member states, including South Africa, will come into effect in January 2022 (WHO, 2019). The ICD-11 has proposed a change from 'Mental

Retardation' to 'Disorders of Intellectual Development (DID)' as the terminology was changed due to the negative descriptions of this population (Girimaji & Pradeep, 2018).

In contrast, the term 'intellectual disability' has been in wide use for at least 20-30 years (Fisch, 2011). According to Fisch (2011), the term is less precise than 'mental retardation' as it does not incorporate a developmental nature and could result from brain trauma or a neurodegenerative disorder. Fisch (2011) further proposes that there are better terms available that incorporate a developmental aspect.

Also framed within the medical model, in the fifth edition of Diagnostic and Statistical Manual of Mental Disorders, (DSM V), the term 'intellectual disability' is further elaborated in brackets as 'intellectual and developmental disorder' (American Psychiatric Association, 2013).

In contrast, in the United Kingdom, the term "learning disability" has been the preferred term, instead of 'intellectual disability' as it has been chosen by people with disabilities themselves as a means of self advocacy (Cluley, 2017). It was noted by Fisch (2011) that 'special needs' is an umbrella term that is also used to describe learning disabilities, intellectual disabilities and speech and language delays. And yet in some journals published in the UK, they refer to the same population as intellectually disabled (Fisch, 2011).

This shows that there is a clear need for consciousness and sensitivity in the use of terms to describe people, given the social stigma and discrimination associated with labels. Fisch (2011) proposes that in the future the term 'disabled' may be as offensive as 'retard.' With regard to people with disabilities, the White Paper on The Rights of Persons with Disabilities (Parliament of the Republic of South Africa, 2015) notes that language reflects the social context in which it is being used. This plays an important role in perpetuating discrimination and segregation, emphasizing that the use of language needs to be considered as a powerful tool to facilitate change (Parliament of the Republic of South Africa, 2015). Negative words and stereotypes are a barrier to understanding the reality of disability (Parliament of the Republic of South Africa, 2015).

Watermeyer (2006), addresses the concept of 'othering,' and explains that this is how we construct views of ourselves, our identities, and how we view those who are different from us. Watermeyer contends that disability discourse has created the social construct that people with disabilities are viewed as broken, damaged, defective, creating an environment where someone who owns an identity such as 'disabled' may come with a series of stereotypes and assumptions. Clegg and Bigby (2017) found that often many people with mild intellectual disability, in fact, reject the label of intellectual disability, rejecting the stigmas that are associated with the label of being disabled, and "prefer the social model position where society should change and not them (p.82)". This highlights how labels have been constructed by people without disabilities who have created a disability discourse which 'others' people with disabilities, showing the need for greater societal change.

This disability discourse indicates that disabled people, as a group, have suffered marginalization, shaped by power relations, and have been assigned an identity that is based on stereotypes and assumptions. Recently people with disabilities have sought to change their circumstances, focusing on their rights, in part by changing the words used to describe them, and rejecting certain labels (Clegg & Bigby, 2017). The sense that people with disabilities need 'fixing' suggests that they cannot have a good life with their current level of functioning. This results in a necessary consciousness around language, as terminology affects and shapes the lives of people with intellectual disabilities (Cluely, 2017).

1.2.2 Definitions:

According to the ICD 11, DID refers to disorders of intelligence which encompass a wide range of skills within the umbrella term of intelligence, including: cognitive abilities, adaptive function, and new learning ability.

In the DSM V, the term 'intellectual disability' is elaborated in brackets as 'intellectual developmental disorder'. Intellectual disability is defined here as having impairments of general mental abilities that impact adaptive functioning in three domains, specifically the

conceptual domain, the social domain and the practical domain (American Psychiatric Association, 2013). Intellectual disability is clustered into four subgroups, mild, moderate, severe and profound intellectual disability, depending on standardized psychometric testing as well as adaptive functioning scales, conducted in a clinical assessment (American Psychiatric Association, 2013).

The World Health Organization's International Classification of Functioning, Disability and Health (ICF), shifts away from the medical model and instead uses a social model lens where intellectual disability is viewed as a multi-dimensional phenomenon, known as a biopsychosocial classification system which includes participation restrictions, environmental barriers and limitation such as those in body functions, personal factors and activity skills (Arvidson, Granlund & Thyberg, 2008).

The UNCRDP's definition of disability, considers more than just a medical condition, instead looking at a whole person in context. This convention states that people with disabilities are characterised as those who have long-term physical, mental, intellectual or sensory impairments where: "disability results from the interaction between persons with impairments and attitudinal and environmental barriers that hinders their full and effective participation in society on an equal basis with others" (United Nations, 2006).

For the purpose of the study, the term "intellectual disability" will be used, as it best encompasses the term used in South African legislation "intellectual disability" but also implies that there is a developmental component and is considered to be a developmental disability. The definition of intellectual disability will be framed through the UNCRPD's definition, which highlights the transactional relationship between disability and context.

1.3 The Young Adult Life Stage

A particularly vulnerable life stage is the transition from childhood to adulthood: the young adult stage. Given the barriers to participation they face, this is especially true for young people with intellectual disability (Tarleton & Ward, 2005; Mill, Mayes, McConnell, 2009).

The transition from childhood to adulthood is commonly associated with a shift to greater autonomy in relationships and occupations, but for many young people with intellectual disability, adulthood might continue to be marked by lack of autonomy and a sense of being controlled by others, leading to a feeling that "adult status therefore remains illusory" (Witsø & Kittelsaa, 2017; Mill et al, 2009, pg 195). Autonomy refers to one's ability to be self directed, and deals with volition and drive, while independence refers to one's capacity to engage without the influence or assistance of others.

Bosch (2016) highlighted the importance of promoting the ability to represent one's own choices, or self-advocacy from a young age: "If we do not promote self-advocacy (or a sense of autonomy) from an early age – we keep the people with intellectual disabilities in a state of dependency, relying on the assistance of others, reducing their ability to make critical decisions or understand they have the right to express themselves (p.55)." It has been shown that opportunities for choice making have been limited across all life domains, from choice-making in ordinary challenges of growing up, school, college or employment, and also from child to adult social support and health services (Tarleton & Ward, 2005).

This notion was echoed by Sparks (2013), in that the common act of denial of young people with intellectual disability's right to choose the occupations they engage in, is an act of disempowerment, preventing them from learning to advocate for themselves and improve their quality of life, and ultimately from living a self-determined life.

1.4 Occupation and Occupational Choice

a) What is Occupation?

Motimele and Peters (2017) agree that there is no shortage of definitions of the term occupation and believe in its simplest form, took a combination of definitions, and constituted occupation as:

All the things that people need, want or have to do, on a daily basis both ordinary and extraordinary (Clark et al, 1991; Fisher, 1998)

Christiansen, (1999) describes how engaging in positive, healthy everyday occupations is crucial for the development of a person's identity and self-image. "When we build our identities through occupations, we provide ourselves with the contexts necessary for creating meaningful lives (p. 547)." Van Niekerk (2014) echoed this sentiment and stated that "an individual needs occupation to survive, flourish and have needs met and maintain physical, mental and social capacities (p. 49)." Wilcock, (1999) acknowledges that occupation is inherently built by doing, being and becoming, highlighting the importance of engagement in occupation for the development of one's identity.

b) What is Occupational Choice?

Occupational Choice is a concept within the field of occupational science which provides a lens or a perspective through which to look at how and why people make their everyday choices (Galvaan, 2015).

In the past, occupational choice focused on a person, and their unique choices, but neglected to address the influence of context (Galvaan, 2015). Occupational choice was historically viewed from an individualist perspective, looking at individual clients, not at general populations, similar to older literature on choice making for young adults with intellectual disabilities. The literature mainly comes from higher income countries, valuing independent, individual choice making (Galvaan, 2015; Fyson, 2013).

Fyson et al (2013), say that all people are interdependent, and every decision is relational rather than independent. This is in line with the construct of occupational choice, in that a person's choice of occupations, is co-constructed (Galvaan, 2015). Van Niekerk (2014), as well as Townsend and Wilcock (2004) agree that occupational engagement is in nature, interdependent and context related. Any activity you engage in is dependent on the people you engage with and the space or context in which you find yourself.

Choice making (also referred to as acts of self-determination, or autonomy) is complex and multi-dimensional (Brown & Brown, 2009). When a person makes a choice about any occupation, or daily activity, they have a multitude of things to consider, such as: past experience, understanding of the topic at hand, cultural and contextual influences and expectations. Smyth and Bell (2006) identified factors that affect choice-making for people with intellectual disabilities, which illustrate that choices are indeed contextually bound, indicating that it is about far more than just capacity. They found the following individual factors: cognitive ability, lifestyle, socio-economic status, past experience of choice, (lack of) knowledge, degree of dependency, physical ability, genetic and physiological features, and in their study, (specific to food choices), oral and dental health (Smyth & Bell, 2006, p. 231).

In focusing only on the individual; these frameworks did not account for the influence of historical, economic, cultural and political dimensions of the environment (Galvaan, 2015). This perspective excluded the value and complexity of context, and did not consider socio historical circumstances, intersectional identities, and a person's positionality within contexts, and the way those factors affected occupational choices (Galvaan, 2015). The facets of a person's identity, gender, race, sexuality, personal and cultural histories are all influenced by power relations, and in turn, the intersectionality of these identity labels leads to the occupational choices we make.

Occupational choice has been reimagined through a South African lens, by Galvaan (2015) who describes occupational choice as the investigation of the selection of occupations, (everyday, ordinary activities) as co-constructed through individual, group and community's

transactional relationship with their context. Ramugondo (2018) echoes this idea in her keynote address at the World Federation of Occupational Therapy Congress, where she said that "human occupation in itself, is contextually situated." This means that the way that people engage in occupations, is inextricably linked with their contexts and their positionality.

In her study, Galvaan (2015) built upon Bourdieu's (1997) social theories of action, using the concepts of habitus, doxa, social capital, and practical consciousness, and investigated how certain doxa can reinforce patterns of choices. In order to understand how a context works, Bourdieu breaks it down into several concepts which can influence a person's choices which will be unpacked.

After reading Bourdieu (1997), Galvaan (2015) and Tabb (2018), the following is a simplified explanation of the concept of 'habitus.' In its simplest form, 'habitus' refers to the conscious and unconscious facets of a person's identity with which they meet the world (eg. race, gender, sexual orientation, prejudices, heritage, etc). This is what an individual 'carries' with them when they enter into society, in all different kinds of spaces, or contexts. When a person enters these contexts, they bring with them: their habitus. A person's habitus has different signifiers of power, (such as race, gender, sexual orientation, and social positions) depending on which context they find themselves in. One needs resources, different types of capital (social, economic, cultural) in particular contexts. Habitus shapes our world, and our world shapes our habitus (Tabb, 2018). Bourdieu proposes that choices are made under the constraints of habitus and the conditions of social fields (Bourdieu, 1990). Perhaps for people with intellectual disability, their habitus suggests that there are occupations that are not available to them, or their social fields dictate what is possible for them.

In Bourdieu's own words 'agents classify themselves, expose themselves to classification, by choosing, in conformity with their tastes, different attributes, clothes, types of food, drinks, sports, friends which go well together, and which they find suitable for their position' (Bourdieu, 1990, p.132; Tabb, 2018). Our habitus coincides with our class position, indicating that we share a similar habitus to those of a similar social class (Tabb, 2018). It is worth noting other signifiers are also key components of our habitus.

Each social field, or context, has its own rules, which Bourdieu calls doxa. Bourdieu identified the term 'doxa' which referred to the tacit presuppositions as to the parameters or boundaries to engagement set in a certain context (Galvaan, 2015). In simple terms, the doxa are like bands of restrictions placed on opportunities, reproduced due to socially constructed presuppositions about the everyday occupational choice options. For a community or a group sharing a common doxa, particular patterns of occupational engagement and everyday occupational choices would be seen (Galvaan, 2015).

The social group will evaluate the person and ascribe the person their position in the field (Bourdieu, 1997). Galvaan (2015) found that occupational choice is informed by "practical consciousness", or commonly accepted ways of thinking, behaving and engaging. These thought patterns and behaviours are not always well articulated, but are the expectations of how a person will or should behave within a particular context. In her study, Galvaan (2015) named this finding within the context of her study as "It's just like that."

Galvaan contended that occupational choices are formed and shaped by context, in that expectations that society places on a person, may enable or hinder their occupational choices, in the latter instance possibly reinforcing patterns of occupational injustice (Galvaan, 2015; Townsend & Wilcock; 2004). Townsend and Wilcock, (2004), describe the study of occupational justice as the synergy of the ideas of justice and occupation, where there is the enablement of fairness and equal opportunity for engagement and accessibility, with no discrimination based on ability, age, or any other factors (Townsend & Wilcock, 2004).

McIntosh (1989) devised the concept known as the 'invisible knapsack.' This is similar to the concept of habitus as it is also premised on the notion of power or social capital, that a person carries, and the effects of their privilege in terms of social justice. In 2015, she wrote:

"As I see it, there is a hypothetical line of social justice running parallel to the ground. Below it people or groups are pushed down in a variety of ways. Above it, people and groups are pushed upward in a variety of ways. I believe that all of us

have a combination of experiences that place us both above and below the hypothetical line of social justice (McIntosh, 2015, p. 9)."

The 'knapsack' or 'backpack' that they carry, with their habitus inside, may influence their everyday, occupational choices. Carrying a label of intellectual disability could potentially influence their access to opportunities, and place bands of restriction on occupational everyday choices. If a person chooses to accept their everyday occupational choices, due to their positionality, habitus, and doxa, they will continue in the same patterns of occupational choices and engagement as "It's just like that."

It is therefore important to investigate the occupational choices made by young adults with intellectual disabilities, to identify current opportunities and barriers for occupational choice, that is, issues which are "it's just like that", and what is needed to create opportunities for needed change, that is, where "it doesn't have to be like that."

1.5 Summary of the Background to the Study

It is well documented in literature in the intellectual disability field that choice making for people with intellectual disabilities is often problematic and not actualized (eg. Stalker & Harris, 1998; Witsø & Kittelsaa, 2017; Brown & Brown, 2009; Wolf & Joannou, 2013). Not being able to make choices is an infringement on one's human rights and affects identity, self esteem and participation in occupations. Choice making and self-determination have been incorporated into the disability rights and empowerment movement, as both are inextricably linked with quality of life (Wehmeyer & Abery, 2013). People with intellectual disability need to be seen as full participants in society and must be treated as such (Van der Meulen, Hermsen & Embregts, 2018). Stmadova and Evans (2011) discuss that there are stigmas, social stereotypes and prejudices that perpetuate the perception that people with intellectual disabilities are unable to become self-determined and make choices. Choice can be presented in multiple formats and can be expressed in multiple ways. People with significant intellectual disability may have limited communication skills or limited mobility, but that does not mean that they are unable to engage in choice making (Wolf & Joannou, 2013).

Wolf and Joannou (2013) acknowledge the well-established barrier of few choice making opportunities in the environment for people with intellectual disabilities. However, they note that there are other potential barriers such as the urgency of the decision, adherence to common rules and procedures, and a lack of empowerment and training to enhance choice making skills for people with intellectual disabilities. It is evident that choice-making is inhibited or enabled by a range of factors, such as intrapersonal as well as environmental factors (Stalker & Harris, 1998, Nota, Ferrari, Soresi & Watermeyer, 2007, Stmadova & Evans 2011).

1.6 Rationale

Individuals with intellectual disabilities who live in community settings have few opportunities to make choices, become self-determined and have a say in their everyday occupational choices. There is legislation, policy and opinion that promote the human rights of people with

intellectual disability and their right to engage in choice making. However, in practice there are often negative attitudes, stigmas and barriers to choice making and the range of occupational choices for young people with intellectual disabilities. As such, the conflict between the desire to control their own lives, and having few opportunities to do so, results in a contemporary health and human rights issue (Stancliffe, 2001, Brown & Brown, 2009; Smyth & Bell, 2006, Wolf & Joannou, 2013; Bush & Tasse, 2017).

Exploring the everyday occupational choices within this context can raise consciousness about the how choice for young adults with intellectual disabilities in our local context may or may not reflect inequalities they may experience. Exploring these experiences of young adults with intellectual disability can help generate insights into their choices. In this case, everyday occupational choices refers to choices around global occupational engagement over several performance areas, such as relationships, work and diet. By beginning to understand the complexity of choice for people with intellectual disability, we can develop strategies for the individuals, their supporters, professionals and political and environmental systems, to improve their quality of life.

1.7 Research Question

The research question in this study is: What informs occupational choice among young adults with intellectual disability in a community context in South Africa?

1.8 Aim and Objectives:

The aim of this study is to document young adults with intellectual disabilities' experiences of what informs everyday occupational choices made by in a South African context.

The objectives of this study are:

- a. To identify barriers to everyday occupational choices in young adults with intellectual disability
- b. To identify enablers to everyday occupational choices in young adults with intellectual disability

1.9 Layout of thesis:

This thesis consists of five chapters. The first chapter introduces the background to the study, and the context of disability in South Africa.

The literature review, in Chapter Two, provides a scoping review of the literature around choice for young adults with intellectual disability.

Chapter Three outlines the methodology for this study, including research design, sampling, data analysis approach and how the study aims to ensure rigour.

Chapter Four details the findings of the study.

Chapter Five discusses the findings of the study, and notes limitations of the study and suggests areas for future study.

Chapter Two: Literature Review

Scoping Review of Choice Making for Young Adults with Intellectual Disabilities

2.1 Introduction

Considering the background literature which suggests that choice making for young adults with intellectual disabilities is not actualized, it becomes important to investigate the enablers and barriers to choice making for this vulnerable population. Quality of life may be improved if the barriers which prevent people from making their own choices are removed, to support a person to act in a self determined manner, and to have a sense of greater control of their own lives (Stmadova & Evans, 2011; Pilnick, Clegg, Murphy, Almack, 2011; Wehmeyer & Abery 2013).

With this in mind, the researcher conducted a scoping review to explore what is already known about the following question: What are the enablers of, and barriers to, choice making for people with intellectual disability?

2.2 Methods

The process was conducted using a number of steps suggested by Arksey & O'Malley (2005) to ensure that the relevant literature is documented in a rigorous and transparent manner.

2.2.1 Establishing search terms:

The first step was to establish suitable search terms. Initially, a search of MeSh terms in Pubmed was conducted using terms such as choice-making, autonomy, and self determination, but this did not yield terms which comprehensively captured the focus of this study. The closest term to Choice making, for example, was Choice Behaviour(s), and for autonomy was separated into personal and professional autonomy, while "self determination" was addressed as an act rather than a concept or occupation.

Through multiple iterations of search terms, in other databases, specifically, Ebsco Host and Academic Search Premier, the following search terms were selected:

- Intellectual disability, or mental retardation or learning disability or developmental disability or learning disabilities AND
- choices or decision making AND
- young adults

2.2.2 Search Strategy:

The databases searched using the above search string were Ebscohost, Academic Search Premier, Africa-Wide Information, CINAHL, Health Source – Consumer Edition, Medline, PsycARTICLES, PsycINFO and SocINDEX.

Inclusion criteria were:

- Articles from 1990, as this was the beginning of the self determination or choice making focus.
- Articles that were about young adults with intellectual disabilities (young adult in this study refers to ages 18 – 35)
- Articles that dealt with
 - Definitions of choice and choice making
 - Self determination and /or autonomy
 - Conceptual frameworks for choice making for young adults informing how young adults with ID experience choice and choice making
 - Barriers and enablers of choice making for young adults with ID

Exclusion criteria were:

- Articles from before 1990
- Articles that were about children or older adults
- Articles that were not about intellectual disability

2.2.3 Identification of Studies:

Figure 1 provides a summary of the process of identifying articles for inclusion in the study.

These search terms yielded a total of 538 articles. Duplicates were eliminated, leaving a total of 338 articles. Abstracts, titles, and keywords were assessed, leaving 56 relevant articles. There were 23 articles that, when read, met the inclusion criteria. 19 of these articles were

accessible via the web-based library and efforts to retrieve the other four were not successful during the time of the literature review.

The 19 articles ranged from a series of journals: Three journals had multiple articles,
British Journal of Learning disabilities (4),
Journal of Applied Research in Intellectual Disabilities (3),
Journal of Intellectual Disability Research (2).

The rest of the articles were spread across 12 other journals.

At this point, the researcher did a secondary search through the three journals named above that had multiple hits. They were electronically searched with the same search terms, with the exception of the search term 'intellectual disability'. This produced 506 references. An online review of the abstracts identified a further 11 articles which met the inclusion criteria.

This left a total of 30 articles for the scoping review. At this point, the researcher read the full 30 articles and selected 19 articles which met all the inclusion criteria for the review and provided relevant information to inform the review question. Given the low number of articles generated, all 19 articles were included in the review, without further quality assessment to provide the researcher with sufficiently broad a range of information to inform the review question.

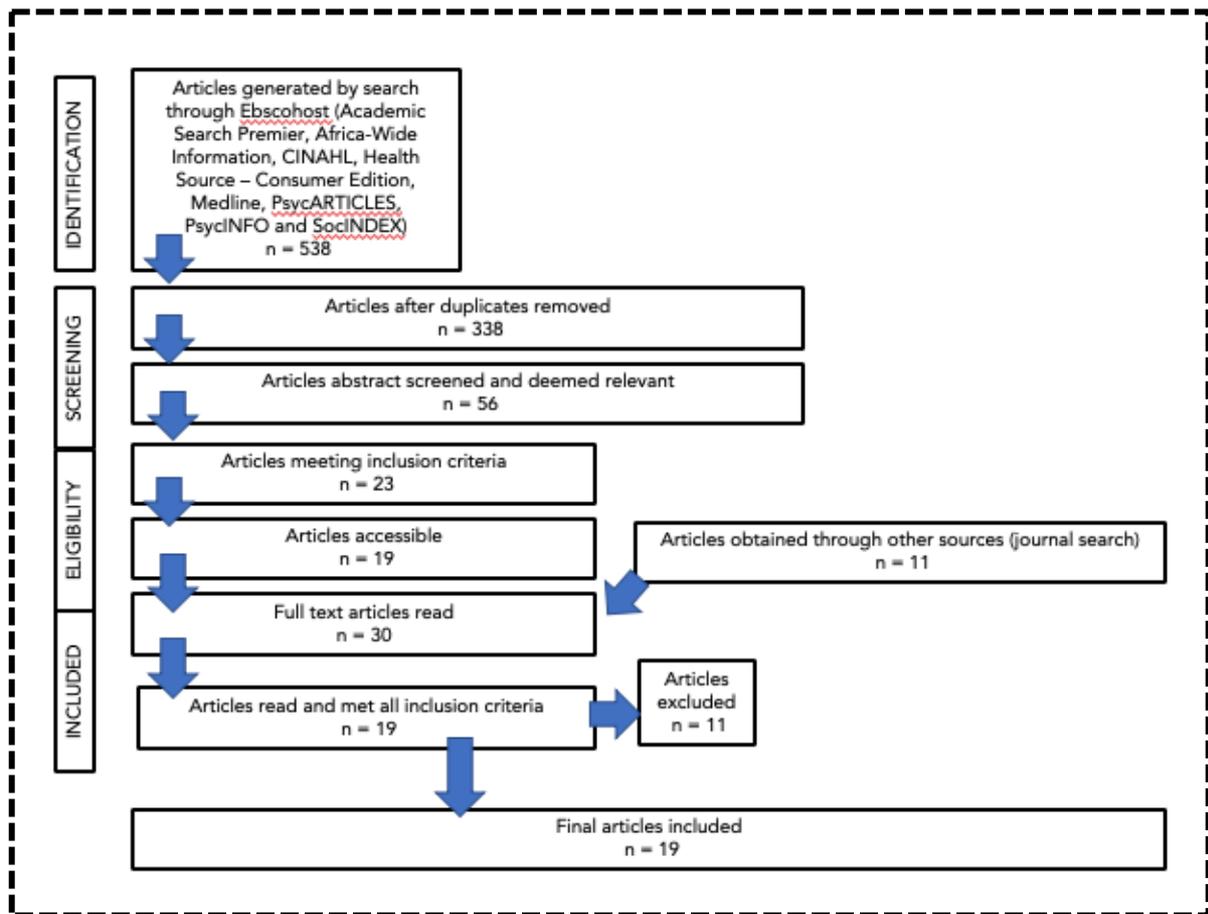


Figure 1: Selection process for the inclusion of studies

2.2.4 Analysis:

In terms of analysis, a data extraction template was developed to capture the following data: Author and year; definitions/perceptions of choice and self determination; factors that could be barriers or enablers; the experience of young adults with ID making choices, and special considerations.

The articles were read multiple times in order to identify data relevant to the research question. The articles were highlighted, hand-coded for themes relevant to the research question, moving systematically from one article to the next, inserting similar ideas under themes which emerged from already-coded articles. New ideas were entered as a new theme. If there were special considerations or perspectives, this was added into the final column to add depth and varying views. The ideas entered under themes were reviewed several times,

during the multiple readings, to refine core ideas and identify similarities and differences across the articles.

2.3 Results

2.3.1 Descriptions of included studies

Studies exploring the perspectives of people with intellectual disability are a relatively recent development, possibly indicative of the general stereotype that “the less competent cannot say who they are, and what they want to become” (Mill et al, 2009, p195). Similarly, in the period under review, the numbers of papers studying choice and self determination, specifically in the context of people with intellectual disability has grown. However, it remains a small number relative to the large body of work on choice and self determination. In the 1990s there was only one relevant article. Between 2000 and 2009 there were 6 relevant articles, and between 2010 – 2018, there were 12 articles. This growth could be a result of the changing focus on human rights, choice making, self determination, support and empowerment (Van der Meulen, Hermsen & Embregts, 2018). It is also noted that all 19 articles in the review come from middle to upper-income countries.

Table 2 below shows a summary of the articles.

Author and year	Definitions / Perceptions of Choice SD	Factors that could be barriers or enablers	The experience of YA with ID and making choices	Special Considerations	Study Design / Type / Sample / Data Collection
McConkey & Collins (2010) Ireland	Aimed to facilitate person centered goal planning	Opportunities available Staff and supporters Living arrangements	Goals were set for everyday activities. Sometimes they were achieved and sometimes they weren't.	Personal goal planning can improve social inclusion	130 participants recruited with a learning disability Individual structured interviews were conducted at 3 time points, 9 months apart
Haigh et al (2013) UK	Choice as meaningful to achieve happiness and wellbeing	Environmental: choice and independence, activities, valuable social roles, relationships Enabling and disabling: staff, family and boundaries Personal characteristics	People want to feel like they have access to opportunities to find meaning, in a number of ways.	Participator research study to provide the voices	Qualitative interview 20 people with ID Sampling through institutions where people with ID attend
Wehmeyer and Abery (2013) USA	Self determination is a complex process there the ultimate goal is personal control over one's life's within the areas one perceives as important	Personal characteristics (eg. social skills, adaptive behaviours and IQ) Environmental and contextual factors : choice opportunity, size and restrictiveness of work and living facilities	Young adults with IDD are less self determined than their non disabled peers	More self determination results in more positive school and adult community and quality of life outcomes. More independence, higher rates of employment, and greater community living	Descriptive writing piece n/a
Van der Meulen, Hermesen, & Embregts (2018) The Netherlands	Discussions around empowerment and support around self determination to improve quality of life	Supporter attitudes and and the relatedness of the relationship between client and supporter How well you know the client The ability to communicate with the client	Often everyday choices have restraints of freedom placed on them	Tension between allowing SD and protection, moral and ethical dilemma The vulnerability of the population	Qualitative Semi Structured Interviews Sample: 15 support staff workers
Carter et al (2012) USA	Self-determination is increasingly advocated as one essential focus of transition services and support	Parental involvement and perceptions Skill development in self determination	Youth have limited awareness about self determined behaviour, and diminished ability to perform these behaviours and low confidence	Schooling should include the development of these skills	Surveys Parents describe value on self determination skills Descriptive statistics
Almack, Clegg, & Murphy (2008) United Kingdom	Aim to express their wishes and aspirations to make meaningful choices. The right to live an ordinary life and take associated risks.	Fear of risk Parental perspectives Capacity to make choices	Transitions are challenging Young people need to and want to negotiate risk	Promoting autonomy and self-determination can be fraught with risk for parents and their children with ID	Qualitative Cohort of 28 young PWID Interviews from parents
Tarleton & Ward (2005) United Kingdom	The notion of choice can be very unclear to man people with learning disabilities	Fear of risk A lack of information to support parents and people with Id themselves	Choices may be difficult for young people, particularly around times of transition They often have minimal involvement in planning their own futures	By providing resources, more issues of empowerment, rights and responsibilities at transition can gain attention	1. Systematic review 2. Review on available resources 3. Qualitative focus group interviews
Arvidsson, Granlund, & Thyberg (2008) Sweden	Self determination as a key factor to participation	Self reported: involvement in community, perceptions of self, self determination and psychological wellbeing Reported by others: 1. environmental factors such as: social support, living arrangements, school, work, leisure, choice opportunity, attitudes, physical availability, society 2. Individual characteristics such as: adaptive skills, physical health, age and gender	Participation in everyday activities is largely supported by being self determined and motivated	Value of asking for self reported questionnaires	Systematic Literature Review 756 abstracts examined, 24 studies evaluated in depth
Saaltink, MacKinnon, Owen, Tardif-Williams (2012) Canada	Focus on the nature and promotion of participatory rights, or rights to express opinions, desires and preferences and to be heard and taken seriously in decision making Freedom as being relational and achieved by acting responsibly with the support of others.	Familial values Personal characteristics (such as decision making skills, flexibility, self advocacy)	Guided to make the 'right' choice as determined by family morals and conventions. This involves discussions and negotiations. Parents makes adaptations to enable choice making.	Balance the desire to protect individuals who are perceived as vulnerable Young family members with ID follow an age typical yet restricted pattern of participation in decision making because they are likely to be seen as at risk of harm	Qualitative Phenomenological approach 4 young people with ID, their mothers and siblings Semi Structured interviews
Mill, Mayes, & McConnell (2009) Australia	All people want to exert self determination and strive for autonomy	Opportunities available Parent attitudes and involvement Sense of place in the family	YA with ID strive to achieve more autonomy Relationships as independent, interdependent and dependent	Voices of young people with Id are under-represented	Qualitative Life Story approach Semi structured interviews 6 young adults interviewed

Table 2: Characteristics and Findings of Included studies

Author and year	Definitions / Perceptions of Choice SD	Factors that could be barriers or enablers	The experience of YA with ID and making choices	Special Considerations	Study Design / Type / Sample / Data Collection
Pilnick, Clegg, Murphy, & Almack (2011) United Kingdom	Self determination viewed in 2 ways: 1. independence and separation (outcome based) 2. Interrelatedness and relationship with others (process based)	Parental involvement Views of parent vs views of young person	Participation in everyday activities is largely related to family and parental input Transition period between child and adult is particularly difficult	Balance of parental involvement in a discourse of self determination	Longitudinal qualitative study design Repeat Interviews Individual and group interviews and observation
Fulford & Cobigo (2018) Canada	Advocating for rights to make choices	Living situations Supporters	Do not often question caregivers decisions	There is a need to balance protection of persons with ID from harm while promoting choice and autonomy	Literature Review and Synthesis n/a
Fyson & Cromby (2013) United Kingdom	Efforts to uphold and promote the human rights of people with intellectual disabilities re being affected by the emphasis on 'choice'	The heterogenous capacities of the population of people with ID Few meaningful choice options available	Choice is problematic for people with ID in terms of capacity and practice	Conflict between intervening in poor choices and allowing the expression of free will	Conceptual assumptions and positions are examined n/a
Harris (2003) United Kingdom	Confusion around the nature of choice	Capacity to make decisions Environmental influences: group living, resource limitations, environmental structure Social influences: previous experience of choice making, supporters, routines	Many people with ID live in settings where choices are restricted	Making choices in a complex, and also poorly understood activity which involves both psychological and social processes	Conceptual understandings n/a
Nota, Ferrari, Soresi & Wehmeyer (2007) Italy	Self determination is correlated with improved quality of life	Environmental factors: living or work settings Intra-individual factors: intelligence level, age, gender, social skills and adaptive behaviour	People with ID can become more self determined given the necessary supports	Improved self determination results in more positive adult outcomes	Quantitative evaluation instrument 141 people with ID
Witsø & Kittelsaa (2017) Norway	Concepts such as autonomy, self determination and independence are commonly promoted as the antithesis of dependency and universally desired goals	Professionals lack of knowledge of how to promote autonomy Professionals perceptions	For people with learning disabilities, adulthood may imply a lack of autonomy and being controlled by others People who need assistance are often met with paternalistic attitudes and given few opportunities to make personal decisions	Professionals play a key role in developing self determination discourse	Phenomenological Qualitative interviews Sample of professionals
Williams & Porter 2017 United Kingdom	Control over day to day life is seen as an element of well being Relational autonomy here we are all interdependent, allowing agency, autonomy and choice to be promoted as a matter of degree for everyone	Perceptions of self Other people such as supporters	People commonly make decisions with others	Too many choices can be bewildering and time consuming and make use feel inadequate We all fail at times to make good decisions	Qualitative interviews 9 people with ID Analysed with an interpretive approach
Stalker & Harris (1998) United Kingdom	Choice as a factor to quality of life, as both an indicator and desirable goal. Choosing is referred to as the act of selection of a preferred alternative from several familiar options	Environmental: Residential settings, Opportunities for choice making Supporters Individual: eg. communication abilities	People with ID sometimes trap themselves into the cycle of learned helplessness	Choice is linked to empowerment, decision making and autonomy. It is evident that choice is multidimensional.	Literature review n/a
Stmadova & Evans (2012) Australia	Self determination is key to quality of life	Environmental: live and work settings and context Intra-individual : intelligence level, age, gender, social skills and adaptive behaviour as well as the awareness of the disability	Choices for people with ID are limited	Gender has been debated in terms of self determined behaviour, different studies reports	Qualitative Semi Structured interviews, grounded approach 55 women with ID

Table 2: Characteristics and Findings of Included studies

2.3.2 Definitions and Perceptions of Choice:

Making a choice is a multidimensional, complex and poorly understood activity which involves both psychological and social processes (Stalker & Harris, 1998; Harris, 2003) Furthermore, the relationship between choice and its related concepts, such as decision-making, self-determination, personal autonomy, and empowerment is often unclear (Stalker & Harris, 1998). Concepts such as choice, autonomy, self-determination, and independence are described as the opposite of dependency and are therefore considered universally desirable goals (Wisto & Kittelsaa, 2018). While the notion of independence is considered the ideal, it becomes important to consider that all humans are in nature, interdependent (Wilcock & Townsend, 2009). While the concept of dependency suggests that a person needs help, a pervasive sense of being less, with a lack of capacity, and this appears undesirable (Wisto & Kittelsaa, 2018), in truth, all humans are interdependent to a greater or lesser degree.

Harris (2003) explains that there is confusion around the term 'choice,' due to a lack of consensus regarding the meaning of the word itself. Choice is a word with a wide currency in services for people with intellectual disabilities, but it is noted that there is an absence of clear definitions and theoretical frameworks (Harris, 2003), illustrating how choice can refer to: a performative action, a perceived range of options, as well as the process of decision making. In 1998, Stalker and Harris described 'Choosing' as: the act of selection of a preferred alternative from several familiar options. Harris (2003) acknowledges that often in literature, 'choice' is used to refer to relatively insignificant response options, while 'decision' is commonly applied to choices which are likely to have a greater impact on the person's life, however he stated that it is an arbitrary and somewhat subjective distinction, and used the term 'choice' (Harris, 2003). Similarly, the term "choice" will be used throughout this thesis.

While the terminology itself requires further conceptual clarification, there is no question that choice making fosters self-determination and can lead to an improvement in quality of life (Nota, Ferrari, Soresi & Wehmeyer, 2007). In their study on what makes people with intellectual disability happy, it was noted that being able to make meaningful choices is vital to achieving happiness and wellbeing (Haigh et al 2013). Choice discourse in the context of intellectual

disability is largely about empowering this population to become self-determined and providing the support to do so (Van Der Meulen, et al, 2018).

2.3.2 Potential barriers or enablers of choice-making:

Articles in the review clustered around 3 main categories which contribute to choice making: societal, relational and personal:

A) Societal

Societal factors that can influence choice making can include physical, cultural, structural, and social. An environment can be structured in a number of ways to promote choice making and can affect the range of choices available (Mill, 2009; Arvidsson et al, 2008; Wehmeyer & Abery, 2013; Fulford & Cobigo, 2018; Harris, 2003; Haigh et al 2013).

Arvidsson et al (2008) structure their perspective through the social model, using the ICF's definition of disability which is largely shaped by society. They believe that all types of institutions can be permissive or place restrictions on the nature and number of choices available to people with intellectual disability (Arvidsson et al, 2008). Van der Meulen et al (2018) refer to barriers placed on how the individual chooses to engage in every day life, which includes, for example, deciding what to eat, use of social media, or restraints placed upon sleeping or waking times. The Netherlands has adopted a Care and Coercion bill which discourages these restraints, and states that having an intellectual disability cannot be legitimate grounds to restrict these daily choices (Van der Meulen et al, 2018).

Stmadova and Evans (2011) acknowledge that there are stigmas, social stereotypes and prejudices that perpetuate the perception that people with intellectual disability are unable to become self-determined and make choices. This results in a population of people who are dependent on others to make choices on their behalf.

Harris (2003) further describes this in a variety of contexts such as group homes, community residences, parents' homes or independent living, and explains that the structure of the environment can support or hinder choice making (Nota, Ferrari, Soresi & Wehmeyer, 2007; Stalker & Harris, 1998; Arvidsson, Granlund & Thyberg, 2008). Wehmeyer and Abery (2013) and Harris (2003) acknowledge that the size and restrictiveness of the institution itself impacts

the choice making opportunities, in that there may be constraints that arise from, for example, the rules of a group home living arrangement, or resource limitations that may lead to limitations in choices for occupational engagement.

B) Relational

The term 'supporters' is used to refer to people who have a direct impact on participants' lives and provide guidance to them. This can refer to parents, support staff, carers, guardians, family members and close friends. This term will be used in this thesis to denote these individuals as well.

Service providers, at all levels, play a role in facilitating or inhibiting the way people with intellectual disability make choices (Stalker & Harris, 1998). In the service system, Witsó and Kittelsaa (2018) describe how people with intellectual disability are often confronted with a negative attitude from professionals, reinforcing stigma which limits their choice-making. Professionals in their study complained about the lack of time and resources to support self-determination and choice, and were unsure of a clear way to promote autonomy and choice (Witsó & Kittelsaa, 2018). Fyson and Cromby (2013) highlight the challenge of a uniform approach to creating strategies to promoting choice and autonomy given the wide range of capacities among people with intellectual disability.

The way in which the role of support staff within a care organisation, or the role of supporters in the community unfolds, can place or lift restrictions on choice within the domains of eating and drinking, daily structure, bedtimes, means of communication, relations and hygiene (Van der Meulen, Hermsen & Embregts, 2018). In a study by Haigh et al (2013), people with intellectual disability stated that it is important to have staff who are flexible and can provide choice opportunities across everyday life areas, like daily activities and relationships, creating meaning and helping them live the lives they want to live.

Pilnick et al, state that the transition period between child and adult, the young adult life stage, is particularly difficult. Carter et al (2013) acknowledge the limited number of studies on the young adult age for people with intellectual disabilities in this area. There is a small but expanding body of literature about the transition to adulthood for young people with intellectual disabilities (Mill, et al, 2009). For people with intellectual disabilities, adulthood might even imply a lack of autonomy and being controlled by others (Witsó & Kittelsaa, 2018). Parental involvement and attitudes about choice making and independence, and the quality of the relationship between parents and the young adult, are key to choice making skills and opportunities (Pilnick et al 2011; Mill, 2009; Saaltnick, et al 2012; Van der Meulen et al, 2018, Fulford & Cobigo, 2018). It is possible for young adults with intellectual disability that “dependency, obedience, and child-like behaviours may, in fact, be promoted by parents, rather than independence, self-direction, and the assumption of responsibility and greater autonomy” (Mill et al, 2009, p.195). By reinforcing this, one reinforces patterns of engagement, where people with intellectual disability perpetuate a cycle of a habitus where the expectation is dependency, they are not given a voice and are subjects of infantilisation.

The difficulties arise as young people confront not only the ordinary challenges of growing up and moving from school to college or employment but also the challenges associated with having an intellectual disability, both impairment-related and socially related challenges (Tarleton and Ward 2005). Many young adults with intellectual disability resent what they perceive is too much parental control and interference in their everyday lives (Mill et al, 2009). Young people need to and want to negotiate risk (Almack et al, 2009).

In the past, marriage, sexual relations and parenthood were forbidden for people with intellectual disability, and while this is slowly changing, it remains a contentious issue for supporters (Mill et al, 2009). This is one example where promoting autonomy and self-determination can be fraught with risk for parents and their children with intellectual disability (Almack et al 2009) This transitional period between childhood and adulthood is often characterised by tension within the family home (Mill et al 2009). Young family members with intellectual disability follow a typical yet restricted pattern of participation in decision making as they are likely to be at risk of harm (Saaltnick et al, 2012). Parents of young people with

intellectual disability are often uncertain or in conflict, about what their adult-child's roles will be, and thus are unsure of how to prepare their son or daughter for this transition (Mill et al, 2009). Fyson and Cromby (2013) acknowledge the conflict between intervening in the young adult's poor choices and allowing the expression of free will. For these young adults, living active adult lives is negotiated between their individual choice, control and responsibility (Witsó & Kittelsaa, 2018) and the needs and concerns of their supporters.

There are often restrictions placed on choice making opportunities, which Van der Meulen et al (2018) refer to as 'restraints of freedom.' Often these restraints of freedom are instituted as a means of protection, (Van der Meulen et al, 2018). The literature identifies a possible conflict between the views of the parent, and the views of the young adult, where parents' fear of risk taking is countered by young people's natural desire and need to explore and take risks (Almack et al, 2009; Tarleton & Ward, 2005). Almack et al (2009) describe how parents find it challenging to negotiate the amount of protection given to their children, in that they could become overprotective. There was notable parental difficulty in adjusting their level of support, as parents voiced uncertainty about whether their fears are helpful protection of their vulnerable child or overprotection, given the child's transition to adulthood. Harris, (2003) highlights the need for further research to promote greater understanding of how social and other supports can assist people with intellectual disability to participate in making choices.

C) Personal

Another factor that could act as an enabler or a barrier to choice making is the amount of involvement one has in community, family and friendship groups (Arvidsson, Granlund & Thyberg, 2008; Mill, 2009).

There are factors within a person that can impact the nature and number of choices available, acting both as potential barriers or enablers. These factors are: adaptive functioning skills, physical health, age, gender, intelligence, social skills and communication skills (Arvidsson,

Granlund & Thyberg, 2008; Stalker & Harris, 1998; Wehmeyer and Abery, 2013; Nota, Ferrari, Soresi & Wehmeyer, 2007).

Capacity to make decisions was also discussed in the literature, as one's choice making capacity includes executive functioning skills for example, reasoning skills and flexibility (Harris 2003; Almack et al 2009).

Lastly, perceptions of oneself was described as a factor in choice making (Mill, 2009; Saaltink et al, 2012; Williams & Porter, 2017, Arvidsson, Granlund & Thyberg, 2008). Haigh et al (2013) discuss how the way one views oneself and one's disability can act as a barrier. Williams and Porter (2017) echo this in their description of how one's self esteem, confidence and ability to self advocate are important influencers to choice making.

2.3.3 Experience of Choice Making:

Research suggests that young people with intellectual disability are less self determined and have fewer choice making opportunities than their non disabled peers (Wehmeyer and Abery, 2013) and that there are few contexts that afford opportunities to make choices (Stalker & Harris, 1998, Harris, 2003).

The literature reports that there is a lack of awareness by young adults about self-determination and choice making (Carter et al 2012; Harris, 2003). This lack of awareness is accompanied by diminished choice-making behaviours, lack of questioning of caregivers' decisions (Fulford & Cobigo, 2018), minimal involvement in planning their own futures (Tarleton & Ward, 2005) and low confidence in their capacity to do so (Carter et al, 2012). The literature in this review suggests that young people with intellectual disability have limited awareness due to limited access to resources for choice-making (Harris, 2003), and because they become trapped in a state of dependency due to their lack of active choice-making opportunities (Stalker & Harris, 1998).

At the same time, the literature also presents a sense of people with intellectual disabilities being dissatisfied with their experience of choice making, wishing for more choice making opportunities. People with intellectual disability want to feel like they have access to opportunities to find meaning, in a number of ways, expressing a desire for greater independence in the future and the skills they were learning to help them achieve this (Haigh, et al 2013). It is noted that the research reflects that people with intellectual disability can become more self determined if they are given support to do so (Nota, Ferrari, Soresi & Wehmeyer, 2007).

2.3.4 Choice as Interdependent

The ability to make an informed decision, as a rational human being, was described as being embedded in Western societal values (Williams & Porter, 2017), where independence is highly valued. In contrast, several papers in the review described a reconceptualization of the notion of self-determination in many recent articles, where autonomy is viewed as relational. Pilnick et al, (2011) refer to Young (2001) and the model of self-determination that she proposes, whereby instead of viewing self-determination as independence and separation, we use a lens of relationship and connection, and positioning within a context (Pilnick et al, 2011). Young (2001) argues that agents are embedded in institutional relations that make them interdependent in many ways. Fyson and Cromby (2013) echo this notion and state that “we are all fundamentally, irreconcilably, both relational and interdependent (p1165.)” Saaltnick et al (2012) similarly view freedom as being relational, rather than independent, and it is achieved by engaging with the support of others. It is better to describe all persons, whether or not impaired, as ‘interdependent’ (Williams & Porter, 2017). This perspective suggests that the development of autonomy and choice making rests not only on the person, but also on the support they receive from professionals, communities, and supporters (Witsó & Kittelsaa, 2018). This is a crucial element for the development of choice-making capacity. This review shows that choice making is often absent from the experiences of young people with intellectual disability. Fyson and Cromby (2013) believe that relational understandings of

personhood are what it means to be human. Autonomy is then rather viewed as a matter of control within a context, not isolated independence (Williams & Porter, 2017).

2.4 Discussion of the Scoping Review

Choice is multidimensional and is linked to empowerment, decision making and autonomy (Stalker & Harris, 1998). Choice making and self-determination have become part of the demands by people with disability in the self-advocacy movement. This is important as in the disability rights and empowerment movement having people with intellectual disability voicing their concerns about choice making is inextricably linked with quality of life (Wehmeyer & Abery, 2013). Quality of life is known to be improved if the barriers which prevent people from being more independent and making their own choices are removed, and a person can act in a self determined manner, being 'in control' of their own lives (Pilnick, et al, 2011; Stmadova & Evans, 2011, Wehmeyer & Abery 2013). Control over day to day life is seen as a key element of well-being (Williams & Porter, 2017). While this in principle is ideal, in practice this review shows that people with intellectual disability often lack the opportunities and access to make choices for themselves, and some people can make certain choices but not others (eg. Wehmeyer & Abery, 2013; Stalker and Harris, 1998).

The review clearly indicates that choice-making is inhibited or enabled by a range of factors, intrapersonal as well as environmental or contextual (Stalker & Harris, 1998, Nota et al 2007, Stmadova & Evans 2011).

The literature makes no clear distinction between enablers and barriers. Instead, there are factors that can act as both enablers or barriers, depending on the context and the agents within. The discussion below highlights how each facet can be either enabling or disabling for the choices of people with intellectual disability. Arvidsson et al (2008) state that understanding the factors that shape and enhance everyday participation, for people with intellectual disability, is important in all areas of intervention.

The factors in one's context have the power to influence the number and nature of choices available. The review placed a large emphasis on parents, or supporters, and highlights a conflict between people with intellectual disability and their supporters; a conflict around allowing choice making opportunities and avoiding risk, resulting in a moral and ethical dilemma (Van der Meulen, 2018). For people with intellectual disability, adulthood might imply a lack of autonomy and being controlled by others (Witsó 2018). Van der Meulen et al (2018) also acknowledge the tension between being permissive and allowing choice making opportunities, and protecting the vulnerable, resulting in a moral and ethical dilemma.

The transition to adulthood is commonly associated with shifts, both in relationships, as well as from dependence to independence; and towards the assumption of responsibility. For young people with intellectual disability such milestones are often difficult to attain (Mill et al, 2009).

All people want to exert self-determination and strive for autonomy; to express their wishes and aspirations and make meaningful choices (Mill et al 2009; Almack et al, 2009). Saaltink et al (2012) acknowledge the desire of people with intellectual disability to be taken seriously in decision making, as well as advocating for their right to live an ordinary life and take associated risks (Saaltink et al, 2012; Almack et al, 2009).

2.5 Limitations of the Scoping Review

There are several limitations to the literature review. Despite the measures taken for rigour, this review presents some limitations. It should be noted that only English language articles that were indexed were used. Considering this was not a systematic review, it does not represent the entirety of the global scholarly work on choice making for young adults with intellectual disability. The 4 articles not sourced could have added more depth to the discussion. The thematic analysis was conducted by only one person, the researcher, where multiple researchers could have added other perspectives.

Chapter Three: Method of Inquiry

The first sections of this chapter include a description of the research design, the study setting, the researcher and the sample selection. Thereafter the methods of data collection, and data analysis are fully explained. It is contended that the process, procedures and integrity with which data was generated assured the trustworthiness and credibility of the research highlighted in the rigour section below.

3.1 Research Design:

A qualitative, descriptive research approach was followed to conduct the study. Qualitative research is conducted from the perspective that multiple realities are represented in participant perspectives, and that context is critical in exploring and understanding the phenomenon being investigated. Qualitative enquiry best suits this study as it captures the richness of the participants' experiences of choices and choice-making (McMillan, 2016).

In the past, research conducted in this field focused on caregivers, parents or professionals' perceptions, instead of asking the population with intellectual disability themselves (Capri & Coetzee, 2012). Capri and Coetzee (2012), highlight the way in which researchers have historically used a third-party reporting style in this field, speaking on behalf of people with intellectual disability rather than actually asking them for their views.

Basing research about people with intellectual disability on their own perspectives is essential. It upholds their constitutional rights, as citizens of South Africa, for self expression and participation. It also provides opportunities for their voices to be heard, and potentially impact on decisions which affect their lives. Importantly, exposure to the first hand perspectives of people with intellectual disability can also impact on reducing stigma, by breaking stereotypes about their lack of ability for self-representation. This is important as having a voice when it comes to matters that concern one's life can be empowering (Chan and Chiu, 2007). This is why semi structured interviews were the methodology of choice, as they would allow the

participant to tell their own story, in line with the tenets of the social model, where one values the lived experience and expertise of people who live with a disabling condition (Byng & Duchan, 2005). In addition, a phenomenological interview is structured in a way which aims to understand a person's perspective, and for this study "people with intellectual disability can be very open about their experiences and appreciate opportunities to discuss their lives, and therefore make significant contributions as participants in research" (Corby, Taggart, Cousins, 2015, p 462).

3.2 Study setting:

The study took place in a community based setting in the Western Cape, South Africa. The Living Link, situated in Maitland, a suburb on the outskirts of Cape Town, is a non-profit organisation that provides a programme for young adults with intellectual disability regardless of race, gender and religious background (The Living Link, 2018). The organisation aims to encourage, enhance and support the development of intellectually disabled adults, helping them attain a high quality of life. The training at The Living Link has four modules, namely, Employment Orientation, Lifestyle Management, Personal Empowerment and Community Survival. These modules train the young adults to become more independent, and ready for the world of work in the open labour market, as well as teaching techniques to boost self esteem. There are Living Link centres in both Johannesburg and Cape Town. The minimum group size for the training is 6 participants, although the average group size is 10 trainees. Trainees need to be between the ages of 18 and 35 years old.

The Living Link Johannesburg branch, which opened in 2000; has two different courses, a short term and long term course. In the Cape Town centre, which opened in 2017, there is only the longer course, which runs for a year. The course is split into classroom based skills training for five months, and then trainees move onto job sampling where they practice the skills learned in the classroom for six months. The trainers of the programme currently are two occupational therapists and one teacher. After trainees have graduated from the programme, The Living Link, where possible, assists to place their graduates into suitable positions in the open labour

market, supporting the trainee as well as the employer (The Living Link, 2018). This is a service offered at a small cost for as long as the trainee feels that they need support.

While The Living Link does charge course fees, they provide sponsorship to candidates where there is limited/no family income. This allows for a wider pool of candidates and a more diverse group of participants. Potential candidates for this programme include young adults from various socio economic and cultural backgrounds. The following criteria result in eligibility for the programme:

- The candidate is between 18 and 35 years old

- The candidate can understand basic English

- The candidate's intellectual disability is classified as mild

- The candidate is required to obtain a score of 13 or above on the Montreal Cognitive Assessment (MOCA) and have basic life skills

- The candidate has the potential to thrive in the open labour market

- The candidate must be able to understand and agree to the terms and rules of The Living Link, and sign a participation document when he or she begins the course

The Living Link in Cape Town opened in 2017 and has a new intake of participants every 6 months. Each group runs a programme that lasts a year. There have been four groups that have completed the programme to date. The fifth group started in January 2019.

3.3 The Researcher:

I am a registered occupational therapist, who has been practicing in the field of intellectual disability for three years. I have been working at The Living Link, in Cape Town, since they opened in February 2017. As one of the trainers, I have spent 5 months with each group, training them on the following two modules: Employment Orientation, as well as Community Survival. In the past few months, as there has been a changeover of staff, I have had the opportunity to occupy different roles, conducting admission procedures for new trainees, meeting trainees and their parents, and filling out and signing forms with trainees and their

guardians. I have also been able to observe the trainees while on job sampling, which gave me an opportunity to see what happens after the trainees have finished the theoretical training on The Living Link's premises. These opportunities have enriched my understanding of the scope and limits of the trainees' opportunities for choice-making. This has therefore enhanced my capacities for appropriate communication with trainees to optimize their opportunity to articulate their views. This informed the methodology for the study described below. I have considered the possible impact of my work roles on my role as the researcher and have made plans to address this as discussed below in the section on rigour.

The independent second researcher who did the coding of the first two interviews is a PhD student at another South African University. This researcher has a special interest in inclusion, disability and teaching tolerance.

3.4 Study population and sampling:

This study used criterion sampling, a form of purposive sampling that refers to all cases that meet a certain criterion from information-rich cases (McMillan, 2016, Palinkas, Horowitz, Green, Wisdom, Duan, & Hoagwood, 2015). With this type of sampling, the researcher selects participants on the basis of identified characteristics (McMillan, 2016). In this case, the inclusion criterion was that the participant should be a candidate from The Living Link. An exclusion criterion is if a candidate is not able to speak English.

In terms of sample selection, the Living Link management gave permission to recruit participants through their institution. The manager emailed 23 potential participants, sending the flyer with information and asked if they would be willing to participate in a study. Six people replied to the email noting their willingness to participate and gave their permission for direct contact with the researcher.

Participant 1 is a young woman who is 25 years old, who speaks English and who lives with her parents in Rondebosch.

Participant 2 is a young man who is 27 years old who speaks English at home, who lives with his father and sister, and has subsequently moved to London with his family

Participant 3 is a young man who is 29 years old who lives with his brother in Sunningdale. He speaks English at home.

Participant 4 is a young man who is 19 years old, who lives with his parents in Heideveld. He speaks Afrikaans and English.

Participant 5 is a young woman who is 21 years old, who is Xhosa and English speaking. She lives with her mother.

Participant 6 is a 35 year old man who lives with his parents in Brackenfell. They speak Afrikaans and English at home.

3.5 Data Collection

3.5.1 Data collection tools

Interviews are the most widely used method of collecting qualitative data. A well conducted interview allows you to capture the thoughts and feelings of participants in their own language, using words, phrases and meanings that reflect their perspective. The interviews help you understand in rich detail participant experiences that you cannot observe directly (McMillan, 2016). Semi structured interviews with each participant were used as the primary method of data generation.

Commonly in qualitative research, an emphasis was placed on data saturation, continuing to interview until no new information was gleaned (Palinkas et al, 2015). Each participant was interviewed using the interview schedule and vignettes described below for approximately half an hour. Each participant chose a location that was suitable for them, for example: a local fisheries shop, an office block, a coffee shop or their home.

3.5.2 The interview schedule

The questions were developed by the researcher and primary supervisor, and structured in a particular way, in line with the conceptual framework of unpacking occupational choices and

experiences of negotiating choice. The interviews aimed to explore the key dynamics which impact choice making for people with intellectual disability.

In similar studies with similar populations, they started with what is known and concrete, and moved to more abstract concepts (e.g. Moyson & Roeyers, 2011; Cartwright, Reid, Hammersly, Blackburn, Glover, 2015), a method of enquiry particularly suited to people with intellectual disability. Choices and choice making were investigated through open-ended questions. The questions were structured so as to elicit the participants' experiences around making every day occupational choices. It is noted that the question schedule was in English.

3.5.3 Vignettes

Vignettes were created by the researcher, based on experiences and situations that have arisen from real life situations at The Living Link. These were used to assist those who could not think of choice making scenarios spontaneously. In some cases, the study participant was able to think of a choice making scenario from their own life but used the vignettes to support the discussion. The vignettes were constructed to capture typical choice making situations which trainees experience and discuss at the Living Link. A vignette is a short story that is written about a hypothetical person or situation, used in qualitative research to glean the participants' beliefs (Gourlay, Mshana, Birdthistle, Bulugu, Zaba, & Urassa, 2014). Participants are typically asked to comment on how they think that the character in the story would feel, or what they believe the character should do in the specific situation (Gourlay et al, 2014), (see appendix 3).

3.5.4 Pilot interviews

Two pilot interviews were conducted to assess time taken for the interview, whether the interview schedule and vignettes were appropriate and understood, and whether the questions adequately elicit data which informs the research questions. This informed the amendment of the draft questionnaire and vignettes, the length of the interview, the researcher stance and the context within which the interviews took place in the interests of

improving the depth of data collected from the participants. The suitability of the phrasing of these questions in our local context was examined during the pilot and amendments were made accordingly, which were then included in the study.

3.5.5 Informed consent procedures

Each participant was briefed, and the researcher explained why they were being asked to participate in the study. The participants were read an information sheet, explaining the purpose of the study and how the data could be used in the future, such as for presentations and publications.

Informed consent was obtained from the participants themselves, as they are over 18 years old. The informed consent document included a statement that the participants could refuse to participate in the study or withdraw at any time. The participants were briefed on the fact that a transcriber could potentially hear their interviews before they consented.

The researcher has observed these trainees in multiple settings, and therefore felt confident that the participants were able to choose to participate of their own free will, giving informed consent for their participation. No additional supports were needed to the informed consent form, such as having visual cues or representations included. These trainees have the capacity to say yes or no, and most are literate. The informed consent form was read to each potential participant. However, to bring rigour to the study, in line with Horner-Johnson and Bailey's (2013) study, the researcher had planned to ask key questions to ensure participants understood the nature of participating, as follows:

1. Please tell me, in your own words, what is this study about?
2. What will you be doing if you take part in this study?
3. What are the risks of being in this study?
4. When I say your taking part is completely voluntary, what does that mean to you?
5. When I say that your answers will be kept confidential, what does that mean to you?
6. What can you do if you start the study but don't want to finish it?

It was noted after reading the informed consent form that all participants clearly understood what was required of them and what the process would entail. It was therefore not necessary to specifically ask the questions, and in the actual research situation, the researcher felt that it would have been patronising of participants to ask these questions.

3.6 Data Management

Data were collected through audio recordings on a cellphone and then transferred onto a secure laptop before deleting the cellphone recordings. Notes were taken of key themes which emerged during the interviews, as well as writing up an impression of the depth of data from each interview at the conclusion of the interview.

Information that was recorded, both the audio recordings, as well as written transcriptions were kept on a password protected computer with secure access. This information was backed up onto a secure hard drive in a password protected folder.

Since the researcher transcribed the interviews, there was no need for a confidentiality agreement with an external transcriber. The transcriptions, once completed, were read, while listening to the audio recordings in order to ensure the transcription accuracy. Identities were coded so that the independent researcher had no access to the identities of the participants.

3.7 Data Analysis

Transcriptions were read through several times by the researcher to obtain an overall view of what themes may be emerging from the data. The goal of a thematic analysis is to identify themes, which are patterns that present from the data so as to pick up something interesting about the research question or a particular issue (Maguire & Delahunt, 2017).

Braun and Clarke (2006) provide a six-phase guide on the conduct of a thematic analysis which was used as follows.

Step 1: Familiarise with data

The transcripts were loaded to Atlas TI, a software programme to assist with the analysis of qualitative data. The researcher and an independent qualitative researcher read the first two interviews and independently coded data relevant to the objectives of the study.

Step 2: Generate initial codes:

The primary researcher and independent researcher compared data highlighted from their independent reading, and jointly organized the data into meaningful codes (initial theme nodes of experiences, barriers and enablers), comparing and adjusting codes to arrive at consensus baseline codes to use for coding the remaining transcripts. After this surface level code, a secondary coding took place to identify and investigate the codes and their meanings on a deeper level. Codes were given descriptions to ensure that the researcher maintained the integrity of individual codes across the analysis

Step 3: Search for themes:

The initial codes were used by the researcher to code the remaining transcripts.

Step 4-5: Review and define themes:

As the transcripts were coded, themes were modified and developed to arrive at a coherent and distinct set of themes, building up a coding frame (thematic map) to iteratively deepen the analysis. The coding frame is described in Appendix 6.

Member checking: In order to check that the data were an accurate representation of the interviews of the participants, a focus group was held with three available participants to discuss the findings from the analysis. This not only provided an opportunity for validation of the researcher's analysis of the data, but also provided additional insights to the data from participants responses which deepened the understanding of participants perspectives. Notes and audio recordings were taken

during this session, with permission of the participants, which were also analysed for inclusion in the dataset.

Step 6: Write up

The researcher wrote up the themes, going back and forth between the themes and their elaboration in the write-up, in a critically reflective process of refining the write up across several drafts.

3.8 Special Considerations

3.8.1 Considerations around participation

Considering that the nature of this study is around choice, it is important to acknowledge that participants' agreement to be involved could have stemmed from more than just their capacity to consent. It is possible that they could have agreed to participate because they think it is the right thing to do, or in order to please the researcher, as their previous programme trainer. In order to address this, the setting for the study was different from the usual training settings. As the researcher has built relationships with the potential participants, this could be either an asset or a limitation.

To reduce the risk of coercion or bias, the potential participants were contacted by the manager of The Living Link, the researcher did not contact them directly. An "advert"/ information sheet (see Appendix 1) was sent out and participants who were interested volunteered, emphasizing the importance of volition and choice in terms of participation. The young adults who were recruited have already completed the part of the programme that the researcher is involved in. They have finished the theory training. This means that there was less risk in terms of coercion and bias both with participation in the study and what they felt that they could say.

3.8.2 Considerations around language

It was necessary to consider that should the trainees had the opportunity to be interviewed in their home language, this could also impact the richness of their contribution, a constraint and limitation for this master's level study where interviewer resources are limited to the researcher who only speaks English.

3.9 Ensuring Research Rigor

Rigor can be defined as a measure of trustworthiness. The purpose is to ensure that the findings are relevant and meaningful (Lincoln & Guba, 1985).

3.9.1 Credibility

Credibility is defined as the confidence in whether the findings are truthful and accurate, and if they represent a realistic conceptual interpretation of the data (Lincoln & Guba, 1985; Anney, 2014). This was achieved through the following strategies:

- Prolonged Engagement in Field or Research Site: As the researcher works at The Living Link, it has helped to gain insight into the context and minimized the risk of distorting information. This also has improved the understanding of the participants, culture and context.
- Reflexivity: The researcher kept field journals in order to reflect on the process as well as issues that may have arisen for her, that may have influenced her perspective on respondents and their responses and impacted on her interpretation of the data.
- Triangulation: This was done through the focus group mentioned above. The focus group was used for data verification and methodological triangulation within my study group. The findings were presented to the participants on a whiteboard, and they were asked to comment on their thoughts. Questions were posed for clarity and discussion ensued. The content of the focus group discussion acted as an action of triangulation, and confirmed the results of the interviews.

- Member Checking: This strategy allows participants to provide feedback on whether the research findings accurately reflect their intended input, counteracting the researcher bias. Participants could say if they agreed with the findings or if something needed to be changed. The focus group provided the space for member checking.

(Anney, 2014)

3.9.2 Dependability

Dependability establishes the research study's findings as consistent and repeatable, and is an assessment of the quality of the processes of data collection, data analysis, and theory generation, ensuring that it has been conducted in a dependable way (Lincoln & Guba, 1985; Baillie, 2015). This was achieved through an audit trail, where researcher could account for all the research decisions and activities (Anney, 2014). In order to achieve this, interview audio clips and notes were kept for cross-checking the entire process should this be required: (Anney, 2014). Due to the nature of this qualitative study, the researcher kept written journal entries throughout the research process so as to position herself in the study, writing reflexive notes about the process as a whole.

3.9.3 Transferability

Transferability is the degree to which the findings of this inquiry can be applied into other contexts, being able to 'generalize' their findings (Anney, 2014; Lincoln & Guba, 1985). To ensure transferability, thick descriptions of the facility, choice of participants and procedures followed have been captured in this chapter to allow other researchers an in-depth understanding of what was done, to the point where it should be possible for replication of the study by another researcher (Anney, 2014). While this research data cannot be applied generally, as the nature of context is unique, the rich descriptions above can, however, assist in giving information that can be used for similar future studies or contexts.

3.9.4 Confirmability

Confirmability refers to the degree to which the results of the research would be confirmed by other researchers (Anney, 2014). This was achieved through getting a second researcher to review the transcriptions and the findings to ensure the results are not a figment of the researcher's imagination (Anney, 2014).

As the researcher has built relationships with the potential participants, this could be either an asset or a limitation. It would be unreasonable not to acknowledge that this influence may have a confounding impact on the conduct of the study.

3.10 Ethical considerations

This proposal was discussed with the Director of The Living Link and permission was obtained to conduct the study, subject to ethical approval of the study from the researcher's institution.

Ethical approval was obtained from the University of Cape Town's Faculty of Health Sciences Research Ethics Committee of the University of Cape Town (HREC, 746/2018).

This study adhered to the guidelines of ethical considerations outlined in the Declaration of Helsinki (World Medical Association, 2013).

3.10.1. Autonomy

Autonomy is defined as the ability of an individual to make informed, un-coerced decisions (Health Professions Council of South Africa, 2008). This principle of autonomy was upheld by ensuring that an informed consent form was signed by each participant. This ensured that participants understood their contribution and had the capacity to decide based on the information whether or not they would like to participate. In addition to this, the way in which the interviews were conducted encouraged free speech, and expression of opinions in a contained space. Participants were also free to withdraw from the study at any point in time. This was also promoted by the use of plain language in the study.

3.10.2. Beneficence

The Health Professions Council of South Africa (2008) states that beneficence is a concept whereby the researcher acts to benefit or promote the good of the participants. While there were no specific direct benefits of the study to the participants, the study aimed to provide an opportunity for self-representation, to capture first-hand experiences of young adults with intellectual disability.

3.10.3. Non- Maleficence

Non-maleficence means to “do no harm” (Health Professions Council of South Africa, 2008). This principle means that the welfare of the research participant is not threatened. This study involved no physical risk and no emotional risk to participants. In the unlikely event that questions about the concept of choice making evoked any discomfort, the researcher, a qualified occupational therapist in the field of mental health, was qualified to address these concerns in the context of the interviews in a non-judgmental manner. The educational institution gave permission for the study to take place, and the occupational therapist who is a trainer at the centre will have ready access to any other supports the trainee might need to address concerns. In the conduct of the study, no such incident arose. In fact, several participants actually vocalized enjoying the interview process.

3.10.4. Confidentiality

Confidentiality is one of the pillars of a research study which limits the amount of information which can be shared; and in turn can ensure protected and willing participants. As the participants have shared many details of their private lives during the course of the training, they do trust me as the researcher. Confidentiality was to be maintained outside of the interview setting. The researcher responsibly secured all data collected. The names of the participants were protected, ensuring that no private information was shared. The audio recordings were kept in a safe place and only the researchers, transcribers and research supervisor had access to these recordings. After the transcription process, the recordings

were destroyed. Transcripts of the audio data will be stored for approximately five years after the study has been done, in a secure location within the department of Psychiatry and Mental Health.

3.10.5. Justice

In research ethics, justice is the fair selection of research participants, as well as giving equal opportunities to all participants (Cozby, 2012). This concept tries to ensure fairness in both receiving the benefits and burdens of participating in research (Cozby, 2012). In this study, the researcher selected appropriate participants based on the inclusion criteria mentioned in the participant section of the report, and beyond the constraints of those limitations, did not unfairly further exclude anyone from being recruited. It is noted that the true potential pool of participants was not realised because they may not have had access or heard about The Living Link at all. In addition, The Living Link only accepts those who speak English, and therefore in terms of justice it could be perceived as unfair as it does not truly reflect the entire young adult population with intellectual disabilities.

Chapter Four: Results

4.1 Introduction

The analysis of the interviews yielded four main themes.

The first theme, entitled "*Being Different*" details participants' perceptions of how living with intellectual disability has left them feeling different from other people, and how this can affect their perceptions of themselves.

The second theme entitled "*Limited Choices*" addresses the limitations that are placed on participants making everyday occupational choices.

The third theme, entitled "*Accepting and Staying Small*" addresses the perceptions and experiences of participants accepting that others can make choices on their behalf, and accepting what is offered to them.

The fourth theme, entitled "*Challenging and Growing Up*" describes participants' experiences of challenging the expectations placed upon them, asking for more, and challenging stereotypes and societal perceptions of people with intellectual disability. The theme of "Challenging and Growing Up" has two subthemes namely: a) Trying new things and b) Graded independence.

Quotations are used to illustrate participants' first-hand experiences of the issues they raised. Participant quotations from the focus group have also been included in the results chapter as further illustrations of the four themes.

A) Theme 1: Being Different

This theme represents the way in which the participants view themselves, which has been constructed and influenced by their societal contexts and supporter environments.

All participants noted that they are made to feel different by people without an intellectual disability, and that being a person with an intellectual disability comes with associated perceived limitations and challenges. The result is that these participants expressed a feeling of being 'othered.' Participant 6 highlights how other peoples' views can negatively impact on the person's view of themselves, as well as what is available to them.

"Almost like stuff you wanna do and they ask you like, "do you think you can do it" or "do you think you will be able to do it?" and it really feels like, ja, it feels like they want you to feel like you can't do anything right. So you... basically... you can't stand on your own two feet and stuff like that."

Participant 2, in describing how people with intellectual disability might have a difference in appearance and behaviour, compared with people without intellectual disability, noted how this "difference" can impact on their choice-making experiences.

Interviewer: "So they have the same choices then? Where were the choices that they couldn't have about relationships and marriage and children?" ... Participant 2: "They are different Cole." Interviewer: "What does that difference mean?" Participant 2: "They think... they are different to other people..." and "They don't look the same Cole. They act differently ja."

Participant 6, reflecting on the lack of privilege, or disadvantage, which comes with having a label of intellectual disability, spoke about how this creates a sense of inner negativity which may evoke a need to distance oneself from this difference.

Participant 6: "I feel almost like.. almost like ashamed you know. I don't really want other people to know why, and I don't want other people to know I have a learning disability, so they will, they obviously gonna treat you different than normal people."

Remarks from Participants 1, 3 and 5 again reflect participants experience of being different, implicitly comparing themselves to others without intellectual disability.

Participant 3 described his experience of being different and how it is associated with negative connotations and limitations.

Interviewer: "What does it mean to have special needs?" Participant 3: "Challenges. limitations."

Participant 5 also echoed the same idea about being different:

Participant 5: "How can I say? People that don't think the same, they don't think the same. They have different minds."

The desire to "go forward" may be seen as a positive aspect of all human being's desire for growth and development, but in Participant 1's comment below, she has an added dimension, that of comparing herself to typically developed people, and highlighting that as a 'disabled' person, she has reason to behave in a manner that is not acceptable for typically developed people. She perceives different as 'different from normal' which is seen in a negative light, evident in her joining of the words 'challenges' and 'different.'

Participant 1: "We are different in every way. We have a disability. Our minds work differently. Our bodies work differently. We even clap our hands when we feel like it. So, we have challenges that we have to put in order that, to go forward."

Participant 6's comment below illustrates the depth of this experience of being different and being othered, in that while struggling to articulate this experience, he- and possibly others

who struggle to articulate their experiences- still live with an inner sense of being othered, of being different in a negative way. This participant was not able to articulate why he feels different but acknowledged a pervasive sense of himself as less than 'normal' people.

Interviewer: "Why do you think they treat you differently?" Participant 6: "I don't know. It just feels to me like that. Like I can... - sometimes I can.... - feel like someone treats me different like the normal people." ... (later) ... Interviewer: "So how can we help people? How can we help this process?" Participant 6: "Yoh. I don't know. The first thing is to try boost their self confidence."

"Being Different" highlights how the participants' have a shared habitus where the label intellectual disability creates a sense of being different from 'normal people' and how society has created a lens through which they see themselves, as well as what is possible for them.

B) Theme 2: Having Limited Choices

This theme presents how the nature and number of everyday occupational choices are restricted across contexts. Participants noted that their occupational choices are limited by the rules and norms of different contexts, including institutions such as, group homes, training facilities, and their own homes.

Participant 6 believes that society perceives people with intellectual disabilities as incapable of being independent and are treated differently. The doxa or social rules have dictated which challenges and tasks are acceptable to give a person with an intellectual disability.

Interviewer: "Do you think they would treat you differently in terms of the choices they would give you?" Participant 6: "Basically that. Ja. That's the main thing ja. They give you easier challenges and tasks to do than a normal person."

Participant 3 shared his view on how the limitations placed on people with intellectual disability might leave them with an internalised sense of restriction:

Interviewer: "And how do you think they are feeling?" Participant 3: "Stuffed in a cage, like a chicken. Not having the freedom to roam free... (Later)... "some of them feel they are stuffed, stuffed like a chicken in a cage, and the key... locked up, and the key is thrown away."

Initially, Participant 4 stated that a person with an intellectual disability can work anywhere but upon further reflection he acknowledged limitations:

Participant 4: "You can go work anywhere you want to! ... (after reflecting for a minute) Maybe not in an office." Interviewer: "Why?" Participant 4: "Because you have a learning disability." Interviewer: "What does that mean?" Participant 4: "You struggle how to learn. Stuff like that." (Later) "Maybe if you have a disability then you can't do it yes."

Participant 1 commented on the fact that when choices are made, others may not be supportive of those decision, or encouraging of those choices. When she does make choices, she is made to feel incompetent and hurt, resulting in negative emotions associated with having to make choices:

Participant 1: "There's always someone telling you what to do, giving you other options in your life. And then sometimes they get angry with you with the choice you made" ... (later)...

"My obstacles were, my mom, all of you at The Living Link, my dad, and (my step dad) and the rest of my family and friends." Interviewer: "Do you feel that there are often obstacles or restrictions, or whatever you want to call it?" Participant 1: "Yeah... I get disappointed a lot.

Well, they do. They get disappointed a lot. And I get hurt... from their disappointment."

Participant 3, describing his experience in a group home, noted that institutional attitudes remain constricting, and lack focus on supporting residents to explore their full potential. This shows how the everyday occupational choices that are made have been co-constructed within a specific context:

Interviewer: "What stopping them from reaching their potential? You said the one thing is that they don't have is a home to go to? What else could be stopping them?" Participant 3:

"Maybe the way the system works. Maybe the people in charge at (residential village for people with intellectual disability) should be focusing more on the residents and trying to train the residents to reach their full potential instead of just giving them work to do. And teach them, not what they already know, but what they do not know"

Beyond institutional settings, participants felt that parenting styles and attitudes can also affect the range of everyday, occupational choices of young people with intellectual disability:

Interviewer: "Are there any things that get in the way of you getting what you want, is there anything that stops you from making the choices you want to make?" Participant 2: "Family, Cole." Interviewer: "In what way?" Participant 2: "When I just want to do what I want to do."

Interviewer: "Who stops you?" Participant 2: "My family." Interviewer: "What do they do that makes you not able to do that?" Participant 2: "Because they older than you and, you have to respect them."

Asking participants why they would choose specific supporters to assist them with difficult decisions, most deferred to what they felt was greater wisdom in the other, rather than drawing on their own knowledge about issues. When asked why Participant 3 would consult his brother he replied:

"Maybe because he has more experience than I have."

In contrast, Participant 4 described how his experience of parents making decisions on their young adults' behalf promotes failure:

Interviewer reads Vignette 1... "What do you think about that?" Participant 4: "It's not right. He's gonna fail every time because his parents make him do that." Interviewer: "His parents are doing it for him, you mean?" Participant 4: "Uh Uh. His parents wanna let he do that, but he don't like it. So he's gonna fail it every time."...(shortly after)... Interviewer: "How do you think he feels?" Participant 4: "He don't feel nice." Interviewer: "Why?" Participant 4: "Because he wanna do what he wanna do."

This notion of having more experience was a common thread, which led into discussions around having choices taken away. A strong concept of having choices taken away was noted, with all participants noting that there were times that they were not able to make their own choices. Participant 1 described a time where her mother wanted her to try out a group home context, but she voiced that she did not want to go:

Participant 1: "Well my mom, she hooked me up with (group home) and I didn't want to go." Interviewer: "Did you have to go? You didn't have a choice?" Participant 1: "I didn't have a choice." Interviewer: "How did that feel? Not having a choice?" Participant 1: "It

didn't feel nice. I just wanted to be at home." Interviewer: "So what stopped you from doing what you wanted to do?" Participant 1: "My mother's choices."

Participant 6 echoed this idea, demonstrating a double bind: parents could be limiting the number of choices available in order to protect, but in reality they may hinder the process of growing and learning to become independent:

Participant 6: "I could sense something like she don't want him to get dirty and he don't want to work in the places that is dirty and I thought like, how are you ever going to stand up for yourself and how are you going to get like a real job if your mom is going to like have a hold on your life? He won't ever decide for himself."

This idea of limited options was reinforced by Participant 5 who said the following about her job site placement for job sampling (the practical component of training) at The Living Link:

Interviewer: "Why? Why didn't you like it? Participant 5: "Yoh! The clothes! I didn't like it!"

Interviewer: "How did it feel having to go to a place that (your job coach), or (your manager) chose for you?" Participant 5: "It was okay, like okay, I have to go. I have no choice."

There were varying perspectives on relationships and children. Participant 3 said that in his life, his brother is the one to make his bigger decisions and has 'given him permission' to get married and have children.

In contrast, Participant 1 spoke about relationship constraints imposed upon people with intellectual disabilities. These views reflect what she has been told is possible for her:

Participant 1: "You know, also, we can't have children." Interviewer: "Tell me a little bit more about that?" Participant 1: "Well, for instance, we can't look out for ourselves, we always

have our guardians or parents or friends of our parents looking out for us, guiding us."

Interviewer: "So you're saying you wouldn't have a choice of whether or not to have children. You're saying that you can't?" Participant 1: "Yep. But we can get married."

Participant 2: echoed this notion, but then voiced his view that these limitations should not be set in stone:

Interviewer: "So they have the same number of choices?" Participant 2: "Yes." Interviewer: "Even for work?" Participant 2: "Yes." Interviewer: "And for relationships and marriage and children?" Participant 2: "Maybe not so much there Cole." Interviewer: "Tell me a little bit more about why you say that?" Participant 2: "Because they have a disability Cole. (mumbles indistinctly)." Interviewer: "They can or they can't? Are you saying that people with disabilities should have relationships or shouldn't?" Participant 2: "They should, Cole."

"Having Limited Choices" highlights how the participants' have different experiences of occupational choices that they have or have not been able to make. Their social contexts have placed restrictions on their choices, leading to feelings of limitations. Participants 1 and 2 reflected on intimate relationships and spoke of the limitations that they have had placed on them. All participants could identify in themselves, or their peers, where parents have made decisions on their young adult's behalf.

C) Theme 3: Acceptance and Staying Small

Several participants could identify friends or colleagues who have intellectual disability who have a general sense and feeling of acceptance of the limitations placed on their everyday occupational choices. There were also participants who felt comfortable with their choices being managed by others and being willing to accept what they are offered.

After being read Vignette 3, Participant 2 spoke about having to accept what you are given:

Interviewer: "So, what do you think about Sarah?" Participant 2: "She needs to take what she gets ya.." (shortly after) Interviewer: "Are there ever times you feel like you have to take what you get?" Participant 2: "yes. ya."

Participant 3 echoed this when listening to the same vignette and reflected on the fact that in some situations, other people do know better and it is acceptable for them to make decisions on the young adult's behalf.

Interviewer: "What do you think?" Participant 3: "Okay firstly she must learn to accept her, why they placed her where they placed her. As well, her friend was put there for a reason. Maybe her friend is a more faster learner than she is since she is a slow learner."

Participant 6 suggested that acceptance of others' choices might be due to the constant supervision engendering a sense of 'not knowing' if required to make independent choices. He described a colleague who is always enabled by his parents, both parents and young person then locked in a cycle of fear:

Participant 6: "he let his parents decide for him what to do... and although he have a license, he don't drive. And sho... I would be so... Sho.... If I had my license I would be so.... Do everything on my own.... (later)... he is too afraid to broke loose from that chain"... (later)... "I think the main thing is she's afraid he get hurt. I think that's what she's afraid of."

Related to the notion that parents' fears might lead to overprotection through restrictions on opportunities to engage in new occupations, to take risks and to learn how to be independent, was participants' frustrations that parents have the capacity to stunt their family member's development.

Participant 3: "Maybe she's just, I don't know how to say it, but over something, coz you get over protective, and then there's something over... I'm trying to think of what word to use. Maybe shelters him too much." Interviewer: "And do you think maybe that's why she didn't want to leave his side?" Participant 3: "But then how's he going to grow? That's what I'm worried about."

There seemed to be a feeling of a conflict between personal growth and the social expectations one experiences. The doxa placed on these participants highlight the struggle between their preferred ways of doing, being and becoming, and the expectations placed on them by others. While several participants acknowledged that there are many cases where acceptance of the norm takes place, they added that it is "not okay" because it places an emphasis on the person's weakness. All participants who attended the focus group could identify colleagues and friends that have unconsciously accepted this option, continued with the doxa and habitus the way that it is. Participant 4 stated in the focus group that this acceptance could result in a person "*staying small.*" This was a recurring theme in both the interviews and the focus group where participants spoke about disrupting the passive option of acceptance.

D) Theme 4: Challenging and Growing up

There were several participants who discussed the availability of supporters and structured environments being fleeting, highlighting the importance of developing independence. Participant 6 displayed insight into the importance of motivating young adults to take action improve choice making skills, as important to develop a sense of independence.

Participant 6: "Ja so your parents aint gonna be there forever so, you need to come to a point that you will decide, you're gonna be on your own one day you need to take responsibility as well, so you must, you need to, choose your, choose your stuff and choose right."...(later)... "Interviewer: "Then what happens when they are not around?" Participant 6: "You won't be able to stand on your own, because where's mom and dad? I can't decide without mom and dad."

In discussion, Participant 5 spoke about making choices for yourself, even if they are not the best choices, as one cannot be completely dependent and unable to make their own choices.

Interviewer: "Should he wear the one they tell him to wear or the one he wants to wear?" Participant 5: "The one, I think... the one he wants to wear." Interviewer: "Why?" Participant 5: "Because end of the day, those people won't be there. He has to make his own...choices what to do."...(later)... "Because, you see. We won't live with the people that will die in your life. People, they come and go."

From the theme of "Challenging and Growing Up", two sub-themes emerged.

1) Subtheme 1: Trying new things

Participant 5 was of the opinion that supporters providing opportunities to try new things, is vital to development.

Interviewer: "Do you think they have opportunities to make choices?" Participant 5: "In their homes? Ah... I don't think so" (...later...) Interviewer: "What would you tell her mom?" Participant 5: "I think she must give her a chance to learn."

Similarly, Participant 4 emphasized the need for his friend to be given opportunities by his parents to foster independence.

Interviewer: "What advice would you tell him?" Participant 4: "He must do it for himself." Interviewer: "What advice would you tell the mom?" Participant 4: "She must leave him. Because, let he get.. to try himself." Interviewer: "He didn't even have the opportunity to try." Participant 4: "His mom was selling (at a market day) there. He must do it for himself."

A description of learning to do something new from Participant 1 illustrates her joy at trying a new skill at work, and how this contrasts with a more restrictive home environment. This highlighted the importance of engaging in an occupation that is viewed as meaningful and how that made her feel. She discussed one instance where, as part of the course, they were required to plan their own menu, face her fears and cook for themselves, and she described how the situation unfolded:

Interviewer: "And how did it feel? Knowing that you made something that you chose?" Participant 1: "It felt good but scary." Interviewer: "I suppose making choices can be scary sometimes." Participant 1: "The room was totally smoked out!!!! The chicken!!! (laughs) They said to me that I was burning the chicken and all there were was the burnt bits!!!! It was black!!! And the windows were all closed!!!" Interviewer: "How funny! How did it feel? Looking down at what you had made?" Participant 1: "I was amazed at what I could do! Amazed that it was still delicious!" Interviewer: "Do you cook at home?" Participant 1: "No I'm too terrified."

Participant 2 also used the Independent Living Tour as a way to explore new occupations. He described positive feelings around the experience, promoting a sense of wellbeing and meaning:

Interviewer: "On the independent living tour you got to choose the menu for the food you were going to cook. How was that experience?" Participant 2: "It was really good ja nice ja."

Participant 3 also reflected on the feelings associated with being given opportunities by his relative to make choices in his home context and gain experience and reported his experience, implying that by being given access to a wide range of choices, leads to his development and growth. Participant 3 further described the discrepancy between where one finds themselves and where they should be. He spoke about restrictive structures being disempowering and hindering people with intellectual disabilities from reaching their potential. He believes that people with intellectual disability: "should be given the opportunity to express their potential and reach their potential." He highlighted the influence of his brother as an icon of empowerment:

Interviewer: "And how does it feel, having someone who gives you access like that?"

Participant 3: "Empowered. Motivational." Interviewer: "Can you imagine if you had someone who was the opposite of (his relative)? How would that be?" Participant 3: "Downgrading."

Participant 2 reflected on the meaning associated with being able to make choices and how having choices is life enhancing, highlighting the relationship between choice and quality of life:

Interviewer: "What do you think it means to choose things? Do you think it's important? Do you think it's not important?" Participant 2: "It is very important, ja." Interviewer: "Do you want to tell me a bit more about why you think it's important?" Participant 2: "Life would be boring if there weren't choices ja."

2) Subtheme 2: Graded Independence

Sub Theme 2 presents participants desire to have supporters be there in the beginning providing graduated support, with supporters stepping back at times. This desire to learn for themselves came up in all of the interviews, with participants describing how they wanted to try things in a safe, constructive environment, having supporters present at key points of growth.

Participant 3 described how he likes being given a chance to try on his own, and will ask for advice if it is challenging:

Participant 3: "Some things I can do on my own. Others I just need advice. And then I'll think it through and figure out which is the best route to go." ... (later)... "Because, lets see, if you learn from, for example. See what works. If this doesn't work, try another thing, and see if that works. It's like you're putting a plug, there's a socket right, you're putting a plug that doesn't fit there, and then it doesn't fit there so you try another plug until it fits." Interviewer: "Do you think that people with special needs need extra help?" Participant 3: "Let's see. On some instances yes but you can just give them a little bit of help, don't give them for example the whole plate. Don't bombard them with everything at once. Just give them a little bit at a time and see how they cope with it and then back off and see how it goes. See if they can cope with it."

Participant 6 also discussed the importance of disrupting the protection held by fear and having parents allow safe spaces to learn and make mistakes.

Participant 6: "I would actually, to be honest, I would tell him parents to give him a week and kind of leave him, let he go on his own and see how he goes. And if he don't work, then fine okay go back to the normal routine, but like, a part of that.... he must, he must go to that point where is going away from his parents, because already he is old enough for, I think, he is old enough to go in his own place already..."

During the focus group, this disruption to the traditional views of people with intellectual disability as being incapable was discussed. Participant 5 spoke about "looking rather at our

strengths" as a strategy to build young people which focuses on the positive aspects of the person, and not on their perceived limitations.

In the focus group, in terms of consciousness, Participant 3 noted that by raising awareness we can empower people with special needs, thereby changing perceptions and disrupting the dialogue. It was evident that there is a desire to break away from the norm of being 'sheltered' and 'spoonfed' and be given the opportunities to broaden the occupational choices available and become more independent. He said:

"we also want freedom!" and later... "how do you grow as a person?"

There seemed to be a feeling of a need to dismantle the doxa in the way that these expectations restrict the number and nature of choice opportunities made available to these participants. They expressed a desire to focus on personal growth, in spite of the societal norms.

Chapter Five: Discussion

5.1 Introduction

This study aimed to provide qualitative insights into the lived experience of the occupational choices and choice making by young adults with intellectual disability. The study highlighted factors that could hinder or enable choice making. The findings of this study are in agreement with the literature in the intellectual disability field, in which it is known that choice making for people with intellectual disability is complex and is often not actualized (eg. Stalker & Harris, 1998; Witsø & Kittelsaa, 2017; Brown & Brown, 2009; Wolf & Joannou, 2013). As described in Chapter One, where it was said that the conflict between the desire to control their own lives, and having few opportunities to do so, results in a contemporary health and human rights issue (Stancliffe, 2001, Brown & Brown, 2009; Smyth & Bell, 2006, Bush & Tasse, 2017), so the results of this study have shown similar experiences. While the literature review reported a lack of awareness by young adults about self-determination and choice making (Carter et al 2012; Harris, 2003), this study has shown a different perspective, in that all of the participants were conscious of the meaning and value of choice making.

5.1.1 Factors that affect choice

As discussed in Chapter Two, the literature review identified no clear distinctions between enablers and barriers, and the findings of this study have also shown how each factor can act as both an enabler or barrier, depending on the context and the agents within.

Consistent with the international literature, this study found that opportunities for choice making varied based on a range of factors, both intrapersonal as well as environmental, or contextual (Stalker & Harris, 1998; Nota, et al, 2007; Stmadova & Evans, 2011).

Participants referred to several broader contexts that presented barriers or enablers of choice-making, which included group homes, training facilities, work spaces, as well as family homes. The choice opportunities depended on the expectations, rules and norms of the institutions. This is doxa in action, where the 'rules' define the choice opportunities, and these affect

engagement in occupation. The power of context is brought to attention by the study results which found that the same individual might be comfortable with choice-making in one context, and less so in another.

Below, the influence of supporter attitudes and attitudes of the young adults themselves will be discussed, as per how it links to choice.

5.1.2 Supporter Attitudes

Supporters' attitudes were found to have a significant impact in choice. Permissive, empowering supporters promoted choice making and allowed for a wider range of occupational choices, while stricter supporters could be overprotective and limit the choices of their young adults. Supporter involvement and attitudes, and the quality of the relationship between supporters and the young adults are key to choice making skills and opportunities (Pilnick et al 2011; Mill, 2009; Saaltnick, et al 2012; Van der Meulen, 2018, Fulford & Cobigo, 2018).

Haigh et al (2013), report people with intellectual disability's views on the importance of having supporters who are flexible and can provide choice opportunities across everyday life areas, creating meaning and helping them live the lives they want to live. This was echoed in the study, where several participants described their experiences in their parents' homes as well as group homes, noting that attitudes are often constricting, and lack focus on supporting the young adults to strive for success and reach their full potential.

It is possible that supporters are trapped in a double bind where they want to allow their young adult the scope to become independent, however they fear the process of letting go and allowing them to grow up given the stigmatizing challenges which they face. These parents may feel that their children are 'othered' and viewed as 'broken', 'damaged' or 'defective' (Watermeyer, 2006), resulting in a fear of letting go. This was highlighted in the findings of this study, where several participants identified a sense of fear in supporters around the issue of letting go, and having a fear that their child may get hurt. This finding is supported

in the literature where Tarleton and Ward (2005) as well as Almack et al (2009) state that there is a fear from supporters around allowing their young adults to make choices and take risks.

5.1.3 Own Attitudes

The published literature emphasises personal factors that can impact the nature and number of choices available, such as adaptive functioning skills, physical health, age, gender, intelligence, social and communication skills, and importantly, one's perceptions of oneself (Arvidsson et al, 2008; Stalker & Harris, 1998; Wehmeyer & Abery, 2013; Nota, et al, 2007).

Perceptions of oneself was in fact described in the literature as a large factor in choice making (Mill, 2009; Saaltink et al, 2012; Williams & Porter, 2017, Arvidsson, Granlund & Thyberg, 2008). The views of participants in this study demonstrate the value of positive self-perceptions and self esteem as a factor in choice making and how one's self esteem, confidence and ability to self advocate are important influencers to choice making.

A key theme found in this study was that young adults with intellectual disability feel different and can feel the lack of privilege and social capital associated with the label of intellectual disability. These young adults identify as the 'other', marginalized, stigmatized and different from "normal people." Participants highlighted societal prejudice, stigma and stereotypes that question their ability to make choices, which is in line with the literature that states that in practice there are often negative attitudes, stigma and barriers to choice making and occupational choices for young people with intellectual disabilities that perpetuate the perception that people with intellectual disabilities are unable to become self-determined and make choices (Brown & Brown, 2009; Stmadova & Evans, 2011; Wolf & Joannou, 2013). While several participants were not able to articulate why they feel different; some acknowledged a pervasive sense of themselves as less than 'normal' people, and due to their disability, are left feeling othered. This suggests that people with intellectual disability, though poorly able to express themselves verbally, may nevertheless have an acute internal sense of their value-or lack thereof- based on their interaction with supporters and carers, which impact on their sense of self and self agency in their environment.

This feeling underpins their experience of being human and the way that they experience the world. Having to constantly test the nature of the spaces they occupy to determine if they are 'friendly' or not friendly toward people with intellectual disabilities only reinforces this sense of othering, and the construction of their identity as 'less'.

As discussed in the introductory chapter, Clegg and Bigby (2017) found that often many people with intellectual disability in fact reject the label of intellectual disability, rejecting the stigmas that are associated with the label of being disabled, and "prefer the social model position where society should change and not them (p.82)". This was consistent with the findings of the study where participants described feelings around disability linked with shame and stigma.

5.1.4 Promoting Accepting and Staying Small

For people with intellectual disabilities, the study findings are consistent with the literature which contends that adulthood (or, 'growing up') might actually imply a lack of autonomy and being controlled by others (Witsó & Kittelsaa, 2018). While being a typical 'adult' would suggest autonomy and independence, for these young adults this may not become a reality. Several young adults in this study have expressed a sense of being obligated to rely on the experience and authority of others in their family, with little sense of encouragement to develop their own experience and opportunities to make decisions. This presupposes that due to their able-mindedness they have access to more experience and exposure to new and novel things. Participants described why they would choose specific supporters to assist them with difficult decisions, and most acknowledged greater wisdom in the other, rather than drawing on their own knowledge about issues.

It was found that how 'being different' has given participants permission to behave in a manner that is not acceptable for typically developed people, perhaps associating acceptable childlike behaviours with intellectual disability. This is reflected in the literature where Mill et al (2009) state that "dependency, obedience, and child-like behaviours may in fact be

promoted by parents, rather than independence, self-direction, and the assumption of responsibility and greater autonomy” (p.195).

In the past, marriage, sexual relations and parenthood were forbidden for people with intellectual disabilities (Mill et al, 2009). While this is slowly changing, participants described this as a contentious issue for supporters (Mill et al, 2009) which was evident in the findings of this study. This could be one example where promoting autonomy and self-determination can be fraught with risk for parents and their children with intellectual disabilities (Almack et al 2009). Intimate relationships were seen as a controversial issue in this study, which represents much of what the literature says. Navigating the complexities of relationships can be challenging for anyone, with or without a disability, and this study highlighted the divided opinion on relationships for people with intellectual disabilities. Restricting relationships for this population infringes upon their human rights, and the rights set out in the UNCRPD (United Nations, 2006).

Parents could be limiting the number of choices available in order to protect their young adult, but in reality, they may hinder the process of growing and learning to become independent. One participant described how when she does make choices, she is made to feel incompetent, resulting in negative emotions associated with having to make choices. This results in a default to allow the parents to make decisions on her behalf, named by one of the participants as the notion of ‘staying small.’ Most adults with intellectual disability in South Africa are compared with children, causing concern over respecting these adults with dignity and respect (Capri & Swartz, 2018), which will ultimately suggest that their choices are taken away, and made on their behalf, like the children that they are compared to.

This idea of “staying small” is reflective of possible infantilisation of young adults with intellectual disabilities. Conversely, staying small could also refer to one’s limited ability to create meaningful and purposeful lives, and without choices and asking for more, one settles with less, a small amount, and lives a small life.

5.1.5 Having Limited Choices

Participants could all identify with restrictions placed on choice making opportunities, which Van der Meulen et al (2018) refer to as 'restraints of freedom.' This notion of freedom was brought up both in the interviews as well as the focus group, likening having choices to a feeling of freedom. Often restraints of freedom are instituted as a means of protection (Van der Meulen et al, 2018). This was identified in the interviews as participants who perceive parents not wanting their children to get hurt, or to have to navigate risky situations. As mentioned the findings of this study highlight a double bind for some parents in that the parent may be seen to be withholding choices, when they are striving to promote independence.

The experiences of participants in this study illustrate how young adults with intellectual disability have been denied opportunities to make choices and prevented in their self-advocacy efforts to obtain what they want or need. Examples of these restrictions span across life domains, including restrictions placed upon: work settings, romantic relationships and other daily choices. These limitations were described by all the participants, and it was noted how inextricably linked choice making was to each unique participant's context.

This brings forward the cycle that is perpetuated by limiting occupational choices for these young adults. They are not given opportunities to have new experiences and learn from mistakes, and as such do not have the spaces to grow, therefore perpetuating the cycle of dependency, and entrenching their powerlessness.

Townsend and Wilcock, (2004), describe occupational injustice as a situation whereby a person cannot assert autonomy to engage in meaningful occupations. Townsend and Hocking (2018), described occupational justice as "the freedom to do or be", occupational injustice can therefore be described as a lack of freedom to engage. The participants in this study referred to being given choice as a matter of freedom, and implied that there is no freedom without choice.

According to Townsend and Wilcock (2004), one form of occupational injustice is occupational marginalization. This is the exclusion of people with disabilities based on invisible societal norms, which dictate which occupations they should engage in, resulting in social exclusion, and limited access to opportunities and resources (Townsend & Wilcock, 2004). Durocher, Gibson, and Rappolt (2014) explain that occupational marginalization is simply when a person is restricted from participation due to invisible norms, habits, traditions and tacit expectations of behaviour. This is in line with the findings of the study, whereby the participants described being different as leading to limited choice opportunities. This also fits in with the concepts of Bourdieu's concepts of habitus and doxa, as owning an intellectually disabled identity has limited the occupational choices of these young adults (Bourdieu, 1990). The participants, despite their differences, have a shared element of identity through their habitus, their label of intellectual disability, and identified that this habitus has resulted in a doxa that limits the expectations placed on them. "Because I have an intellectual disability, society expects less from me, and gives me fewer choice opportunities because they believe I am different, not normal, even considered as 'less.'"

The findings of this study have highlighted the importance of the factors and agents within a context, and how a context can determine what occupational choices are made available to the young adult. It becomes clear, that in line with Galvaan (2015), occupational choices are formed and shaped, and are co-constructed with context and the agents within. By considering this co-construction and interdependence in context, one would need to identify whether there are sufficient supports in each context to empower people with intellectual disability to engage in choice making and broaden their occupational choices, striving for occupational and social justice.

5.1.6 Or: Challenging and Growing Up

Much like the literature review which found that people with intellectual disability are dissatisfied with their experience of choice making, wishing for more choice making opportunities, all participants in this study described a feeling of dissatisfaction with their experience of choice making and a desire for more. The literature suggests that many young

adults with intellectual disability may resent what they perceive is too much parental control and interference in their everyday lives, as they need to and want to negotiate risk (Mill et al, 2009; Almack et al, 2009).

These young adults have expressed the need to try things for themselves, and this was seen in their responses that ask for new and novel opportunities to engage in different occupational choices from what they are used to. They spoke about wanting more, from all areas of daily living, jobs that they are passionate about, romantic relationships and good relationships with family, and leisure occupations from which they derive meaning and purpose.

The study highlighted how these young adults want more for themselves, challenge the perceptions and stereotypes that society hold of people with disability, and disrupt the norm where people with intellectual disabilities are not afforded choice. It is important to acknowledge different ways of doing, being, belonging and becoming. Acting in this manner dismantles the doxa, or expected rules, and challenges the dialogue, breaking open the figurative cage that is placed on these young adults with intellectual disability.

5.1.7 A framework for change

The participants in this study vocalized the desire to be given a chance, to be exposed to new and novel occupations and to be supported in their search for meaningful and purposeful occupations. The participants are self advocating for the opportunity to grow up and become independent. Below I discuss the beginning of a developing conceptual framework which has emerged from participants' views. This can inform an approach to reflecting on and creating opportunities to address the enablers and barriers to choice identified by participants. By using and expanding on the work by Bourdieu (1990), Galvaan (2015), and McIntosh (1989) the illustration below has been developed as a graphic representation of a lens through which to view the scope of occupational choices available to young adults with intellectual disability.

The young adult with an intellectual disability has to carry the label of intellectual disability like a knapsack, and packed inside are the expectations and limitations that have been placed on them. The invisible habitus refers to conscious and unconscious facets of a person's identity with which they meet the world (eg. race, gender, sexual orientation, prejudices, heritage etc). The young adults in this study identify the feelings associated with owning the label of 'intellectual disability' and describe how this influences the nature and number of choices in a negative way. The doxa, or social rules and expectations, dictate that there are certain everyday occupational choices that are limited and restricted for people with intellectual disabilities. The doxa place bands of restrictions on the bands of opportunity. See Figure 1 for a diagrammatic representation below.

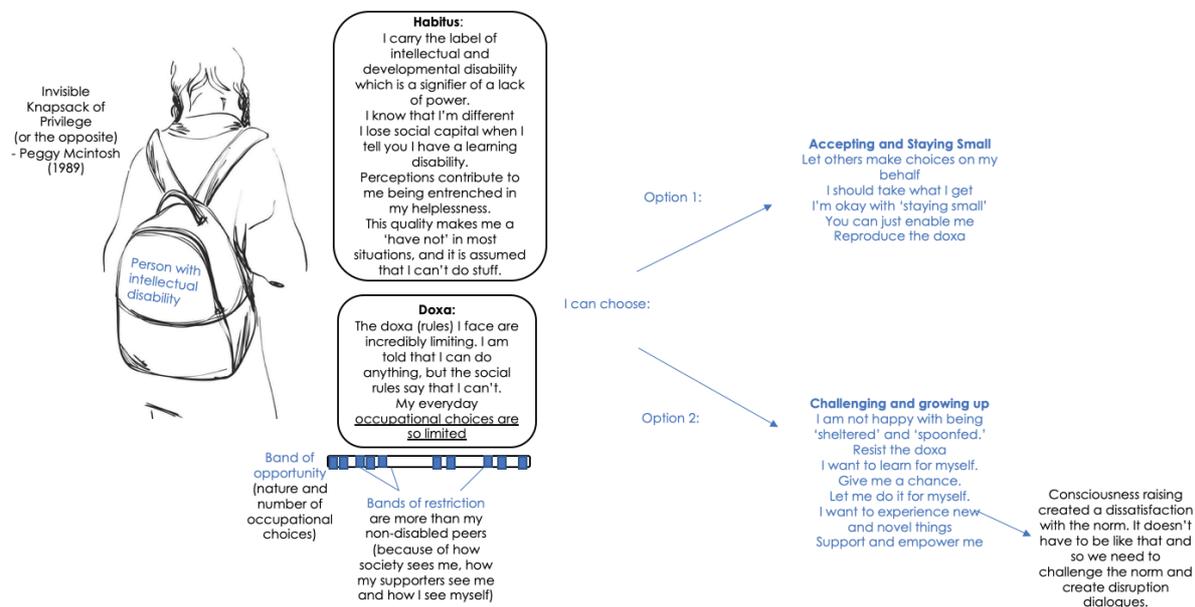


Figure 1: "Knapsack of The Lack of Privilege": A model created to illustrate the study findings in young adults with intellectual disability

People with intellectual disability may continue "staying small" if they always accept what is offered to them, remaining unchallenged, perpetuating the norm. These young adults could be resigned to their situations and the bands of restrictions that society, their supporters, and they themselves have placed on the bands of opportunity. Or on the other hand, they can raise their voices and demand better for themselves, advocating for their rights, challenging, growing up, and disrupting the dialogues of what society perceives of people with intellectual disability.

This conceptual framework highlights how a person with an intellectual disability (or in fact, any person within a minority group), carries a backpack with an invisible habitus packed inside. The figure shows how societal and contextual expectations place bands of restrictions on the wide bands of opportunities for occupational choice. Furthermore, the figure shows that any person has two choices, firstly: to accept the norm, and 'stay small,' to live in the label, the stigmas and shame associated with the labels. These stigmas can perpetuate powerful discourses about who and what characteristics are valued and preferred in society. People with intellectual disability are immersed in these discourses their whole lives, and may internalize them, not necessarily questioning what could be otherwise. On the other hand, if consciousness is raised, one can disrupt the dialogue, build resilience, dismantle the doxa and

form new ways of doing, being and becoming. This will be further described in the implications for the study.

6. Implications of the study

a) Improve Self Worth, Address Othering and Build Resilience

The response in this study calls for the addressing of stigma, othering and feelings of shame associated with having an intellectual disability. Results show that this is achieved through the action of doing and being exposed to new and novel occupations. By increasing exposure, and allowing for the act of doing and succeeding, the participants highlight how it may be possible to raise one's self esteem. This can be done by providing everyday choice opportunities, as well as allowing young adults the room to try new experiences, perhaps unveiling a hidden talent or passion. This was evident in the findings of this study, where several participants expressed pride in succeeding in activities that they had never thought possible. In turn, this can reduce feelings of shame, as well as an increase resilience.

Exposure within contexts and communities will create more representation of people with intellectual disability, ideally reducing stereotypes and stigma. The White Paper on the Rights of Persons with Disabilities (2015) echoes this notion and state that harmful and negative stigmas and stereotypes that are associated with disability continue to segregate people with disabilities from mainstream social and economic life and highlight the great importance of changing attitudes and perceptions. Saaltnick et al (2012) propose an education programme which could reduce stigma and discrimination and lead to a new conception of choice making for people with intellectual disability which could be aimed at parents and professionals. The National Mental Health Policy Framework and Strategic Plan of 2013-2020, (Parliament of the Republic of South Africa, 2013) suggests that exposure and inclusion in mainstream society is key to reducing stigma.

b) More opportunities to make choices in context

Participants all expressed the need for supporters and contexts to provide daily choice making opportunities. The participants describe that their choices can be facilitated, but there needs to be a feeling of involvement and autonomy. This is reflected in the literature where

Witsó & Kittelsaa (2018) suggest that the development of autonomy and choice making rests not only on the person and their ability to exert it, and the environmental opportunities to practice it, but in addition on the support they receive from professionals, communities, and supporters.

Several of the participants suggested that supporters provide small choice making opportunities, similar to Saaltink et al (2012) who described the concept of 'scaffolding'. In this study it was likened to being given a taste, instead of being given the whole plate, which illustrates the need for supporters to provide small daily choice making opportunities to empower the young adults to take ownership and advocate for themselves. Tarleton et al (2005) suggest that supporters can partner with their young adults with intellectual disability in terms of choice making and planning of their lives.

c) Reducing Supporter Fears

Supporters' sense of fear and reluctance to allow their young adult to navigate risk may lead to perpetuating child like behaviours, and infantilisation. One example of a strategy to reduce the supporter's fears is to have supporters be exposed to the successes of their children (or young adults), particularly around development and growth, especially around tasks they did not deem achievable. With this witnessed success, they should be more inclined to allow more scope for growth opportunities.

d) Strategies for Supporters

The participants described choice making as a process that needs support in the beginning also referred to as graded support. Several participants voiced how ideally, they would want their supporters to be there to show them how to do something, then give them an opportunity to try, and to support them in case they make mistakes. As referred to above, one strategy for parents to achieve this, is through 'scaffolding' (Saaltink et al, 2012). It is noted that research reflects that people with intellectual disability can become more self determined if they are given support to do so (Nota, et al. 2007).

e) Strategies for professionals

“Since silence implies compliance with the status quo, the authors encourage occupational therapists to develop their own dialogue about occupational injustices in order to address them openly with others” (Townsend and Wilcock, 2004, p.75). This statement is true for all professionals providing care and support to people with intellectual disability.

Professionals should maintain a rights-based approach when dealing with disability, as per the White Paper on the Rights of Persons with Disability (2015).

In 2015, the Gauteng Department of Health in South Africa took a decision to cancel a contract for the 2000-bed Life Esidimeni facility, which accommodated people with mental health conditions and intellectual disabilities. These people were transferred into the communities, to their families, to local non governmental organisations and acute psychiatric settings (SASOP, 2016). At least 144 patients with mental illnesses and disabilities have subsequently died in appalling circumstances. Reports indicate that the conditions in which these patients were moved perpetuated their vulnerability to poor treatment and injustice (Moseneke, 2017) In light of the gross violation of the human rights of the mental health service users involved in the Life Esidimeni tragedy, this further shines a light on the importance of the role of professionals, and the need to practice with an ethical and human rights perspective (Dhai, 2018).

Dhai (2018) suggests that professionals should uphold the values of compassion, competence and autonomy in all scopes of practice. This was reflected in the study where participants expressed a need for institutions to consider the young adults’ interests, needs and unique being when making decisions that concern them. Institutions and supporters need to focus on a strengths-based approach rather which fits into the social model framework as well as an occupational justice lens which prioritizes personal meaning and purpose.

f) Society, Awareness and Occupational Justice

The experience of occupational marginalization presupposes an infringement on the human rights of these young adults. It then becomes necessary from an occupational and social justice perspective, to find strategies to disrupt the norm, where a lack of choice is widely accepted for young adults with intellectual disability. Williams and Porter (2017) believe that as a society we should be challenging assumptions that people with intellectual disability are incapable of being self determined, and emphasise the need to support their choice making and autonomy. This was reflected in the findings of this study highlight how the participants have called for the importance of raising awareness and consciousness in society.

The White Paper on The Rights of Persons with Disability (Parliament of the Republic of South Africa, 2015) states that raising awareness is key to fostering respect for the rights and dignity for people with disability, as well as promoting awareness of their contributions and capabilities, and to combat stereotypes and stigma. Arvidsson et al (2008) state that understanding the factors that shape and enhance everyday participation for people with intellectual disability is important in all areas of intervention. This is also in line with Galvaan (2015) who states that understanding the personal, relational, socio-historical, socio-economic and cultural contexts in which these young adults with intellectual disability find themselves, can guide the promotion of occupational justice.

7. Limitations

This qualitative study aimed to investigate the depth of meaning around choice and choice making for participants where the sample was small. Though data saturation was reached with this group, a larger, more diverse sample, including participants from other settings, might have produced further insights into the research. Only 6 out of the 23 potential participants responded, which could indicate a response bias, as it is not known why the others (or their parents) chose not to get involved. Another limitation is the fact that the researcher is an employee of The Living Link, and while her familiarity with the context might have added depth of discussion with the participants, at the same time relevant threads in the dialogue

might have been missed due to embeddedness in context. The language exclusion of participants who do not speak English could also be perceived as a limitation.

8. Further Research

Further research is needed to confirm and elaborate on the findings of this study. It could be beneficial to identify choice making empowerment strategies, and how foundational choice making skills are developed in children with intellectual disability. It could also be beneficial to investigate the context of choices in order to advance our understandings of what choices are possible or denied or limited and why. This could highlight ways to change the social contexts and structures to support the individual. A longitudinal study could also add to the body of knowledge to see how the process of negotiating choice and autonomy could be examined in more detail and at multiple points over time. Studies could be conducted examining the feelings of shame associated with having an intellectual disability, and the resilience to overcome these feelings. Studies could investigate the ways in which choice making is successfully implemented, where young adults feel empowered, and can review the features of this success. Further studies could overcome the limitations of the study as mentioned in the limitations section.

9. Conclusion

Understanding the factors that shape the occupational choices of young adults with intellectual disability in a South African context has generated insights into their lived experiences and has the potential to open a platform for discussion. The implications of the young adults' perceptions of being different and having limited everyday occupational choices, makes for an urgent case for education and awareness raising about practices within institutions and among supporters in South Africa regarding the empowerment of people with intellectual disability. This study has highlighted how contextual factors can act as both enablers and barriers to choice making, and the implications thereof. The findings of the study

can be used to address human rights in a South African context, drawing on the values of the social model to make use of contexts to enact change. This study has highlighted the call to improve both the nature and number of the occupational choices that are available to these young adults with intellectual disability, working towards the goal of meaningful and purposeful occupational engagement, occupational and social justice.

References

- Almack, K., Clegg, J., Murphy, E. (2009). Parental Negotiations of the Moral Terrain in Relation to Young People with Intellectual Disabilities. *Journal of Community & Applied Social Psychology*. 19. Pp 286-298.
- American Psychiatric Association. (2013). Diagnostic and statistical manual of mental disorders (5th ed.). Washington, DC: Author
- Anney, V. (2014). Ensuring the quality of the findings of qualitative research: Looking at trustworthiness criteria. *Journal of Emerging Trends in Educational Research and Policy Studies.*, 5(2), pp 272-281.
- Arvidsson, P., Granlund, M., Thyberg, M. (2008). Factors related to Self-Rated Participation in Adolescents and Adults with Mild Intellectual Disability – A systematic Literature Review. *Journal of Applied Research in Intellectual Disabilities*. 21, pp 227-291
- Baillie, L. (2015). Promoting and evaluating scientific rigour in qualitative research. *Nursing Standard*. 29(46), pp 36. 10.7748/ns.29.46.36.e8830 Retrieved from <http://www.ncbi.nlm.nih.gov/pubmed/26174283>
- Bosch, C. (2016). Self Advocacy. In Johns, R., & Adnams, C. Understanding Intellectual Disability: a handbook for families, staff, students and professionals. Western Cape Forum for Intellectual Disability. pp 52-55
- Bourdieu, P. (1977). Outline of theory of practice. New York: Cambridge University Press.
- Bourdieu, P. (1990). Logic of practice. Stanford University Press: California
- Braun, V. & Clarke, V. (2006). Using thematic analysis in psychology. *Qualitative Research in Psychology*, 3, pp77-101
- Brown, I., & Brown, R. (2009). Choice as an Aspect of Quality of Life People with Intellectual Disabilities. *Journal of Policy and Practice in Intellectual Disabilities*. Vol 6. Number 1. Pp 11-18
- Bush, K., & Tassé, M. (2017). Employment and choice-making for adults with intellectual disability, autism, and down syndrome. *Research in Developmental Disabilities*, 65, pp 23-24.
- Byng, S., & Duchan, J. (2005). Social model philosophies and principles: Their applicatons to therapies for aphasia. *Aphasiology*. 19 (10/11). Pp 906-922
- Byrne, L., Happell, B., & Reid-Searl, K. (2016). Lived experience practitioners and the medical model: world's colliding? *Journal of Mental Health*. Vol 25. Issue 3. Pp217-223
- Capri, C., & Coetzee, O. (2012) 'On the unethicity of disablism: Excluding intellectually impaired individuals from participating in research can be unethical', *African Journal of Disability*, 23, pp4

- Capri, C., & Buckle, C. (2015). 'We have to be satisfied with the scraps': South African nurses' experiences of care on adult psychiatric intellectual disability inpatient wards. *Journal of Applied Research in Intellectual Disabilities*, 28(3), pp 167-181
- Capri, C. & Swartz, L. (2018). "We are actually, after all, just children": caring societies and South African infantilisation of adults with intellectual disability, *Disability & Society*. Vol 33. Issue 2. Pp285-308
- Carter, E., Lynne Lane, K., Cooney, M., Weir, K., Moss, C., & Machalicek, W. (2013). Self-Determination Among Transition-Age Youth With Autism or Intellectual Disability: Parent Perspectives. *Research & Practice for Persons with Severe Disabilities*. Vol. 38. No. 3. Pp 129-138
- Cartwright, L., Reid, M., Hammersley, R., Blackburn, C., & Glover, L. (2015). Food choice by people with intellectual disabilities at day centres. *Journal of Intellectual Disabilities*, 19(2), pp 103-115.
- Chan, K.K.K.L & Chiu, M.Y.L (2007). The Politics of Citizenship Formation: Political Participation of Mental Health Service Users in Hong Kong. *Asian Journal of Social Science*, 35, pp 195-215
- Christiansen, C. (1999). Defining lives, occupation as identity: an essay on competence, coherence, and the creation of meaning. *American Journal of Occupational Therapy*. Vol 53. Pp.547-558
- Corby, D., Taggart, L., & Cousins, W. (2015). People with intellectual disability and human science research: A systematic review of phenomenological studies using interviews for data collection. *Research in Developmental Disabilities*.47. (451-465)
- Cozby, P. C., & Bates, S. C. (2012). *Methods in behavioral research*. New York: McGraw-Hill.
- Clegg, J. & Bigby, C. (2017) Debates about dedifferentiation: twenty-first century thinking about people with intellectual disabilities as distinct members of the disability group, *Research and Practice in Intellectual and Developmental Disabilities*, 4:1, pp 80-97
- Correia, R. A., Seabra-Santos, M. J., Campos Pinto, P., & Brown, I. (2017). Giving voice to persons with intellectual disabilities about family quality of life. *Journal of Policy and Practice in Intellectual Disabilities*, 14(1), pp. 59-67
- Dhai, A. (2018). The Life Esidimeni tragedy: Moral Pathology and an ethical crisis. *South African Medical Journal*. 108.5 pp 382-385
- Du Plessis, M. (2013). The Social Model of disability, rights discourse and the impact of South Africa's Education White Paper 6 on access to the basic education system for persons with severe or profound intellectual impairments. *Law, Democracy & Development*. Vol 17
- Durocher, E. Gibson, B. & Rappolt, S. (2014). Occupational Justice: A Conceptual Framework. *Journal of Occupational Science*. 21:4. Pp 418-430
- Emmett, T. (2006). Disability, poverty, gender and race. In *Disability and Social Change: A South African agenda*. Chapter 16, 207-233 HSRC Press. South Africa.
- Fisch, G. (2011). Mental Retardation or Intellectual Disability? Time for a Change. *American Journal of Medical Genetics*. Part A. 155. 2907-2908

- Fulford C., Cobigo, V. (2018). Friendships and Intimate Relationships among people with intellectual Disabilities: A Thematic Synthesis. *Journal of Applied Research in Intellectual Disabilities*. 31. E18-e35
- Fyson, R., & Cromby, J. (2013). Human rights and intellectual disabilities in an era of 'choice'. *Journal of Intellectual Disability Research*, 57(12), 1164-1172. 10.1111/j.1365-2788.2012.01641.x
- Galvaan, R. (2015). The contextually situated nature of occupational choice: Marginalised young adolescents' experiences in South Africa. *Journal of Occupational Science*, 22(1), 39-53. 10.1080/14427591.2014.912124 Retrieved from <http://www.tandfonline.com/doi/abs/10.1080/14427591.2014.912124>
- Girimaji, S.C., & Pradeep, A.J. (2018). Intellectual Disability in International Classification of Diseases-11: A developmental perspective. *Indian Journal of Social Psychology*. 38. Pp.68-74
- Gourlay, A., Mshana, G., Birdthistle, I., Bulugu, G., Zaba, B., & Urassa, M. (2014). Using vignettes in qualitative research to explore barriers and facilitating factors to the uptake of prevention of mother-to-child transmission services in rural Tanzania: A critical analysis. *BMC Medical Research Methodology*, 14(1), 21. 10.1186/1471-2288-14-21 Retrieved from <https://www.ncbi.nlm.nih.gov/pubmed/24512206>
- Haigh, A., Lee, D., Shaw, C., Hawthorne, M., Chamberlain, S., Newman, D., Clarke, Z., Beail, N. (2013). What things make people with a learning disability happy and satisfied with their lives: An Inclusive Research Project. *Journal of Applied Research in Intellectual Disabilities*. 26. 26-33
- Harris, J. (2003). Time to make up your mind: why choosing is difficult. *British Journal of Learning Disabilities*. 31. 3-8
- Health Professions Council of South Africa, (2008) Guidelines for good practice in the healthcare professions. Retrieved from: http://www.hpcsa.co.za/downloads/conduct_ethics/rules/generic_ethical_rules/booklet_1_guidelines_good_prac.pdf
- Hollomotz, A. (2018). Successful interviews with people with intellectual disability. *Qualitative Research*. 18. (2) pp 153-170
- Howell, C., Chalklen, S., & Alberts, T. (2006). A history of the disability rights movement in South Africa. In *Disability and Social Change: a South African agenda*. Chapter 5, 46-84 HSRC Press. South Africa.
- Horner-Johnson, W., & Bailey, D. (2013). Assessing understanding and obtaining consent from adults with intellectual disabilities for a health promotion study. *Journal of Policy and Practice in Intellectual Disabilities*, 10(3), 260-265. 10.1111/jppi.12048
- Levitt, J. (2017). Exploring how the social model of disability can be re-invigorated: in response to Mike Oliver. *Disability & Society*. 32:4, 589-594, DOI:10.1080/09687599.2017.1300390
- Lincoln, Y. S., & Guba, E. G. (1985). *Naturalistic enquiry*. Beverly Hills, CA.: Sage.
- Maguire, M. & Delahunt, B. (2017). *Doing a Thematic Analysis: A practical step-by-step guide*

for learning and teaching scholars. *All Ireland Journal of Teaching and Learning in Higher Education*. Vol 8. No 3. 3351-33514

McConkey, R., & Collins, S. (2010). Using personal goal setting to promote the social inclusion of people with intellectual disability living in supported accommodation. *Journal of Intellectual Disability Research*. Vol 54. Part 2. Pp135-143. Doi:10.1111/j.1365-2788.2009.01.224.x

McIntosh, P. (1989). White privilege: Unpacking the invisible knapsack. *Peace and Freedom*, July/August, 10-12. Philadelphia, PA: Women's International League for Peace and Freedom

McIntosh, P. (2015). Extending the Knapsack: Using the White Privilege Analysis to Examine Conferred Advantage and Disadvantage, *Women & Therapy*, 38:3-4, 232-245, DOI 10.1080/02703149.2015.1059195

McMillan, J. (2016). *Fundamentals of educational research* (Seventh Edition ed.) Pearson.

Mill, A., Mayes, R., & McConnell, D., (2009). Negotiating autonomy within the family: the experiences of young adults with intellectual disabilities. *British Journal of Learning Disabilities*. Vol 38. Pp 194-200.

Moseneke, D. (2017). *Life Esidimeni Arbitration Parktown*, Johannesburg

Moyson, T., & Roeyers, H. (2011). The quality of life of siblings of children with autism spectrum disorder. *Exceptional Children*, 78(1), 41-55. 10.1177/001440291107800103 Retrieved from <http://journals.sagepub.com/doi/full/10.1177/001440291107800103>

Nota, L., Ferrari, L., Soresi, S., & Wehmeyer, M. (2007). Self-determination, social abilities and the quality of life of people with intellectual disabilities. *Journal of Intellectual Disability Research*. Vol 51. Part 2. Pp. 850-865

Office of the Deputy President. (1997). *Integrated National Disability Strategy: White Paper*. Retrieved from: <http://www.thepresidency.gov.za/pebble.asp?relid=677>

Palinkas, L., Horwitz, S., Green, C., Wisdom, J., Duan, N., & Hoagwood, K. (2015). Purposeful sampling for qualitative data collection and analysis in mixed method implementation research. *Administration and Policy in Mental Health and Mental Health Services Research*, 42(5), 533-544. 10.1007/s10488-013-0528-y Retrieved from <http://www.ncbi.nlm.nih.gov/pubmed/24193818>

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

Parliament of the Republic of South Africa. (1997). *Integrated National Disability Strategy*.

Parliament of the Republic of South Africa. *Human rights*. Retrieved from https://www.parliament.gov.za/storage/app/media/EducationPubs/human_rights_email_eng.pdf

Parliament of the Republic of South Africa. *National Mental Health Policy Framework and Strategic Plan 2013-2020*. (2013). Retrieved from <https://www.health-e.org.za/wp->

[content/uploads/2014/10/National-Mental-Health-Policy-Framework-and-Strategic-Plan-2013-2020.pdf](#)

- Parliament of the Republic of South Africa. (2016). White paper on the Rights of Persons with Disabilities. https://www.gov.za/sites/www.gov.za/files/39792_gon230.pdf
- Pilnick, A., Clegg, J., Murphy, E., & Almack, K. (2011). 'Just being selfish for my own sake....' Balancing the views of young adults with intellectual disabilities and their carers in transition planning. *The Sociological Review*. Vol 59, Number 2. Pp. 303-323
- Ramugondo, E. (2018). (2018). Keynote address. Paper presented at the World Federation of Occupational Therapy
- Retief, M. & Letsosa, R. (2018). Models of Disability: A brief overview. *HTS Theological Studies* 74(1).a4738.
- Reynolds, T., Zupanick, C., & Dombeck, M. (2018) Historical and Contemporary Perspectives on Intellectual Disability. Retrieved from <https://www.mentalhelp.net/articles/historical-and-contemporary-perspectives-on-intellectual-disabilities/>
- Sarto-Jackson, I. (2018). Time for a Change: Topical Amendments to the Medical Model of Disease. *Biological Theory*. Volume 13. Issue 1. Pp 29-38
- Saaltink, R., MacKinnon, G., Owen, F., & Tardif-Williams, C. (2012). Protection, participation and protection through participation: young people with intellectual disability and decision making in the family context. *Journal of Intellectual Disability Research*. Vol 56. Part II. Pp 1076-1086
- Smyth, C., & Bell, D. (2006). From biscuits to boyfriends: the ramifications of choice for people with learning disabilities. *British Journal of Learning Disabilities*. Vol 34. Pp. 227-236
- South African Society of Psychiatrists (SASOP). 2016. SASOP guide statement on clinician and discharged patients from the Life Health Esidimeni facilities: editorial. *Mental Health Matters*. Volume 3. Issue 4. Pp 3-7
- Sparks, S. (2013). Increasing Choice-Making and Choice Awareness for Students with Intellectual Disability. UNLV Theses, Dissertations, Professional Papers and Capstones, 1953.
- Stalker, K., Harris, P., (1998). The Exercise of Choice by Adults with Intellectual Disabilities: A literature review. *Journal of Applied Research in Intellectual Disabilities*. Vol 11. No 1. Pp 60-76
- Stancliffe, R. J. (2001). Living with support in the community: Predictors of choice and self-determination. *Mental Retardation and Developmental Disabilities Research Reviews*, 7(2), 91-98. 10.1002/mrdd.1013 Retrieved from <http://www.ncbi.nlm.nih.gov/pubmed/11389563>
- Stmadová, I., & Evans, D. (2012). Subjective Quality of Life of Women with Intellectual Disabilities: The Role of Perceived Control over their Own Life in Self-Determined Behaviour. *Journal of Applied Research in Intellectual Disabilities*. Vol 25. Pp. 71-79
- Sulla, V., Zikhali, P. (2018). Overcoming Poverty and Inequality in South Africa: An assessment of Drivers, Constraints and Opportunities (English). Washington D.C: World Bank Group.

- Swartz, L., & Watermeyer, B. (2006). Introduction and overview. In *Disability and Social Change: a South African agenda*. Chapter 1, 1-6 HSRC Press. South Africa.
- Tarleton, B., & Ward, L. (2005). Changes and Choices: finding out what information young people with learning disabilities, their parents and supporters need at transition. *British Journal of Learning Disabilities*. Vol 33. pp 70-76.
- The Living Link. (2018). The living link. Retrieved from <http://thelivinglink.co.za/about-the-living-link/>
- Townsend, E., & Wilcock, A. A. (2004). Occupational justice and client-centred practice: A dialogue in progress. *Canadian Journal of Occupational Therapy*. 71(2), 75. Retrieved from <http://www.ncbi.nlm.nih.gov/pubmed/15152723>
- United Nations (2006). *Convention on the rights of persons with disabilities*, New York: United Nations General Assembly Cong. Retrieved from <http://www.un.org/disabilities/documents/convention/convoptprot-e.pdf>
- Van der Meulen, A.P., Hermsen, M., & Embregts, P. (2018). Restraints in daily care for people with moderate intellectual disabilities. *Nursing Ethics*. Vol. 25 (1). Pp. 54-68
- van Niekerk, L. (2014). The relevance of occupational science to occupational therapy in the field of mental health. *Occupational therapy in psychiatry and mental health* (pp. 33-42). United Kingdom: John Wiley & Sons, Ltd.
- Watermeyer, B. (2006). Disability and psychoanalysis. In *Disability and Social Change: a South African agenda*. Chapter 4, 32-44 HSRC Press. South Africa.
- Wehmeyer M., Abery, B., (2013). Self-determination and choice. *Intellectual and Developmental Disabilities*, 51(5). 399-441
- Williams, V., & Porter, S. (2017). The Meaning of 'choice and control' for People with Intellectual Disabilities who are Planning their Social Care and Support. *Journal of Applied Research in Intellectual Disabilities*. Vol 30. 97-108
- Wilcock, A. (1999). Reflections on doing, being and becoming. *Australian Occupational Therapy Journal*. 46. 1-11
- Witsø, A., Kittelsaa, A. (2018). Active adult lives for persons with learning disabilities – The perspectives of professionals. *British Journal of Learning Disabilities*. Vol 48. P.10-16. DOI: 10.1111/bld.12207
- Wolf, J., & Joannou, K., (2013). Choice making and individuals with significant disabilities. *LC Journal of Special education*. Vol 9.
- Woods, R. (2017) Exploring how the social model of disability can be re-invigorated for autism: in response to Jonathan Levitt. *Disability & Society*. 32:7. 1090-1095. DOI:10.1080/09687599.2017.1328157
- World Health Organisation. (2017). Definition: Intellectual Disability. Retrieved from: www.euro.who.int/en/health-topics/noncommunicable-diseases/mental-

[health/news/news/2010/15/childrens-right-to-family-life/definon-intellectual-disability](https://www.who.int/news/news/2010/15/childrens-right-to-family-life/definon-intellectual-disability).
Retrieved on 13 April 2019

World Health Organisation. (2019). WHO releases new International Classification of Diseases (ICD 11). Retrieved from: [https://www.who.int/news-room/detail/18-06-2018-who-releases-new-international-classification-of-diseases-\(icd-11\)](https://www.who.int/news-room/detail/18-06-2018-who-releases-new-international-classification-of-diseases-(icd-11)) Retrieved on 12 April 2019.

World Medical Association. (2013). Declaration of Helsinki, 64th WMA General Assembly; October 2013, Fortaleza, Brazil

Young, I.M., (2001). Two concepts of self-determination, in A. Sarat and T.R. Kearns (eds.), Human Rights: Concept Contests, Contingencies, Michigan: University of Michigan Press: 25-44.

Appendix 1: Information Sheet / Advert



Life's About Choices

A 2019 Study

Information for Participants

Why?

I want to find out about the experiences, and what helps or interferes with making daily choices made by young adults with intellectual or learning disabilities. I will use this information to write up a report for my university study.

Who am I?

My name is Cole and I am an Occupational Therapist studying a Masters degree at UCT.

What information will I collect?

I will ask you some questions about the choices you make on a daily basis.

When?

We will set a date to meet up and discuss your views on making choices.

How will this affect you?

We will voice record our discussion so that I make sure that I do not make any mistakes about what you said. Your name will be hidden when I write up my findings, so it will be kept confidential.

For more information, contact me on 0844928255 or email colegoldberg.ot@gmail.com or Prof. Sharon Kleintjes (+27 21 404 2166 sr.kleintjes@uct.ac.za), Department of Psychiatry and Mental Health, University of Cape Town, Private Bag Rondebosch, 7700

Appendix 2: Informed Consent



INFORMED CONSENT FORM FOR RESEARCH PARTICIPANTS Information Sheet and Consent Form

This is a research project conducted by a Masters of Philosophy Student for degree purposes.

Purpose of the Study: This study is to describe young adults with learning challenges' or intellectual disabilities' experience of choices. In short, to find out your experience of making choices, as well as what helps or interferes with making choices in daily life.

What will your participation in the research study include?

The study will need one or two short interviews of about 30 minutes

Why have you been asked to take part?

You have been asked to participate in this research because we would like to improve our understanding of making choices when you experience learning challenges.

What will it the research process involve?

If you decide to be a part of this research study:

- You will have a half hour interview where I will ask you some questions about making choices in your life, and what has helped, or interfered with making choices.
- The interviews will be recorded so that we can type up exactly what you said so we don't make any mistakes.
- After a few months, I will make another meeting with you to share what I have found as well as find out what you think of the findings.
- Lastly the results will be put in a report to share our findings of our research study with others.

Will your participation in the research study be kept confidential?

Yes, your name will not be used. When we use the recordings, all hints that make us know that it is you will be hidden so nobody else will know. These recordings will be kept in a safe place, and all information will be kept on one of the researcher's laptop with a secret password.

What will happen to the results?

The results will be put in a thesis report. They will be seen by two research supervisors, and the examiners. The report may be read by future students or for other researchers in other faculties. The findings may be written into an article and published.

What are the benefits of taking part in the research study?

There are no personal benefits of taking part in this study.

What are the possible disadvantages of taking part?

The researcher does not see any negative consequences for your participation.

Are there any risks in taking part in the research study?

One risk is that you may feel uncomfortable about sharing your thoughts with the researcher. You do not have to share what you do not feel comfortable sharing as there are no right or wrong answers.

What if I decide not to take part in the research study?

Taking part in this research study is done so on a voluntary basis. You do not have to participate. If you do agree to take part but choose later that you do not want to anymore that is also okay. Refusing to take part in the study will not affect your position with me, nor your position at The Living Link.

What if I have questions?

If you have any questions, you can ask the researcher now or contact me at a later stage:

Cole Goldberg	gldnic006@myuct.ac.za	0844928255
---------------	-----------------------	------------

or Prof. Sharon Kleintjes (+27 21 404 2166 sr.kleintjes@uct.ac.za), Department of Psychiatry and Mental Health, University of Cape Town, Private Bag Rondebosch, 7700.

The Research Ethics Committee of the Faculty of Health Sciences at the University of Cape Town has given permission for the research to take place. If you have any concerns about the way this research is conducted please contact Prof. Mark Blockman, Chair: Research Ethics Committee, Faculty of Health Sciences, University of Cape Town, 7700, Tel. + 27 21 – 406 6338 or 0214066492
Email: shuretta.thomas@uct.ac.za and nosi.tsama@uct.ac.za

Masters of Philosophy in Intellectual Disability, 2018, Department of Psychiatry and Mental Health, School of Health and Rehabilitation Sciences, University of Cape Town.

If you agree to take part in the study, please sign below:

I agree to participate in this study: _____

Date: _____

Appendix 3: Vignettes

Vignettes

Vignette 1: Coming to TLL

John did not finish matric. He has learning challenges and found that school was a bit too difficult for him. He stopped studying and has been sitting at home watching TV for a few months. He often fights with his parents because they want him to do chores that he doesn't feel like doing. John wants to hang out with his friends, play soccer on the weekend and just chill and play PlayStation. His parents keep giving him other activities to do instead. One Saturday he had to do gardening all day, which he hates. His parents find out about The Living Link and sign John up for a screening without asking him.

Vignette 2: Training at TLL

Siwe is in his seventh week of training at TLL. Today is his interview day for Employment Orientation. His trainer has told him that he needs to dress in a formal way. He has a disagreement with his mother about what to wear at home, so he brought different options to The Living Link, as he thought he would decide there. He wore black pants, a white shirt, and had two choices for a tie. The one had South Park cartoon characters on it, and the other tie was a red plain tie. He asked his fellow trainees which one they think is more professional and they all agreed that the plain red tie is for the best. But Siwe likes the South Park one better. He got very frustrated.

Vignette 3: Job Sampling

Sarah is on job sampling and is working at Deli Spices in the HR department. Sarah wishes she could be working at Vida like her colleague Pam. The trains to Deli Spices are always late and she gets in trouble with her manager because she often comes late. She has asked if she can go to Vida instead, but her job coach said that Vida can only take one person at a time. She believes that she would be really good at another job but thinks that because she is a slow learner that there are millions of jobs that she can't do. She would rather just be told what she should do instead.

Appendix 4: Question Schedule

Question schedule:

1. Tell me a little about what you understand about the word choice
2. What does it mean to you to choose things? Or to make choices?
3. Describe areas of your life where you make choices
4. Some people use the term intellectual disability and other people prefer learning challenges. Which do you prefer and why?
 - a. How do you think having learning challenges / intellectual disability affects choices you'd like to make?
 - b. Have you noticed if having learning challenges has any effect on choices for other people you know with a learning challenge?
5. On the independent living tour you were able to choose your own menu for the food you were going to cook. How was that experience?
6. You spoke about something (name the incident) that may have gotten in the way of making a choice
 - a. How was that experience for you?
 - b. Can you think of what might have gotten in the way?
 - c. Can you think about what could have helped to improve making a choice?
7. On the other hand you mentioned that when you have an opportunity to choose (mention the incident)... it was... can you tell me a bit more about that?
 - a. How was that experience for you?
 - b. What do you think helped?
 - c. Can you think of anything that could have made it better?
8. What kind of activities do you do that you enjoy?
 - a. Who gets to choose your activities?
 - b. How do you spend your weekend? Who gets to choose?
 - c. How do you feel about that?
 - d. If it was totally up to you to plan a weekend, what would you choose to do?
9. After speaking about how you and other people you know make choices, is there anything you want to add that this interview has made you think about? Or something you want to mention?

Appendix 5: Coding Frame

The following is a screenshot taken of the coding framework established through Atlas Ti.

Code Group	Name	Groups	Comment
acceptance of self a... 1 Group(s)	desire for more / better / disruptions to...	67	0
	parents / supporters	51	0
	context as a factor to choice oppotuni...	47	0
	dissatisfaction	42	0
	a challenge / barrier to choice making	38	0
	empowered and supported	32	0
	feelings of being caged / stopped / just	29	0
	acceptance	28	0
	choice making is harder / different for...	26	0
	perception of disability as a hindrance	26	0
	give a chance	25	0
	choices as meaning making / important	22	0
	I do make choices	17	0
	a feeling of being different	16	0
	descriptions of ID	14	0
	opportunity to grow	12	0
	sense of fear	11	0
	insight into the other	10	0
	lack of growth	10	0
	choice making is easier for others than...	9	0
concrete examples of what a choice is	8	0	
conflict	8	0	
difficulty relating to self	5	0	
laziness	5	0	
trying her / his / my best	2	0	
examples of choice settings	1	0	
giving up	1	0	
reflecting into the nature of choice	1	0	

No Preview Available

No Selection