Social and health-related policy priorities of adults with intellectual disability in South Africa

Submitted in partial fulfilment of Master of Philosophy in Intellectual Disability

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Abstract

Background: People with intellectual disability are rarely consulted on what should be prioritised in public policy to improve their quality of life. It is also well documented in the literature that people with intellectual disability experience barriers when accessing social and health services. The aim of the study is to gain an understanding of policy priorities from the perspective of people with intellectual disabilities. **Method:** The study is qualitative in nature, with data collected through a scoping review from 1994 to 2021 on policy priorities for people with intellectual disability, and semi-structured interviews on the views of South African adults with intellectual disability on their policy priorities. The study participants comprised a sample of six participants with intellectual disability, aged 18 years and older, who were recruited through a non-profit organisation that offers a range of services for people with psychosocial and/or intellectual disability and their families; ranging from counselling and support, special education and care centres for children and adults, as well as training and employment opportunities for those who are able to work. **Results:** Policy priorities identified in this study include the need for support in education and skills training, adequate healthcare access, work opportunities, inclusive housing, and supportive relationships. **Conclusion:** It is evident from the findings of this study that people with intellectual disability are still largely excluded from policy participation. Public policy makers and implementers should consider reasonable accommodations to enhance involvement of people with intellectual disability in discussions and decisions about policy and practice which impact on their lives. Research documenting the voices of people with intellectual disability can also assist to inform policy development and needs to include adaptations to data collection methods to optimise participants opportunities to share their views on what they need. **Study implications**: This study highlights the importance of reasonable accommodations for people with intellectual disability to inform policy developments, and the need to eliminate barriers encountered by people with intellectual disability when accessing social, health and other public services.

Keywords: Intellectual disability, self-advocacy, lived-experiences, health policy, social policy

Definition of Terms

Intellectual disability	Life-long disability that is characterised by general impairments in intellectual functioning and adaptive behaviours (Emerson, Hatton, Robertson, & Baines, 2014).
Self-advocacy	Deciding on what you want, what is the best for oneself, and speaking up for oneself (David & Christine, 2016).
Social inclusion	The process of encouraging social interaction, particularly among disadvantaged groups, through enhancing opportunities in all life domains (Silver, 2015).
Social and health-related policies	The focus on "social and health-related policy" is conceptualised in line with the integrated approach to health and wellbeing adopted by the South African National Development Plan 2030 (National Planning Commission, 2012, p. 303).
Socio-ecological model	Introduced in the 1970's, Bronfenbrenner's socio-ecological model describes an individual's interactions at different levels of the social context (Bronfenbrenner, 1979).

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Chapter One

Introduction

In many low- and middle-income countries (LMICs), the social and health needs of people with intellectual disabilities remain under-recognized and under-funded. Therefore, more attention is needed in both research and practice to challenge existing policies that prioritize services for people with intellectual disabilities. This research captures what people with intellectual disabilities think government should include in their written promises or policies on services they will offer to them to support their health and wellness.

This chapter will provide an overview of disability in general and provide an overview of intellectual disability in the context of South Africa. The chapter will further provide an overview of social and health needs of people with intellectual disability and how the lack of prioritisation of these needs impacts the lives of people with intellectual disability. An overview of existing social and health-related policies in the South African context is also provided. This chapter will further outline the objectives, aims and research questions of the study.

1.1 Background

1.1.1 Disability in the South African context

Under South Africa's Apartheid government, the legislative system, which supported a segregation policy for "non-White" citizens from 1948 to 1990, disability was addressed as a social welfare and medical concern. Informed by the medical model, a person with disabilities was assessed and provided with services based on their medical condition (Republic of South Africa, 2016). The medical model focussed on the impairment that the person presented rather than their abilities. This model did not consider other issues, such as the full inclusion of people with disabilities into mainstream society; the importance of a barrier-free environment and the role it can play in their independence; and the human, economic and

political rights of a person with disabilities. Under Apartheid, South Africans received services according to assigned racial categories, with citizens categorised as the White race group receiving better service provision compared to citizens categorised as Black African, Coloured and Indian (The Population Registration Act of 1950) (Union of South Africa, 1950; Republic of South Africa, 2016), an additional burden for some persons with disabilities in South Africa.

Post-1994, a newly elected democratic government introduced a transformation agenda aimed at establishing an equitable society for all South African citizens. In 1996, the Constitution of the Republic of South Africa (Republic of South Africa, 1996) outlawed discrimination, including discrimination based on disability, and assured the right to equality for persons with disabilities (Republic of South Africa, 2016). The White Paper on the Rights of Persons with Disabilities (WPRPD) (Republic of South Africa, 2016) intended to create a free and just society inclusive of all persons with disabilities as equal citizens.

1.1.2 Prevalence of disability in South Africa

Using Census 2011 data, Statistics South Africa (Stats SA) estimated a national disability prevalence rate of 7.5% (Statistics South Africa [Stats SA], 2014). Disability prevalence across the nine provinces of South Africa ranged from 5.4% and 11.1% with Northern Cape (11.0%), North West (10.0%) and Free States (11.1%) reporting the highest proportion of people with disabilities; and the Western Cape (5.4%) and Gauteng (5.3%) reporting the lowest percentage (Stats SA, 2014). Disability is reported to be more prevalent among females (8.3%) than males (6.5%), and most prevalent among Black African (7.8%) followed by the White population with (6.5%), with other population groups such as Coloured and Indians population groups showing no variation (Stats SA, 2014)[1].

Census data remain an important data source that provides policy makers and other government planners with data on which to base their planning for social and economic developments. Census survey data in 2001 showed a prevalence of 0.5% for intellectual

[1] Racial classification statistics are based on the Population Registration Act No 30 of 1950 (Union of South Africa, 1950) which is kept as a measure to monitor redress to the racial-based inequalities that arise as a result of racialised policies and practices in South Africa, in particular those that arose during the Apartheid system of government from 1948 to 1994.

disability and an overall disability prevalence of 5.0%, despite this survey not including people from institutional care, with a large proportion of the population of people with disabilities excluded (Adnams, 2010). In 2011, Census survey-based disability prevalence on six domains only, namely, seeing (11%), hearing (3.6%), remembering/concentrating (4.2%), and about 2% had communication, walking and self-care difficulties, again with no disaggregation specifically for intellectual disability (Stats SA, 2014).

1.1.3 Intellectual disability in the South African context

South Africa is recognised as an upper-middle-income country where social and economic disparities are prevalent between different socio-economic groups, and people with intellectual disability are among the less privileged, most marginalised and vulnerable population groups (Adnams, 2010). People with intellectual disability are still suffering from inequalities that existed during the Apartheid regime when they were confined to hospitals and asylums. These inequalities are visible among different socio-economic, gender and racial groups (McLennan et al., 2016). Addressing inequalities, and social and economic disparities, in South Africa requires a unique approach because South Africa has a distinct history of racism that was supported by the Apartheid regime (Francis & Webster, 2019).

There is limited data describing intellectual disability across different age groups and populations, either from low- or high-income geographical areas, which challenges the identification of existing inequalities (Adnams, 2010). Little is known about the lived experiences of people with intellectual disability, especially in low-income countries and other upper-middle-income countries such as South Africa (McKenzie & McConkey, 2016). There is a gap in the recognition and provision of the needs of people with intellectual disability, with their needs seemingly disregarded (Adnams, 2010). They experience exclusion and the violation of their human rights, such the right to participation and equal opportunities (Capri, Abrahams, et al., 2018).

The documentation of the voices of people with intellectual disability and their families in setting and driving their own priorities is still in its infancy in South Africa. There is a gap in literature with regards to the documentation of the views of individuals with intellectual disability, especially those who cannot self-represent or those we assume are unable to do so

(Capri & Swartz, 2018). Further research is needed to address how best to include the views of those who cannot self-advocate, such as those with profound to severe intellectual disability.

1.2 Definition and Terminology

1.2.1 Intellectual disability

The definition of intellectual disability has changed several times over the years, as people's understanding of the disability has improved and due to the responses to social, political and professional factors (Shree & Shukla, 2016). The American Association of Intellectual Disability and Developmental Disabilities (AAIDD) define intellectual disability as a disability that is characterised by significant limitations in both intellectual functioning and adaptive behaviour that covers everyday social and practical skills (Arimoro, 2019; Salvador-Carulla et al., 2011; Shree & Shukla, 2016). On the other hand, the World Health Organization (WHO) defines intellectual disability as being significantly characterised by the reduced ability to understand new information and to learn and use new skills (Arimoro, 2019; World Health Organization [WHO], 2011).

In the literature, intellectual disability is defined as a global concern that is characterised by significant impairments and limitations in intellectual functioning and adaptive behaviours, such as performance of tasks of daily living, including self-care, learning skills, and the ability to work or live independently (Emerson et al., 2014; Shogren et al., 2009). It is also defined as a neurodevelopmental disorder that is characterised as having a major impact on adaptive behaviours such as conceptual, social and practical skills (Abbo, 2017; American Psychiatric Association, 2013).

1.2.2 Intellectual disability terminology

Historically, terms such as idiots, imbecile, mentally deficiency, retard and moron were used before the term "mental retardation" was introduced to replace these terms (Harris, 2013; T. R. Parmenter, 2011). The term "mental retardation" was introduced by the American Association of Mental Retardation (AAMR) in 1961 (Bhaumik et al., 2016; Harris, 2013), known as the American Association on Intellectual and Developmental Disabilities (AAIDD) since

1992 (Cluley, 2018). However, this term has been replaced with “intellectual disability” in many developed countries and other low-middle-income countries (Salvador-Carulla et al., 2011).

The Diagnostic and Statistical Manual for Mental Disorders (DSM), which is an international classificatory system for mental disorders, and the International Classification of Diseases (ICD), have replaced the term “mental retardation” with “intellectual disability”(ID) or “intellectual developmental disorders” (IDDs) (Bhaumik et al., 2016; Shree & Shukla, 2016). The DSM-5 and ICD-11 use a similar description to refer to ID/IDD and these systems base the nature of intellectual disability on both intellectual and adaptive functioning and not only on intelligence quotient (IQ) (Bhaumik et al., 2016). The term “intellectual disability” is currently used instead of “mental retardation” because it is consistent with international terminology, is less offensive towards persons with disability and better fits with current professional practices focused on functional and contextual factors (Shree & Shukla, 2016).

1.3 Social and Health-Related Needs of People with Intellectual Disability

In South Africa there is a gap in health and mental health resources and services for people with intellectual disability. This could be caused by the shortage of mental health professionals, community mental health centres that remain under-funded and undeveloped, and exclusion of people with intellectual disability in policy development and implementation which addresses their needs (Burns, 2011).

People with intellectual disability are faced with challenges depriving them of the opportunity to access services and resources to meet these needs (Whittle et al., 2018). This is influenced by the shortage of literature and discussion around access barriers which makes it difficult to develop measures or models that will address unmet needs and improve the quality of service accessibility (Whittle et al., 2018).

With regards to health needs specifically, their health needs remain unmet and disregarded, putting them at risk for premature mortality when compared with the general population (Gibbs et al., 2008; Weise et al., 2017). The health needs of people with intellectual disability may also be more complex than those of the general population, requiring highly specialised

healthcare services, the provision of which varies between high-income countries (HIC) and low-income countries (Bhaumik et al., 2016).

National service providers and non-governmental organisations (NGOs) have been advocating for greater prioritisation of health and social services needs and yet little attention has been paid to addressing the views of people with intellectual disability with regards to accessing health and social services (Capri & Swartz, 2018). Currently, health needs for people with intellectual disability are mainly provided by NGOs in urban areas, with an even greater problem for people from rural and under-privileged communities who encounter difficulties in accessing those services (Capri & Swartz, 2018).

Notwithstanding that many countries are starting to accommodate the needs of people with intellectual disability, there has been little direct empowering for health-advocacy (Feldman et al., 2012). People with intellectual disability might be given options but they are rarely involved in the construction of those options (Gilmartin & Slevin, 2010). Thus, people with intellectual disability are faced with challenges when accessing services and facilities that are usually designed to cater for people without intellectual disability (Feldman et al., 2012).

Health and social needs of people with intellectual disability, as well as service provision, remain overlooked (Moodley & Ross, 2015), despite South Africa's ratification of the United Nation Convention on the Rights of Persons with Disabilities (UNCRPD) (United Nations [UN], 2006) which emphasises the full participation of people with disabilities (Mji et al., 2013). In South Africa, laws relating to disability have been on statute book for years, yet their implementation has been inconsistent (Majola & Dhunpath, 2016). Notwithstanding that people with disabilities hold high positions in parliament, nonetheless there is still an existing gap between "good policy" and its "practical implementation" (South African Human Rights Commission [SAHRC], 2012).

1.4 Social and Health-Related Policies

In this study, the focus on "social and health-related policy" is conceptualised in line with the integrated approach to health and wellbeing adopted by the South African National Development Plan 2030 (Republic of South Africa, 2012, p. 303). This approach is also

reflected within South Africa's crosscutting Social Protection, Community and Human Development Cluster which includes several ministries which work together for the health and social wellbeing of South Africans (Republic of South Africa, 2022). The key ministries included are health, education, social development, agriculture, land reform and rural development, cooperative governance and traditional affairs, environment, forestry and fisheries, employment and labour, human settlements, water and sanitation, justice and correctional services, public works and infrastructure, sports, arts and culture, transport and the ministry for women, children and people with disabilities in the presidency.

South Africa has included and prioritised disability issues within its Constitution (Heap et al., 2009). Post-1994, the Constitution of South Africa had to be revised to accommodate every South African citizen, including people with disabilities (Kruger, 2015). The Constitution protects the human rights of people with disabilities by enshrining their rights to equality; the rights of people with disabilities are equal to those of all South African citizens and they should not be discriminated against because of their disabilities. Thus, people with disabilities, including intellectual disability, are protected by the Constitution, therefore their rights should be protected, and their health and social needs' provision should be prioritised. Much has been done regarding the protection of rights of people with disabilities by the Constitution, however the implementation of these rights are yet to be experienced since people with disabilities are marginalised (Heap et al., 2009).

The country does have legislation that promotes and protects the rights of people with disabilities, but these policies are not discussed frequently amongst governmental sectors and for this reason people with intellectual disability have not been motivated nor empowered to participate in their implementation (Kock et al., 2012).

In South Africa, the prioritisation of policies that favour people with intellectual disability may raise public awareness, contributing to the elimination of stigma, and empowering and encouraging the social and political inclusion of people with intellectual disability in community and governmental practices (Capri, Abrahams, et al., 2018). Consulting with self-advocates and researchers with intellectual disability should be prioritised in order to obtain

data which ensures the prioritisation of the rights and needs of people with intellectual disability in policy (Capri, Abrahams, et al., 2018). Hussey et al. (2017) argue that a dearth of data in South Africa on people with disabilities impacts significantly on government policy planning, their inclusion, and the implementation of those policies.

Public health and social policies influence the general population, including people with intellectual disability (Shogren et al., 2009). Historically, services for people with intellectual disability were offered primarily within custodial psychiatric hospitals, care, and rehabilitation centres. Post-1994, the department of health prioritised developments within mental healthcare with initiatives to deinstitutionalise and reintegrate patients into their communities (Lucas & Stevenson, 2006). Post-Apartheid government also introduced policies that prioritised equity in health policy, especially at local government level (Binns & Nel, 2002; L. Gilson & McIntyre, 2007).South Africa developed a new policy strategy for mental health (2013–2020) that aligns with the prioritisation of human rights and calls for the involvement of users of mental health services in the development of these services. This policy was recently updated and approved in March 2023 and extends the period of implementation to 2030 (National Mental Health Policy Framework and Strategic Plan 2023-2030). Despite these policy developments, people with intellectual disabilities are still experiencing challenges (Stein et al., 2018).This is partly rooted in the fact that there are few existing data on disability to influence government to make informed decisions regarding people with disabilities including people with intellectual disability (Foskett, 2014). Additionally, the centralisation and inadequacy of mental health services in both rural and urban areas still hinder the accessibility of these services for both families and individuals with intellectual disability (South African Human Commission, 2019). Issues related to the inaccessibility of mental health services can have a profound impact on the mental health and wellbeing of South Africans with intellectual disability.

1.5 The Social-Ecological Model (SEM) as a Theoretical Framework

In order to gain a layered perspective of the experiences of people who have intellectual disability from various sectors of society, Bronfenbrenner's (1979) socio-ecological model, adapted by Simplican et al. (2015), was used as a conceptual framework to conduct the current study.

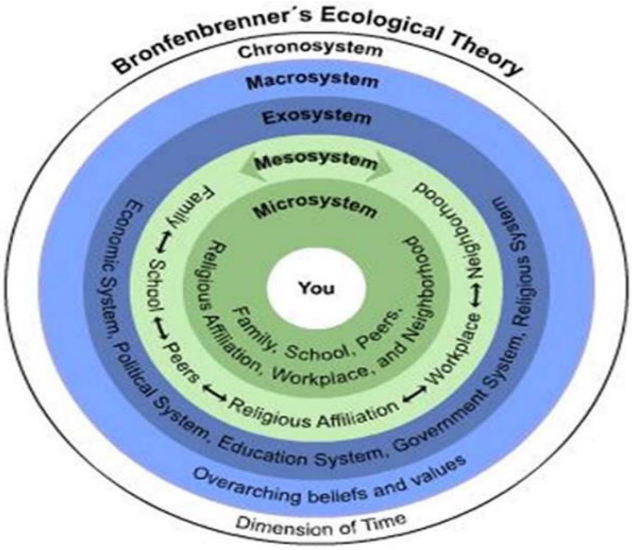
In the socio-ecological model, individuals have continuous interactions on distinct levels of the social context. Bronfenbrenner (1979, 1994) stated that individuals can be influenced or can influence the environment in which they live and grow through their continuous interaction within the system (Garbarino & Ganzel, 2000).

Based on this conceptual framework, people with intellectual disability may have a positive or negative experience of this condition through their interactions with the distinct levels of the society, and these may vary between individuals. Bronfenbrenner's original conceptualisation included five levels, namely, the microsystem level (the individual in his/her/their immediate neighbourhood), the mesosystem level (interaction between school and home, school and workplace), exosystem level (parents workplace, family social networks and neighbourhood community contexts), macrosystem level (material resources, customs, beliefs and values, opportunity structures and life-styles) and chronosystem level (change over time in socio-economic structures, family structures, employment and place of residence).

These levels, as conceived by Bronfenbrenner, are depicted in Figure 1 below.

Figure 1

Bronfenbrenner's Ecological Systems Model (1979)

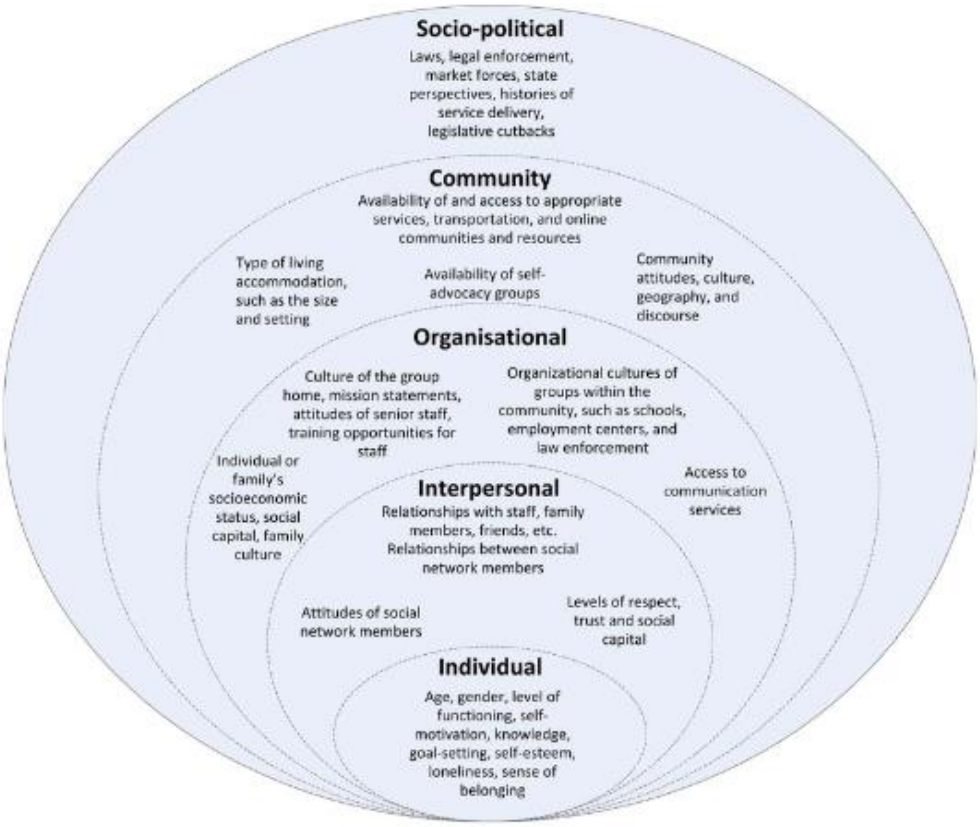


Source: Bronfenbrenner, U. (1979). *The Ecology of Human Development*. Harvard University Press.

This model has undergone numerous modifications for different applications. As graphically represented in Figure 2 below, the socio-ecological model, as reconceptualised by Simplican et al. (2015), identified five different levels; the individual, interpersonal, organisational/institutional, community and socio-political level, within which individuals interact with the environment. The rationale for selecting the adapted socio-ecological model by Simplican et al. (2015) as a conceptual framework for understanding the work to be conducted for this study was that it covers all aspects where the rights and needs of people with intellectual disability are marginalised and need redress. Thus, this model framed an in-depth understanding of what to prioritise to meet the rights and needs of people with intellectual disability within multiple levels of society (see Figure 2 below).

Figure 2

An Ecological Model of Social Networks and Community Participation



Source: Simplican et al. (2015).

Below, each level is briefly described and linked to distinct aspects of enquiry which will be included in the study. The suggested areas of inclusion in the study will be refined further based on information obtained from the literature review.

The first level, the individual level, is comprised of the individual (age, gender, physical, emotional and intellectual capabilities or challenges, and skills) in interaction with their immediate neighbourhood (family, friends, schools and religious organisations, and the conditions within which they live in their neighbourhoods). Adnams (2010) suggests that the overall South African prevalence rate of intellectual disability may be higher than in other LMIC, closer to 3% of the population, due to the exceptionally high rates of preventable conditions that may cause onset of intellectual disability in the early period of life. These interactions can impact on lived experience and functioning within that neighbourhood.

Other person-level characteristics also interact with the environment. Personal interest could be leisure activities which are important for their personal growth and may assist in developing peer relationships, for example, sports, singing and other outdoor activities. Occupational capabilities interact with environmental supports, such as receiving government social grants or not.

The second level, the interpersonal level, comprises relationships among family, friends and healthcare providers, attitudes of social network members, and levels of respect and social support (Simplican et al., 2015). In this study, this aspect relates to what extent these actors are able and prepared to support people with intellectual disability. Socialisation and interacting is of fundamental importance for people's wellbeing and psychological development (Lippold & Burns, 2009).

People with intellectual disability have been known to have very limited social support, this usually being provided by their families and informal carers (Lippold & Burns, 2009) who may themselves have attitudinal, economic and other challenges which affect their capacity to provide the necessary support. At a policy level, the South African Constitution[2] and its Bill of Rights[3] (Republic of South Africa, 1996) aims to ensure that all citizens' basic needs are met, and that families have access to basic social resources to support their children, the elderly and relatives with disabilities.

The third level, the organisational/institutional level, relates to access to health and social services, employment centres, education facilities and the impact of organisational rules, regulations and resources governing their capacity for support (Simplican et al., 2015). In this study this aspect will focus on the availability and accessibility of health and social services, education and employment, and other services raised by the respondents. The researcher will explore how unavailability and inaccessibility of health and social services, education and employment impacts on their psychological and developmental wellbeing. Service provision

[2] The South African Constitution describes the social values of the country, and sets out the structures of government, what powers and authority a government has, and what rights citizens have.
[3] The Bill of Rights of the Constitution of South Africa contains the human rights that will be protected in South Africa; it sets down the rights of all people in our country and declares the democratic values of human dignity, equality and freedom.

for people with intellectual disability has transitioned from institutionalised to community-based care at all policy levels, therefore this level would focus on service provision to people with intellectual disability in the context of NGOs.

The fourth level, the community level, will be concerned with the availability and cooperation between support structures within the community which are aimed at improving the quality of life of people with intellectual disability and their supporters (Simplican et al., 2015). These support structures could be advocacy groups, developmental groups, or skills training programmes for people with intellectual disability that may help them to enhance their abilities and capabilities, offer emotional support, improve confidence, and provide them with a sense of belonging, as well as prepare them to access social, relational and work opportunities available in their community. This level is also concerned with whether appropriate opportunities have actually been developed for them to engage with, including stigma-free open labour and protective workshops for employment, supported housing and other basic needs that people with intellectual disability might require to assist them to achieve their life goals.

The fifth level, the public policy level, comprises laws, policies and mechanisms for the legal enforcement of these laws and policies (Simplican et al., 2015). In this study this aspect relates to needs identified at all the other levels which require legislative and policy support within the ambit of "health and social policy," as defined within South Africa's cross-cutting Social Protection, Community and Human Development Cluster (as described in section 1.4 Social and Health-Related Existing Policies). It should be noted that many of the focal areas under this cluster echo the areas identified in our outline of Bronfenbrenner's levels, as adapted by Simplican et al. (2015).

In this study the focus was placed on identifying respondents' views on how best social and health-related policies promote health and social wellbeing of all citizens at all levels of society and whether and how they need to take into account the particular provisions and accommodations needed to improve their wellbeing, human welfare and opportunities for social relations (Njor et al., 2019) as citizens living with intellectual disability.

1.6 Summary of the Background of the Study

It is documented in the literature that people with intellectual disability are faced with barriers when exercising their fundamental rights. The United Nations Convention on the Rights of Persons with Disabilities (UNCRPD) (UN, 2006) is an international human rights instrument that is aimed at protecting the rights of people with disabilities including people with intellectual disability (Vergunst et al., 2017). Rights satisfaction and realisation will require the elimination of stigma towards people with intellectual disability, as well as encouragement and facilitation of participation in skills development and social participation (Capri, Abrahams, et al., 2018).

In African countries, research has shown that people with disabilities are faced with stigmatisation and discrimination because of the insufficiency of awareness about disabilities (Braathen & Loeb, 2011). Stigma attached to intellectual disability has received little attention in research, thus people with intellectual disability remain socially excluded (Ditchman et al., 2013). People with intellectual disability are faced with day-to-day challenges associated with labelling, discrimination and stigma (Davidson, 2015), with these “negative perceptions” posing barriers to accessing health and socials services (Hussey et al., 2017).

People with intellectual disability are often aware of stigma, and may internalise those negative perceptions, resulting in self-stigmatisation, that is, believing that they are incapable and that society will never value them (Ali et al., 2015). They may be prohibited from making their own choices about issues that concern them (Goldberg, 2019) at intrapersonal, interpersonal, organisational/institutional, community and public policy level. They remain marginalised and labelled based on assumptions (Goldberg, 2019), face unfair discrimination (Kakuma et al., 2010), are underprivileged globally (Hussey et al., 2017), thus being deprived of their constitutional right to equality because of barriers to social, cultural, educational, political and physical needs (Marumoagae, 2012; Raub et al., 2016).

Lack of resources can limit low-income people with disabilities from accessing public health services in rural areas, such as specialised treatment only available in cities. Government

social grants may be insufficient for travel costs, especially if there is no other form of income in the household (Grut et al., 2012).

In summary, the rights of people living with intellectual disability have been neglected, thus more research is needed to raise awareness and provide better insight about intellectual disability to lessen stigma and discrimination by the general population towards people living with intellectual disability. This might lessen myths attached to intellectual disability and increase the prioritisation of their rights in policymaking. More evidence on the needs of people with intellectual disability in South Africa may support the lobbying of policy makers to prioritise the inclusion of people living with intellectual disability, to ensure that their rights are protected as the South African Constitution proclaims, and to ensure that they have equal accessibility to available services, in particular health and social services.

Thus, documentation of the views of people living with intellectual disability may assist government regarding what to include in social and health-related policy and service development processes to ensure that the rights of people with intellectual disability are protected and prioritised.

1.7 Problem Statement

People with intellectual disability experience daily life challenges related to labelling, stigma and discrimination (Davidson, 2015). They are amongst the most vulnerable people in society, with poor understanding of the nature and presentation of their disability (Muswera & Kasiram, 2019). This stigma and poor understanding have contributed to their social exclusion in different life domains, such as education, community participation, work, and other social and health domains (Overmars-Marx et al., 2014).

While social inclusion is not equivalent to health and social policy, nor can social inclusion be brought about by social policy directives per se, as members of civil society, communities and families of people with intellectual disability are generally not included in civil society action and spaces where they can exercise their civil right to give input to policies which impact on their lives. For this reason, it is of importance to include people with intellectual disability in

research that concerns them, especially regarding public policy which should promote access to social resources enjoyed by others.

Including the views of people with intellectual disability in setting policy directives may lessen the stigma attached to this population and enable them to explicitly communicate their needs and priorities in policy processes.

1.8 Rationale for the Study

To my knowledge, there has been no systematic study to document the views of individuals with intellectual disability on the inclusion of their priorities in social and health-related policy processes in South Africa. The present study is a sub-study within a broader study that comprises three sub-studies which aim to examine how citizens with intellectual disability might better participate in policy-related issues, as one form of civil participation. The first study is about a conceptual framework for self-advocacy by people with intellectual disability which will include the views of parents and other role-players on what is needed to support self-advocacy by people with intellectual disability. The second study is about strategies to promote the participation of people with intellectual disability in policy related issues. The present study is aimed at documenting the views of people with intellectual disability on their policy priorities. In this small sub-study, I aim to start documenting local people's views on these matters as we have found no other local studies of this nature. I hope to contribute to beginning evidence which challenges existing assumptions about the possibilities for direct participation of people with intellectual disability in civil action at the policy level.

Family involvement and other support from carers is essential for people with intellectual disability, as it is apparent in many LMIC that people with intellectual disability are living under the care of their families and carers (McKenzie & McConkey, 2016). Until recently, mainly families have played the vital role of advocating for the rights and needs of their family members. More recently, people with intellectual disability have begun to contribute to these efforts through self-advocacy (speaking for themselves), where they have the capacity to do so, although this has not yet taken place significantly within the South African context (Kleintjes et al., 2020). The present study aims to provide South Africans with intellectual

disability with a platform where they can voice their concerns and policy priorities as first-hand accounts.

The documentation of the views of people with intellectual disability will give better insight into what government should include in social and health-related policy and service development processes to meet their needs. This documentation of the voices of people with intellectual disability will also provide self-advocates with intellectual disability and their supporters (family or their carers) with evidence to support raising awareness about their concerns. This study is envisaged to provide information to inform the work of numerous role players, such as government officials, researchers, advocacy groups, family members, people with intellectual disability, service providers and policy makers or implementers.

1.9 Research Question

What are the perceptions and experiences of people with intellectual disability with regards to their health and wellbeing needs and what are their views on how social and health-related policy can support their needs?

1.10 Aims and Objectives

The main aim of this study is to explore the social and health-related policy priorities identified by people with intellectual disability.

Objectives of the study:

(1) To conduct a scoping review on social and health-related policy priorities for people with intellectual disability in LMIC from 1994–2021.
(2) To document the views of South Africans with intellectual disability on what they need and barriers they experience to enjoying a decent life, and to highlight the implications of these for future priorities for social and health-related public policy development in South Africa.

1.11 Layout of the Thesis

Chapter One of this thesis introduces the background to the study, disability and intellectual disability in the context of South Africa and literature background of the study.

Chapter Two outlines study objectives and how they were carried out. This chapter describes how the scoping review was conducted and details the scoping review findings.

Chapter Three describes how data were collected from people with intellectual disability during semi-structured interviews, using pictures and booklet to orientate and support participation in the study.

Chapter Four details the findings from the interviews.

Chapter Five discusses the findings from the study interviews.

Chapter Six notes study implications, limitations of the overall study and recommendations.

Chapter Two

Scoping Review

2.1 Introduction

Considering the background literature which suggests that provision for the social and health-related needs of people with intellectual disability remains inadequate in many low-, middle- and high-income countries, it becomes important to explore what is known about policy priorities of people with intellectual disability in low-, middle- and high-income countries.

The objective behind this scoping review was to provide an overview of existing literature about the policy priorities of people with intellectual disability in low-, middle- and high-income countries. Munn et al. (2018) state that the scoping of literature is the best tool to provide a map of the extent of existing literature on a topic. For this study, a scoping of literature enabled the researcher to identify and map existing evidence about the research topic to inform her understanding of the research area and the conduct of the interviews for the study.

2.2 Method

The scoping review was conducted following the steps suggested by Arksey and O'Malley (2005) to ensure that the scoping review was conducted in a rigorous manner. Scoping review steps, as recommended in Arksey and O'Malley (2005), are elaborated below.

2.2.1 Identifying the research question

The first step was to identify the research question:
What do we know about the health and social welfare policy priorities for people with intellectual disability in low-, middle- and high-income countries?

2.2.2 Identifying relevant studies

The second step was to identify relevant studies by firstly establishing suitable search terms, followed by setting inclusion and exclusion criteria. The researcher consulted a university librarian in order to locate the most suitable databases to search for this study, as well as to

determine what the most appropriate Medical Subject Headings (MeSH) terms were to include for each database.

Thus, the following databases were searched: Ebscohost (Academic Search Premier, African-Wide, MEDLINE, ERIC, Science Direct, CINAHL and PsychInfo), Scopus, Web of Science and PubMed, using the following search terms:

TOPIC: "intellectual disability" OR "Intellectual disabilities" OR "mental retardation" OR "learning disability" OR "developmental disability" OR "developmental disabilities" OR "learning disabilities"

AND TOPIC: "Adults"

AND TOPIC: "public health policy," "health policy" OR "social policy," "social assistance policy," "social protection policy"

AND TOPIC: "perceptions" OR "attitudes" OR "views" OR "experiences"

Inclusion and exclusion criteria

The following inclusion and exclusion criteria were set for the study:

Inclusion criteria:

- Publications focusing on adults with intellectual disability
- Qualitative and quantitative studies
- Publications which address health and social policy priorities of people with disabilities
- Published in English
- Published between January 1 1994 and April 30 2021
- Full text available
- Publications on stakeholders' views on policy priorities for people with intellectual disability
- Peer reviewed articles

Exclusion criteria:

- Publications on children and adolescents with intellectual disability
- Publications on disability but not intellectual disability

- Publications that were not published in English.
- Publications outside the selected time span
- Full-text unavailable

2.2.3 Study selection

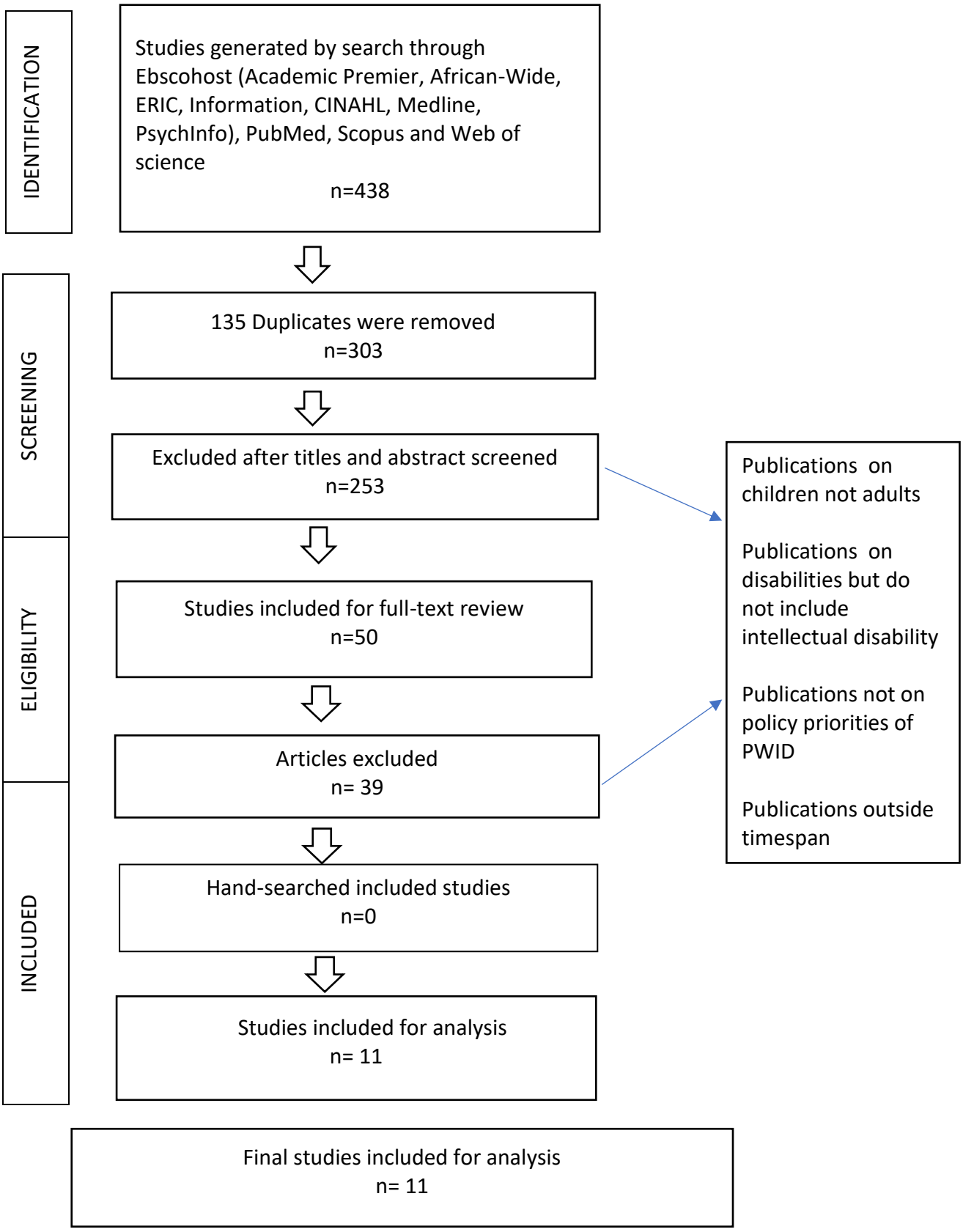
The databases were searched, using the above search terms, between1 January 2021 and 30 April 2021.

The initial search was conducted by the primary researcher (SZ), which yielded a total number of 438 articles from the different databases that were searched. Duplicates were removed leaving a total of 303 abstracts.

To minimise risk of bias, a research assistant and the researcher worked separately to assess each sourced article for inclusion. The primary researcher (SZ) and the research assistant (AN) screened these results by title and abstract using the inclusion and exclusion criteria. Agreement was reached on which articles to in- and exclude which yielded 50 abstracts, which at this stage included studies where abstract review was insufficient to determine final in- or exclusion. The full text articles were retrieved for these 50 articles. Thereafter both the researcher and research assistant reviewed articles by full text independently to identify articles that meet the study inclusion criteria. These lists were compared, with discrepancies between the two reviewers discussed and resolved to agree on the final included (n=11) and excluded (n=39) articles. The included articles reference lists were hand searched but yielded no possible articles for further review. Figure 3 below provides a summary of the process of identifying and including publications

Figure 3

Flow Chart of Inclusion Process



2.2.4 Charting of data

Data were charted onto a data charting form using the database programme, Excel. Three data extraction templates were developed by the primary researcher for qualitative, quantitative and excluded studies (Appendix 5) based on the research question and informed by the findings of the scoping review. The extraction sheets capture the following data from the selected articles: study citation, title of the paper, study aims, study design, participants, context, challenges and experiences of people with intellectual disability, and policy priorities identified by participants, caregivers, professionals, service providers and/or stakeholders.

2.2.5 Collating, summarising and reporting the results

The first step was for the researcher and research assistant to independently read through each article several times to familiarise themselves with the data in order to identify data relevant to policy priorities of people with intellectual disability as reflected on the data extraction spreadsheet.

The researcher and research assistant then coded ideas together and the researcher moved systematically from one article to the next, until all similar ideas were extracted and placed under correct categories in the data extraction sheet. The researcher and research assistant also conferred regarding similarities and differences in coding and grouping ideas correctly, with consensus reached through discussion.

Thereafter, the initial codes that emerged from the spreadsheet enabled the researcher and research assistant to agree on meaningful themes.

2.3 Results

2.3.1 Characteristics of included papers

It was noted from the review that most studies are from middle- to upper-income countries, and they principally address the lack of healthcare policy and the need for inclusive policies which are lacking regarding development and implementation. There were no relevant articles from the 1990s. Between 2000–2009 there were only five relevant articles, and between 2010–2021 there were only six relevant articles; nine of these articles were from HIC

and only two from low-income countries (see summary in Table 2.1 below). All included studies were published in peer-reviewed journals. Included studies used different data collection methods/tools to collect their data, such as focus groups, semi-structured interviews, storytelling, participatory-action research, web-surveys and government policies analysis.

In addition, opinion pieces were included in this study as they were noted to give better insight into the policy priorities of people with intellectual disability, and these articles captured stakeholders, researchers, caregivers, parents and professional's perspectives.

Table 2.1

Summary Table of Included Publications

Characteristics	Number
Inclusion criteria	11 included articles
Publication year	2000 to 2009 – 5 publications 2010 to 2021 – 6 publications
Publication type	Journal articles: Qualitative – 4 Quantitative - 1 Reviews - 3 Opinion pieces - 3
Population	Persons with intellectual disability, parents, caregivers, professionals, service providers and/or stakeholders.
Context	HIC– 9 LIC– 2

Table 2.2 below presents the findings of the included publications

Study citation	Title of the paper	Study aims	Study design/study type (opinion piece, intervention study, etc.)	Participants (stakeholders (parents/carers/service providers/others)	Context	needs, key concerns and/or problems identified by participants and/or stakeholders	Social or health-related policy priorities generated by researchers
Adnams (2010)	Perspectives of intellectual disability in South Africa: epidemiology, policy, service for children and adults	To summarize data published in the scientific literature and available on official websites on the epidemiology, policies and service for children and adults with intellectual disability in South Africa.	Review	Not applicable	LMIC	Poor policy implementation in most governmental sectors. Centralisation of services of people with intellectual disability – located in urban areas. Unmet social, health and educational needs.	Low prioritisation, budget, and resource commitment through all levels of government. Lack of prioritisation of resources and intersectoral coordination. Inadequate provision for multidisciplinary health service for people with intellectual disability. Failures in policy implementation and service delivery. Unmet social, health and educational needs.
de Chenu et al. (2016)	A critical comparison of welfare states and their relevance to people with an intellectual disability	The purpose of the comparison is to develop an understanding of the welfare state and institutional contexts of the country-specific policies and to develop a critical analysis through a comparative method based on selected secondary literature.	Review	Not applicable	HIC	Employment difficulties, poor social welfare services. Limited accommodation choices.	Policy ideas are set by different welfare states and institutions which results in poor implementation. Poor prioritisation of this population by national employment agencies. PWID hardly enter work labour and they live primarily in small group accommodation where they are supported and catered for by the municipality.
Iriarte et al. (2014)	Identifying the key concerns of Irish person with intellectual disability	Aims at defining the key concerns of adults with intellectual disability in relation to their participation in the society	Qualitative study: focus groups	23 focus groups (168 individuals with intellectual disability) facilitated by two co-researchers, one co-researcher with ID.	HIC	Difficulties in relation to becoming a house owner, flatmate; becoming a paid employee; becoming a partner in a relationship; becoming a respected citizen; enjoying leisure time; becoming a money manager; becoming a self-advocate and becoming a good communicator.	Poor social welfare provision. Need for education, forming and maintaining relationships and need for employment.
Halperin et al. (2005)	Health policy for persons with intellectual disability: experiences from Israel	This review presents a literature overview of global health policy for intellectual disability with the intent to focus specifically on the policy and treatment within Israel.	Review	Parents, guardians, physicians, social workers, nurses, physiotherapists, occupational therapists, speech language therapists, and policy makers.	HIC	Poor healthcare access. Poor support offered to families and carers of PWID. Poor communication between service providers and patients (PWID).	Current health services for persons with intellectual disability are characterised by severe financial shortages. Without the proper policy and resource allocation from the top down, the issue of health education and intellectual disability will not be rectified.

Lin et al. (2004)	An exploratory study into health care policy for persons with intellectual disabilities in Taiwan	The purpose of the present study was to examine the general beliefs about the current healthcare policies for persons with intellectual disability in Taiwan.	Qualitative	40 participants. Stakeholders and senior staff in institutions involved in the care of people with intellectual disability (medical doctors n=8, allied medical professionals n=13, parent's organisations n=11 and scholars in the field of health and social welfare n=8).	HIC	Poor healthcare access.	Limited attention in the healthcare system. No health policy specifically designed for PWID. Current health policies neglect the health needs of persons with disabilities. Uneven healthcare resource distribution amongst PWID.
Mung'omba (2008)	Comparative policy brief: Status of intellectual disabilities in the Republic of Zambia		Opinion piece	Not applicable. Opinion piece written by professionals.	Zambia, LMIC	Poor social welfare service provisions. Limited employment access. Dependence on families and NGOs.	Insufficient social welfare benefits and extremely limited access to government-led trust funds. Lack of useful data to develop sound policies. No specific policy for PWID and poor progress in achieving education for all. Not sure if inclusive policy will support all the needs of PWID.
Northway et al. (2007)	'Policies don't protect people; it's how they are implemented': policy and practice in protecting people with learning disabilities from abuse	Aimed at gathering information concerning policy development and implementation in the context of services for people with a learning disability in Wales.	Survey and focus groups	n=70 (focus group) n= 67 surveys.	HIC	Poor collaboration to develop sound protection policies.	Lowered development of policies designed to protect adults with ID. Complexities of policy developments present lots of challenges. More attention required not only to policy development but also to issues relating to implementation and review.

Sitter et al. (2019)	Supporting positive sexual health for persons with developmental disabilities: stories about the right to love	This research investigated the barriers and supports of sexual health and disability by exploring the topic of sexual health from the perspective and experiences of person with developmental disabilities.	Participatory action research study – Photovoice.	9 adults with intellectual disability (advocates) and 3 allies.	HIC	Lack of support form caregivers. Lack of education about sexual health. Absence of direct policies that acknowledge and protect sexual rights of people with developmental disabilities.	The absence of agency policies that acknowledge and protect the sexual rights of persons with developmental disabilities. Lack of funding to support sexual rights of PWID.
Thompson et al. (2014)	Barriers to sexual health provision for people with intellectual disability: a disability service provider and clinician perspective	Examine the barriers to sexual health provision of people with intellectual disability as experienced by disability service providers and clinicians.	Constructionist grounded theory approach (semi-structured interviews).	Phase 1: 8 disability service managers (four females and 4 males); phase 2: 23 clinicians (8 males and 15 females).	HIC	Sexual health remains an underfunded sector. Lack of formal requirements to address sexual health. Lack of sexual health policy. Limited sexual health and disability resources. The lack of lifelong sexual health education. Sexual health provision remains low priority.	Sexual health remains one of the most overlooked areas of life for PWID. There is no specific policy on sexual health provision. Sexual health is typically not a feature of individual plans or service delivery models. Lack of funding in the disability factor. Lack of formal requirements to address sexual health. Lack of policy that protects people with intellectual disability from sexual abuse. No specific policy on sexual health provision. Lack of collaboration of different service providers on sexual health of people with intellectual disability.
Turner & Cooper Ueki (2015)	Current policy and legislation in England regarding older people – what this mean for older people with learning disabilities: a discussion paper	This paper seeks to explore the opportunities and challenges generated by current policy, guidance and legislation in England relating to older people, in terms of practical implications for older people with learning disabilities.	Opinion piece	Not applicable. Opinion piece written by professionals.	HIC	Older people with intellectual disability are not included in policies.	Need for inclusive policies and plans. Little progress has been made over the past decade in generating a more inclusive approach. It is still debatable whether these policies will fully support the needs of PWID.

Wapiennik (2008)	Comparative policy brief: Status of intellectual disability in the Republic of Poland		Opinion piece	Not applicable. Opinion piece written by professionals.	HIC	Insufficient governmental activities that promote employment. Lack of inclusive education. Limited accommodation choices. Insufficient financial support.	Inclusive education does not exist in practice. Access to quality vocational training and employment is still an issue for people with intellectual disability. Community-based support services are insufficient with low financial support to cover supplementary cost of ID.

Table 2.2 *Findings from the Included Publications*

Note: LMIC=low- and middle-income country; HIC=high-income country; PWID=people with intellectual disability

2.3.2 Quality ratings/assessment of the identified studies

While quality assessments are not obligatory for a scoping review, as the purpose of the review is to gain an understanding of the field as a whole (Munn, 2018), quality assessment was conducted in order to determine the rigour of the included publications

2.3.2.1 Quality assessment of included qualitative and quantitative studies

The Critical Appraisal Skills Programme (CASP) was used to assess the quality of eligible qualitative and quantitative studies (see Table 2.3). Critical appraisal involves systematic and careful examination of research papers to test and check their trustworthiness and relevance to the particular context (Burls, 2014).

Each study was assessed for quality using 10 CASP tool criteria. CASP criterion: 1. Was there a clear statement of the aims of the research? 2. Is a qualitative/quantitative methodology appropriate? 3. Was the research design appropriate to address the aims of the research? 4. Was the recruitment strategy appropriate to the aims of the research? 5. Was the data collected in a way that addressed the research issue? 6. Has the relationship between researcher and participants been adequately considered? 7. Have ethical issues been taken into consideration? 8. Was the data analysis sufficiently rigorous? 9. Is there a clear statement of findings? 10. How valuable is the research? (Long et al., 2020).

Study quality was scored and assessed using the CASP critical score as follows: a) Criterion is completely met = 2; b) criterion is partially met = 1; c) criterion not applicable, not met, or not mentioned = 0; Total score 20 = high quality; 16–19 = moderate quality; ≤ 15 = low quality (Njau et al., 2019)

Table 2.3

Critical Appraisal of Qualitative Studies (n=4) and Quantitative (n=1) Included in this Review

Study citation	CASP criterion										Total score
	1	2	3	4	5	6	7	8	9	10	
Iriarte et al. (2014)	2	2	2	2	2	0	0	2	2	2	16
Lin et al. (2004)	2	2	2	2	2	0	0	1	1	2	14
Northway et al. (2007)	2	2	2	2	2	0	2	2	1	1	16
Sitter et al. (2019)	2	2	2	2	2	0	2	2	2	2	18
Thompson et al. (2014)	2	2	2	2	2	0	2	2	2	2	18

With the exception of Lin et al. (2004), which narrowly missed the moderate range, all other papers were rated to be of moderate quality.

2.3.2.2 Quality assessment for included opinion papers

Each paper was assessed for quality using 6 JBI critical appraisal checklist for opinion papers. JBI criterion: 1. Is the source of the opinion clearly identified? 2.Does the source of opinion have standing in the field of expertise? 3. Is the interest of the relevant population the central focus of this opinion? 4. Is the stated position the result of an analytical process, and is there logic in the opinion expressed? 5. Is there a reference to the extant literature? 6. Is there any incongruence with the literature/sources logically defended? (McArthur et al., 2015). Study quality was scored as “yes,” “no,” “unclear” and “not applicable”

Table 2.4

Critical Appraisal of Opinion Pieces (n=3)

Study citation	JBI criterion					
	1	2	3	4	5	6
Mung'omba (2008)	Yes	Yes	yes	Yes	Unclear	No
Turner & Cooper Ueki (2015)	yes	Yes	Yes	Yes	Unclear	No
Wapiennik (2008)	Yes	Yes	Yes	Yes	Unclear	No

Again, these papers were assessed to be of acceptable quality.

2.3.2.3 Quality assessment for included reviews

Included reviews (n=3) were not critically assessed for inclusion in this study because they did not meet the criteria of systematic reviews. These reviews seem to be policy reviews and not systematic reviews of policies. Despite these limitations, these reviews were noted as adding valuable insight with regards to answering the review question on health and social welfare policy priorities of people with intellectual disability.

2.3.3 Key themes related to policy priorities of people with intellectual disability

2.3.3.1 Poor health policy developments and inadequate healthcare access

This review shows insufficient attention in healthcare policy to the specific needs of people with intellectual disability, resulting in inadequate care being available to people with intellectual disability, who often have high physical and mental health needs (Adnams, 2010; Lin et al., 2004; Mung'omba, 2008). Similarly, current mental health policies continue to neglect the mental healthcare needs of people with intellectual disability, with mental health service provision remaining a low priority (Adnams, 2010; Lin et al., 2004).

The exclusion of sexual rights and the absence of agency policies that acknowledge and protect the sexual rights of persons with intellectual disability result in poor sexual education

and thus poor sexual health knowledge (Sitter et al., 2019; Thompson et al., 2014). People with intellectual disability express a desire for human connection, however, social, economic and educational barriers make opportunities to nurture intimate relationships challenging (Iriarte et al., 2014; Sitter et al., 2019). Thompson et al. (2014) recommend that in order to support sexual health for people with intellectual disability, clinicians and service providers need more guidance on sexual health provision. These policy guidelines and directions should include people with intellectual disability for effective policy development and implementation.

Some authors agree that there is a need to reframe policies and programmes that include acknowledging and protecting the sexual rights of people with intellectual and developmental disabilities, and that these policies should be enforced at the local level to promote good day-to-day practice (Northway et al., 2007; Sitter et al., 2019). Northway et al. (2007) further state that attention is required not only to policy development but also to issues of implementation.

2.3.3.2 Insufficient social welfare service provision

This review notes the poor intersectoral and interdisciplinary collaboration between social welfare, education and healthcare sectors, including policy makers and implementers, which then leads to poor policy development, and with low prioritisation, budget, and resource commitment through all levels of government, this has resulted in few of the policies being effectively implemented to support and provide for people with intellectual disability (Adnams, 2010; Halperin et al., 2005; Lin et al., 2004).

People with intellectual disability remain vulnerable, with little entitlement to social benefits and limited access to available governmental funds, and disadvantaged when attempting to enter the work force, and very few find work (Mung'omba, 2008; Turner & Cooper Ueki, 2015; Wapiennik, 2008). People who have been assisted by NGOs to acquire life skills have remained unemployed and those who have graduated from special vocational schools have been inadequately prepared to enter the labour market (Mung'omba, 2008; Wapiennik, 2008), thus undermining the efforts of both service providers and the donors of such services (Mung'omba, 2008). Barriers to employment include negative attitudes when looking for

employment, unsatisfactory treatment from employers at work and insufficient governmental activities promoting the employment of people with intellectual disability (de Chenu et al., 2016; Iriarte et al., 2014)

While there is increased participation of people with intellectual disability in day activity centres non-prioritisation of this sector of the population by the national employment agencies, and higher requirements for employment by the public employment agencies remain (de Chenu et al., 2016). People with medium to more severe intellectual disability are generally outsiders in the labour market and are often relegated to support groups with no work-related support (de Chenu et al., 2016).

A couple of studies noted that people with intellectual disability who are employed are found in the agriculture sector because it is often the easiest way for them to find work, however they are dissatisfied with the low pay in those sectors (Iriarte et al., 2014; Mung'omba, 2008).

Social community-based services are insufficient and the financial support received by people with intellectual disability and their families is inadequate to cover the supplementary costs and expenditures of persons with intellectual disability (Halperin et al., 2005; Wapiennik, 2008). Failure in policy development, policy implementation and service delivery, and the low priority of people with intellectual disability, continue to result in unmet social, health, employment, housing and educational needs (Adnams, 2010).

2.3.3.3 Intersectoral and interdisciplinary collaboration

While some authors note that inclusive policies may address concerns faced by people with intellectual disability, others state that it remains debatable whether these policies can address the specific difficulties faced by people with intellectual disability (Mung'omba, 2008; Turner & Cooper Ueki, 2015).

For successful policy development and implementation, some authors emphasise the importance of intersectoral and interdisciplinary collaboration in policy development, which is recognised as being complex, presenting with a number of challenges, especially when

translated into practice (Lin et al., 2004; Mung'omba, 2008; Northway et al., 2007). These challenges are caused by existing gaps in policy and services systems for people with intellectual disability, and issues that range from limited research studies on social economic issues as regards persons with intellectual disability, to not having the comprehensive data required for efficient and effective planning (Lin et al., 2004; Mung'omba, 2008), as well as poor consultation of people with intellectual disability regarding issues that impact their lives (Mung'omba, 2008; Northway et al., 2007).

2.4 Discussion

This review, covering a 27-year period, sourced only 11 articles which addressed the needs of people with intellectual disability, these being priority needs that should be addressed in public health and social welfare policy development and implementation. This relatively small collection of articles was able to indicate clear areas of need, both from the perspective of people with intellectual disability themselves, and of other stakeholders, including their parents, caregivers, professionals and other service providers. The views of people with intellectual disability on their priority needs were in many instances similar to those identified by other stakeholders, including having limited employment opportunities, often lacking skills that are required for employment, insufficient funds/grants to support their needs, often being denied sexual relationships, and inadequate healthcare provision as they often experience challenges when accessing healthcare.

The main findings of the review indicate significant gaps in policy development in low-, middle- and high-income countries. This is compounded by a lack of intersectoral-disciplinary collaboration and coordination which contributes to poor prioritisation and implementation of the needs of persons with intellectual disability in policy. Intersectoral collaboration should be adopted in policy and services and an intersectoral approach should be implemented by social welfare, education, employment and health sectors to ensure adequate service provision for people with intellectual disability.

It was apparent from the review that without collaboration amongst stakeholders, and tangible data on the needs of persons with intellectual disability to inform policy

development, the development of effective policies is severely negatively impacted. In the South African context, where health policies are in place, there is poor allocation of services to people with intellectual disabilities and the implementation of those services which are available are insufficient (South African Human Rights Commission, 2019). Thus, to enable effective policy development and implementation, consultations with stakeholders, parents and carers, including people with intellectual disability and others who work with them in other sectors, should be put in place to increase understanding of the requirements for policy development using evidence-based information (Dew et al., 2018).

The review findings raise the issue of the need of developing supportive and inclusive policies that will support the needs of people with intellectual disability in both policy and practice. Some studies (Lin et al., 2004; Mung'omba, 2008; Turner & Cooper Ueki, 2015) note that there is as yet little evidence of whether inclusive policies can fully support the needs of people with intellectual disability. Other studies (Halperin et al., 2005; Northway et al., 2007; Sitter et al., 2019; Thompson et al., 2014) are in agreement with an inclusive approach towards the development and implementation of policy to ensure that the needs of people with intellectual disability are met.

In South Africa, an intersectoral inclusive approach is embedded in the legal framework of the country, with intellectual disability service needs not fully articulated, and Capri et al. (Capri, Abrahams, et al., 2018), writing in this context, contend that there is a need for disability-specific legislation, including the needs of citizens with intellectual disability, to draw these disparate intersectoral threads together. These developments must include consultation with people with intellectual disability in the consultation processes for policy and service development (Kleintjes et al., 2020).

2.4.1 Value and limitation of the scoping review

The review highlights the scarcity of research in the area of policy priorities for people with intellectual disability and contributes to the limited information on this topic by providing an update on global scholarly work on policy priorities of people with intellectual disability. However, the few available articles provide only a glimpse into these priorities, and future studies engaging the views of people with intellectual disability can add more depth to our

understanding of these priorities to promote lobbying for more adequate attention to these needs.

As a Master's study, limited resources for the conduct of the study were available for this scoping review. Only papers in English were included, limited grey literature was included, and only two reviewers were used for aspects of the review. A larger team of reviewers and a wider search could use this initial scoping review as a basis on which to conduct a more comprehensive and rigorous review of the literature in this area.

Chapter Three

Methods

This chapter describes the research design, study population and sampling, study setting, data collection and analysis process employed for the semi-structured interviews and focus group. It includes descriptions of steps taken to ensure rigour in data collection and analysis, as well as ethical considerations which guided these aspects of the research.

3.1 Research Design

In order to understand the subjective experience of individuals, it is important to engage directly with them regarding their perceptions, as they are the centre of that experience (Sigstad & Garrels, 2018). Qualitative methods are used to explore, interpret and reach an in-depth understanding of the problem or question under investigation (Kemparaj & Chavan, 2013; Palinkas et al., 2015). There has been greater utilisation of qualitative methods in research involving people with intellectual disability, as qualitative methods are considered best suited to people with intellectual disability voicing their views about their lived experience to relevant stakeholders (Beail & Williams, 2014). A qualitative research design was therefore used to conduct the semi-structured interviews and a focus group discussion, with the two methods triangulated to enhance the depth of understanding of the focus of the study's research question.

3.2 Study Setting

Participants were recruited from one branch of one of the oldest non-profit organisations (NPOs) in the country. The organisation offers a range of services for people with psychosocial and/or intellectual disability and their families; ranging from counselling and support, special education and care centres for children and adults, as well as training and employment opportunities for those who are able to work.

The participants for the study were recruited from one of this organisation's workshops which offers training and employment to adults with intellectual disability and was fully operational under Covid-19 safety conditions at the time of data collection, making it possible to recruit from the workshop with assistance from the workshop management, trainers and supporters

working at the facility. The organisation had developed general and Covid-specific inhouse research policy guidelines, which were compatible with Covid-19 research guidelines expected of students at the University of Cape Town, further enabling the safe and ethical conduct of the study.

3.3 Positionality and reflective statement

I am a 27-year-old Black female from the oldest town of Zululand called Eshowe (Rural settlements). I hold a Bachelor of Arts (Honours) Psychology degree from the University of the Witwatersrand and a Bachelor of Arts (Health Sciences and Social Services) in Community and Health Psychology from the University of South Africa. I hope to train as a clinical psychologist in the near future and I am currently involved in voluntary work at Durban and Coastal Mental Health. The organisation that I have been involved in for voluntary work serve people with intellectual disability and psychosocial disability, and persons with co-occurring intellectual and psychosocial disability. This work has provided me with exposure to the issues people with intellectual and psychosocial disability face in their everyday lives, as well as created an opportunity for me to learn, through my volunteer work, ways in which I may best support their quality of life as a person who aims to train as a mental health professional. Experience gained during this work has enhanced my skills in communicating with the participants in this study and has strengthened my capacity to engage participants to express themselves more fully.

The process of undertaking this research project has also been a learning experience which has honed my research skills over the past three years. I was supervised by clinicians and supported by an advisory group with clinicians and self-advocates with intellectual disability who advised on the various stages of the research undertaken in this study. They informed the methodology for this study described below, and interaction with them have helped me to reflect on my research judgments and decisions, and how they link to my prior experiences as well as my growing capabilities as a researcher. These new research skills I can now also fold into the skillset I take into my future plans to bring evidence to practice as a mental health practitioner.

3.4 Recruitment

The organisation gave permission to conduct the research at their organisation, with the proviso that the interviews be conducted online, as outlined in their current research protocol. Online interviews were more compatible with lockdown restrictions, permitting greater safety for the research student and the participants.

The workshop manager was identified as the liaison person for the researcher to bring the study to the attention of workers at the workshop, to ascertain potential interest in participating in the study, to support recruitment of participants, identify supporters at the organisation to assist the participants during the interviews and to provide the researcher with logistical support for the conduct of the online interviews. The workshop manager provided potential participants with the easy-to read information sheet (Appendix 1) to ascertain who might be interested and willing to participate in the study.

3.5 Supporter's Role

Participants who expressed interest in participating in the study were allocated supporters to assist them with study procedures. Supporters were drawn from the staff at the workshop who already act as supporters during training and work activities. Potential supporters were informed about study objectives and the proposed role of supporters via a letter provided to the centre manager (Appendix 9). Supporters who agreed to assist with the study were asked to sign a confidentiality form to ensure confidentiality (Appendix 7). They assisted participants with understanding and signing of informed consent forms, provided support to participants finding pictures to use for the study (see explanation below) and acted as on-site contacts for the researcher regarding participants' progress with finding pictures for online interviews and the setting up of interviews at times which suited the participants. Supporters also assisted participants with the use of the desktop computer at their workshop to participate in a Zoom call and provided participants with a supportive presence during the online interviews for those participants who requested this support (n=2), with other participants (n=4) noting that they did not need the presence of their supporters during online interviews, beyond the setting up of the Zoom call for the interview.

An initial online orientation session was held with each participant to discuss and clarify study procedures and to obtain informed consent from participants. Informed consent forms (Appendix 2) were read out by the researcher during the orientation interview, explanations were provided as needed, test questions noted to confirm understanding of the informed consent process (see informed consent section below) and signed by both the participant and the researcher. Supporters were encouraged to provide support but not to interfere with participants' choices in selecting their pictures.

3.6 Study Population and Sampling

This study used purposive sampling to recruit participants. This method allows the researcher to select participants with characteristics which make them well-informed about the phenomenon under research, enabling them to provide in-depth information about the key focus of the research (Etikan et al., 2016). Purposive sampling requires the researcher to generate inclusion and exclusion criteria for the study. Participants for this study were adults with intellectual disability who had the ability to verbally communicate their lived experiences and needs relevant to policy development. Participants whose degree of intellectual disability did not permit them to verbalise their thoughts and comment on the focus of the study were not recruited for the study. For the purpose of this study, participants' names were replaced with pseudonyms to ensure anonymity.

3.6.1 Informed consent procedure

During the orientation interview, the interviewer read the informed consent form to each participant who had shown interest in participating in the study, based on the easy-to read information sheet provided prior to the first interview. Following this initial consent procedure, prior to each study activity, the researcher explained and read an informed consent form again to ensure that participants understood what was to happen in that particular session and were aware of and agreed to partake in each activity. Each study activity therefore had separate informed consent forms which related specifically to that study activity (Appendices 2a, 2b and 2c). Informed consent was read out loud by the researcher to each participant and a set of questions was asked to assess participants' understanding of the activities to take place during each interview (Horner-Johnson & Bailey, 2013). The set of questions asked of participants to assess understanding were:

1. Please tell me in your words, what is this study/study activity about?

2. What will you be doing if you take part in this study/study activity?
3. Do you think there could be any harm in taking part in this study/study activity ?
4. When I say your participation in the study/study activity is 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/activity but do not want to finish it?

3.6.2 Distribution of study materials to participants

Due to Covid-19 restrictions and organisation protocols, the researcher could not deliver hard copies of the study materials to the training workshop. Information sheets and informed consent forms were sent to supporters via email prior to scheduled interviews and these were also made available to participants via WhatsApp as it is the platform they are familiar with. Supporters printed out these forms for participants' signatures. After signing the form, these were sent back by the supporters via email.

3.6.3 Data collection: Booklet, pictures and semi-structured interviews

3.6.3.1 Booklet

The researcher developed a booklet that aimed to (a) explain the role of government and government policy developments to guide its services and supports to citizens, and (b) guide the participants to identify their needs and the policy priorities to which these might relate. The use of a booklet was also to ensure that participants were familiarised with these issues in order to make an informed contribution to the study. This was done to help participants fully understand study objectives, how policy decisions can impact on our lives, and to elicit their views on what policy-related needs they might have.

The booklet was also put together in a way that could guide participants in identifying their policy needs and priorities using magazine and newspaper pictures. Guided by the booklet, participants were able to collect pictures that reflected their policy needs. These pictures

were then discussed by the researcher and participants in their individual semi-structured interviews to help the researcher understand the meaning of each picture.

The booklet was therefore used as a tangible reasonable accommodation tool to assist participants in selecting pictures that identify what they need in life and then discussing these areas in terms of what they might want government to include or to change in their policies to meet their needs. The booklet has two sections: section 1 outlines what is meant by policy, who is responsible for formulation and implementation of policies, and how ordinary citizens might contribute their views on policies to support their health and social wellbeing.

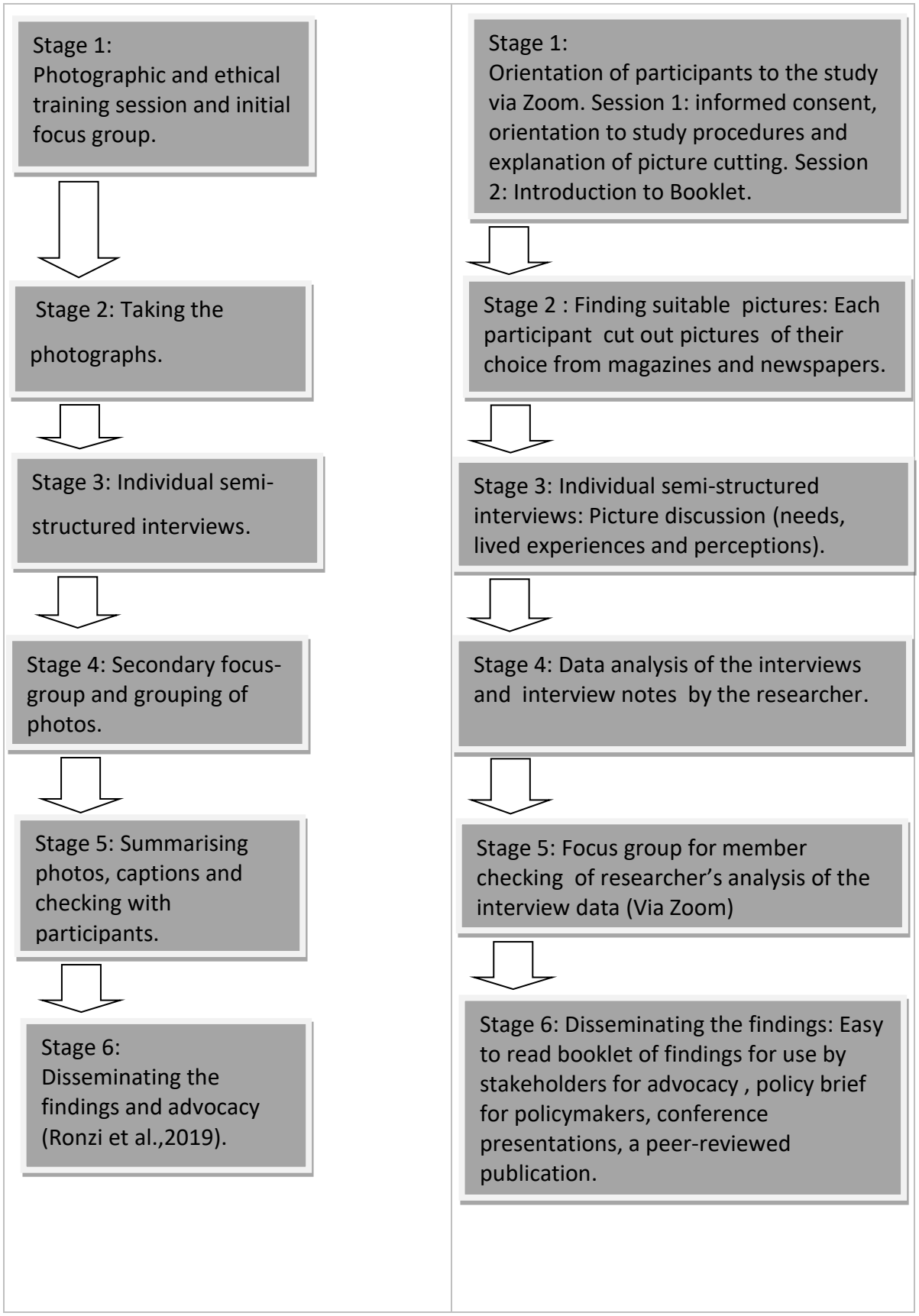
Section 2 of the booklet has blank spaces with two columns; the left column for pasting participants' chosen pictures that represented their needs and policy priorities which might relate to these needs, and the right column providing space for the researcher to write down the participants' comments on the meaning of each chosen picture. The comments written down were checked with the participants to ensure that the researcher had recorded their views correctly, and fully understood what they meant.

3.6.3.2 Pictures

Photovoice was initially identified as an appropriate method for enabling people with intellectual disability to communicate their experiences and viewpoints on the topic which impacts on their lives (Heffron et al., 2018). Covid-19 restrictions on student research required ethics approval obtained for the planned face-to-face interviews to be changed to online interviews. As online intervews and lockdown restrictions did not allow the researcher to guide participants through a photovoice process using cameras to capture photographs that reflected their policy-related needs, this process was adapted to account for the Covid-19 restrictions, as summarised in Figure 4 below. Five distinct stages were used to explore pictures selected by participants. This study adapted stages outlined by Ronzi et al. (2019) for photovoice procedures to best fit the present study

Figure 4

Summary of the Adapted Photovoice Process to Meet the Present Study Objectives



In the left-hand column of Figure 4, above, are the stages adopted by Ronzi et al. (2019) to outline the process of photovoice. Ronzi et al. (2019) adapted these stages from the original methodology by Wang and Burris (1997), and slight changes were made from the original version to best fit his study. Similarly, for this study the researcher has adapted Ronzi et al.'s (2019) stages to outline the process that best suited the circumstances of the present study context.

3.6.3.2.1 Sourcing pictures which represented participants' needs

Participants were given a period of two weeks to source pictures that represented their needs and policy priorities. Participants collected pictures from magazines and newspapers from their households. The progress of participants was monitored by both the researcher and supporters. After each participant had collected pictures, they were asked to send these pictures to the researcher via WhatsApp prior to their scheduled interview to enable the researcher to print their pictures for her reference during interviews.

3.6.3.3 Semi-structured interviews

Semi-structured interviews were used to elicit stories about the lives and the needs of people with intellectual disability and how government policy can help them achieve identified needs. All interviews were recorded and transcribed verbatim to ensure that all information was captured from participants' perspective. During the semi-structured interviews, each participant was asked to select 5–8 pictures from those they had cut out at the previous stage, to best reflect their policy needs. Participants were asked to take one picture at a time and to display the picture on the WhatsApp video call so that the researcher could see which picture the participant was referring to. Thereafter the researcher used the following questions to explore each picture shown by the participant:

1. Tell me why you selected this picture?
2. Tell me what is really happening here?
3. What is important to you about this?
4. Do you already have this or is it something you feel you still need?
5. What can be done about this?
6. What can you do to make the change you need in this?
7. Who do you think can help you with this, and what help do you need?

8. What can be done by government that would be helpful for you and other people with intellectual disability who have similar needs as you?

After each interview with participants, the researcher spent about half an hour completing an administrative sheet that was aimed at assessing the quality of each interview and to summarise her impressions of the themes that might have emerged during the interview, to start building preliminary impressions of the themes emerging from the interviews ahead of analysing the interviews in more detail, as described below.

3.7 Data Management

Interviews were audiotaped using the researcher's personal computer recorder and these audio recordings were securely stored on the password-protected computer before they were sent to the transcribers for verbatim transcription. Transcribers were required to sign a confidentiality agreement to ensure that they did not disclose data to external parties (Appendix 6).

Administrative sheets (Appendix 8) and research notes that were used to summarise and keep track of each interview were kept in a secure place at the researcher's household. Transcribed interviews and meeting recordings were kept on the password-protected computer with secured access.

After transcriptions were completed, the researcher removed participants' names from the transcripts and used pseudonyms to identify participants. These transcripts were also securely stored on the password-protected computer. All data were backed up on a hard-drive and this was kept in a secure place at the researcher's household during the study processes. However, at the conclusion of the write-up of the research report, all data will be stored in a locked filing cabinet in the University of Cape Town Department of Psychiatry and Mental Health's research repository room in the Neuroscience Centre, Groote Schuur Hospital, Cape Town. Details of the study will be stored on the research registry of the Division of Intellectual Disability, and access to the data will be through the office of the Vera Grover Chair of Intellectual disability. All records held on the password-protected computer will be deleted.

3.8 Data Analysis

Prior to data analysis, transcripts were read while listening to the audio tapes to confirm the accuracy of the transcriptions, and thereafter loaded onto Atlas-ti 9 software for analysis. The objective of thematic analysis is to identify themes which answer the research question. Ritchie et al.'s (1994) framework analysis approach, based on that which is widely used to analyse qualitative data applied to policy research, was used to analyse the data and identify themes.

Ritchie et al. (1994) describe framework analysis as "an analytical process which involves a number of distinct though highly interconnected stages". Ritchie et al. (1994) outlined five key stages, which are: familiarisation; identifying a thematic framework; indexing; charting; mapping and interpretation.

3.8.1 Stages of framework analysis

Step 1: Familiarization

Themes were identified inductively from summary notes and transcripts. Transcripts loaded onto the Atlas-ti software programme were read several times to obtain an overall view of emerging themes that were relevant to the study aim and objectives. Through this process of familiarisation, the researcher was able to decern emerging themes for each participant and similarities and differences between participants views. The researcher captured notes on her first impressions of these themes to be used at the next stage of the development of a coding frame for the data.

Step 2: Identifying a thematic framework

Researcher notes, notes captured in the booklets and summaries made of emerging themes directly after each interview in response to the interview questions were reviewed to refresh the researcher's recollection of potential themes. These notes and the preliminary themes, which were noted inductively during the reading of the transcripts, were triangulated to develop a set of data categories or codes to form an initial coding frame within the Atlas-ti software package. Each code was given a name which best described the themes represented.

Step 3: Indexing

The transcripts were then systematically coded against relevant preliminary themes and sub-themes created during the previous stage. Where a theme emerged from this detailed coding of segments of the transcripts which had not been captured in the initial coding frame, this theme was added to the coding frame.

Step 4: Charting

Data captured under each theme and preliminary sub-themes in the previous stage were then reviewed and summaries made of the content of the themes and sub-themes, capturing both individual participants views represented under each theme, as well as similarities and differences in perspectives across the participants' views under that theme. Quotations and pictures illustrating the summarised perspectives were also noted during this stage.

Codes reports were imported onto an Excel spreadsheet to assist in the organisation, identification of categories and development of themes. The researcher generated a matrix and data were charted to enable the researcher to interpret and compare similarities and differences in perspectives. On Excel, where a matrix was generated, each column represented participants' quotations and pictures in relation to the theme and sub-theme; and each row represented themes and sub-themes.

Step 5: Mapping and interpretation

The researcher analysed key characteristics that were laid out at the charting stage. The researcher reviewed data, systematically checking how each theme and sub-theme related to each other and if participants' views were similar or dissimilar.

3.8.2 Member checking

A focus group discussion, held via Zoom, facilitated checking with the participants whether the researcher's interpretation of the research findings at Stage 5 accurately reflected their views on their needs and policy priorities. Participants were assisted by their supporters to connect to the meeting on Zoom. The researcher prepared a PowerPoint presentation that reflected research findings and provided verbal feedback to the participants in an intellectual

disability-friendly manner using participants' pictures, and easy-to-understand dialogue. Thereafter, participants were asked to share their views about whether the researcher had correctly captured their ideas, if any ideas where not reflected, and whether the findings presented accurately reflected their policy needs and priorities. This was facilitated by asking follow-up questions that enabled the researcher to note whether participants agreed with the findings or not. Participants were asked to respond to the questions below:

1. Have the researcher captured all your views?
2. Is there anything the researcher missed that you would like me to add?
3. Is there anything else you wish government to help you with?
4. Of all the things that we have discussed today, what do you think has been most important to you?

Participants were in agreement with the findings presented to them, with no additional information added by participants. Participants in particular placed emphasis on the findings related to their need for education and skills training, employment, access to healthcare and access to inclusive housing. Participants who did not share their views on a particular issue during their individual interviews then, unprompted, shared their views on those issues, which were consistent with the findings from the interviews. The meeting was recorded and transcribed for analysis. The focus group was also coded to ensure that the views of participants formed part of the final analysis and write-up of the findings of the study.

3.9 Ensuring Research Rigour

3.9.1 Credibility

Credibility relates to the degree of confidence with regards to the originality of the research findings, that is, the extent to which the interpretation of data reflects the original views/ideas of the participants and not those of the researcher (Anney, 2014). This was achieved through the following strategies:

- Reflexivity: The researcher kept a reflexive journal to incorporate personal reflections on the study processes which occurred during the course of the research (Anney, 2014). The researcher engaged with the possible impact of her own world view on her understanding and experience of the research process and participants' responses on her interpretation of the data, both in supervision, as well as in field notes kept during the research process. Field notes/summary notes

enabled the researcher to reflect on the research process and the issues that might have interfered with the understanding of participants views.

- Peer debriefing: Support from other professionals, such as academic staff or a dissertation committee, can offer valuable insights to qualitative research (Anney, 2014). Over and above the review of the research process, transcripts and other documents by the researcher with her two co-supervisors, the researcher presented aspects of the study (data collection methods, preliminary analysis of data, findings of the study) to an advisory group of three disability researchers and two persons with lived experience of intellectual disability (and their supporter) at various points in the study, for their feedback and advice. This advisory group was constellated at the inception of the overall study on self-advocacy, of which this research project is one of three sub-studies.
- Member Checking: This strategy allows participants to give feedback and reflect on the findings (Anney, 2014). Participants were invited to participate in a focus group meeting as a means to member checking. During the focus group the researcher verbally summarised research findings in an intellectual disability friendly manner to confirm with the participants that she had captured their views and needs in policy correctly. Thereafter participants were given a chance to reflect on the findings, whether they fully represented their needs/policy concerns, or if they felt they needed some changes to be made.
- Triangulation: This involves the use of multiple research data sources such as interviews, focus groups and participant observations or the collection of data from different informants to develop a comprehensive understanding of the phenomenon under study (Anney, 2014). This study collected data through a scoping review, semi-structured interviews and a focus group discussion, providing different lenses through which to capture and reflect on the question of policy priorities for people with intellectual disability.

3.9.2 Dependability

Dependability refers to whether the quality of the data collection and analysis process has assured that the reported study findings are consistent with the data collected. A review of

the interpretation and recommendations of the study should show that the analysis and interpretations are supported by the data collected from participants (Anney, 2014). This was achieved as follows:

- The researcher used a code-recode strategy for data analysis, where the researcher coded similar data more than once, giving a week between each coding (Anney, 2014). The comparison of the two coding sessions revealed that both coding's yielded similar results. Interview audio clips and notes were also available for cross-checking analysis and interpretation of the data.
- An audit trial of the research process involves the researcher noting research decisions and activities undertaken during the study (Anney, 2014). To achieve this the researcher completed an administrative form (Appendix 8) at the end of each interview summarising the interview processes for the study, as well as taking personal notes on the processes she followed during the logistical arrangements for the study, and during the interviews and focus group.

3.9.3 Transferability

Transferability refers to the extent to which the findings of this study can be transferred to other participants in other contexts (Anney, 2014). Interrogation of transferability can be facilitated by the research using thick (detailed) descriptions of aspects of the study. This chapter provides thick descriptions of the setting for the study, participants involved in the study, as well as data collection, data analysis and write-up processes used for the study. Despite this study context differing from that of other studies, the thick description described above may provide information which can enable other researchers to conduct similar studies in similar contexts using a similar methodology (Anney, 2014).

3.9.4 Confirmability

Confirmability refers to the degree to which the results of the study can be confirmed if conducted by other researchers (Anney, 2014). Confirmability was ensured through reflective journaling and an audit trial, as described above. The administrative form used to record administrative information and reflections from each interview (her impressions of the emerging themes, the quality of the interview and personal reflections) on the data collection

process was also helpful during analysis as the researcher could use the information recorded to recall what happened during each interview. These summary notes/reflections on each interview and the interpretations of findings can assist in assessing whether reported findings were derived from research data and not from the researcher's imagination.

3.10 Ethical Considerations

Ethical approval was obtained from the University of Cape Town's Faculty of Health Sciences Research Ethics Committee (HREC, 020/2021).

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

The organisation management was approached to advertise and recruit potential participants from their organisation and permission was granted, based on their internal research policy, adapted for use during Covid-19 conditions. A memorandum of understanding was completed by the researcher noting commitment to adhering to the research protocol of the organisation for safe and ethical conduct of the study, as well as an undertaking that the organisation would be included in the dissemination of the findings of the study to the organisation.

The following ethical principles pertain to the study:

3.10.1 Confidentiality

The researcher securely stored all collected data in a password-protected computer. Participants' names were removed and replaced with pseudonyms, and no confidential information was shared with external parties other than those involved in the study, and the researcher ensured that everybody that had access to the data had signed a confidentiality agreement form. In addition to data, audio recordings were safely kept in a password-protected computer and only accessed by the researcher and research supervisors. For the focus group discussion, confidentiality was not guaranteed, however, participants' feelings were protected at all times by ensuring that participants were aware of the fact that they could withdraw at any time without consequence and were in their rights to only share information that they were comfortable sharing.

3.10.2 Beneficence and non-maleficence

Beneficence entails the researcher's obligation to promote wellbeing and benefits to the participants (Pietilä et al., 2020). Despite the fact that there was no direct benefit from participating in the study, participants were given an opportunity to advocate for themselves with regards to what they would like government to help them with.

Non-maleficence refers to the researcher's obligation to ensure minimal risk. Usually, qualitative research does not pose physical harm to participants, however, discussions may trigger past uncomfortable memories and experiences, thus it is the researcher's obligation to minimise those risks (Pietilä et al., 2020). This study posed no physical harm, and no significant emotional risk was envisaged nor found during the conduct of the study. This project was supported by clinicians and service providers that are highly experienced in working with people with intellectual disability, and the research team as a whole was supported by an advisory committee of experienced clinicians as well as self-advocates with intellectual disability that provided oversight to the ethical conduct of the study.

3.10.3 Justice

In research ethics, the principle of justice refers to equal and fair selection of participants in a research study (Pietilä et al., 2020). In this study participants were selected fairly, based on the inclusion criteria that was set by the researcher.

3.10.4 Autonomy

Autonomy refers to participants' freedom of will. This implies that participants should have control over their participation and should not feel forced or influenced by external forces (Pietilä et al., 2020). This principle of autonomy was upheld by ensuring that participants understood the study objectives and were able to decide to participate in the study by signing the informed consent forms. Consent was established at each of the sessions with participants to ensure their full understanding of what each session involved. In addition to the signing of informed consents, participants were encouraged throughout the study to fully express themselves regarding study objectives that aimed to capture the voices of this population group.

Chapter Four

Results

4.1 Introduction

In this chapter the results of the study, based on the interviews and focus group discussion, are presented and discussed. Quotations are used to illustrates participants' first-hand experiences with regards to the concerns that were being discussed. Pictures chosen to illustrate their needs and priorities are provided to further illustrate the experiences of the participants.

The characteristics of the study participants are summarised in Table 4.1 below.

Table 4.1

Participant Demographic Information

Participant's name (pseudonyms)	**Age range : Adults (18 years or older)**	**Gender**	**Home language**
Patrick	30-39	Male	English
Precious	30-39	Female	English
Penelope	30-39	Female	isiXhosa and English
Peter	18-29	Male	English
Parker	30-39	Male	English and Afrikaans
Prince	30-39	Male	English and Afrikaans

4.2 Themes from the Findings

The analysis of the interviews yielded six main themes which participants identified as areas of priority need, as illustrated in the screenshot below (Figure 5), followed by an Excel (spreadsheet) screenshot showing how main themes and sub-themes were grouped (Table 4.2).

Figure 5

Coding Frame

Name	Grounded	Density	Groups
need for education and training	33	0	
access to health care	23	0	
equal opportunities	20	0	
need to get a job/ need to be employed	16	0	
helping others	15	0	
job preferences	14	0	
health care challenges	14	0	
housing and personal space	13	0	
family support	11	0	
willingness to learn	10	0	
learning new things/skills	10	0	
open spaces for people with ID to learn new skills	8	0	
leisure activities	7	0	
getting help from others and helping in return	6	0	
insufficient social benefits	6	0	
need to be heard	5	0	
workshops for people with intellectual disability	5	0	
unfairly treatment	4	0	
access to basic education	4	0	
getting support from companies	3	0	
spending time with family	3	0	
helping people in hospitals	3	0	
learning practical skills	3	0	
importance of family	2	0	

Table 4.2

Interlinked Codes, Main Themes and Sub-Themes

Grouped interlinked themes	Main themes and sub-themes
need for education and training willingness of learning learning new things/skills access to basic education learning practical skills workshops for people with intellectual disability open spaces for people with intellectual disability to learn new skills	Main theme: Need for education and skills training Sub-theme 1: Need for education Sub-theme 2: Skills training Sub-sub-theme: Open spaces for people with intellectual disability to learn new skills
access to healthcare healthcare challenges right to medicine	Main Theme: Need for healthcare Sub-theme 1: Access to healthcare Sub-theme 2: Challenges at healthcare
equal opportunities	Equal opportunities
need to get a job/need to be employed job preferences working in farming owning a business job that doesn't require level of education	Need for employment Sub-theme 1: Finding a job Sub-theme 2: Job preferences
housing and personal space insufficient social benefits	Need for housing
family support spending time with family helping others getting help from others and helping in return importance of family Relationships/marriage support from others/peer support right to be protected	Main theme: Supportive relationships Sub-theme 1: Supportive families Sub-theme 2: Intimate relationships Sub-theme2: Helping others Sub-theme 3: Getting help from others

Below is a brief summary of each theme before detailing the findings below:

4.2.1 Summary of themes

The most frequently mentioned priority participants mentioned, entitled “need for education and training“, has two sub-themes, namely “need for education” and “skills training,” with a subset entitled “open spaces for people to learn new skills.” These address how persons with intellectual disability wish to receive education and skills trainings to improve their quality of life and opportunities.

The second most frequently mentioned priority, entitled “need for healthcare,” has two sub-themes entitled “access to healthcare” and “healthcare challenges,” details participants’ perceptions of the importance of accessing healthcare services, especially for people with disabilities, and further elaborated on the challenges within primary healthcare.

The third most frequently mentioned priority, entitled “equal opportunities”, how participants wish to be offered equal opportunities in order for them to have better and improved wellbeing.

The fourth most frequently mentioned priority, entitled “need to be employed,” has two sub-themes entitled “need for employment” and “job preferences,” and addresses how people with intellectual disability wish to be employed in income-generating work to support themselves and their dependents.

The fifth most frequently mentioned priority, entitled “housing,” describes how participants wish to have access to personal space where they currently live, or preferably, their own housing.

The sixth most frequently mentioned priority, entitled “supportive relationships”, has four sub-themes entitled “supportive families”, “Intimate relationships”, “helping others” and “getting help from others”, describing participants’ view of the importance of helping other people, and the importance of family support that often ensures their own wellbeing and protection.

4.2.2 Theme 1: Need for education and skills training

This theme comprises of two sub-themes, which are (1) Need for education and (2) Skills training. Respondents associated education, skills training and employment with limited access to education and skills training, resulting in limited possibilities for securing employment. They emphasised the need to access education and skills training in order to be employable. This theme, therefore, represents respondents’ wish to receive adequate education and skills training to enhance their livelihood.

4.2.2.1 Sub-theme 1: Need for education

Respondents indicated a need for accessing education, as this may help them to grow as individuals and provide options that are currently scarce because of their level of education. Participants expressed how they would like to have access to education as their fundamental right:

We have a right to education because … we don't have that, like, we … can't go to colleges or go to get education because of the disability. (Peter)

Later, Peter commented on how access to further education and training is inaccessible due to financial constraints:

I want to study further, but the fees are expensive miss and now I can't, if I want to go to college.… I want to be an engineer. (Peter)

Picture 1. *Peter: Picture 1: The need for access to further education .*

Penelope acknowledged the limitations and difficulties in relation to learning, and her interests and willingness to learn:

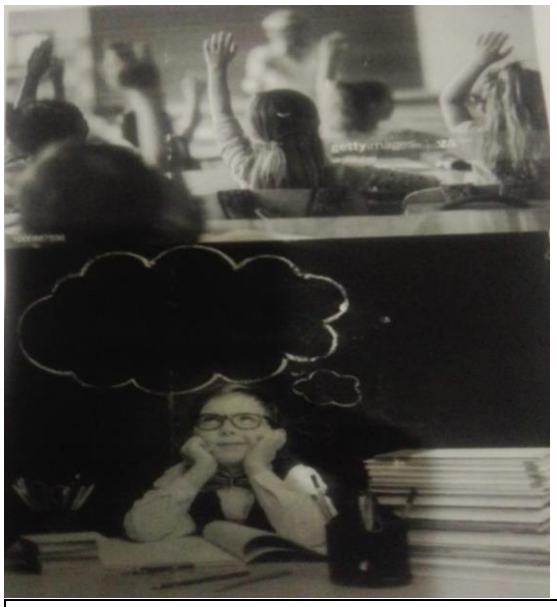
I need this, I need books to learn.… I'll take the challenge. I know it might be hard for me, but I'm willing to try.… I want to learn first and then I'll go to the work at the workshops, yeah.

Picture 2. *Penelope: Her interest in opportunities to gain new knowledge*

Patrick echoed similar eagerness with regards to learning:

I'm eager to read, if there's an easy-to-read programme, I never say no to it. (Patrick)

Parker expressed his desire and willingness to learn to read and write but noted that his disability was a barrier:



Uhm, first of all, I got a disability man, you, see? I can't actually read, that's the thing actually…. I would like to learn how to read and write…. I need to study. (Parker)

Picture 3. *Parker: The need for appropriate ways to gain new knowledge when reading is difficult*

With regard to what government could do, Precious stated: *Because uhm, they must have education … so, I can write and read…. the government can help people read and help the school children also.* (Precious)

Picture 4. *Precious: The importance of accessing basic education.*

4.2.2.2 Sub-theme 2: Skills training

Respondents showed interest in learning new skills, however, skills training programmes are not available to them, which makes it difficult for them to acquire these skills.

Patrick emphasised the benefits of skills training:

> *Yes, there is a lack in training. That's what it is. Like me, I first went to l (mentions training workshop organisation where he works), I didn't know nothing. From the time I'm there to now, I'm really like a supervisor.* (Patrick)

In the focus group meeting, Patrick said:

> *Yes, practical skill, if you don't have a certificate, they won't just offer you a job on site, you must have a certificate to say you did do this job and someone did train you for it.…* (Patrick)

4.2.2.3 Sub-sub-theme: Open spaces to learn new skills

Respondents expressed a wish for country-wide workshops or support structures that aim to equip and enhance the livelihood of people with intellectual disability, granting them an opportunity to learn new skills:

> *Now if we can make our workshop expand, I'll be very happy. Expand it bigger and more places in the, in the country can have it.… and we can get a certification from the workshop to get a better job.…* (Patrick)

> *If they can buy a land or something, and then build a big workshop.… we have been waiting for many years to find new things, new work …* (Penelope)

> *Open another workshop like this, a place where people can learn to get a job for what they want to do in life … a training facility like (mentions training workshop organisation where he works) …. For people to learn how to get a job in the in the outside labour market*. (Patrick)

Other participants spoke of the need to provide fit-for-purpose infrastructure at existing facilities:

> *They don't paint the workshop there, outside and inside. Inside by the toilets, lots of doors are broken. And uhm, they can paint the floor, and the doors also*. (Precious)

… there by our workshop, there's like the roof is leaking, they can make the roofs right … and put maybe heaters in like when it's winter for us. There's some like, doors are broken, they can make it right. (Peter)

Picture 5. Below – Peter: The need for reasonable accommodation to access other societal benefits.

Peter: *… a right to have a driver's license … I am busy but because of my sickness, they won't allow me to, Miss.*

Interviewer: *… is there anything that government can do to help you?*

Peter: *I am not sure, Miss, if there is something that government can do…. But I would like to have a driver's license just like everybody else…I will appreciate any help to have a right to have a license.*

In the focus group, Patrick supported this idea, but noted the importance of government introducing reasonable accommodations to enable securing a driver's license, if you have an intellectual disability:

For a person who can't read and write … the facilitator can read a question out to you and then you can, or must say like, the road sign … also people at home will help you to study the book and then you can learn how to do it oral, and you can say the road signs. (Patrick)

4.2.3 Theme 2: Need for healthcare

4.2.3.1 Sub-theme 1: Access to healthcare

Respondents highlighted the need for the government to improve the healthcare system by building suitable infrastructures and ensuring the availability of medication, so ensuring that everyone has access to healthcare:

The government should build other hospitals … and must help people to stay healthy and mustn't get sick. People in hospitals should be taken care of and give people a right to medicine. (Precious)

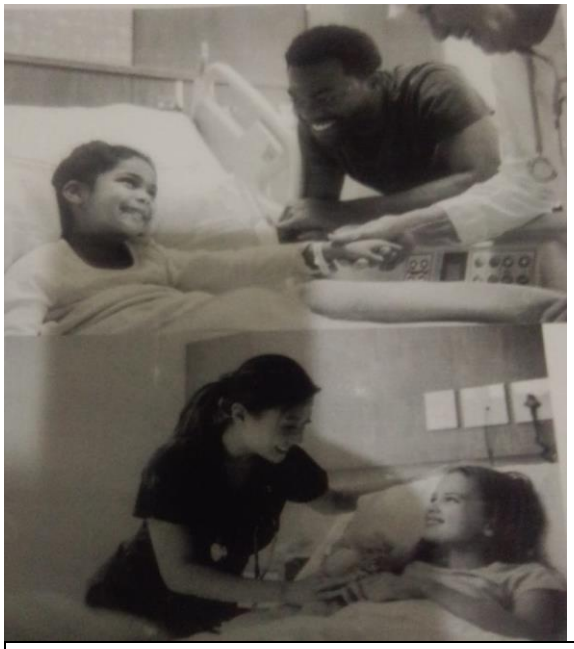
Picture 6. *Precious: The importance of providing adequate services to ensure that all people have access to proper healthcare.*

4.2.3.2 Sub-theme 2: Healthcare challenges

This theme presents the experiences and challenges respondents encounter when they are accessing healthcare. These challenges include the service they receive, such as spending lengthy hours outside hospital premises, nurses and medical doctors being short staffed, and overcrowding in hospitals which delays attendance:

> *Uhm … when we go to the hospital in the, uhm early in the morning … then we stand outside by the gate. Then uhm, the doctors take very long to call us and attend us, so that we can go inside in the hospital waiting rooms….* (Prince)

> *If you go to the hospital, they take their time to help the people…. Sometimes I don't get help quickly…. I was at the hospital, so they keep saying they going to help me, but then they didn't come back.* (Precious)



Uhm ... I go to the hospital to get my tablet every month … yeah there is always lines yes and…(pause)…yes, the hospital is full. (Parker)

Picture 7. *Parker: The need for healthcare access and his experience of overcrowding in hospitals.*

> *… there's a lot of people at the hospital, it's very full…. And the doctors don't have enough medicine.* (Precious)

The interviewer asked if there is anything that can be done to change the situation:

> *Yes, there is. When people go to the hospital … it should depend on the appointment…. People should get appointment cards.* (Prince)

4.2.4 Theme 3: Equal opportunities

People with intellectual disability feel left out because of their disability. Some participants noted that they also deserve to be given equal opportunities just like the general population. Participants felt that the inclusion of people with intellectual disability should exist in all life domains, while at present they do not enjoy equal opportunities in the areas of employment, education, access to healthcare, access to adequate housing and vocational training, which then limits their ability to succeed within these life domains:

> *The person with a disability plays tennis. Tennis is the sport with a whole lot of movements. He's in a wheelchair but is playing the professional sport that's very*

good. In life, people can also do that, make a career for yourself. That's what it is, with his disability, he is making other people see what he can do. (Patrick)

Government must help. They can't keep people in the dark of doing things then they give other people who don't have disabilities better jobs. But the person with the disability can also do the same job, but they don't see that. (Patrick)

Picture 8. *Patrick: People with disabilities should not be limited by their disability*

4.2.5 Theme 4: Need to be employed

4.2.5.1 Sub-theme 1: Need for employment

Respondents wish to be offered job opportunities that match their abilities, not only in protected workshops but also in the open labour market, because they are capable beings who can do much with their hands:

We have the right to work, Miss. Because, outside, we don't, how can I say? We don't have a work; we can't get the work. It's very difficult to get work outside because of our disability, that's why. (Peter)

Picture 9. Peter: Limited employment opportunities for persons with intellectual disability.

In a focus group meeting, Patrick shared a similar sentiment with regards to finding it difficult to make it into the open labour market, but noted that it was not specifically the disability that caused the problem, but rather prejudice regarding people with intellectual disability's capacity to work, as well as a lack of focus on people with intellectual disability's strengths which could assist them in doing well in the job market, rather than on their areas of difficulty:

> *Some people they won't give us work all the time because we are considered disabled people. People think, oh no, we can't do the job. But maybe with our physical hands we can do better and not with our brain.* (Patrick)

> *People with disabilities also must have a job. Don't keep them out of the way and say no you can't, you got disabilities. You can't do that.* (Patrick)

Penelope is aware of her capabilities and possible limitations, noting that work that she would be expected to do has to match her capabilities, and emphasised that she still wants to and needs to earn a living like everyone else: *Uh, I need the job, I just want a normal job, just like everyone. And salary, like everyone…. Uh, work has got to be easy for me. Yeah, I will understand completely, what I'm doing.* (Penelope)

Picture 10. *Penelope: The need for appropriate training to facilitate being employed.*

Patrick felt that people with intellectual disability can work anywhere and do any kind of job, with good leadership and required kills. However, like Penelope, he suggested that they may benefit from someone to guide them at first in how to perform the given task so that they can eventually be able to complete the task or work.

Any job if you showed him how to do it. They can learn and do it and they can work anywhere, not only in farming … people with disabilities can also pack stuff for you in your warehouse or anything. They can make it better and easy for you. But do not keep them out of the job … a person with disabilities can also be a checker. They can check the food if it is not rotten or is a hundred percent healthy. (Patrick)

Picture 11. *Patrick: With someone to guide them, people with intellectual disability can work in any context.*

Penelope said, *"but if maybe someone that knows how to do it, if maybe they can show me, I can learn … we need people that knows these things, to train us."*

In response to the question, *"Is there anything that can be done by the government to help you and others to get employed? Or is there anybody that can help you and others to be employed?" ,* four of the six respondents expressed the view that government intervention to improve the challenges of people with intellectual disability to secure paid employment in the open labour market would change their lives for the better:

> *If maybe government can help me to get a job.* (Prince)

> *I need a job…. If government can help me get a job so that I can take care of myself and move on, yes.* (Parker)

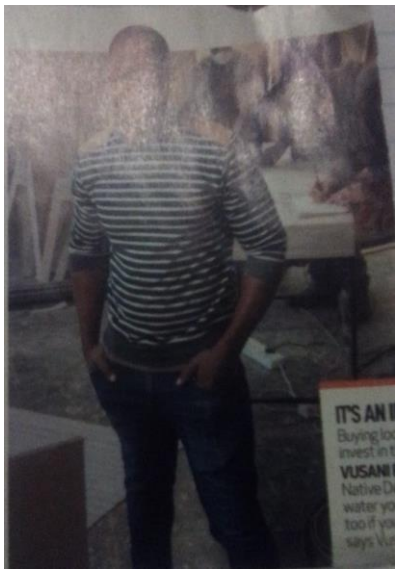
> *I would like government to help me with a job or something…. I wish companies like Pick' n Pay, Shoprite or Woolworths to employ people like us, with disabilities.* (Peter)

If the government can remove a degree or all of that and then people with disabilities can have a job that does not require a CV because we do not have that. (Penelope)

4.2.5.2 Sub-sub-theme: Job preferences

Some of the respondents showed interest in different fields of employment:

I cannot get a job because I do not have grade nine. So, if I can learn how to fix cars or maybe do woodwork, I will be happy because I can make money there … they want grades, grade nine and I don't have that….(Later) I would like to make wood tables and wood floors … and make money (Penelope)



Picture 12 and 13. *Penelope: Interest in woodwork and fixing cars.*

Peter shared his interest in mechanics, evidencing the need for programmes that teach job skills:

My uncle is a mechanic, so I used to work with my uncle down the road … that's why I want to be my own mechanic so when the car breaks down, I know what to do. (Peter)

Prince also shared his job preference:

I am looking for a job for me on the open market…. A cleaner job. (Prince)

Parker shared his ideas for his future employment, noting he would like to use his experience from working in the protective workshop to start his own business, illustrating the importance of seeing these workspaces' original purpose, not as an end in itself, but

rather as an opportunity to upskill people with intellectual disability for other paid work opportunities:

Parker: *I want to get a job. But there's something else that I want to do…. I would like to have my own business.*

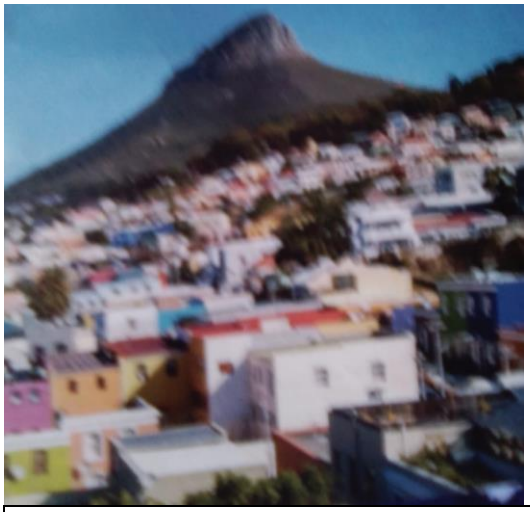
Interviewer: *What kind of a business would you like to own*?

Parker: *Like, woodwork.*

Picture 14 *Parker: The need for considering people's interests in training them for employment.*

4.2.6 Theme 5: Housing

Most of the respondents reported living in family households, with housing unaffordability being a crucial concern for people with intellectual disability who live on social grants. Some believed government had the responsibility of building houses for those who cannot afford to buy one:



The government need to give people houses…. The government must … build houses for people who do not have houses. (Precious)

Picture 15. *Precious: The need for housing for people with disabilities.*

Respondents mentioned the importance of having their own homes, enabling them to have personal spaces within which they can pursue relationships and start families. Lack of housing limits their independence and the possibility of starting their own families:

> *Yes, there is something I want one day … I want my own house one day … because I have a life partner …* (Prince)

Peter: *We sometimes need our personal space … it's difficult to get a house. ….He further stated: Well, we have a right to houses but it's difficult, for people like me, people with disabilities with SASSA*[4] *benefits we can't get houses, it's too expensive.*

Picture 16 . Peter: The impossibilities of securing a house with only a social grant .

In the focus group, Patrick and Precious agreed with the above sentiments:

> *They must build houses for people who have disabilities … so that they can be independent.* (Patrick)

> *The government must give it for free. They must give disabled people houses for free.* (Precious)

[4] SASSA *[South African Social Security Agency]*

4.2.7 Theme 6: Supportive relationships

4.2.7.1 Sub-theme 1: Supportive families

This theme presents the relationship of respondents and their families who serve as their primary carers or caretakers. Respondents reported that their families provide them with immense support that ensures their wellbeing and is, mostly, likely to meet their needs:

They are very important to me, yes ... they really like, a hundred percent important to me and I like spending time with my family. (Parker)

Picture 17 *Parker: The importance of family roles and family support.*

I took this picture because they always there to help me … they are always there all the time if I need them. (Precious)

Picture 18. *Precious: Families as primary service providers*

Uh, my right to be protected … by people who love you like, your parents your guardians, and to be kept safe in wellness … even if you get sick or good times, they are always there. (Peter)

Picture 19. *Peter: Family responsibilities in caring for people with disabilities*

4.2.7.2 Sub-theme 2: Intimate relationships

This theme represents participants interests in pursuing intimate relationships.

Peter: "I want to start a family; I want to get married one day"

Prince shared the same view as Peter with regards to wishing to pursue an intimate relationship.
He stated: *"I want a life partner in my life."*

4.2.7.3 Sub-theme 3: Helping others

Respondents expressed interest in helping those in need and those who would appreciate their help:

> *I like to support people that need help … I'm talkative to everybody. If you are still new at the workshop. I welcome you and talk to you…so yeah, I love helping people that needs help.* (Penelope)

> *I like helping others.* (Parker)

If I got food or anything, I would give it to someone. Because what happens if I'm the one in that situation … at the moment, I don't have …. If I had more stuff, more things to do for other people I will do it. (Patrick)

Picture 20. *Partrick: The importance of supporting others.*

4.2.7.4 Sub-theme 4: Getting help from others

> *I like getting help from others…. If there's … someone to help me to work on the computer or something like that.* (Parker)

> *People with uhm, disabilities … can't help themselves…. So, people with disabilities need someone to help them.* (Prince)

Patrick commented on getting help from the private sector by employing people with disabilities. This highlights the need for collaboration between workshops/centres working with people with intellectual disability and the open labour market or private sector:

> *If we can maybe get companies like Pick 'n Pay or Checkers to help us go further.* (Patrick)

Chapter Five

Discussion

5.1 Introduction

The conceptualisation and implementation of this study took place through the lens of an adaptation (Simplican et al., 2015) of the socio-ecological model of Bronfenbrenner (1979, 1994). Bronfenbrenner's model asserts that individuals are in continuous interaction within distinct levels of life, and they may experience negative or positive interactions within those levels. As indicated in Chapter One, Bronfenbrenner's original conceptualisation includes five levels: microsystem level (the individual in his/her/their immediate neighbourhood), mesosystem level (interaction between school and home, school and workplace), exosystem level (parents' workplace, family social networks and neighbourhood community contexts), macrosystem level (material resources, customs, beliefs and values, opportunity structures and life-styles) and chronosystem level (change over time in socio-economic structures, family structures, employment and place of residence).

5.2 Simplican et al.'s Adapted Socio-Economic Model of Development

The reconceptualised socio-ecological model by Simplican et al. (2015) consists of five different levels: the individual, interpersonal, organisational/institutional, community and socio-political levels, within which individuals interact with the environment. Simplican et al.'s (2015) adapted model provides an apt conceptual framework within which to describe how people with intellectual disability see themselves within different life levels and social contexts. This conceptual framework was used to aid my understanding of the experiences of people with intellectual disability in different life domains and to understand social and health-related policy priorities of adults with intellectual disability. This model also informs the discussion of the findings of my study, with core issues which emerged from the findings relative to the influence of each level.

Figure 6

Summary of Findings of Study per Level of Simplican et al.'s (2015) Adapted Socio-Economic Model of Development

5.2.1 Individual level

The first level, the individual level, is comprised of the individual with their individual characteristics (i.e., age, gender, physical, emotional and intellectual capabilities or challenges, and personal interests). Therefore, this aspect is concerned with the lived experience of people with intellectual disability in relation to their own capabilities (how they are able to interact with the environment, and how they are supported or not by that immediate environment).

The literature states that the environment where people with intellectual disability live, learn and work plays a positive role in advancing self-determination (Wehmeyer & Garner, 2003), suggesting that the support from the immediate environment may enhance the quality of life

of people with intellectual disability. In the findings of this study, respondents did not reflect on their individual characteristics, such as age and gender, but rather on the challenges and their first-hand experiences when interacting within the immediate environment. They highlighted their interests in different life domains, how they hoped they would achieve their personal interests and what support they would appreciate in terms of fulfilling their personal interests. This is further elaborated on at the levels below.

5.2.2 The interpersonal level

The interpersonal level comprises relationships of people with intellectual disability with their family, friends and other care providers (Simplican et al., 2015). The findings of this study indicate that participants perceive their families as their primary support system, expressing their gratitude towards the support they receive from their families. This is supported by the literature which indicates that people with intellectual disability often live with and are cared for by family caregivers (Riches et al., 2022), with their social networks centred around people they depend on and spend most of their time with, such as their families, carers, and friends with similar disabilities (Emerson et al., 2014).

However, the respondents voiced a need for the maturation of their roles within their families, from protected child to young adult, able to engage in income-generating work, to start a family and live in their own homes, or at minimum have their own dedicated space within the family living situation. Spaces able to support these new relationships include supported housing or accommodation (Bigby & Beadle-Brown, 2018), and supported employment (SE) (Banks et al., 2010) for people with intellectual disability. In South Africa, citizens struggle with high levels of unemployment (Kingdon & Knight, 2004) and housing shortages (Mafukidze & Hoosen, 2009), and face many socio-economic challenges to family life and caring for children, thus needs expressed by people with intellectual disability, who are greatly marginalised, are significantly more difficult to realise.

Socialisation and interacting with others improve quality of life and has many benefits, such as improved emotional wellbeing, positive engagement, increased sense of belonging and improved mental health (Friedman & Rizzolo, 2018; Lippold & Burns, 2009; McCausland et al., 2021). Yet none of the respondents in this study spoke about interaction with their friends as

an important aspect of their lives. Research indicates that friendship is a concern for people with intellectual disability as they have limited opportunities to develop and maintain friendships (Callus, 2017; Friedman & Rizzolo, 2018), due to the more restricted social networks within their families or staff members at services they access, with few social networks outside family and staff settings (McCausland et al., 2021). This may be the case for respondents to this study, who have limited opportunity for non-familial relationship-building, as they move primarily between home and work settings, and might also live in disadvantaged neighbourhoods (Cooper et al., 2011) which do not offer opportunity for safe recreational and community interaction.

Obstacles that restrict people with intellectual disability in maintaining friendships include lack of time available to spend with their friends, not having enough money to go out with them, lack of transportation (Fulford & Cobigo, 2018) and a lack of ability to understand how to be a friend and how to look after one's friends, possibly due to poor guidance in how to maintain relationships and lack of experience (Sigstad, 2016).

In this study, respondents reflected on wishing to pursue intimate relationships and starting their own families, This was also found in the scoping review where the review showed that people with intellectual disability have a desire for human connection. However, the literature reveals the complexity of this aspect of the lives of people with intellectual disability, due to their vulnerability to sexual abuse (English et al., 2018). Research indicates that people with intellectual disability are often targets of sexual abuse and it is often difficult to obtain justice because of the mental examination that is taken prior to court proceedings, which makes it difficult for people with intellectual disability to fight for justice (Capri, Abrahams, et al., 2018). Although there is an increase in efforts to assist societies to understand sexual violence and maximise possible responses when faced with such situations in South Africa, people with intellectual disability are exposed to sexual violence and little has been done to protect, care for and support them (Phasha, 2009). The injustices around sexual violence towards people with intellectual disability result from the fact that they are seen as incapable of recalling and communicating the incidence, hence they are not regarded as reliable witnesses to their abuse (Phasha, 2009).

Pasha (2009) further states that the exclusion of people with intellectual disability from campaigns, workshops and awareness that addresses sexual and reproductive health issues impacts on their vulnerability in communities where they are located because they lack understanding of abuse, may be dependent on the abuser in terms of their mobility, and may lack communication skills to tell the abuser to stop or to report the offence. This point is echoed in the scoping review findings which notes the need for reframing policies and programmes to include acknowledging and protecting the sexual rights of people with intellectual disability.

The UNCRPD, Article 23 (UN, 2006), states that people with intellectual disability should exercise similar rights to marriage and relationship as the general population (English et al., 2018; UN, 2006). Just as do the general population, people with intellectual disability have sexual and intimate relational needs, but these needs are often poorly understood (Medina-Rico et al., 2018). Difficulties when forming social and intimate relationships may be caused by inadequate sexual education for people with intellectual disability, which then limits their opportunities to develop social and sexual relationships (Frawley & Wilson, 2016; Medina-Rico et al., 2018). Thus, to enable people with intellectual disability to have healthy relationships, sexual education should be made accessible to people with intellectual disability (Medina-Rico et al., 2018).

Understanding how people with intellectual disability perceive, understand and describe relationships would assist stakeholders in developing strategies and policies that aim to support their relationships, either with their families, carers or partners, to improve their quality of life (English et al., 2018; Fulford & Cobigo, 2018). Current practices and research in sexual education and relationships for people with intellectual disability is still primarily informed by others (Frawley & Wilson, 2016). A step towards achieving increased sexual relationship opportunities for people with intellectual disability includes enabling them to advocate their sexual needs, expressing themselves about the things that are important to them, including talking about their sexuality and types of relationships they would like to have, where they have capacity for this, and with reasonable accommodations to assist with the expression of these needs by helping professions and families (Azzopardi-Lane & Callus, 2015).

It is apparent from the literature that opportunities for sexual education and relationships of people with intellectual disability are often restrained by family, carers, professionals and other supporters' attitudes (Lafferty et al., 2012). People with intellectual disability need to be aware of their rights in relation to intimate relationships and will have to be educated in how to communicate their intimate needs and the kind of relationship they desire (Rushbrooke et al., 2014).

In addition, people with intellectual disability will need to be aware of the potential risks that may accompany intimate relationships (Fulford & Cobigo, 2018). As they are most likely to be at risk of exploitation when in a relationship with people who are more functional, there is a need to be mindful about the issues of choice with regards to who they decide to be with, thus issues of consent should be addressed. Therefore, educating people with intellectual disability on potential risks and safe measures regarding intimate relationships should be a priority in order to create a safe space for them to fully understand potential risks and be able to express themselves (Fulford & Cobigo, 2018).

Increased exposure to other relationships may help people with intellectual disability to learn what relationship involves. This may be provided through increased social interaction, support networks and increased sexual education and interpersonal relationships (Rushbrooke et al., 2014). Education should also include strategies on how to build a relationship and how to deal with conflicts. This will empower people with intellectual disability to make their own choices and decisions within their relationships (Fulford & Cobigo, 2018).

5.2.3 The organisational/institutional level

The organisational/institutional level relates to access to health and social services, employment centres, and education facilities. In this study, this aspect focused on the availability and accessibility of services needed by respondents, in particular health and social services, education, and employment.

The study highlighted the services available to people with intellectual disability and the accessibility of those services. The study findings focus on the inability to access basic education, finding and keeping employment, and access to healthcare without difficulties (Abaerei et al., 2017; Grut et al., 2012; Kakuma et al., 2010; Saloojee et al., 2007).

5.2.3.1 Access to education

The published literature states that people with intellectual disability are often faced with exclusion from educational programmes in mainstream education (Townsend, 2011). This concurs with this study's findings in that respondents reflected on the need for education and their inability to access basic education because of their disability.

Approximately 5% of people with intellectual disability receive any form of education in developing countries (MacQuarrie & Laurin-Bowie, 2014). Respondents in this study expressed their greatest worry with regards to literacy and limited accessibility to education. It is stated in the literature that literacy is crucial in the modern world where everything is modernised and digitalised, thus people with intellectual disability should be accommodated regarding literacy and other skills developmental programmes (Sermier Dessemontet et al., 2019). Some of the challenges that exclude people with intellectual disability in mainstream education is overcrowding in schools, where teachers often lack training in approaches to teaching children with intellectual disability (MacQuarrie & Laurin-Bowie, 2014). People with intellectual disability have limited opportunities for accessing basic education and other educational programmes that may assist them to develop skills (Capri, Abrahams, et al., 2018). Participants concur by sharing that they have limited access to basic education and skills development programmes.

Respondents further reflected on how lack of education and lack of required skills has excluded them from entering the labour market. This finding is similar to previous literature findings which state that the exclusion of people with intellectual disability in mainstream education prevents them from finding employment (Bialik & Mhiri, 2022), this often due to lack of opportunity for getting certificates which are often the prerequisite to secure employment. Employers are reported as considering people with intellectual disability as

poor candidates for employment because they are not in possession of certificates (Bialik & Mhiri, 2022).

Currently, Post-Secondary Education (PSE), which in known as Post-School Education and Training (PSET) in our context, is one of the important educational and employment options for people with intellectual disability who wish to enter the labour market (Alqazlan et al., 2019; McConkey & Haddock, 2012). In this study respondents expressed the importance of having access to skills development and educational programmes to have better options in the labour market. Thus, expanding opportunities within the post-school education system could be an option for people with intellectual disability to acquire required skills.

5.2.3.2 Access to healthcare

The findings of this study highlight the overcrowding in healthcare centres which then impacts on the capacity for service delivery by doctors, nurses and other healthcare professionals. This results in spending lengthy hours in primary healthcare or hospitals when collecting monthly medication or going for monthly check-ups. This is a national issue for the majority of South Africans who access primary healthcare. The findings of this study concur with the existing literature which states that despite attempts that have been made to eliminate overcrowding in primary healthcare to ensure healthcare for all, overcrowding continues to limit accessibility of services (Bahadori et al., 2017; Kautzky et al., 2008).

It was clearly stated in the scoping review that mental health service provision remains a low priority because of the neglect in mental health policies. The literature further reports on the challenges which result in limited primary healthcare service delivery (Coovadia et al., 2009). One of the challenges that acts as a barrier towards adequate healthcare access is time, as people with intellectual disability are reported to be spending lengthy hours waiting to be seen yet spending a short time with healthcare professionals during their appointments (Doherty et al., 2020).

Globally, as in our context, people with intellectual disability are faced with barriers when accessing healthcare services, and these barriers increase health disparities for this population group (B. St. John et al., 2021; B. M. St. John et al., 2018). The inequalities in

healthcare faced by people with intellectual disability are most likely to impact their health and everyday lives, thus limiting their day-to-day participation in, and quality of life (Bollard et al., 2018; B. M. St. John et al., 2018).

The transitioning of people with intellectual disability from institutional care to community-based settings has resulted in a shift in responsibility for their care (Jansen et al., 2004). A local example of the implications of this situation is the Esidimeni Life Care Centre crisis, which took place in 2016, in which the constitutional right to life of people with intellectual disability was violated and neglected by the Gauteng Health Department. In this crisis, 144 people with psychosocial and/or intellectual disability lost their lives after being discharged from a specialist care facility to NGOs who were not able to provide appropriate services to them (Capri, Watermeyer, et al., 2018).

There is a great need to reduce barriers to healthcare access for people with intellectual disability in order to improve their quality of life. Healthcare access for people with intellectual disability has been recognised internationally as a policy priority (Brown et al., 2017). The *South African Health Review* (Kathard et al., 2020) recommends strategies for improving healthcare access for people with disabilities, who experience higher healthcare needs as compared to those without disabilities, and are mostly likely to require disability-related services, however they have poor health experiences (Kuperi & Hanass-Hancock, 2020). The review identifies the most prominent existing barriers faced by people with disabilities. These barriers include, poor accessibility of services and transport, finance-related difficulties, negative attitudes and discrimination, lack of knowledge regarding health and health services, and existing gaps in the availability of disability-specific care (Kuperi & Hanass-Hancock, 2020).

In combating existing barriers towards healthcare access by people with disabilities, the SAHR (Kathard et al., 2020) recommends strong leadership for the implementation of existing strategies by encouraging the distribution of funds and resources to disability and rehabilitation services within the National Department of Health (NDoH) and relevant stakeholders and collaborators; healthcare workers must be trained in order to understand the complexities and uniqueness of disabilities so that they will able to respond effectively to

the needs of people with disabilities; healthcare facilities must meet a certain standard to accommodate and allow accessibility; and more data are required on the health status and quality of healthcare of people with disabilities in South Africa (Kuperi & Hanass-Hancock, 2020). Since these recommendations are mostly focused on physical disabilities and other impairments, stakeholders and collaborators within the field of intellectual disability will have to expand on these recommendations to ensure that the needs of people with intellectual disability are included and prioritised when implementation takes place.

The international literature recommends collaborative work to meet the future health needs of people with intellectual disability (Brown et al., 2017), such as aiming at developing new ways of educating professionals working with people with intellectual disability in order to eliminate existing barriers (Brown et al., 2017).

5.2.3.3 Employment access

The published literature emphasises employment disparities resulting from stigma attached to intellectual disability (Soeker, 2020), this hindering the recruitment of people with intellectual disability and their mistreatment in the workplace (Ditchman et al., 2013). Capri, Abrahams, et al. (2018) state that people with intellectual disability often struggle to find work placements on their own because of the myths surrounding their disability. People with disabilities have been labelled worldwide as individuals who are not willing to work or who are unemployable, which limits their chances of being employed (Majola & Dhunpath, 2016). As found in both the scoping review and interviews, people with intellectual disability are often at a disadvantage when attempting to enter the work force. In this study, respondents stated that they seldom find employment because of their disability and are not granted opportunities to at least prove their abilities and capabilities, with the myths and beliefs attached to their disability inhibiting their possibilities for employment.

The literature further reports that high job requirements and lack of skills training limits and excludes people with intellectual disability from entering the labour market (Bialik & Mhiri, 2022; Kocman et al., 2018; Soeker, 2020; Viljoen, 2018). This aligns with the findings of this study where respondents noted that they are often excluded from entering the labour market because they lack required skills and because of high job requirements.

Article 27 (1) of UNCRPD (UN, 2006) states that a person with disability is entitled to enter the labour market and work environment that is open and inclusive for people with disabilities. However, people with intellectual disability are reported as continuing to encounter barriers that hinder them from exercising their fundamental right to employment (Heymann et al., 2021; Trembath et al., 2010). These barriers include internal and external barriers (Shier et al., 2009). Trembath et al. (2010) highlighted internal barriers, which include low levels of literacy and numeracy skills, with which participants in this study concur. Other barriers that were found in the scoping review includes negative attitudes, and insufficient governmental activities to enhance the employability of people with intellectual disability.

Trembath et al. (2010) further highlighted external barriers which include discrimination and stigmatisation attached to intellectual disability, which then excludes people with intellectual disability from successful employment. Thus, necessary measures, such as Supported Employment (SE) and job coaching, should be put in place to improve the employability of people with intellectual disability. In South Africa, the need for an effective employment strategy is evident to support people with disabilities who are faced with barriers, as well as competing with the general population who is also unemployed (Engelbrecht et al., 2017).

Engelbrecht et al. (2017) further stated that SE has shown to be effective and has produced positive employment outcomes for people with disabilities. However, in our context, the development of this strategy has been limited due to financial factors (Engelbrecht et al., 2017). Amongst other barriers that have been identified as hindering the implementation of SE in the South African context is the employment of job coaches in the NGO sector. On moving from NGO-based training to employment, the NGO sector often ceases SE, thus ongoing SE depends on the employer's willingness to pay the job coaches (Van Niekerk et al., 2011).

These examples provide impetus to work toward a broader national strategy for inclusion of people with disabilities in the economy. Respondents to the study concur with this, in that they identified the need for greater governmental involvement in improving the pipeline from education to employment in their recommendation that people with intellectual disability

should be explicitly included in national initiatives for education, vocational training, job creation and employment for people with intellectual disability. Such initiatives may l lessen the economic and social impact of unemployment and provide people with disabilities an opportunity to play a positive role in their societies and influence their health and wellbeing (Van Niekerk et al., 2011). Further, with the employment of people with disabilities, the cost associated with disability grants will be alleviated and people with disabilities might make contributions as tax-payers (Van Niekerk et al., 2011).

Parmenter reports on two SE projects in South Africa and one in Zambia for people with intellectual disability (T. Parmenter, 2011). The SE project, run by The Living Link in Gauteng Province in South Africa, supports the integration of people with intellectual disability into the community and assists them with transitioning from school to independent living and work. They offer a variety of services, such as job market screening, job site observation, job sampling, job-related training and placement, and training for employer and employees. The Ntiro project for Supported and Inclusive Employment, in Tshwane District of Gauteng Province in South Africa, addresses the obstacles that persons with intellectual disabilities experience and strives to build integrated community-based support, concentrating on supplying district officials, NGOs, and community organizations with knowledge and skills. The SE project in Zambia was primarily concerned with comparing the advantages of the SE model in small businesses, the self-employed, and the formal and informal sectors. However, this project was completed in 2005, and more than 100 graduates had jobs in the formal or informal sector (T. Parmenter, 2011).

The Living Link in Gauteng Province, South Africa, is still operating and recently partnered with Sasol Energy Business to assist in integrating their graduates into the open labour market (Sasol, 2021). The Living Link is a development organisation offering an adult integration and workplace readiness programme that enables students to find employment placements in the open labour market upon completion of the programme, through the implementation of the Supported Employment Model.

Health and Welfare Sector Education and Training Authority (HWSETA) has partnered with Pietermaritzburg Mental Health (PMBMH) Society in the KwaZulu-Natal province. PMBMH

Society is an NGO providing services to persons living with mental disabilities. HWSETA partnered with PMBMH Society for a mental health awareness project in which learners with mental health disabilities are placed with employers for on-the-job training, within a working environment that can accommodate their disabilities, for a period of 12 to 18 months. During this period learners receive work skills training while preparing for employment (HWSETA, n.d.).

Cape Mental Health (CMH) in the Western Cape Province provides Training Workshop Unlimited (TWU) which is a life and work skills training and development project for people with intellectual disability that aims to ensure that persons with intellectual disability have equitable access to life-long learning, training and capacity-building and can fully participate equally in the mainstream economy. Their programmes include Eagles programme, Life Skills Programme, Work Skills Programme, Skills Development and Learnerships, Siyakwazi Integration Company project, Garden Pot Centre and Supported Employment programme (Cape Mental Health [CMH], 2022).

There is a need for programmes such as these to be supported and established across the country and continent as a whole, as they enable social inclusion and participation, introducing learning strategies and techniques that will enable people with intellectual disability to be employable. This further calls for funding and collaboration among private and public sectors.

This study revealed a dearth of research exploring the relationship between protective workshops and the open labour market, and clear strategies to narrow the gap between these two sectors. Future research is needed to inform government and other stakeholders regarding partnerships between protective workshops and other public funded skills training initiatives and the private sector, to enhance the employability of people with intellectual disability.

With that being said, government should consider offering skills development programmes for people with intellectual disability through NPOs or through skills development centres or government institutions (Van Niekerk et al., 2011). Skills development programmes might be

financed through a levy-grant scheme and National Skills Fund (NSF), as stipulate by the Skills Development Act No. 97 of 1998 (Republic of South Africa, 1998b). As noted by respondents to this study, these training programmes should not be considered as the ceiling for employment opportunities for people with intellectual disability but should strive to prepare them for the open labour market in cooperation with the private sector.

The government has set targets for the inclusion of people with disabilities in the open labour market, but the strong emphasis is on appointing people with physical disabilities, with little emphasis as yet on the inclusion of persons with intellectual disability, besides the training and coaching programmes of prominent NGOs in the mental health and intellectual disability sector in South Africa.

5.2.4 Community level

This level is concerned with the availability of support structures within the community which are aimed at improving the quality of life of people with intellectual disability. These support structures could be advocacy groups, developmental groups, skills training programmes and protective workshops that do not only provide rehabilitation for people with intellectual disability but also enable them to acquire skills that may enhance their abilities and capabilities, offer emotional support, improve confidence, and facilitate a sense of belonging.

Community learning centres and protective workshops seek to provide social support, skills training and knowledge (Viljoen, 2018), and independence (Gajewska & Trigg, 2016). These workshops provide people with intellectual disability an opportunity for psychological and personal growth. Respondents in this study reported either the unavailability and inaccessibility of these services or that their experience was that existing workshops have limited skills development programmes, which fail to focus on their goal of generating a living income beyond the low stipend they earn at such centres, or through being able to gain the skills to seek open labour employment .

Gajewska and Trigg (2016), writing in a high-income context, concur with some of the results presented in this study, which highlights the importance of attending life skills training centres and protective workshops to enhance psychological wellbeing and offer a sense of belonging,

as well as offering an additional context within which to enhance opportunities to form enjoyable relationships, and thus improve self-esteem.

In the South African context, however, where there are high levels of poverty and unemployment (Altman et al., 2014; Chibba & Luiz, 2011), and a limited social security system given the need of the population (Altman et al., 2014), respondents to this study also want opportunities outside of the NGO sector. They reported wanting to go beyond protective workshops to enter training opportunities and job experiences within the wider world, as other people do, and to become part of mainstream society, thus echoing many of the needs expressed by the majority of South African citizens, for government policy – which is world class – to move from the stated ideal to implementation on the ground, a goal the country is struggling to achieve 25 years into democracy.

The existing literature states that training increases employment possibilities for people with intellectual disability, as compared to sheltered work (Nevala et al., 2019). However, there have been poor developments with regards to coordinating an education and skills development framework to assist in the transitioning from protective workshops to the open labour market. The current education and training opportunities are almost exclusively for typically developed people.

With regard to housing, respondents reported living with their parents and having limited living options, whereas they wished to have flexible living options as they need their personal space. Respondents further expressed their housing need and how not having their own home impacts negatively on their forming and maintaining interpersonal relationships, that is, intimate partners and their own families. Housing is one of the fundamental basic rights that everyone should enjoy without discrimination or exclusion (Chenwi, 2021; Nokulunga et al., 2018), and people with disabilities are amongst the disadvantaged population group that often experiences challenges in accessing their right to housing (Chenwi, 2021). These challenges include not having accommodation flexibility because they rely on their carer's, friends and families to support them in managing their day-to-day activities (Shaw et al., 2011)

Due to the vulnerability of people with intellectual disability, and thus their inability to live independently, family carers housing should be considered for this population. This is informed by the finding of the current study that most respondents reported staying with their families who serve as their primary carers, and concurs with international literature (McConkey et al., 2004).

However, not all people with intellectual disability can live at home with their family carers due to complexities of health, mental health and behavioural difficulties that make it difficult for them to live in the open community. These individuals are still resident in psychiatric hospitals and other mental health institutions, rather than in less restrictive community-based living. Fit for purpose accommodation options should be available to this population within the open community, as set out in the *Department of Human Settlements: Revised: Strategic Plan 2015-2020* (Republic of South Africa, 2015). The South African Human Rights Commission's (SAHRC, 2015) brief states that individuals with special needs who cannot live independently due to their vulnerabilities require group care homes that are primarily provided by registered NPOs, including foster care homes and residential care facilities. However, at the time of writing, these facilities are sparsely available and the development of community-based accommodation needs attention, as well as housing options for families with relatives with intellectual disability, or people with intellectual disability themselves, with support, to be eligible for access to special housing initiatives (SAHRC, 2015).

Socio-historical injustices rooted in the Apartheid era impacted housing provision for the majority of the South African population, as the Apartheid government did not prioritise housing provision for Black South African citizens (Chenwi, 2021; Lorraine & Molapo, 2014). The African National Congress (ANC) post-Apartheid government and stakeholders have been addressing housing issues and put forward initiatives such as the Reconstruction and Development Programme (RDP) to resolve imbalances and injustices occurring during Apartheid (Lorraine & Molapo, 2014; Nokulunga et al., 2018). The inclusion of housing as a priority focus of the RDP was intended as one of a range of initiatives aimed at addressing the socio-economic challenges caused by Apartheid through ensuring housing provision for the previously excluded population (Gunter & Manuel, 2020), with this programme becoming commonly known as "RDP houses".

Respondents reported their wish to be offered RDP houses by the government as they cannot afford to purchase houses for themselves. Despite the RDP housing initiative, a large proportion of the South African population is still faced with inadequate, poor housing with the rapid spread of informal settlements (Bradlow et al., 2011; Gunter & Manuel, 2020).

Deinstitutionalisation of people with intellectual disability is not restricted to community inclusion or community living, but includes their right to housing choice (Wiesel & Fincher, 2009). Notwithstanding that people with intellectual disability may require additional support from their carer's and families, access to suitable state housing may enhance their independence, autonomy and decision-making opportunities (Björnsdóttir et al., 2014).

5.2.5 Socio-political level

The public policy level comprises laws, policy, legal enforcement, and legislation. This section focuses on social and health-related policies that aim at improving human welfare and opportunities for social relations at all levels of society thus promoting the health and social wellbeing of all citizens (Njor et al., 2019). In addition, this section will echo the areas identified in the levels above as policy priorities of people with intellectual disability in this study.

Internationally, the United Nations Convention on the Rights of Persons with Disabilities (CRPD) (UN, 2006) is a human rights convention which sets out the fundamental human rights of persons with disabilities. As stated in Article 1, its purpose is to "promote, protect and ensure the full and equal enjoyment of all human rights and fundamental freedoms by all persons with disabilities, and to promote respect for their inherent dignity" (UN, 2006).

Nationally, the government, civil society, and the corporate sector are, according to the White Paper on the Rights of Persons with Disabilities (WPRPD) (Republic of South Africa, 2016), expected to collaborate in order to ensure the socio-economic inclusion of people with disabilities. The WPRPD states that "Persons with disabilities must be accorded equitable social rights as all other people in society because the provision of these rights enables full participation in the life of society. It includes the right to education, healthcare, housing,

transport, sport, recreation, culture, social development services, food security and family life" (Republic of South Africa, 2016, p. 46, section 2.3 Social Rights).

As can be gleaned from the discussion above, in South Africa, policies and legislation regarding disability do not guarantee a satisfying life for people living with intellectual disability since these policies have not been thoroughly implemented. Policy-making and the promulgation of legislation should involve people with disabilities at all levels to ensure manifest and accurate service provision for people with disabilities (WHO, 2011).

Therefore, more data are required on the needs of people with disabilities, including data on intellectual disability, for policy development and implementation, as evidence to support advocacy and self-advocacy, ensuring that policy makers urgently prioritise the needs of people with disabilities within their implementation priorities (WHO, 2011).

With respect to health and policies that safeguard this right, the United Nation Convention on the Rights of People with Disabilities (UNCRPD), Article 25 on health, states that "states parties recognize that persons with disabilities have the right to the enjoyment of the highest attainable standard of health without discrimination on the basis of disability" (UN, 2006). The UNCRPD further states that "parties shall take all appropriate measures to ensure access for persons with disabilities to health services that are gender-sensitive, including health-related rehabilitation" (UN, 2006).

Nationally, the health needs of people with intellectual disability are acknowledged within the Department of Health and by Section 27 of the Constitution of South Africa (Republic of South Africa, 1996), which guarantees the right to access equal healthcare for all citizens, but this population group is faced with inequalities, remain vulnerable and experience health problems which then result into poor accessibility of healthcare-related services (Abaerei et al., 2017; Ruddick, 2005; Vergunst et al., 2017).

Mental health services for people living with intellectual disability remain a low priority as compared to other national problems in South Africa, with the Esidimeni tragedy serving as a

stark reminder that mental health services are underfunded and under-resourced (McKenzie et al., 2019).

With regard to education, access to education is a fundamental right that is supported by both international and national legislations. Internationally, the Convention on the Right of Persons with Disabilities affords all persons with disabilities the right to education. Article 24 of the CRPD recognises the right of persons with disabilities to education without discrimination and on the basis of equal opportunity, and parties should ensure inclusive education systems at all levels (UN, 2006).

Nationally, Section 29(1) of the South African Constitution (Republic of South Africa, 1996) affirms the right to basic education, including adult basic education for everyone, including children and adults with disabilities. The Constitution further accords that the state must make reasonable measures to make further education progressively available and accessible. Although the right to education is the constitutional right of both adults and children, it is often denied people with intellectual disability (Boezaart, 2012).

Internationally, the United Nations Convention on the Rights of Persons with Disabilities, Article 27, affirms the right to open access and inclusive and accessible workplaces for people with intellectual disability (UN, 2006). However, this is not the case for people with intellectual disability as they are often faced with challenges that hinder their securing employment, these challenges including lack of required skills, low level of education and lack of experiences (Bialik & Mhiri, 2022).

Nationally, the South African Constitution's Bill of Rights (Republic of South Africa, 1996), the Employment Equity Act, No. 55 of 1998 (Republic of South Africa, 1998a), as well as the Promotion of Equality and Prevention of Unfair Discrimination Act 4 of 2000 (Republic of South Africa, 2000) are some of the legislations that safeguard the right of people with mental disabilities to gain access to employment without discrimination and exclusion because of their disability. The Employment Equity Act, No. 55 of 1998 (Republic of South Africa, 1998a), protects people with disabilities against unfair discrimination by promoting equal opportunities and fair treatment. In addition, the purpose of the Act is to provide equity in

the working place by being proactive in addressing the employment disadvantages experienced by specific group so that they are fairly represented in all occupations and at all levels of the workforce. Nevertheless, Statistics South Africa (Stats SA) (2014) reports that there is a low labour market absorption of people with disabilities as compared to people without disabilities.

With regard to housing, the United Nations Convention on the Rights of Persons with Disabilities (UN, 2006) states that person with disabilities have the opportunity to choose their place of residence and have access to a range of in-home, residential and other community-support services (Article 19). Section 26 of the Constitution of the Republic of South Africa (Republic of South Africa, 1996) mandates that everyone has the right to access to adequate housing, and the state must take reasonable legislative and other measures, within its available resources, to achieve the progressive realisation of this right.

In addition, the Housing Act 107 of 1997 (Republic of South Africa, 1997) states that all spheres of government, national, provincial and local governments, must work together towards housing development and the financing of national housing programmes. South Africa, therefore, has both international treaties and national legislation that affirm the right to adequate housing. However, a large proportion of the South African population, including people with disabilities, is still faced with barriers that hinder their enjoyment of this right, (Chenwi, 2021).

Chapter Six

Implications of the Study

6.1 Reasonable Accommodation in Education, Employment and Healthcare Access

The findings of this study call for addressing inadequate education, healthcare access and employment provision for people with intellectual disability by putting in place reasonable measures to ensure that people with intellectual disability enjoy their fundamental rights. Reasonable accommodations are measures that are put in place either at individual or organisational level to combat existing inequalities experienced by people (Moloney et al., 2021), and must be aimed at overcoming unsatisfactory experiences regarding access to education, employment and receiving care. What is required is the provision of equal opportunities, as well as the development of strategies and interventions that best align with the capabilities of people with intellectual disability.

It is evident from this study that existing reasonable accommodations require further development to fully accommodate the policy needs identified by people with disabilities. Government and related stakeholders need to adapt strategies for people with intellectual disability to enable them access to education. The National Department of Education committed to providing learning opportunities for adults with no formal schooling by utilising Adult Basic Education and Training (ABET, n.d.), which is the reasonable measure that aims to facilitate further education and training (FET) and employment. However, this does involve alternative learning techniques and strategies for adults with disabilities whose capacity to read and write is limited.

In 2018, the Minister of Higher Education and Training, Dr B. E. Nzimande, argued that the Strategic Policy Framework on Disability for the Post-School Education and Training (PSET) system aims to achieve accessibility of PSET by people with disabilities, as most Technical and Vocational Education Training (TVET) colleges do not have the capacity and policies to support the needs of people/students with disabilities (Department of Higher Education and Training [DHET], 2018.

Nonetheless, there are no courses of this nature for people with intellectual disability at post-school educational facilities. Thus, government, related stakeholders and service providers need to extend opportunities for post-school education and training for people with intellectual disability whose capacity to read and write is limited. As indicated earlier, internationally, post-school education has been associated with improving education, skills development and employment of people with intellectual disability (Alqazlan et al., 2019; McConkey & Haddock, 2012). To date there is no formal policy in South Africa that aims to address the inclusion of people with intellectual disability in these fields.

Additionally, it was reported in the findings of this study both the scoping review and interviews that people with intellectual disability often find it challenging to secure employment because of high employment requirements and lack of skills training. Thus, reasonable accommodations must be put in place to ensure that people with intellectual disability are employable. Employment accommodation includes adaptations and adjustments that will make a workplace and job more convenient to the capacity and the needs of people with intellectual disability. Secondary school, job coaching, post-school education, career guidance and SE have been associated with employment increase in the labour market among people with intellectual disability (C. B. Gilson & Carter, 2016; Nevala et al., 2019). Thus, government stakeholders should expand and implement these strategies within government educational centres or within NGOs who serve as primary service providers for this population group.

In healthcare settings, reasonable accommodation involves strategies adapted by service providers, such as healthcare providers and practitioners, to ensure that people with intellectual disability receive an equivalent level of care as those without disabilities (Wilson et al., 2022). Lack of reasonable accommodation in healthcare has been identified as a barrier towards accessing healthcare by people with intellectual disability and their carers (Navas et al., 2019). Therefore, reasonable accommodations that best align with the needs of people with intellectual disability should be implemented, especially in primary healthcare where the needs of this population are least likely to be supported.

6.2 Inform Policy Development and Policy Implications

As stated in the scoping review, here are existing gaps in policy and service provision for people with intellectual disability (Townsend, 2011). Poor policy development could be rooted in poor empirical research that aims to describe and identify individuals with unmet needs (Burke & Heller, 2017). Thus, a change is required both in research and practice to improve the service delivery system for people with intellectual disability across the life span. More research identifying areas of difficulty faced by people with intellectual disability is needed to inform policy developments and provide evidence-based interventions (Townsend, 2011).

Partnership with a range of stakeholders in the field of intellectual disability, including people with intellectual disability, may influence and provide policy makers with evidence-based strategies (Townsend, 2011). In the South African context, more research evidence is needed elucidating life challenges, lived experiences, community participation and inclusion, personal interests and other concerns that impact on the functioning and overall wellbeing of people with intellectual disability.

Therefore, the findings of this study support a call for informing policy development and practice in relation to services available to people with intellectual disability. Results of this study show a lack in policy implementation and service provision for people with intellectual disability. Thus, this study intends to inform an understanding of best practice and fair service provision and provide policy makers and government with first-hand experiences of people with intellectual disability, which might then assist in policy development, resource allocation and service provision.

6.3 Proposed Organisational Change

Globally, services for people with intellectual disability are now provided at community level, since deinstitutionalisation, or the shift towards community-based settings and integration of mental health services at a primary healthcare level (Fakhoury & Priebe, 2002; Mavundla et al., 2009). Nonetheless, many countries experience different problems rooted in poor funding, and political and other socio-economic factors (Fakhoury & Priebe, 2002), thus

primary healthcare continues to be overloaded with limited specialised community mental health services.

In South Africa, in spite of existing policies, service provision for people with intellectual disability has low priority, with services primarily located in urban areas and, in most cases, offered by NGOs, and families being the main providers of care (Adnams, 2010; Mavundla et al., 2009; Meer & Combrinck, 2017).

People with intellectual disability are more likely to be affected by organisation policies, as NGOs have been the primary service providers for people with intellectual disability, with skills development programmes, workshops and job readiness and guidance (Samadi, 2008), and have played a role in providing community-based disability services. Furthermore, NGOs have been ensuring the welfare of, and giving proper support and assistance to, people with disabilities and their families (Rasi & Ashifa, 2020). Therefore, any positive change in these organisations may change the lives of people with intellectual disability, be it offering activities that best suit the needs, interests and concerns of people with intellectual disability.

Hence, this study calls for organisational change to ensure that services offered at NGO level support the wellbeing and enhance the livelihood of people with intellectual disability within their communities. These services should incorporate the interests of people with intellectual disability, such as work-related, educational and skills development opportunities, and/or healthcare-related services that aim to improve the livelihood of people with intellectual disability, especially within their immediate environment.

Currently, the primary focus of specialised care, support and services for people with intellectual disability is to assist them in overcoming their limitations and the effect of their disability, in order to help them experience the quality of life afforded the general population (Mansell & Beadle-Brown, 2012). Thus, organisations offering support and care for people with intellectual disability should align with their interests.

6.4 Inclusive Policies

LMIC may benefit from having an overarching "Disability Discrimination Act" which aims at protecting the rights of people with disabilities. This would in turn promote, even enforce, inclusive policies that support the needs of people with intellectual disability by including their needs for access to opportunities such as housing, education, social support, health access and employment (Bhaumik et al., 2016), as detailed in by the findings of this study.

Social inclusion of people with intellectual disability may offer benefits (Simplican et al., 2015), such as community participation and meaningful contact with other people (Overmars-Marx et al., 2014). For people with intellectual disability, their exclusion is characterised by their absence in the labour market, education, community participation, limited socialisation, dependence on their carer's and few meaningful relationships (Overmars-Marx et al., 2014).

Consequently, inclusive policies will provide people with intellectual disability with similar opportunities as afforded the general population. Therefore, findings from this study can motivate for inclusive policy developments. This will assist in eliminating barriers, mentioned below, that often prevent people with intellectual disability from exercising their fundamental rights.

Social exclusion of people with intellectual disability is still a recognised social barrier (Raub et al., 2016). People with intellectual disability have been regarded as incapable, thus they have been excluded from societal roles (Kakuma et al., 2010), denied social participation, and institutionalised (Davidson, 2015). Their exclusion from general society has perpetuated beliefs about their incapacity due to limited interaction of people with intellectual disability with the general population (Davidson, 2015). Therefore, direct participation may alter stigmatising attitudes towards people with intellectual disability by dispelling the myth around their capabilities.

6.5 Eliminating Barriers: Political, Social and Health Barriers

The United Nations Convention on the Rights of Persons with Disabilities (UNCRPD) (UN, 2006) is an international human rights instrument that is aimed at protecting, promoting and ensuring the equal enjoyment of all human rights. Nonetheless, it is apparent from the

literature that people with disabilities are faced with barriers that limit the full enjoyment of their fundamental rights and participation. Thus, the findings of this study support a call for the elimination of social, health and political barriers which limit the participation of people with intellectual disability. Elimination of these barriers should be a great concern for policy makers and service providers. This should involve the adaptation of strategies that promote inclusion, and facilitate communication and cooperation among stakeholders, service providers, service users and policy makers.

In addition to barriers that hinder health, social, education and employment access and participation, policy makers need to identify disparities and ensure equal accessibility of services required by people with intellectual disability to enjoy and live a meaningful life (Burke & Heller, 2017).

In relation to education access, government sectors, stakeholders and service providers working with people with intellectual disability need to ensure that there is intersectoral and interdisciplinary collaborating to ensure that reasonable measures pertaining to the education and training needs of people with intellectual disability are in place and included in structures such as ABET and PSET. The intersectoral and interdisciplinary collaboration should aim at informing policy development and practice, providing learning strategies for people with intellectual disability whose capacity to read and write is limited, and ensuring the accessibility of their fundamental rights.

With regards to access to employment, government stakeholders and other service providers should adapt employment strategies to enable people with intellectual disability to be employable. As indicated earlier, these strategies may include SE and vocational training to enable people with intellectual disability in particular to enter the labour market. The findings of this study demonstrate how people with intellectual disability wish to develop skills needed for successful job-seeking. However, existing barriers show how people with intellectual disability have been discriminated against by practices, policy setting and services to develop needed skills, and by the discriminatory culture and attitudes within the workplace which impacts negatively on the capacity of people with intellectual disability to maintain their work (Meltzer et al., 2020).

With regards to healthcare access, as detailed earlier, related stakeholders and National Department of Health need to fund and prioritise the needs of people with disabilities, especially people with intellectual disability, within NGOs, communities and psychiatric facilities. The findings of this study demonstrate the need for improved infrastructure, elimination of lengthy hours in primary healthcare and improved healthcare provision. Thus, to improve access to a quality healthcare system, reasonable adjustments, such as providing appointment slots, should be introduced into the healthcare system (Ali et al., 2013).

6.6 Study Limitations

This qualitative study aimed at capturing the policy priorities of a small sample of respondents. Only six respondents participated in this study and a larger group might have produced more detailed insights into the phenomenon under investigation. A second limitation was related to Covid-19 restrictions which limited the sourcing and approaching of organisations. Participants who participated in this study were sourced from one organisation which was willing to accommodate the online process of interviews and other study activities.

The third limitation was the substitution, or change, in methodology to comply with Covid-19 rules and regulations. The researcher had initially planned to collect data using photovoice "picture capturing using instant cameras," however this was eventually substituted with "picture-cutting," as lockdown restrictions did not allow the researcher to physically interact with participants, as outside activities and gatherings were restricted at the time of data collection.

6.7 Original contributions of the thesis

Despite the limitations noted above, the thesis makes an original contribution to insights into the perspectives of people with intellectual disability which can inform future inclusive South African social and health policy and service development for people with intellectual disability. This research has also shown that reasonable accommodations and adaptation of research methods can support people with intellectual disability to fully communicate their lived experiences and interests.

6.8 Recommendations for Future Research

This study has attested to the feasibility of collecting the first-hand experiences and views of people with intellectual disability in a South African context, as has been found in previous studies of this nature (Giesbers et al., 2019; Kahonde & Johns, 2022; van Alphen et al., 2009). However, this study revealed a dearth in studies focusing on the views and policy priorities of people with intellectual disability (Robinson et al., 2022).

The study encourages further research directly involving people with intellectual disability to document their views on what is needed from policy makers, policy implementers and service providers to ensure that their constitutional right to be included in actions to support the health and wellbeing of all citizens comes to fruition. Findings of such studies might also be beneficial to service providers and stakeholders that are involved in providing for people with intellectual disability and advocating for their rights to a decent life.

Future research needs to elaborate on the findings of this study, conducting similar research in different contexts, such as rural or underprivileged settings. This will also enable service providers from that context to get detailed and first-hand experience of service users' needs. In different contexts, service users' perspectives may differ from those found in this study. This could highlight ways to support service users in urban areas and those in rural settings.

In addition, inclusion of people with intellectual disability in research will enable stakeholders to reflect upon how future developments may be inclusive and enable opportunities to those that have been excluded. The inclusion of this population in research may also help service providers, health professionals, carers and family with better understanding, awareness and knowledge about people with intellectual disability, and enhance collaboration and reduce barriers (Townsend, 2011).

Policy development and implementation requires teamwork from different stakeholders and service providers. Thus, service providers at the local level need to engage with people with intellectual disability to capture their first-hand experiences. This will enable collaboration between service users and service providers, which will then enhance service provision.

The lack of intersectoral and interdisciplinary collaboration has resulted in poor policy development and poor service provision for this population (McGilloway et al., 2020; Whittle et al., 2019). Therefore, involvement of different stakeholders in research can foster improved partnership amongst governmental agencies, possibly promoting increasing the services available to people with intellectual disability at both primary and tertiary level.

With regards to interpersonal relationships, to better understand the qualities of friendships that people with intellectual disability want, and to understand what friendships mean to them, more research is needed to address these issues (Sigstad, 2016) and the barriers they face when forming and maintaining relationships. More research is needed on the strategies to better support the interpersonal relationships of people with intellectual disability (Fulford & Cobigo, 2018).

For improved healthcare provision for people with intellectual disability, there is a need for evidenced-based research on healthcare needs for this population. In addition, to further develop an inclusive society that supports the health needs of people with intellectual disability, developments are required in special health education and adequate health management (Van Schrojenstein Lantman-de Valk, 2009).

Since there has been limited research on exploring whether protective workshops or centres meet the aims and needs of service users (Gajewska & Trigg, 2016; Nevala et al., 2019), future research should look at the relationship between protective workshops and the open labour market, and elaborate on the strategies that aim to bridge the gap between these sectors to ensure that people with intellectual disability are able to enter the open labour market through services and support from workshops.

6.9 Conclusion

South Africa has disability policies and legislation in place. However, their implementation is ineffective. Governmental sectors and stakeholders still lack intersectoral and

interdisciplinary collaboration in relation to ensuring that the needs of people with intellectual and developmental disabilities are supported. This has resulted in partial or underfunded service provision. Thus, attention needs to be given to intersectoral collaboration of the departments of Education, Welfare, Labour, Health and other stakeholders that are involved in service provision of people with disabilities.

In addition, research documenting the voices of people with intellectual disability needs to include adaptations of data collection methods to optimise participants' opportunities to share their views on what they need. Similarly, public policy makers and implementers should consider reasonable accommodations to enhance the involvement of people with intellectual disability in discussions and decisions about policy and practice which impact on their lives.

With adaptations undertaken in this study to enable people with intellectual disability to communicate their needs and policy priorities, this study is envisaged as providing information to inform the work of numerous role players, such as government officials, researchers, advocacy groups, family members, people with intellectual disability, service providers and policy makers or implementers. Therefore, it is of importance that these structures collaborate for better service provision.

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Appendices

Appendix 1: Information sheet

My name is Siphesihle Thembeka Zihlazi	I am a research student at UCT	My research is about what adults with intellectual disability think government should include in their policies to support the health and wellbeing of people with intellectual disability.

What is self-advocacy?

Speaking for yourself by:

- Knowing yourself
- Communicating your needs
- Knowing your rights
- Knowing what you need
- Learning how to get it

What is research?

- Research means studying things to answer questions you have about them.

Why does the researcher want to do this research?

- The researcher want to know what you feel you need to live a healthy and happy life.

- The researcher want to know which of these needs are met and which still need to be met.
- The researcher want to know what services and supports you think government could provide to help you and others with disabilities live a healthy and happy life.

How will the researcher collect the information?

- You will have to cut out pictures of the things you need and feel are important to live a healthy and happy life, from old newspapers or magazines.
- The pictures can include things you already have, and things you still need to be happy and healthy.
- The researcher will ask you to send me copies of your pictures via email or any other preferable methods.
- After sending me your chosen pictures, we will arrange to meet for about an hour on Zoom to discuss your pictures.
- The researcher will ask you to choose the pictures that you feel are most important for government to assist people with intellectual disability to meet their needs.
- The researcher will ask you which of these needs can be supported by government in the policies they write to support the lives of citizens like yourself.
- The researcher will then record and take notes of your ideas, views and needs (with your permission of course)
- The researcher will ask you to join others who have also participated in the study at the meeting called a "focus group" to ensure that she has understood your views correctly.

How will this affect you?

- The researcher will use your ideas to write up my research report.
- Your name will not be mentioned, so your participation will be kept confidential. But the researcher will give you copies of your pictures and ideas to remember your participation or to share your ideas with others.

For more information contact me on 0671453885 or email me on zhlsip001@myuct.ac.za or my research supervisor Prof. Sharon Kleintjes (+27 72 0568990 or email her on sr.kleintjes@uct.ac.za). Department of Psychiatry and Mental Health. University of Cape Town, Private Bag Rondebosch, 7700.

Appendix 2 (a): Informed consent for participating in the data capturing

INFORMED CONSENT FORM FOR RESEACH PARTICIPANTS

Research study about social and health-related policy priorities of adults with intellectual disability in South Africa (for degree purposes)

Purpose of the study: This research is about what adults with intellectual disability think government should include in their policies to support the health and wellbeing of people with intellectual disability.

How will you take part in the research?

If you decide to be part of this research study:

1. The researcher will have a meeting with you to explain the research to you, why you will be cutting pictures and what we will do with the pictures.
2. You will cut out pictures of the things that you need and feel like are important to you to live a heathy and happy life.
3. Pictures can include things you already have, and things you feel like you still need to be happy and healthy.
4. The researcher will set an online meeting with you; this meeting will take for about an hour and we will discuss your pictures during this meeting.
5. We will meet as planned to discuss your pictures and the researcher will ask you to choose most important pictures with your needs that you think government should include in their policies to support the lives of citizens like yourself.
6. The researcher will attach these pictures in the booklets, and take notes and record your ideas.
7. The researcher will ask you to join others who have also participated in the study at the meeting called a focus group on Zoom.
8. The researcher will give you a verbal feedback/summary using PowerPoint presentation slides with your ideas and also check with you if she has understood and captured everyone's ideas about needs in policies correctly.

Will your participation in the research study be kept confidential or private?

Yes, after interviews and focus group discussion the researcher will keep your booklets, audio recordings and notes in a safe place. The audio recordings will be kept on the password-protected computer where only the researcher, transcribers and research supervisors will have access to these recordings. However, for focus group discussion confidentiality is not guaranteed.

What will happen to the results?

Once the researcher have discussed this with you and others in the focus group, she will write this up in a report to the University of Cape Town, called a thesis, as well as in shorter reports called articles to share our findings with other researchers.

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

There are no personal benefits to taking part in this study, but you may enjoy sharing your views on your life and what you think can help the lives of citizens like yourself.

What are the possible disadvantages of taking part?

The researcher does not think there will be any disadvantages to 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 me. You do not have to share what you do not feel comfortable sharing as there are no right and wrong answers.

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

You do not have to take part in the research if you do not want to do so, it's your own choice. If you do agree to take part but choose later that you do not want too anymore that will be fine. Refusing to take part in the study will not affect your position with me or anyone else.

What if you have a question?

If you have any questions, you or a person of your choice can contact me at:

Siphesihle Zihlazi	zhlsip001@myuct.ac.za	0671453885/0723527766

or my supervisor Prof. Sharon Kleintjes (+27 056 8990 sr.kleintjes@uct.ac.za), Department of Psychiatry and Mental Health, University of Cape Town, Groote Schuur Hospital, Observatory, 7925. 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. Marc Blockman, Chair: Research Ethics Committee, Faculty of Health Sciences, Room G50 Old Main Building, Groote

Schuur Hospital, Observatory 7925 University of Cape Town, (021) 406 6626, Email: ethics@uct.ac.za.

If you agree to take part in picture cutting exercise , please sign below:

I agree to participate in picture cutting exercise

_____

Date: _____

I agree that semi-structured and focus group interviews will be recorded.

Signature: _____

Date:_____

Researcher:

Signature:_____

Date:_____

Appendix 2 (b): Informed consent for participating in semi-structured interviews

INFORMED CONSENT FORM FOR RESEACH PARTICIPANTS

Research study about social and health-policy priorities of adults with intellectual disability in South Africa (for degree purposes)

Purpose of the study: This research is about what adults with intellectual disability think government should include in their policies to support the health and wellbeing of people with intellectual disability.

How will you take part in Semi-Structured interviews?

You have chosen pictures of the things you wish government can assist you and others in policymaking.

1. Today we are meeting to discuss your pictures and the meaning behind them.
2. The researcher will ask you to select about 5-8 pictures that are important to you and that you feel they can be supported by government in the policies they write to support the lives of citizens like yourself.
3. The pictures can include things you already have, and things you still need to be happy and healthy.
4. The researcher will attach your pictures in a booklet, and ask you questions about your chosen pictures.
5. The researcher will then record and take notes of your ideas, views and needs about the pictures in the booklet to make sure that she has fully understood your meaning behind chosen pictures.
6. After meeting with others to complete their booklets, the researcher will then ask you to join others who have also participate in the study at the meeting called focus group where she will give you feedback/summary of your ideas using PowerPoint presentation slides and also check with you if she has understood and captured everyone's ideas about needs in policies correctly.
7. The interviews will be recorded so that we can type up exactly what you and others said, this will give me a better chance of including your ideas properly when writing up my study report on your and others' ideas about the topic for the research.

Will your participation in the research study be kept confidential or private?

Yes, after all data has been correctly captured the researcher will ensure that all data collected is securely stored. The audio recordings will be kept on the password-protected computer where only the researcher, transcribers and research supervisors will have access to these recordings

What will happen to the results?

Once the researcher have discussed this with you and others in the focus group, she will write this up in a report to the University of Cape Town, called a thesis, as well as in shorter reports called articles to share our findings with other researchers.

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

There are no personal benefits of taking part in this study, but you may enjoy sharing your views on your life and what you think can help people with intellectual disability

What are the possible disadvantages of taking part?

The researcher does not think there will be any disadvantages to 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 me. You do not have to share what you do not feel comfortable sharing as there are no right and wrong answers.

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

You do not have to take part in the research if you do not want to do so, it's your own choice. If you do agree to take part but choose later that you do not want too anymore that will be fine. Refusing to take part in the study will not affect your position with me or anyone else.

What if you have a question?

If you have any questions, you or a person of your choice can contact me at:

Siphesihle Zihlazi	zhlsip001@myuct.ac.za	0671453885/0723527766

or my supervisor Prof. Sharon Kleintjes (+27 056 8990 sr.kleintjes@uct.ac.za), Department of Psychiatry and Mental Health, University of Cape Town, Groote Schuur Hospital, Observatory, 7925. 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. Marc Blockman, Chair: Research Ethics Committee, Faculty of Health Sciences, Room G50 Old Main Building, Groote Schuur Hospital, Observatory 7925 University of Cape Town, (021) 406 6626, Email: ethics@uct.ac.za.

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

I agree to participate in semi-structured interviews to explain the research in more detail and to share my ideas for this study:

Signature:_____

Date:_____

I agree that the interviews can be recorded

Signature:_____

Date:_____

Appendix 2 (c): Informed consent for participating in focus group discussion

INFORMED CONSENT FORM FOR RESEACH PARTICIPANTS

Research study about social and health-related policy priorities of adults with intellectual disability in South Africa (for degree purposes)

Purpose of the study: This research is about what adults with intellectual disability think government should include in their policies to support the health and wellbeing of people with intellectual disability.

1. You and others who have also participated in the study will join a focus group discussion.
2. The focus group discussion will take about 45 min-60 min.
3. The researcher will share the summary of your stories about your needs and what you think government can do to support you in their policies using PowerPoint presentation slides.
4. The researcher will do this to make sure that the ideas she has captured represent your needs that can be supported by government.

Will your participation in focus group discussion be kept confidential or private?

For focus group meeting confidentiality will not be guaranteed since we will share ideas and interact with others participating in the study during focus group meeting.

What will happen to the results?

Once the researcher have discussed this with you and others in the focus group, she will write this up in a report to the University of Cape Town, called a thesis, as well as in shorter reports called articles to share our findings with other researchers.

What are the benefits of taking part in focus group discussion?

There are no personal benefits of taking part in focus group discussion, but you may enjoy sharing your views on your life and what you think can help people with intellectual disability

What are the possible disadvantages of taking part?

The researcher does not think there will be any disadvantages to your participation.

Are there any risks in taking part in focus group discussion?

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

What if you decide not to take part in the focus group discussion?

You do not have to take part in the focus group discussion if you do not want to do so, it's your own choice. If you do agree to take part but choose later that you do not want too anymore that will be fine. Refusing to take part in focus group discussion will not affect your position with me or anyone else.

What if you have a question?

If you have any questions, you or a person of your choice can contact me at:

Siphesihle Zihlazi	zhlsip001@myuct.ac.za	0671453885/0723527766

or my supervisor Prof. Sharon Kleintjes (+27 056 8990 sr.kleintjes@uct.ac.za), Department of Psychiatry and Mental Health, University of Cape Town, Groote Schuur Hospital, Observatory, 7925. 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. Marc Blockman, Chair: Research Ethics Committee, Faculty of Health Sciences, Room G50 Old Main Building, Groote Schuur Hospital, Observatory 7925 University of Cape Town, (021) 406 6626, Email: ethics@uct.ac.za

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

I agree that the interviews can be recorded.

Signature:_____

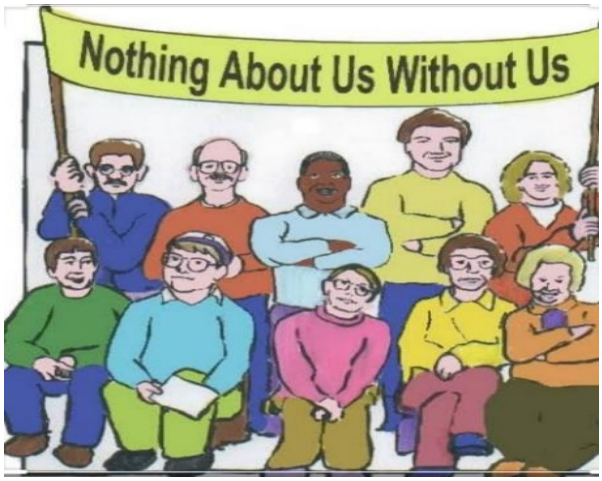
Date:_____

Appendix 3: Booklet

"Everyone is equal before the law and has the right to equal protection and benefit of the law. Equality includes the full and equal enjoyment of all rights and freedoms. To promote the achievement of equality, legislative and other measures designed to protect or advance persons or categories of persons, disadvantaged by unfair discrimination may be taken."

– The Constitution of the Republic of South Africa, 1996 –

Booklet for people with intellectual disability: Self-advocacy study



What are the needs of people?

In order to live, people need food, water, shelter, clothing, to be accepted and being part of your community.

What do people need to be happy and healthy?

- To have a home
- To be loved
- Accepted
- Food
- Care
- Water
- Family
- Friends
- Community
- Money
- Treated fairly
- Respected
- Independence
- Safety

What is an intellectual disability?

A person who may need help with day-to-day living activities such as:

- self-care
- communicating
- taking part in activities with others
- travelling from place to place

May need additional support with:

- solving problems
- making decision

What is self-advocacy?

Speaking for yourself by:

- Knowing yourself
- Communicating your needs
- Knowing your rights
- Knowing what you need

- Learning how to get it

What is government?

There is a group of people that are elected by ordinary citizens of the country to work together to support the needs of people. These elected officials and their staff work together in a structure called Government.

- Government is created by the people
- Government protects people
- Government supports people
- Government cares for people
- Government works for people
- Government helps people to meet their needs

Government does this by making laws and policies that protect the needs and rights of people.

What is policy?

Policies are the ideas written down by the government to meet the needs of people.

These ideas are aimed at:

- protecting people
- supporting people
- caring for people
- providing for people

There are lots of policies and laws, but we will be talking about policies that ensure your health and wellbeing.

Policies about health and wellbeing include policies that make sure that people's rights are protected.

What are the health and social rights of people?

- Right to education
- Right to health
- Right to work

- Right to housing
- Right to social benefits
- Right to be protected
- Right to be safe
- Right to be heard
- Right to be respected
- Right to be listened to
- Right to participation (taking part in what is happening in your community)

Please paste here all the pictures of the things you wish government could help you with in their policies.

My pictures	Meaning of my pictures

Appendix 4: Interview guide

Interview guide for adults with intellectual disability: Self-advocacy study for social and health-related policy priorities in South Africa (for degree purposes).

Questionnaire: Documenting the views of adults with intellectual disability with regards to policy priorities.

Introduction: Thank you for agreeing to take part in this interview. As the researcher mentioned in the consent form, the aim of our discussion today will be to help me understand your ideas about what you need to live a healthy life in your community, and what might be missing in your life, home and community to help you live a healthy life. She will also ask you what you think government should include in their written promises or policies on services they will offer to you and others like you, to support your health and wellness where you live. Do you have any questions before we start the interview?

QUESTIONS		**Notes/key notes**
	Exploring Pictures: *Interviewer says, "In this section* the researcher *will ask you a few questions about the pictures you took."*	
1.	Tell me why you took this picture?	
2.	Tell me what is really happening here?	
3.	What is important to you about this?	
4.	Do you already have this or is it something you feel you still need?	
5.	What can be done about this?	
6.	What can you do to make the change you need in this?	

7.	Who do you think can help you with this, and what help do you need?	
8.	What can be done by government that would be helpful for you and other people?	

Appendix 5: Data extraction sheet

Qualitative and quantitative studies

Study citation	Title of the paper	Study aims	Study design	Participants and study size (N)	Context	Needs, key concerns and/or problems identified by participants and/or stakeholders	Social and health-related policy priorities identified by participants (people with intellectual disability), researchers, professionals, service providers and/or stakeholders

Excluded studies

Study citation	Title of the paper	Study design	Excluded as does not meet the inclusion criteria				
			Criteria 1: Study on adults with intellectual disability Y/N	Criteria 2: Study addresses social and health policy priorities for people with intellectual disability Y/N	Criteria 3: Published in English Y/N	Criteria 4: Published between time span (1994–2020)	Criteria 5: Study on stakeholders about the views on policy for people with intellectual disability Y/N

Appendix 6: Transcriber's confidentiality agreement

Name of study: Social and health-related policy priorities for adults with intellectual disability in South Africa

Dissertation Research

I ……

(Full Name - printed) agree to transcribe the digital recordings provided to me.

I agree to keep confidential all the information provided to me.

I will delete the digital recordings once the transcriptions are completed and will not make any copies of the transcripts or keep any record of them.

Signature ……..……

Date ……

Appendix 7: Supporter's confidentiality agreement

Name of study: Social and health-related policy priorities for adults with intellectual disability in South Africa

Master's dissertation Research

I ……

(Full Name - printed) agree to support the study participant during the duration of the cutting of pictures for the study.

I agree to support the participants to cut out pictures for the research study. I agree that I will support the participant to choose his or her own themes for the picture-cutting areas.

I will not disclose or discuss any information related to the study with anyone else other than the participant.

Signature ……

Date ……

Appendix 8: Semi-structured interview: Administrative information

Research study about social and health-related policy priorities of adults with intellectual disability in South Africa (for degree purposes)

Interviewer	
Date of interview	
Sex of respondent	
Country/Province/Region	
Urban or rural district	
Consent procedure completed	
Start time of interview	
End time of interview	

Interview notes

All relevant aspects of interview completed	
Number of audio files used	
File identification marks	
Files backed-up?	

Observations: Sketch an overview/summary of the interview:
Will this interview contribute to the analysis? Views of participant clearly expressed and verified by interviewer.
Were there any ideas which emerged from the interview which can contribute to our thinking? (Guide: new, contradictory, confirming ideas, trends.)
What are the key themes that emerged from this interview?
Any other observations?

Appendix 9: Supporter's information letter

SUPPORTER'S INFORMATION LETTER

Research study about social and health-related policy priorities of adults with intellectual disability in South Africa (for degree purposes)

Dear Parent/guardian/carer/supporter

I am writing to inform you that your relative/charge has shown interest in participating in my study that is aimed at documenting the views of people with intellectual disability on the things they wish government could help them with in social and health-related policies. Part of the gathering of their views involves participants cutting out pictures of the things that are important to them to meet their needs, and which they would like government to include in policies which impact on their lives.

Purpose of the study: This study aims to document the views of young adults with intellectual disability regarding what they think government should include in their policies to support their health and wellbeing.

As it is crucial that the view of the participant is captured, we would like to request that you allow free rein in the choices of pictures he/she may wish to cut out when assisting him or her. If asked for suggestions, please encourage them to make their own choices for picture cutting.

Please see the attached information sheet for more information on the study, as well as a confidentiality agreement form for your signature. Should you have any queries please feel free to contact me at the details on the information sheet.

Yours sincerely

Siphesihle