Development of a conceptual framework to inform self-advocacy for social and health-related policy priorities of adults with intellectual disability

by

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DEDICATION

I would like to thank God for every blessing He has bestowed upon my life, including this wonderful journey that has now come to an end. To my ancestors, thank you for keeping me grounded, constantly reminding me of who I am and stretching me in ways I never thought were possible.

This thesis is dedicated, with love and gratitude, to my late parents Nandipha Tyabashe and Sam Mashaba for teaching me about the importance of education. To my amazing wife Lebohang Phume, I dedicate this thesis to you. Thank you for your support, love and being the pillar of my strength, for picking me up every time I fell and for standing by my side when the going got tough. To my wonderful daughter Simphiwe Tyabashe, thank you for being patient and understanding that I could not give you 100% of my time because I had to study. Thank you for your support and constantly telling me "If anyone can do it, it's you". To my amazing niece Zinhle Masina, your support and jokes kept me going, thank you. I would like to express my sincere gratitude to my family and friends who have supported and encouraged me during the past few years.

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DECLARATION OF ORIGINAL AUTHORSHIP

This thesis is presented in fulfilment of the requirements for the degree of Doctor of Philosophy (PhD), University of Cape Town. My academic supervisor was Prof. Sharon Kleintjes. The work on which the thesis is based is original research and has not, in whole or in part, been submitted for another degree at this or any other university. The contents of this doctoral thesis are entirely the work of the candidate, who conceptualised and carried out the research project.

Babalwa Tyabashe-Phume
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ABSTRACT

Background: People with intellectual disability are generally not consulted in the development of public policies which impact on their lives. This study focuses on the development of a conceptual framework to support self-advocacy by people with intellectual disability for the inclusion of their priorities in social and health-related policy in South Africa. The study was informed by empowerment theory, with the integration of the concept of *Ubuntu*.

Method: The study design was qualitative and was underpinned by the hermeneutic phenomenological approach. This approach allowed the researcher to understand lived experiences of the research participants in order to gain deeper insights regarding core elements of a conceptual framework for self-advocacy through interpreting their views on how they understand those experiences. Data were collected through a scoping review, semi-structured interviews and focus groups. Twenty-five participants were sampled for this study; 10 participants were policy makers and service managers, five were self-advocates with intellectual disability, five supporters of people with intellectual disability and five parents/carers of people with intellectual disability. Sampling in this study was purposeful, policy makers, service providers, supporters and parents were purposefully sampled to participate in the study. Snowballing was used to identify participants with intellectual disability involved in advocacy groups in local Non-Profit Organisations.

Data were analysed thematically, using ATLAS.ti. software. The framework approached guided the data analysis process. All data sources were triangulated to develop the conceptual framework for self-advocacy by people with intellectual disability. The development approaches used for three similar frameworks were considered in deriving a process to develop this study's conceptual framework. The first framework that focused on strengthening the participation of people with psychosocial disability and their caregiver's involvement in the National Institute for Mental Health England. The second framework was a self-advocacy framework by Test and colleagues, and the third was Cook's multi-cultural and social justice counselling competencies framework.

Results: Data triangulation identified three core elements for self-advocacy, a) personal development, the main contention of this element being that in order for people with intellectual disability to self-advocate, self-development is essential to their participation in self-advocacy in policy processes; b) creating a supportive environment through the empowerment of people with intellectual disability – in order for people with intellectual disability to fully participate in self-advocacy they require empowerment through two main sub-elements: self-advocacy skills development and supported self-advocacy; and c) improved policy participation opportunities, this element focusing on the importance of concerted effort to ensure that there are policy participation opportunities which will permit inclusive participation of people with intellectual disability.

Conclusion: A wholistic approach is needed to increase policy makers understanding of how best to empower people with intellectual disability to provide input to public policy decisions which can improve their quality of life.

Keywords: Intellectual disability, self-advocacy, self-determination, participation, *Ubuntu*, policy

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LIST OF ABBREVIATIONS

ACA	American Counselling Association
ADHD	Attention-Deficit/Hyperactivity Disorder
AMCD	Association for Multicultural Counselling and Development
CBR	Community-Based Rehabilitation
CET	Community Education and Training
DBE	Department of Basic Education
DHET	Department of Higher Education and Training
DoH	Department of Health
DPO	Disabled People's Organisation
DSD	Department of Social Development
FASD	Foetal Alcohol Spectrum Disorders
HREC	Health Sciences Research Ethics Committee
IDD	Intellectual and Developmental Disability
INDS	Integrated National Disability Strategy
LSEN	Learners with Special Education Needs
MCC	Multicultural Counselling Competencies
MeSH	Medical Subject Headings
MHPF	Mental Health Policy Framework
MSJCC	Multicultural and Social Justice Counselling Competencies
NDBE	National Department of Basic Education
NGO	Non-Governmental Organisation
NGT	Nominal Group Technique
NIMHE	National Institute for Mental Health England
NPO	Non-Profit Organisation
NSDS	National Skills Development Strategy
PAR	Participatory Action Research
PICOS	Population, Intervention, Comparison, Outcome, Study design
PRISMA-ScR	Preferred Reporting Items for Systematic Review and Meta-Analysis for Scoping Reviews
SAFMH	SA Federation for Mental Health
SASSA	South African Social Security Agency
SDGs	Sustainable Development Goals

SETAs	Sector Education and Training Authorities
SLD	Specific Learning Disorder
SPIDER	Sample, Phenomenon of Interest, Design, Evaluation, Research type
SSI	Semi-Structured Interview
TVET	Technical and Vocational Education and Training
UK	United Kingdom
UN	United Nations
UNCRPD	United Nations Convention of Rights for People with Disabilities
UPIAS	Union of the Physically Impaired Against Segregation
US	United States
WCED	Western Cape Education Department
WCFID	Western Cape Forum for Intellectual Disability
WHO	World Health Organization
WPRPD	White Paper on Rights of People with Disabilities

CHAPTER ONE

INTRODUCTION

1.1 Outline

This introductory chapter's purpose is to briefly introduce the topic of this thesis, to define some of the essential concepts which inform my comprehension of the topic, and to provide a brief overview of self-advocacy for people with intellectual disability. This study is aimed at exploring the participation of adults with intellectual disability in social and health-related policy development in South Africa.

This study is located within a broader study which aimed to investigate what is needed to support people with intellectual disability to self-advocate for inclusion of their priorities in social and health-related policy and service development processes in South Africa. This broad study had the following objectives:
Sub-study 1: To develop a conceptual framework to guide self-advocacy for people with intellectual disability within a policy and service development context in South Africa.
Sub-study 2: To identify strategies to promote the participation of people with intellectual disability in social and health related policy development and implementation processes.
Sub-study 3: 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.

My research study (sub-study 1) addresses the first objective of this broad study. My motivation for conducting this study is to contribute towards the inclusion of people with intellectual disability in policy processes. It is my hope that this study will produce a conceptual framework that will guide self-advocacy by people with intellectual disability within a policy and service development context in South Africa. Data collected informed the development of a conceptual framework for self-advocacy by people with intellectual disability in the South African context. This study intends to develop a conceptual framework to guide service providers, families, policy developers and administrators, researchers, non-governmental organisations (NGOs) and disabled people's organisations (DPOs) regarding key considerations when planning policy-related work to support including people with intellectual disability during policies development and implementation.

The human rights model of disability was used to highlight the rights of people with intellectual disability as set out by the United Nations Convention on the Rights of People with Disabilities (UNCRPD) (United Nations [UN], 2006) and the South African White Paper on Rights of People with Disabilities (WPRPD) (Republic of South Africa, 2016). The social model of disability was also used to understand existing social barriers to self-advocacy by people with intellectual disability. Empowerment theory was used as a theoretical framework for this study. This theoretical framework, together with the concept of *Ubuntu*, were used to inform the development of the conceptual framework for self-advocacy by people with intellectual disability.

1.2 Defining Intellectual Disability and Self-Advocacy

According to the United Nations Convention on the Rights of People with Disabilities, Article 1 (UN, 2006, p. 3) "people with disabilities include those who have long-term physical, mental, intellectual or sensory impairments which in interaction with various barriers may hinder their full and effective participation in society on an equal basis with others".

The UNCRPD's definition of disability is informed by both the social and human rights models of disability (Lawson & Beckett, 2021). The social model recognises disability as a social state experienced by people with physical, intellectual and other impairments and the human rights model recognises disability as a social construct imposed on people with these impairments, with both asserting that living with an impairment must not be taken as legitimate grounds for the denial or restriction of human rights and access to social, economic and other rights enjoyed by non-disabled people (Retief & Letšosa, 2018; UN, 2018). The medical model, on the other hand, does not explicitly take into consideration the social, economic and other factors impacting on lives lived with disability, instead focusing on the individual and impairment. This model defines intellectual disability as an impairment of a person's cognitive abilities that arise before the age of 18 and continues throughout life, impacting on cognitive and adaptive functioning. The degrees of the disability are usually defined as profound, severe, moderate or mild intellectual disability (American Psychiatric Association, 2013).

This study does not focus on the impairments of people with intellectual disability, but it considers the various barriers that may hinder their and other people with disabilities' full and effective participation in society on an equal basis with others. Article 25 of the UNCRDPD (UN, 2006) highlights the importance of healthcare for people with disabilities, stating that "people with disabilities have the right to the enjoyment of the highest attainable standard of health without discrimination on the basis of disability" (UNCRPD, 2006). In South Africa people with disabilities are still being discriminated against, for example, the dismissive attitudes by health professionals towards mental health service users impact negatively on treatment outcomes (Daniels, 2018). Therefore, it is recommended that people with disabilities should actively engage and participate in matters that affect their health and well-being, which can be achieved through advocacy and self-advocacy (Daniels, 2018).

Advocacy refers to representation of the views of some individual(s) by others, but self-advocacy is the ability to speak on behalf of oneself, motivating for one's needs verbally or in writing, using pictures or gestures (Petri et al., 2017). According to the World Health Organization (2003), advocacy is an important means of raising awareness on health issues and ensuring that health is on the agenda of governments. Advocacy can lead to improvements in policy, legislation and service development. According to Goodley (2005), self-advocacy is about ensuring that people with intellectual disability can have a say about issues important to them, and it is also concerned with building their individual and collective capacity.

Therefore, self-advocacy is an opportunity for people with intellectual disability to have a say. People with intellectual disability's participation in self-advocacy at the level of public policy would uphold their constitutional rights as citizens of South Africa and provide them with opportunities to have their voices heard in making policies that impact their lives. Goodley (2005) states that the participation of people with intellectual disability in decision-making processes can also reduce the stigma of policy makers toward people with intellectual disability and, in turn, empower them.

1.3 Rationale of the Study

Most people with intellectual disability and their families do not have adequate access to health and mental health services and other related public services (Daniels, 2018). There is also a notable gap in service provision between the rural and urban areas in South Africa, as most mental health services are located in urban areas, and some are inadequate (Daniels, 2018; South African Human Rights Commission, 2019). Additionally, community-based intellectual disability services are currently largely absent, or sub-standard, especially services for people with intellectual disability and challenging behaviours (Daniels, 2018). Where community-based services are available, they are primarily run by NGOs, which face several barriers to providing quality services, including funding constraints.

It is thus important to ensure that the needs of people with intellectual disability are better represented in policies to address these issues. Rowland (2004) mentions that the expression, "nothing about us, without us" should be upheld when addressing issues concerning people with disabilities, this expression emphasises self-representation and empowerment. Therefore, involvement of people with intellectual disability and their families must be strengthened in efforts aimed at protecting their rights and promoting inclusion and access to societal resources. There must be a shift from advocacy to self-advocacy, that is, the direct inclusion of the voices of people with intellectual disability in these activities (Andersen & Bigby, 2017; Rowland, 2004).

Advocacy for people with intellectual disability in South Africa is still primarily service provider driven (Daniels, 2018). More work needs to be done to improve the participation of families, and in particular, of people with intellectual disability in advocacy for change. Capacity development and reasonable accommodation must be considered in developing opportunities for participation and self-determination (Andersen & Bigby, 2017; Kasmel & Andersen, 2011). Supporting people with intellectual disability to represent their views in public policy-related processes requires careful consideration of the impact of and supports needed to account for participation restrictions experienced as a result of cognitive and adaptive functioning impairments, and from the lack of appropriate support to reasonably accommodate these restrictions.

Different levels of participation may be possible due to the severity of disability, and where people cannot self-advocate, literature and practice propose supported decision-making and advocacy by carers and supporters (Kleintjes et al., 2013). There are people with intellectual disability who could self-advocate, with the appropriate supports, but are not afforded the opportunity (Kleintjes et al., 2013). This study will not address advocacy on behalf of people with intellectual disability by others but will focus on possibilities for self-advocacy, and support for self-advocacy. As full citizens, people with intellectual disability should be able to self-represent in public policy development and implementation which affects their lives, when they so wish, and should enjoy appropriate environmental supports to such participation (Petri et al., 2017; Ryan & Griffiths, 2015; UN, 2006). For the purpose of this study the focus will be on self-advocacy by people with intellectual disability in social and health-related policy in South Africa. There are notable inadequacies in social and health services for people with intellectual disability (South African Human Rights Commission, 2019) and the participation of people with intellectual disability in efforts to change this through self-advocacy should be encouraged and supported.

1.4 Literature Review

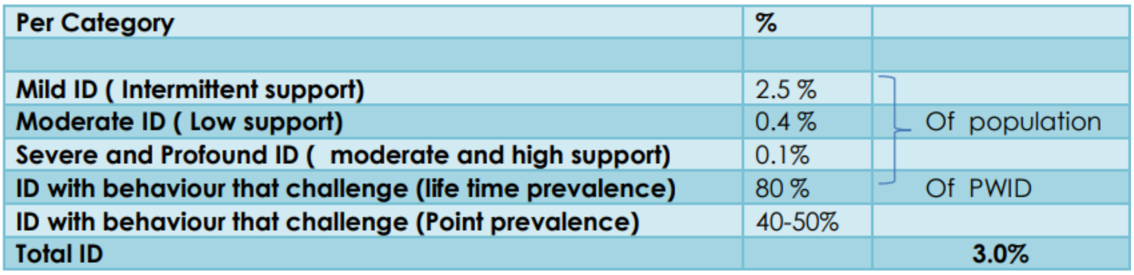
1.4.1 Prevalence of intellectual disability

According to the World Health Organization (WHO) and the World Bank (2011) approximately 200 million people live with intellectual disability, making it the world’s most prevalent disability. International and local studies or estimates variously report a life-time prevalence rate of intellectual disability of between 1%–3%. A study conducted by Maulik et al. (2011), for example, reported that the prevalence of intellectual disability varies between 1% and 3%, globally, with 85% described as having mild, 10% moderate, 4% severe, and 2% profound intellectual disability. Other studies estimate that the global prevalence of intellectual disability is at 1% of the population (American Psychiatric Association, 2013). A study conducted by Emerson (2007) indicates that low- and middle-income countries have more people living with intellectual disability compared to high-income countries, this being due to the high rates of poverty and poverty-related conditions.

South Africa has not conducted a national prevalence study for intellectual disability, but Adnams (2010) estimated the prevalence of intellectual disability in South Africa at 3%, due to high rates of poverty-linked preventable conditions that may impact on onset of intellectual disability, such as nutritional deficiencies, infectious diseases such as HIV/AIDS, tuberculosis meningitis, foetal alcohol spectrum disorders (FASD), as well as violence and injury-related intellectual disability (Adnams, 2010; UNAIDS, 2014; WHO, 2017, 2019). Figure 1 below illustrates the prevalence of intellectual disability in South Africa, these statistics being drawn from findings of a study by Adnams (2010) and utilised by the Department of Social Development (DSD), the lead department on addressing disability amongst South Africans.

Figure 1

Intellectual Disability Prevalence in South Africa



Per Category	%	
Mild ID (Intermittent support)	2.5 %	
Moderate ID (Low support)	0.4 %	Of population
Severe and Profound ID (moderate and high support)	0.1%	
ID with behaviour that challenge (life time prevalence)	80 %	Of PWID
ID with behaviour that challenge (Point prevalence)	40-50%	
Total ID		3.0%

Note: ID = Intellectual disability

Source: Department of Social Development (2015, p. 16)

The White Paper on the Rights of People with Disabilities (Department of Social Development [DSD], 2016) highlights that Statistics South Africa, in their 2011 National Census, estimated a disability prevalence of 7.5%. These statistics exclude “children between 0-4 years, people with disabilities in residential care and school boarding facilities and people with psychosocial, neurological and/or emotional disabilities” (DSD, 2016, p. 35). Capri and Swartz (2018) point to the poor reliability of the census data as estimates of intellectual disability by mentioning that intellectual disability was incorrectly measured during the 2011 Census, as children with disabilities were not profiled at all and people with intellectual disability in residential care settings were excluded from the count. The study conducted by Capri, Abrahams, et al. (2018) estimated the prevalence of intellectual disability to be 4.1%. These statistics are not conclusive and indicate the overall inaccuracy of current South African statistics on intellectual disability.

Studies elsewhere indicate that there may be higher rates of mental distress and mental disorders in people with intellectual disability than in the general population (Yoo et al., 2012). People with intellectual disability are among our most vulnerable citizens, and for some, their vulnerability is increased due to co-occurring intellectual and psychosocial or physical disabilities (Adnams, 2010; Yoo et al., 2012).

1.5 Legislative and Policy Framework for Intellectual Disability in South Africa

In South Africa, mental health legislation has been adapted and changed over the century, and post-apartheid (coined the “New South Africa”), the South African White Paper on Integrated National Disability Strategy (INDS) was published in 1997. The aim of this White Paper is to ensure that disability issues are integrated in all governmental strategies, planning and programmes (Republic of South Africa, 1997). This policy document further highlights that people with disabilities should enjoy equal access to fundamental rights, removing barriers and creating enabling mechanisms.

The INDS states that, despite the Constitution enshrining the rights of people with disabilities, there is no disability-specific legislation (Republic of South Africa, 1997). Therefore, there is a call for a Vulnerable Persons Act (Capri, Abrahams, et al., 2018). Capri et al. (2018) suggest that legislation for vulnerable adults with intellectual disability, can help prevent harm and reduce the risk of abuse or neglect. It should have provisions which safeguard adults in ways that support them in making choices and having control in how they choose to live their lives. The legislation can further raise public awareness so that individuals and communities can play their part in preventing, identifying and responding to the abuse and neglect of vulnerable adults living with intellectual disability (Capri et al., 2018). While no disability-specific legislation has yet been promulgated in South Africa, the National Policy on Disability focuses on the provision of integrated developmental social services, including social security, community development and welfare. This policy builds on the INDS and other policies relating to people with disabilities (DSD, 2009).

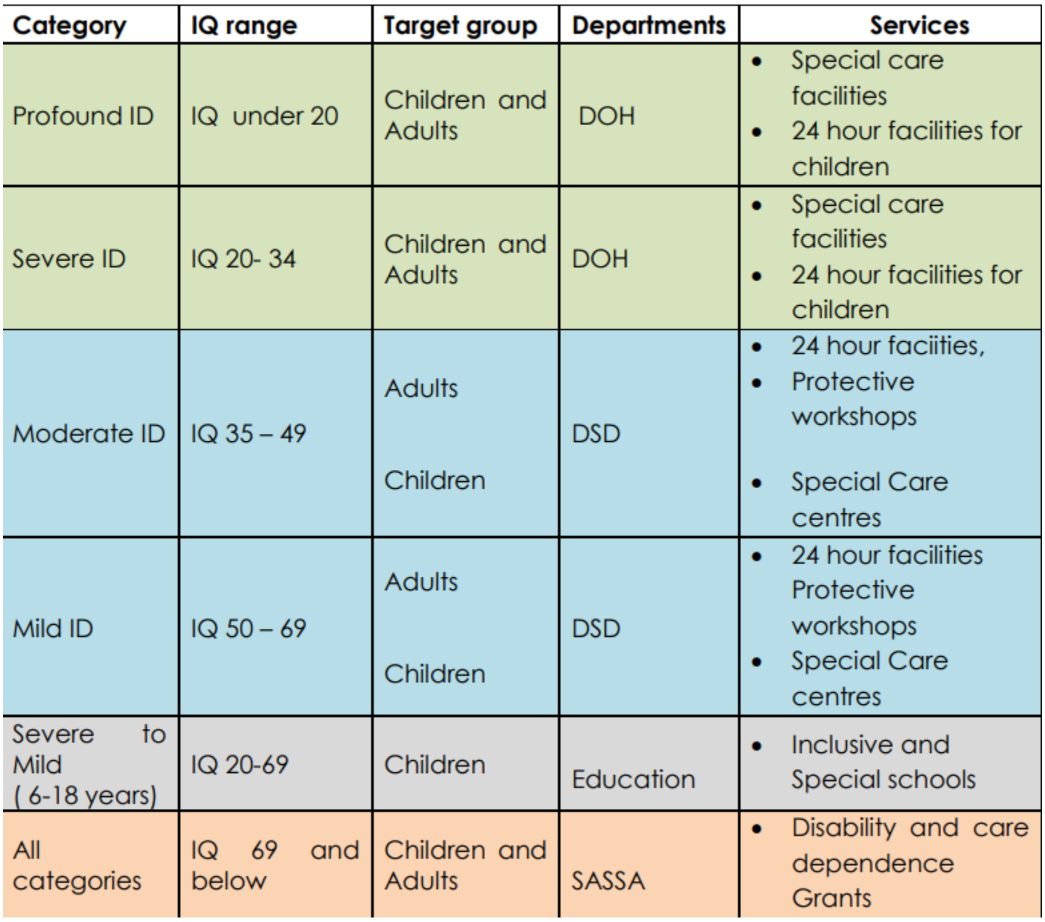
The Education White Paper 6 was published in 2001 (Republic of South Africa, 2001), with the focus on special needs education and building an inclusive education and training systems. This White Paper stems from the notion that everyone has a right to quality basic education, regardless of their gender, age, race and disability. This paper highlights that every learner with and without disabilities should pursue their learning potential to the fullest (Republic of South Africa, 2001). Although the White Paper mentions that children with disabilities have a right to education, there are a significant number of children with intellectual disability who are not in school or excluded from the education system in South Africa (Kleintjes et al., 2020).

Children with mild and moderate intellectual disability are allowed to attend and benefit from basic education, whereas those with severe and profound intellectual disability are placed at special care centres (Kleintjes et al., 2020). Hence the Western Cape Forum for Intellectual Disabilities (WCFID) challenged the National Department of Basic Education (NDBE) and Western Cape Education Department's (WCED) exclusion of children with severe and profound intellectual disability from their right to education. The High Court of the Western Cape, in 2010, made a ruling that the Government of South Africa and the Government of the Western Cape had violated the rights of these learners to a basic education. Despite a constitutional court ruling in 2010 that the NDBE should provide education for children with severe and profound intellectual disability, these children are to date still excluded from the formal education system in South Africa (Kleintjes et al., 2020).

The Policy Framework Services to People with Intellectual Disability is a provincial implementation policy developed in the Western Cape Province following the 2010 court order. The Policy supports the notion that people with intellectual disability's needs are lifelong and need to be met by different sectors in the government throughout their lifespan (Department of Social Development Western Cape [WCDSD], 2015). Figure 2 below illustrates services and support provided by the three Government Departments in the Western Cape Province.

Figure 2

Services for People with Intellectual Disability by Government Departments



Category	IQ range	Target group	Departments	Services
Profound ID	IQ under 20	Children and Adults	DOH	• Special care facilities • 24 hour facilities for children
Severe ID	IQ 20- 34	Children and Adults	DOH	• Special care facilities • 24 hour facilities for children
Moderate ID	IQ 35 – 49	Adults Children	DSD	• 24 hour faciities, • Protective workshops • Special Care centres
Mild ID	IQ 50 – 69	Adults Children	DSD	• 24 hour facilities Protective workshops • Special Care centres
Severe to Mild (6-18 years)	IQ 20-69	Children	Education	• Inclusive and Special schools
All categories	IQ 69 and below	Children and Adults	SASSA	• Disability and care dependence Grants

Source: WC Department of Social Development (2015, p. 18)

The WCFID's Right to Education Campaign highlights the barriers to participation experienced by people with intellectual disability, thus violating both international agreements and the South African constitutional, legislative and policy framework. Currently similar intersectoral implementation policies have not as yet been developed in other provinces, and 11 years later, the provisions of the court order in the Western Cape have not as yet been fully realised (McKenzie et al., 2019).

The goal of the National Health Act (No 61 of 2003) (Republic of South Africa, 2004a) is to ensure the provision of quality health services to the population of South Africa, including people with disabilities. The Act also provides for the establishment of the National Health Council, which is a structure responsible for making health policy, including regulations on rehabilitation and assistive devices for people with disabilities (Department of Health [DoH], 2012). The Framework and Strategy for Disability and Rehabilitation Services in South

Africa (DoH, 2016) aims to facilitate improved access at all levels of healthcare. The emphasis is on health interventions with rehabilitation cutting across the promotive, preventive, curative, rehabilitative and palliative continuum of care. Rehabilitation services make the vital, practical link between medical treatment and the translation of a person's restored capacity for a productive and health promoting social and economic life (DoH, 2016).

This policy and framework strategy focuses on the mandate of the health sector and fully subscribes to the Community-Based Rehabilitation (CBR) philosophy. The CBR is a community development strategy for the rehabilitation, equalisation of opportunities and social inclusion of people with disabilities (DoH, 2016). It focuses on the inclusion of and equal opportunities for people with disabilities, through the co-ordination of services from different government departments.

According to the Mental Health Policy Framework for South Africa and Strategic Plan 2014-2020 (2013), mental health services continue to be guided by the legacy of colonial mental health systems, where the state heavily relies on psychiatric hospitals. However, there have been important policy and legislative developments regarding mental health in South Africa (Lund et al., 2010). These developments have led to mechanisms of decentralisation of services, integration of mental health into general healthcare and the development of community-based care. Another step forward was the adoption of the Mental Health Policy Framework (MHPF) for South Africa and Strategic Plan 2014–2020 by the National Health Council (Stein, 2014). This policy framework adopts a human rights perspective and is in line with WHO recommendations for mental health policy and services. Although the 2020 implementation date for this policy has expired, it is still being used, pending the publication of a new national policy.

The purpose of the mental health policy is to "guide mental health promotion, prevention of mental illness, treatment and rehabilitation in all provinces" (2013). This policy is progressive, and it addresses the full age range of mental disorders, including services for people with intellectual disability. According to the policy, it is the responsibility of the DoH to provide developmentally appropriate healthcare services to people with intellectual disability. The DBE, and later the Department of Labour, are noted in the policy as responsible for educational and vocational-related service needs of people with mild and moderate intellectual disability, while the DSD is noted as being responsible for funding of supported housing and community service needs (2013).

The Social Assistance Act (No. 13 of 2004, p. 9) (Republic of South Africa, 2004b) provides guidelines for the administration of social assistance and payment of social grants. According to the Social Assistance Act of 2004, people with disabilities are eligible for a disability grant if they are adults (18 years and above) and unfit to obtain employment because of their physical or mental disability. In addition, the Act stipulates that a child is eligible for a care dependency grant if they receive permanent care or support services due to their mental or physical disability (Republic of South Africa, 2004b). Thus, including people with intellectual disability as recipients of social grants is a mode of social relief or social security. This is administered and facilitated by the South African Social Security Agency (SASSA) under the DSD.
As of 01 April 2023, the value of both the disability and care dependency grants is R2 080 (approximately $120) and is set to increase by R10 ($0.5) in October 2023 (SASSA, 2023). The following criteria must be met in order to qualify for the disability or care dependency grant (SASSA, 2023):

- You must be a South African Citizen, a Permanent Resident, or a Refugee
- You must be between 18 and 59 years old (for adults)
- You must NOT be receiving permanent care in a state-funded institution
- You must reside within South Africa
- You must have a temporary or permanent disability (physical or mental)
- Your disability must make you unfit to work for a period of longer than six months
- You must undergo a medical examination where a doctor will assess the degree of your disability
- You must NOT be receiving care in a state institution
- You must NOT be receiving any other social grant for yourself
- You must meet the means test: indicates that in order for a person to be eligible for the disability grant they must not have assets valued at more than R1 372 800 and must not earn more than R96 840 a year (SASSA, 2023).

The disability and care dependency grants are seen as effective in reducing hunger in households because the grant is usually used to purchase food and groceries (Kidd, Wapling et al., 2018; Neves, Samson et al., 2009). McKenzie et al. (2019) assert that the disability grant is often used to provide for entire families rather than contributing to the disability specific needs of people with disability within the household. Moreover, Kidd et al. (2018) note that access to the disability grant still proves to be challenging for people with severe cognitive or mental disabilities. Thus, more work needs to be done to ensure accessibility and this can be done through the creation and enhancement of support services.

The NGO sector is predominantly the service provider for people with intellectual disability and receives financial and/or technical support from different government departments, such as the DBE, DoH and the DSD (DSD, 2015). Although some people with intellectual disability receive the grant, this is not enough for their basic needs. Often times they turn to NGOs to seek assistance, more especially for the services that they cannot access due to financial resources. According to Stein et al. (2018), there are high economic costs to failing to provide appropriate interventions for people with intellectual disability. These authors assert that less attention is paid to people with intellectual disability, and they are particularly at risk of being overlooked.

Maladministration of mental health services have dire consequences, including the fatality of patients, for example, the Life Esidimeni Tragedy where 144 patients, including people with intellectual disability died and 44 were unaccounted for in 2017 (Moseneke, 2017). Although some of the patients have been found over the last three years, eight patients were still unaccounted for as of March 2020 (Eight Esidimeni patients still missing, 2020).

1.5.1 The Life Esidimeni tragedy

Human rights of people living with intellectual disability are sometimes neglected in South Africa. For example, in 2015 the Gauteng Department of Health took a decision to cut funding for the 2000-bed Life Esidimeni facility, which accommodated people with long-standing, complex and severe mental health-related conditions, including intellectual disability. This led to the rapid discharge of these individuals into inadequately resourced NGO facilities in Gauteng Province, many of which had been registered at short notice, resulting in the tragic death of at least 144 of these patients. At least half of the deceased lived with severe to profound intellectual disability. Some people who suffered these fatalities lived with intellectual disability and a comorbid mental illness (Capri, Watermeyer, et al., 2018; Makgoba, 2016). This tragedy occurred despite the call from several civil society organisations to government ahead of the discharge of patients to reverse their decision, and the protective policy and legislative frameworks that have been put in place. These include the Mental Health Review Boards specifically designed to protect the human rights of people admitted to mental healthcare facilities (Lund, 2016). This tragedy highlights that a lot can go wrong if decisions are based on budget cuts rather that human rights.

The Life Esidimeni tragedy is a perfect example of systemic flaws in mental health service planning and implementation in South Africa (Stein et al., 2018). While good policies are in place, at times people with psychosocial and intellectual disability are overlooked in policy implementation. Capri et al. (2018) note that the Life Esidimeni tragedy "is not only a medical maladministration scandal. It is a story about the socio-political abuse of people who only matter once they die" (p. 153). The Life Esidimeni patients did not die because they were disabled, they died because of the carelessness of healthcare administrators. They died from neglect, abusive care, starvation, infection, cold and dehydration (Capri, Watermeyer, et al., 2018). This tragedy points to the structural barriers embedded in social injustices and perpetual violation of rights of people with intellectual disability.

1.6 Understanding the Barriers to Participation for People with Intellectual Disability through the Social Model of Disability

According to Oliver (2004), the social model started with the publication of The Fundamental Principles of Disability by the Union of the Physically Impaired against Segregation (UPIAS) in 1976. The union states that it is society that disables people with impairments. Disability is something imposed on people's impairments by the way they are unnecessarily isolated and excluded from full participation in society (Oliver, 2004). From this, Oliver developed the social model of disability in 1983. It was a reaction to the dominant medical model of disability, where he proposed that disability be recognised as a social state and not merely a medical condition (Levitt, 2017; Oliver, 1990; Retief & Letšosa, 2018).

The medical model of disability considers disability as a personal tragedy for both the individual and their family, as something to be prevented and, if possible, cured (Carlson, 2013). The medical model focuses on the impairment first, and it considers the impairment as the cause for people with disabilities being unable to access services or being unable to participate fully in society (Retief & Letšosa, 2018). According to the medical model, people with disabilities deviate from what is deemed “normal”, thus reinforcing the notion that people with disabilities are not comparable to their able-bodied counterparts. That, somehow, able-bodied people are better or superior to people with disabilities (Retief & Letšosa, 2018).

The medical model of disability assigns power to the medical professionals who diagnose people. Medical professionals who subscribe to the medical model tend to treat people as problems to be solved, often failing to consider various aspects related to the person’s life as a whole (Thomas & Woods, 2003). Kasser and Lytle (2005) note that the medical model’s focus on the limitations associated with a person’s disability disregards environments that might intensify or adversely affect a person’s functional abilities. Or, as Oliver asserts, it ignores the fact that it is the society that disables people with impairments (Oliver, 1990, 2004). This model disregards various contextual factors that contribute to the independence and human dignity of people with disabilities. Furthermore, it neglects the abilities of people with disabilities.

On the other hand, the social model of disability highlights systemic barriers, negative attitudes and exclusion by society for people with disabilities. It states that disability is a social concept that has ramifications for whether or not persons with impairments are included in mainstream society on social, political, and economic levels. (Oliver, 1990). Retief and Letšosa (2018) concur by mentioning that the social model is concerned with addressing the barriers to participation experienced by people with disabilities as a result of various ableist social and environmental factors in society. This model does not overlook or deny the person’s impairments, but instead focuses on the capabilities of people with disabilities, recognising people with disabilities as equal citizens with full human rights, political, social and economic rights (Du Plessis, 2013).

The social model of disability highlights that for any meaningful change to occur the solutions should be centred on societal change instead of exclusively on individual adjustment and rehabilitation, as is the focus of the medical model of disability (Shakespeare, 2010). It highlights the need for the mainstreaming of disability to ensure full inclusion of people with disabilities as equals (Retief & Letšosa, 2018). The overall focus of the social model is on the person’s abilities and recognises people with disabilities as equal citizens with full political, social, economic and human rights (Du Plessis, 2013).

Moreover, the social model does not deny the existence and impact of illness, but it identifies the distinction between illness and disability. This model does not deny the role medical professionals play in the lives of people with disabilities; including stabilising and treating their condition, restoring their health and reducing participation limitations to enhance their quality of life, and treating any other illnesses which may arise which may or may not be disability-related (Oliver, 1990).

1.6.1 Criticism of the Social Model of Disability

Although, the social model has demonstrated success for people with disabilities in society, challenging discrimination and marginalisation, it has its shortcomings and has been critiqued over the years. According to Oliver (1990), there are five main criticisms of the social model of disability:

a) The social model is unable to deal adequately with the realities of impairment (Oliver, 1990). It ignores the embodied experiences of people with disabilities thereby limiting understandings of disability, because personal experiences and social barriers remain undifferentiated (Owens, 2015; Shakespeare & Watson, 1997).
b) The subjective experiences of the pain of both impairment and disability are ignored by the social model (Oliver, 1990).
c) The social model is unable to incorporate other social divisions, such as race, gender, ageing, and sexuality (Oliver, 2004).
d) The social model has an inadequate theoretical basis. “The components of disability need to be further conceptualized in order to improve the explanatory power of the social model” (Owens, 2015, p. 403).
e) The social model recognises disability as oppression. It emphasises that all people with disabilities are oppressed and focuses on the extent to which they are oppressed (Shakespeare, 2010; Williams, 1999).

Oliver addresses these critiques by stating that these criticisms are based on a conceptual misunderstanding, as the social model is not about the personal experience of impairment but the collective experience of disablement (Oliver, 1996, 2004). He goes on to say that he is a disabled tetraplegic who experiences pain and disablement on a daily basis and that this criticism coming from non-disabled people is more of a personal attack on him (Oliver, 2004). He further states that the assumption that the social model is not based on disabled people's experiences is absurd, as it emerged out of the experiences of disabled activists in the 1970s (Oliver 1990).

Furthermore, Oliver (2004) mentions that the social model has room to adequately integrate the dimensions of gender, race, sexuality and ageing in the future. He also mentions that it is not the physical and environmental barriers that people with disabilities face that are oppressive, but instead it is the way in which cultural values position people with disabilities as "other", thus oppressing them. Oliver (2004) goes on to say that more theoretical debates need to take place in order to develop the social model of disability.

Taking into consideration the ongoing marginalisation, discrimination and exclusion experienced by people with intellectual disability as a collective, the social model highlights the need for social integration as one of its pillars. This model has demonstrated success for people with disabilities in society, challenging discrimination and marginalisation, linking civil rights and political activism and enabling people with disabilities to claim their rightful place in society (Oliver 1990; Owens, 2015).

1.6.2 The application and implementation of the social model in South Africa

In South Africa after 1994, the newly elected democratic government introduced the social model approach to address disability. This model is captured and integrated in a number of government policies and legislation, making the application and implementation of the social model approach mandatory within policy implementation (DSD, 2009, 2016). The White Paper on disability, known as the Integrated National Disability Strategy (Republic of South Africa, 1997), extrapolates on the rights of people with disabilities as outlined in the Constitution. It emphasises the importance of access to basic human rights for people with disabilities.

The South African government has put in place a mechanism for interdepartmental collaboration or clustering between key departments to address the complex roles of these departments in implementing laws and policies to meet the needs of citizens (Republic of South Africa, 2016). One of these interdepartmental collaborative mechanisms is the Social

Cluster, which has oversite over services aimed at social protection and community and human development. This cluster is comprised of the Minister of Higher Education, Science and Technology, the Minister of Basic Education, the Minister of Human Settlement, Water and Sanitation, the Minister of Health and the Minister of Social Development (Republic of South Africa, 2022).

A lack of access to basic services has an ensuing impact on vulnerable and marginalised groups, including people with disabilities. According to a report presented by the Department of Human Settlement, Water and Sanitation in 2014, (South African Human Rights Commission, 2018), for example, international and national legislation exists to ensure that the rights of people with disabilities are protected, however, their needs are not often considered regarding the provision of water and sanitation. The affordability of water is also an essential element of accessibility for people with disabilities, as they are often more marginalised and poorer than those without disabilities. At the 2012 National Water and Sanitation hearing it was noted that there were facilities with no connections to water pipes or taps, and that no provision was made for people with disabilities (The South African Human Rights Commission, 2014). In addition, communities indicated that the failure to access these services impacted severely on access to other human rights, such as health and education, and that the impacts were felt more by vulnerable groups of people such as women, girls and people with disabilities (The South African Human Rights Commission, 2014). This highlights the barriers that people with disabilities encounter and the infringement of their human rights.

As noted above, there is a gap in the provision of basic education to children with severe and profound intellectual disability. This gap is also evident in post-secondary education. Post school there are no public funded further education and training opportunities for people with intellectual disability (Ellman et al., 2020). There are very few private facilities offering education and training that is appropriate for people with intellectual disability post school, resulting in loss of skills gained at school or in special day care centres and a failure to equip people with skills to enable them to enter the world of work (Ellman et al., 2020; Mahomed, 2020).

According to the Strategic Policy Framework on Disability for the Post-School Education and Training System developed by the Department of Higher Education and Training (DHET, 2018), despite international and national conventions, policies and guidelines, the management of disability in post-school education remains fragmented and separate to that of existing transformation and diversity programmes at the institutional level. Most Technical and Vocational Education and Training (TVET) and Community Education and Training (CET) colleges lack the capacity and policies to cater for students and staff with disabilities (DHET, 2018).

Furthermore, the skills development sector does not have adequate strategies that ensure the inclusion of people with disabilities. Little attention is given to strategic documents such as the National Skills Development Strategy (NSDS) and Sector Education and Training Authorities (SETAs) which do not have disability targets to achieve. Therefore, a Strategic Policy Framework on Disability for the Post-School Education and Training System is necessary to guide the improvement of access to and success at institutions and programmes for people with disabilities (DHET, 2018). Additionally, SETAs have "failed to achieve equal access for people with disabilities, despite the 4% target. SETA has recommitted to significantly open up opportunities for skills training for people experiencing barriers to employment caused by various forms of physical and intellectual disability" (DHET, 2018, p. 33). With regard to people with intellectual disability, for those who are eligible to attend education centres for learners with special education needs (LSEN schools) as children, there are no publicly funded post-school educational facilities (Mahomed, 2020).

Moreover, the DSD's Policy on Disability adopts the social model to address disability in the provision of social services. Despite the government having adopted the social model approach, the delivery of social services by the DSD to people with intellectual disability remains focused on the provision of social grants (DSD, 2009). Despite the progress made by the government in developing progressive enabling policies and putting structures in place to be representative and responsive to the developmental needs of the people with disabilities, the majority of people with intellectual disability are still exposed to restrictive environments and barriers that continue to marginalise and exclude them from mainstream society and its social and economic activities.

Over and above that, people with intellectual disability are also particularly disregarded when confronted with the justice system. Their testimony is often overlooked and not taken seriously, as they are considered unreliable witnesses and they seldom have access to advocates through whom they can speak (Republic of South Africa, 1997). People with intellectual disability have the right to exercise their political right through participation in the National elections, for example. However, to date people with intellectual disability in South Africa are not able to vote or run for election (Capri & Swartz, 2018).

Moreover, people with profound and severe intellectual disability are particularly vulnerable during a period of transition from institutionalisation to community-based services. People with intellectual disability living in rural areas often have a low life expectancy, due to lack of care, support and access to even the most basic services (Adnams, 2010). Families hardly make ends meet and meet the additional financial burden of regular visits to hospitals, additional expenses for equipment and assistive devices, and other necessities. There is no meaningful access to services in the rural areas for people with intellectual disability (Adnams, 2010; Republic of South Africa, 1997).

According to the DoH (2013), as cited in the Mental Health Policy Framework and Strategic Plan 2014-2020, service development and delivery in South Africa should aim to build user capacity to return to, sustain and participate in satisfying roles of their choice in their community. People with intellectual disability should be given equal opportunities and reasonable accommodation to ensure full participation in society, where they can speak out about the infringement of their rights (Department of Health, 2013). They should have equal access to education, healthcare, employment, housing and sanitation, and social support.

1.7 Understanding the Rights of People with Intellectual Disability from the Perspective of the Human Rights Model of Disability

Human dignity is the anchor norm of human rights; each individual is deemed to be of immeasurable value, and nobody is insignificant. People are valuable because of their inherent self-worth and not just because they are economically or otherwise useful (Degener, 2014). The human rights model of disability is based on basic human rights principles. It acknowledges disability as a natural part of human diversity that must be respected and supported in all its forms. People with disability have the same rights as everyone else in society. Impairment should not be used to justify the restriction of people's rights (Degener, 2017; Korolkova & Anthony, 2016). Similar to the social model, this model places the individual at the centre of all decisions affecting them and locates the main problem outside the person and in society (Degener, 2014, 2017).

The UNCRPD (UN, 2006) has had a profound impact on disability law and human rights law globally. It seeks to bring about a shift in disability policy that is based on a new understanding of people with disabilities as human rights holders (Degener, 2016; UN, 2006). The purpose of the UNCRPD is to ensure the protection, the promotion of equal human rights and fundamental freedoms, and respect for the inherent dignity of all people with disabilities. The UNCRPD (UN, 2006) further highlights the recognition by the human rights model that disability is a social construct and impairments must not be taken as legitimate grounds for the denial or restriction of human rights. This model acknowledges that disability is one of several layers of identity. Hence, disability laws and policies must take the diversity of people with disabilities into account. It also recognises that human rights are interdependent, and that everyone is equal under the law.

The White Paper on the Rights of People with Disabilities (WPRPD) states that people with disabilities have political, human, social, economic and cultural rights (Republic of South Africa, 2016). Below is the description of the rights of people with disabilities as outlined in the UNCRPD:

- *Human rights:* Protecting and promoting the human rights of people with disabilities is an underlying principle in all the Articles of the UNCRPD. The State should ensure and promote the full realisation of all human rights stipulated on The Bill of Rights and fundamental freedoms for all people with disabilities without discrimination of any kind, based on disability, and to protect all persons against violation of their human rights.
- *Political rights:* All people with disabilities have political rights and the State must provide equal opportunities to ensure that people with disabilities are able to fully participate in political and public life, for example, being able to vote and be elected. This involves ensuring that voting procedures, facilities and materials are appropriate, accessible and easy to understand and use by people with disabilities. People with disabilities, together with others, have an equal responsibility for ensuring that they are able to exercise their political rights.

- *Social rights:* People with disabilities must be accorded equitable social rights, as are all other people in society. These include the right to education, healthcare, housing, transport, sport, recreation, culture, social development services, food security and family life. The State should build socially cohesive communities, improve education and health outcomes and build safer communities. Critical to building social cohesion is enabling people with disabilities to live in barrier free environments. Social cohesion should also provide individuals requiring support with the means to participate in community life and promote accelerated roll-out of inclusive education which will enable everyone to participate effectively in a free society.
- *Economic rights:* Include access to resources such as land, finance capital, decent work, capital infrastructure and labour. Realising the economic rights of people empowers them with the means to independently meet their basic human needs with dignity and self-respect. People with disabilities must be involved in conceptualising, developing, implementing and monitoring economic development policies and programmes. Also, they must be considered when programmes and projects are planned (as beneficiaries and implementers) and that all barriers to access to the mainstream economy must be eliminated. All economic development indicators and targets must include ratios/ and proportions for people with disabilities. This is, however, not reflected in the South African economy as people with intellectual disability are often excluded and are not placed in employment. There are some NGOs that provide supported employment programmes for people with intellectual disability (Republic of South Africa, 2016). However, these are only limited to those with mild and moderate intellectual disability, thus excluding people with severe and profound intellectual disability (Daniels, 2018; Republic of South Africa, 2016).
- *Cultural rights:* Aim at assuring the enjoyment of culture and its components in conditions of equality, human dignity and non-discrimination. They are rights related to language; cultural and artistic production; participation in cultural life; cultural heritage; intellectual property rights; author’s rights; minorities and access to culture, among others. Article 30 of the UNCRPD places specific obligations on the state to take measures that will promote, protect and uphold the cultural rights of people with disabilities (UNCRPD, 2006). People with disabilities have

the right to enjoy and access scientific information and advances, as well as collaborative work; artistic freedoms and the right to contribute and enjoy the arts; and the rights of indigenous peoples and local communities.

In 2016, the United Nations published the Sustainable Developmental Goals (SDG) adopted by world leaders. These goals are the blueprint to achieving a better and more sustainable future for all. The Sustainable Development Goals (SDGs) (UN, 2016) address the current global challenges, such as, poverty, inequality, climate change, environmental degradation, peace and justice. All 17 Goals are interconnected, and in order to leave no one behind, it is important that they are all achieved by 2030 (UN, 2016). All SDGs apply to people with disabilities, as disabilities are mentioned 11 times in the SDGs. However, of the 17 goals, eight goals in particular need to be achieved to promote the above-stated rights of people with disabilities. Below are the relevant goals that must be achieved to promote the rights of people with disabilities, as outlined by the UN (2016) and Statistics South Africa (StatsSA) (StatsSA, 2017):

- *Goal one:* To eradicate extreme poverty for every person in all countries; this is currently measured as people living on less than $1.25 (R20.00) a day (UN, 2016; StatsSA, 2017). Poverty is significantly associated with intellectual disability, the association between poverty and intellectual disability being evident in studies undertaken on the prevalence of intellectual disability (Adnams, 2010; Capri, Abrahams, et al., 2018; Emerson, 2007). Therefore, the eradication of poverty could have an impact on the prevalence of intellectual disability.
- *Goal two:* To end hunger and ensure access to safe, nutritious and sufficient food by all people. To end all forms of malnutrition in children under five years of age, and address the nutritional needs of adolescent girls, and pregnant and lactating women (UN, 2016). There is an association between malnutrition in children and intellectual disability. Adnams (2010) supports this by stating that childhood undernutrition is generally associated with concurrent and long-term global deficits that are evident in people with intellectual disability. These include deficits in cognition, behaviour and motor skills. Thus, nutritional deficiencies and growth stunting characterise multiple biological and psychosocial risks.
- *Goal three:* To ensure healthy lives and promote well-being for all at all ages. “To strengthen the prevention and treatment of substance abuse, including narcotic

drug abuse and harmful use of alcohol" (StatsSA, 2017, p. 60; UN, 2016, p. 20). There is an association between high levels of alcohol abuse and intellectual and cognitive disabilities. Most children and adults in South Africa with Foetal Alcohol Spectrum Disorder (FASD) function in the mild intellectual disability range (Adnams, 2010). The attainment of this goal will most likely have an impact in the prevalence of intellectual disability in South Africa.

- *Goal four:* Ensure inclusive and equitable education and promote lifelong learning opportunities for all. Children with mild and moderate intellectual disability are able to access basic education. However, the education system in South Africa is not inclusive and equitable for people with intellectual disability, as children with severe and profound intellectual disability are not able to access education (McKenzie et al., 2019). The WCFID's Right to Education Campaign seeks to address this issue in order to ensure inclusive and accessible education for people with intellectual disability.
- *Goal eight:* Promote sustained, inclusive and sustainable economic growth, full and productive employment and decent work for all. "By 2030, achieve full and productive employment and decent work for all women and men, including for young people and people with disabilities" (UN, 2016). Marshall et al. (2014) mention that supported employment aims to assist adults with mental or co-occurring disorders to choose, acquire, and maintain competitive employment. However, due to high unemployment rates, approximately 2% of people with intellectual disability received any form of supported employment (Marshall et al., 2014). In order for this goal to be achieved, more people with intellectual disability need to be placed in protective workshops or other supported employment programmes.
- *Goal ten:* Reduce inequality within and among countries. "By 2030, empower and promote the social, economic and political inclusion of all, irrespective of age, sex, disability, race, ethnicity, origin, religion or economic or other status. Ensure equal opportunity and reduce inequalities of outcome, by eliminating discriminatory laws, policies and practices and promoting appropriate legislation, policies and action in this regard (United Nations, 2016). Further, StatsSA (2017) states that reducing inequality is also a political imperative for improving the social cohesion across the country's diverse population. This goal can be achieved

through involving people with intellectual disability in policy-making and decision-making processes on issues that concern their lives. Petri et al. (2017) mention that people with intellectual disability have the right to self-representation in an environment that allows them to do so. Thus, inequality can be reduced by creating spaces that enhance and ensure participation and self-representation of people with intellectual disability.

- *Goal eleven:* Make cities and human settlements inclusive, safe, resilient and sustainable. By 2030, provide access to safe, affordable, accessible and sustainable transport systems for all, improving road safety, notably by expanding public transport, with special attention to the needs of those in vulnerable situations, women, children, people with disabilities and older persons. Provide universal access to safe, inclusive and accessible spaces, in particular for women and children, older persons and people with disabilities. Inclusion and accessibility in cities have largely focused on people with physical disabilities and often exclude people with intellectual disability (WHO & World Bank, 2011). It is therefore important to promote dialogues and actions to achieve greater, sustainable inclusion of people with intellectual disability in cities and communities.
- *Goal sixteen:* Promote peaceful and inclusive societies for sustainable development, provide access to justice for all and build effective, accountable and inclusive institutions at all levels. "Promote and enforce non-discriminatory laws and policies for sustainable development. Significantly reduce all forms of violence and related death rates everywhere. End abuse, exploitation, trafficking and all forms of violence against and torture of children. Promote the rule of law at the national and international levels and ensure equal access to justice for all" (UN, 2016). People with intellectual disability are usually at greater risk of experiencing violence and abuse than people without a disability. Moreover, they are often denied fair and equal treatment before the court (White et al., 2020). In order for this goal to be achieved, there must be transformative equality when identifying accommodations in court for people with intellectual disability. They should be able to participate equally in the justice system, without barriers and discrimination (White et al., 2020).

The SDGs are all interconnected, and they all help in promoting the rights of people with disabilities and ensuring that their rights are not violated by society, including the rights of people with intellectual disability. The Social and Human rights Models of disability suggest that the violation of people's rights, exclusion and neglect by society are the most disabling for people. It is through advocacy and self-advocacy of people with intellectual disability that their rights will be upheld, thus putting an end to discrimination.

The South African National Development Plan 2030 (Republic of South Africa, 2012) highlights disability in three sectors of government: social development, health and education (i.e., basic and higher education). Self-advocacy within these departments will address people with intellectual disability's priorities in both social and health policies.

1.8 Advocacy for People with Intellectual Disability

Families are usually the primary caregivers to people with intellectual disability and they play a very fundamental supporting role. In addition to their supportive roles, many families become advocates for people with intellectual disability, they educate communities, denounce stigma and discrimination, and fight for improved services (WHO, 2003). Moreover, some NGOs and non-profit organisations (NPOs) and mental health professionals work with families and other concerned individuals to advocate for people with intellectual disability (Daniels, 2018). Over and above that, NGOs contribute to the advocacy movement by supporting and empowering people with intellectual disability and their families.

General healthcare and mental healthcare workers advocate for people with intellectual disability. Their advocacy roles include, clinical work from a service user's and family's perspective, support the development of service user's groups and family groups, and planning and evaluating programmes together (WHO, 2003). The Mental Health Policy Framework and Strategic Plan 2014-2020 (Department of Health, 2013) highlights that Mental Health Review Boards in each province play a key role in advocating for the needs of service users and upholding and protecting their human rights.

1.8.1 Self-advocacy by people with intellectual disability

Self-advocacy by people with intellectual disability has been a point of discussion for decades. It has been defined differently by different scholars. Longhurst (1994) defines self-advocacy as a way of life that encourages people with disabilities to become as independent as possible in their thought and actions, while teaching them to live as equal citizens in society. According to Aspis (1997) self-advocacy is about speaking up for yourself, standing up for your rights, making choices, being independent and taking responsibility for oneself. It is about ensuring that people with intellectual disability can have a say about issues important to them, but it is also concerned with building individual and collective capacity among people with intellectual disability (Goodley, 2005). Mallander et al. (2018) define self-advocacy as an opportunity for people with intellectual disability to have a say and to develop their skills to do so.

Prior to the establishment of organised self-advocacy groups, life-histories were used to reveal the voices of those who have been historically silenced, where people collectively spoke up and challenged the systems (Ledger & Tilley, 2006). Life stories provide a way to identify and validate shared formative experiences, giving self-advocates in a growing movement the chance to strengthen their bonds by sharing their experiences with oppression and resistance across cultural and international boundaries (Ledger & Tilley, 2006).

The self-advocacy movement has emerged over the last few decades, being spearheaded by individuals with developmental disabilities (Goodley, 2005). The origin of self-advocacy dates back to the 1960s in Sweden, the 1970s in the United Kingdom and 1980s in the United States (Caldwell, 2010; Walmsley, Davies & Garratt, 2022). The first national self-advocacy conference was held in 1990 in Colorado, USA (Caldwell, 2010). The self-advocacy movement in the USA paved a way for people with intellectual disability to acquire skills and assume leadership roles, such as participating on boards and committees. The acquired skills help them to see themselves in different contexts and for others to see them in a different, positive way (Caldwell, 2010).

Over the years the self-advocacy movement has grown globally, and many countries are moving in that direction, with literature indicating that self-advocacy is more prominent in middle- and high-income countries (Henderson & Bigby, 2016). However, this is not to say that there are no challenges in these countries, in the UK, for example, self-advocacy movements have been negatively impacted by austerity (Tilley, 2013). Budget cuts were implemented on services for people with intellectual disability, this includes the reduction of funding on self-advocacy organisations (Rouse, Tilley et al., 2022; Tilley, 2013). However, some organisations have risen above this and continue through self-funding, fundraising and donations.

In South Africa, the self-advocacy movement is still at its infancy. Thus far, in South Africa, advocacy groups which include people with intellectual disability have been established in some provinces, often with the assistance of mental health NPOs, functioning at different levels. However, they often lack sufficient capacity to be strong, united and representative of voices for people with intellectual disability (SA Federation for Mental Health [SAFMH], 2022). Self-advocacy by people with intellectual disability is South Africa is nested in organisations, particularly, organisations providing services to mental health service users (Daniels, 2018). According to Daniels (2018) there are approximately six active mental health self-advocacy groups in the country affiliated to the South African Mental Health Advocacy Movement. These programmes include the full participation of service users, including people with intellectual and psychosocial disability (Daniels, 2018). These organisations empower their service users to lobby, advocate and promote their equal participation in initiatives that affect them, and afford them the opportunity to comment on service delivery, policy and legislation and human rights violations.

As yet, funding to develop self-advocacy groups by people with intellectual disabilty in South Africa is as yet not available outside of the budgets raised or allocated for this work by these NPOs. It is important to strengthen existing advocacy groups and create a platform where people with intellectual disability's voices will be heard. They require encouragement and support to participate in the socio-political lives of their communities (Friedman, 2017; Tronto, 2010). The exercise of rights for people with intellectual disability implies negotiating not only with individuals who aim to support their voices, dismantle restrictions and develop political behaviours, but also with those who prefer to maintain barriers. Because compliance and resistance to inclusive processes can be expected, self-advocacy groups and local intellectual disability organisations must be sustained (Capri, Abrahams, et al., 2018).

Self-advocacy enables people with intellectual disability to engage with ideas about rights and empowerment and to share and celebrate their personal resilience, often resulting in feelings of being powerful and strong (Goodley, 2005). Self-advocacy is used as a mechanism for social inclusion, providing a sense of belonging, social connections and occupation (Goodley, 2005). Caldwell (2010) further highlights that participating in self-advocacy is personally transformative for people with intellectual disability.

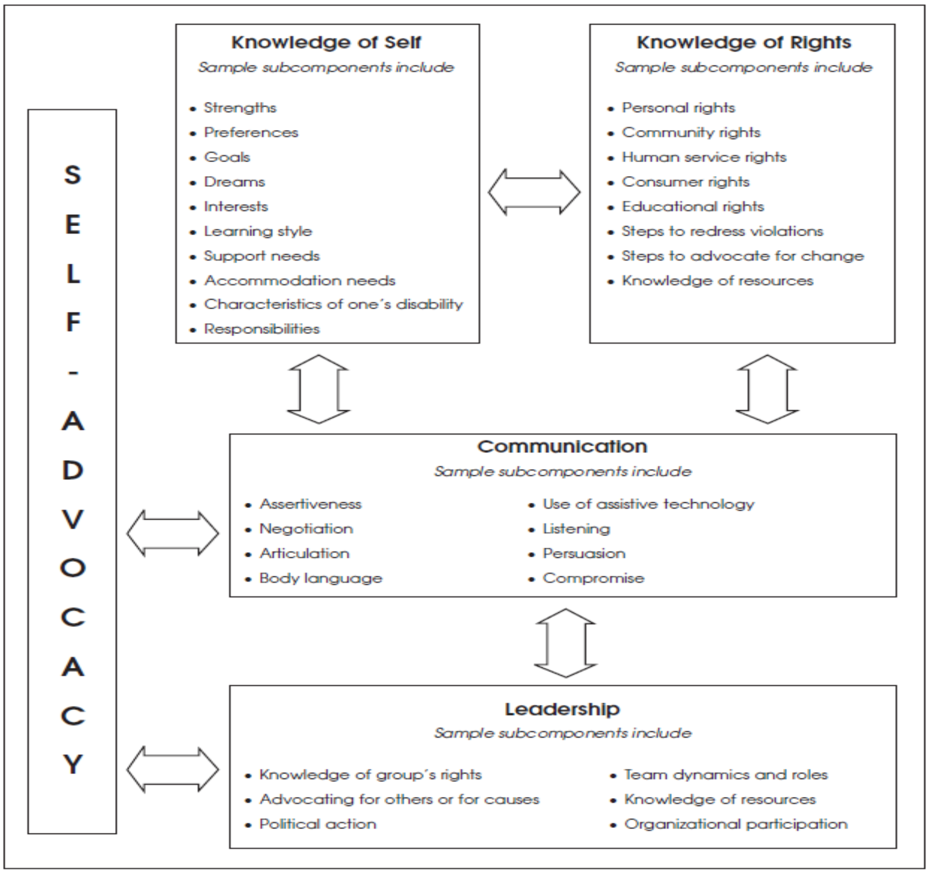
1.8.2 Conceptual frameworks for self-advocacy

Test, Fowler, Wood, et al. (2005) developed a conceptual framework for self-advocacy by people with disabilities. This framework was developed through the review of literature and engagement of stakeholders (i.e., people with disabilities, researchers, teachers, parents, and curriculum developers in the areas of self-determination and self-advocacy). The purpose of this framework is to guide teachers, families, students, administrators and researchers when planning instruction, developing effective instructional strategies, and evaluating student performance.

Below, in Figure 3, is an illustration of the conceptual framework developed by Test, Fowler, Wood, et al. (2005).

Figure 3

Conceptual Framework of Self-Advocacy



Source: Test, Fowler, Wood, et al. (2005, p. 49)

There is paucity of literature regarding conceptual frameworks for self-advocacy. From this brief review of literature, only one conceptual framework of self-advocacy for people with disabilities was found. However, an extensive scoping review of literature was conducted to determine the existence and implementation of other conceptual frameworks for self-advocacy, particularly for people with intellectual disability. The above conceptual framework will be discussed in detail in Chapter Three.

1.9 Theoretical Framework: Empowerment Theory

The empowerment theoretical framework provides a solid basis for understanding the significance of self-advocacy for people with intellectual disability. Rappaport (1987) developed the empowerment theory and defined it as “a process, a mechanism by which people, organizations, and communities gain mastery over their affairs. Consequently, empowerment will look different in its manifest content for different people, organizations, and settings” (p. 122). Empowerment is centred on helping marginalised people gain the personal, interpersonal and political power to improve their lives. It seeks to challenge systems that prevent or hinder people from having their needs met (Rappaport, 1987).

Empowerment has been defined as an intentional ongoing process centred in the local community, involving mutual respect, critical reflection, caring, and group participation, through which people lacking an equal share of valued resources gain greater access to and control over those resources; or a process by which people gain control over their lives, democratic participation in the life of their community, and a critical understanding of their environment (Perkins & Zimmerman, 1995). Empowerment is about the commitment it takes to do all the necessary activities that make groups and organisations effective and give their members a voice and a choice in collective decision-making and shared leadership (Perkins, 2010). These are most commonly found in small-scale grassroots organisations, such as self-advocacy groups. However, empowerment can also occur in larger organisations, such as political movements and campaigns that help participants feel they are a part of large and important causes or changes (Perkins, 2010; Perkins & Zimmerman, 1995).

Empowerment theory focuses on the strengths and is a non-expert driven approach that emphasises the ability of people facing difficult life circumstances or community conditions to define and actively engage in solutions to the problems confronting them (Peterson, 2014). The many interpretations of empowerment are based on the understanding of this concept as either a process or as an outcome. As a process, it occurs in communities or organisations, it involves active participation, critical reflection, awareness and understanding, and involves access to and control over important decisions and resources. As an outcome, empowerment is an interaction between individual and community change with a long timeframe, in terms of significant social and political change (Raeburn et al., 1993). For example, a change in government policy or legislation in favour of individuals and groups who have come together around programmes and community actions (Laverack & Wallerstein, 2001; Zimmerman & Rappaport, 1988).

For the purpose of this study empowerment will be used as the outcome of participation in self-advocacy and as a key part of the process of both developing and applying political and civic leadership. The main reason for this stance is that empowerment through self-advocacy is understood to be the process through which a person gains the actual power needed to make important improvements and contributions in social and health-related policies, and service-related decisions for people with intellectual disability.

1.9.1 Understanding self-advocacy through the empowerment approach

As noted above, self-advocacy by people with intellectual disability enhances their strengths and competencies (Anderson & Bigby, 2017). People with intellectual disability who have been part of self-advocacy groups tend to develop empowered identities, as these self-advocacy groups take on an empowerment approach, focusing on people first instead of focusing on the impairment (Henderson and Bigby, 2017).

Empowerment in mental health can be applied at two levels: micro (community) level and macro (social programme development and policy-making) level. Empowerment at a micro level entails citizen participation in community issues that directly affect them and empowerment at a macro level includes participation in legislative and policy matters (Perkins, 2010). An example of empowerment at a micro level is when people with intellectual disability advocate for their service needs, being allowed to make informed decisions about treatment and matters in their daily lives (WHO, 2003). Empowerment at a macro level entails people with intellectual disability effectively communicating and raising awareness of their needs and self-advocating on all public platforms for their rights to be implemented and their challenges to be addressed.

According to Goodley and Armstrong (2001), self-advocacy is a social movement that aims to promote self-empowerment and resilience. Self-advocacy enables people with intellectual disability to connect with the social and human rights models of disability through collective action (Clarke et al., 2015). Collective action can be achieved through self-advocacy groups that take on the empowerment approach, focusing on people first instead of focusing on the impairment (Goodley, 2005). Self-advocacy is a social rights movement that is about building alliances and coalitions, working together to achieve personal and group goals, looking out for one another, learning, and fighting discrimination (Cone, 1999).

Through self-advocacy people with disabilities are able to challenge the society to remove barriers imposed on them and fight for an inclusive society. Through self-advocacy, people with intellectual disability are able to challenge the government and policy makers to remove these barriers (Daniels, 2018). Self-advocacy is focused on the struggle for a life of quality in places and communities chosen by individuals with disabilities, for more and better services controlled by people with disabilities, and for greater social and political awareness in the disability community as a whole.

1.9.2 Empowerment in the context of *Ubuntu*

Ubuntu can best be described as an African philosophy that places emphasis on interdependence and as being self through others. It is a form of humanism which can be expressed in the phrases, “I am because of who we all are” (Mugumbate & Nyanguru, 2013). The philosophy of *Ubuntu* embraces that people experience their humanity through their interconnectedness and solidarity with others (Kleintjes, 2012; Murithi, 2007). The Xhosa proverb "Umntu ngumtu ngabantu," which translates to "A person is a person because of other people," best expresses the central premise of this philosophy. *Ubuntu* essentially means that a person is who they are because of other people, especially those around them. There are various discussions in literature regarding interdependence in *Ubuntu,* with a consensus that every person forms a link in a chain. An interdependent community is one in which individuals can only discover who they are through others, while recognising the distinctive identity of individuals (Breed & Semenya, 2015; Ewuoso & Hall, 2019; Murithi, 2007; Ngubane-Mokiwa, 2018). *Ubuntu* essentially is a philosophy of self-determination and empowerment, and it is understood to be a reciprocal process (Mji et al., 2011).

The empowerment theory encourages people with disabilities to actively participate in transformation processes that impact on their lives (DSD, 2016, p. 21). According to Kasmel and Andersen (2011), interdependence is an essential aspect of empowerment. Although empowerment emphasises the ability to speak up for oneself, for people with intellectual disability interdependence is essential for their empowerment. In order for some to be able to self-advocate they will need or depend on their supporters and/or families.

That, however, does not take away their self-determination and ability to speak up for themselves. Louw (2003) regards *Ubuntu* as more than just being who you are through others, *Ubuntu* extends to how people relate to and rely on others around them. People with intellectual disability have the right to self-representation in processes and structures of decision-making on issues that affect them (Republic of South Africa, 1997). In situations where they cannot represent themselves, they have the right to nominate anyone they trust to represent them. Empowerment is about having access to peer and other supporters during participation to facilitate self-presentation or co-presentation of ideas of people with intellectual disability.

1.10 Aim and Objectives

The aim of this study was to explore the views of different stakeholders on opportunities for, and barriers to, self-advocacy in order to develop a conceptual framework that will support people with intellectual disability to self-advocate for inclusion of their priorities in social and health-related policy in South Africa.

The research question was: What are the opportunities for, and barriers to, self-advocacy by people with intellectual disability, in social and health-related public policy and service development processes?

Objectives are:

(1). To conduct a scoping literature review of conceptual frameworks for self-advocacy.

(2). To explore the views of parents, carers, and people with intellectual disability about the opportunities for, and barriers to, self-advocacy and strategies to overcome these barriers.

(3). To explore and understand the views of policy makers, policy implementers and service providers and managers on the need for self-advocacy by people with intellectual disability in social and health-related policy development and implementation processes, opportunities for and barriers they might experience in including their views within the policy context and strategies to overcome these barriers.

(4). To develop a conceptual framework to guide self-advocacy for people with intellectual disability within a policy and service development context in South Africa.

1.11 Thesis Outline

Each chapter begins with an introduction providing an outline of the chapter and closes with a comprehensive conclusion. The chapters are arranged as follows:

Chapter One: Introduces the study and the background to the research and proceeds to introduce the components of the remaining chapters.

Chapter Two: Discusses the methodology used in this study. It discusses the research design, the phenomenological approach and rationale for the research methodology.

Chapter Three: Addresses Objective 1 of the study, by reporting the findings of a scoping literature review which explored the question, "*What do we know about conceptual frameworks to support self-advocacy by people with intellectual disability*?". The chapter reports limitations of the review and suggests future research in line with the findings of the review.

Chapter Four: Addresses Objective 2 of the study. It reports on the views of parents, carers, and people with intellectual disability about the opportunities for, and barriers to, self-advocacy and strategies to overcome these barriers.

Chapter Five: Addresses Objective 3 of the study. It reports the views of policy makers, policy implementers and service providers and managers on the need for self-advocacy by people with intellectual disability in social and health-related policy development and implementation processes, opportunities for and barriers people with intellectual disability experience in including their views within the policy context.

Chapter Six: Addresses Objective 4 of the study. It triangulates data from all the data sources reported in Chapters Two to Four, to present a conceptual framework to guide support for self-advocacy by people with intellectual disability within a policy and service development context in South Africa.

Chapter Seven: Is a concluding chapter, it discusses the findings, as well as the study's contributions and limitations. This chapter also includes suggestions for further research.

CHAPTER TWO

METHODOLOGY

2.1. Introduction

This chapter describes the research strategy used in the study. First, the chapter provides a brief overview of research design to locate the chosen research design for this study within the broader field of research, then it provides a brief overview of the philosophical orientation underpinning the chosen design, interpretative phenomenology. This is followed by a positionality statement for the researcher, and descriptions of the study population, sampling, and sampling procedures as well as data collection and data analysis methods used for the study. Finally, issues of trustworthiness and ethical considerations are described.

2.2. Overview of Research Design

A research design is a plan or blueprint of how one intends to conduct their research, it informs the decisions from broad philosophical assumptions to detailed methods of data collection and analysis (Babbie & Mouton, 2002; Creswell, 2003). The selection of a research design is based on the nature of the research problem, issue being addressed, the researchers' personal experiences, and the audiences for the study (Creswell, 2003). Generally, research methodology can be either quantitative, qualitative or be a mixed-methods design(Creswell, 2003).

2.2.1 Quantitative design

Quantitative research has its epistemological roots in positivism, experiential realism, and pragmatism (Kumar, 2011; De Vos, Strydom, Fouche & Delport, 2011). The positivist research philosophy depends on quantifiable observations that lead to statistical analyses. Positivists researchers begin with a theory or hypothesis, collect data that either supports or contests the theory or hypotheis, and makes necessary revisions and conducts additional tests (Kumar, 2011; Klein, 2015). Generally, quantitative research designs are more focused on numerical values while qualitative studies focus on text and soliciting meaning from data.

2.2.2 Qualitative design

Qualitative design is a method of inquiry meant to advance theories and comprehension (Creswell, 2009). Qualitative data collection helps in gaining in-depth and meaningful data from the perspectives of people who experience the issue under investigation, enabling the researcher to understand how people experience the research issue, and focuses on retaining the authentic rich meaning generated from participants when interpreting the data (Wilson & MacLean, 2011).

There are several types of qualitative research approaches.

Ethnographic studies involve the collection and analysis of data about cultural groups and encountering unfamiliar beliefs, behaviours, language, and values, and making sense of them (Creswell, 2007). Researchers immerse themselves in the setting, gathering field notes, interview transcripts documents and other artifacts which are used as data to identify key themes that characterize the group's culture and other practices. Reports present the researchers' findings in thick, comprehensive detail, with the view to assisting the readers to understand the culture (Creswell, 2007).

Grounded theory studies focus on collecting and analysing data to inform developing a theory based on the findings of the research. Data is primarily collected through observations and interviews. Theories generated are self-correcting, with changes made to the theory as new data are received.

Narrative researchers gather stories about people's actual lived experiences through records, group discussions, and oral histories (Creswell, 2013).. Data are gathered through compiling and analysing people's life stories about significant moments in time during the research process (Bruner, 1991). N arrative research conveys the story of individuals as their experiences are chronologically ordered, placed in their personal, social, and historical contexts, and include significant themes from those lived experiences.

Case studies are in-depth examinations of people, researchers are interested in the meaning of participants' experiences, rather than generalizing results to other groups of people (Stake, 1995). This approach involves researchers exploring a case or multiple cases within a bounded system over time through detailed, in-depth data collection involving multiple sources of information, such as observations, interviews, audio-visual material and documents (Creswell, 2007). Content analysis is used by the researcher to search for patterns and themes which the researcher t arranges into a chronology, compares and contrasts them with other cases, or presents them as a theoretical model (Creswell, 2013).

In *action research* putting solutions into practice is a key focus of the investigation in real time. In participatory action research (PAR), which is a specific type of community-based action research, the researcher and study participants work together as co-researchers on all aspects of the study, including selecting the appropriate research methods, analysing the data, and deciding how to use the findings (Buckles & Chevalier, 2019).

Phenomenological studies seek to make explicit the implicit structure and meaning of human experiences. Participants are asked to explain their experiences according to how they understand them. Although they might write about their experiences, interviews are usually used to gather information. The researcher must consider their own thoughts and feelings in order to comprehend the lived experience from the perspective of the subject (Creswell, 2007). Data analysis requires the researcher to immerse themselves in that data, interpret it and uncover the meaning of each participant's lived experience. (Creswell, 2013).

Overall, both qualitative and quantitative research designs are important in the generation of data, it is the researcher's choice to select the most suitable method depending on the nature of the phenomenon being studied, what they want to know about the phenomenon, and their goals for conducting the research (Creswell, 2003). For this study I chose a qualitative research design because I intended to explore and understand the views of different stakeholders on opportunities for and barriers to self-advocacy. Thereafter, I planned to analyse the data to inform the development of a conceptual framework for self-advocacy by people with intellectual disability. The qualitative method used in this study was underpinned by an interpretative phenomenological approach.

2.2.3 Philosophical stance: Phenomenological approach

There are two key perspectives within the phenomenological approach, namely, hermeneutic (interpretive) and transcendental (descriptive) phenomenology (Creswell, 2013). Husserl, the "father" of the phenomenological approach to research established his philosophy in the twentieth century to challenge a philosophy that was objective, empirical and positivist

(Sloan & Bowe, 2014). He viewed phenomenology as a philosophical method for delving deeper into reality in order to discover true meaning. The relationship between consciousness and objects of knowledge was the focus of Husserl's phenomenology, with an emphasis on the objects themselves (Sloan & Bowe, 2014). Husserl’s phenomenology is descriptive in nature and was developed to clarify how objects are experienced and present themselves to human consciousness (Spinelli 2005). Husserl’s perspective was called transcendental phenomenology because the researcher is thought to be able to transcend the phenomena and meanings being investigated to take a global view of the essences discovered (Moustakas, 1994).

The transcendental perspective within the phenomenological approach seeks to describe and understand the everyday experiences of people while suspending the researchers’ preconceived assumptions about the phenomenon (Neubauer, Witkop & Varpio, 2019). This approach has four main characteristics (Umanailo, 2019):

- *Descriptive*: Qualitative phenomenological research design aims to uncover what a particular experience means to a group of people and how they experienced it.
- *Essence*: The essence is the core meaning of individual experiences in certain phenomena.
- *Reduction*: Reduction is a process in which the beliefs, a priori assumptions and prejudices about the phenomenon held by the researcher(s) are set aside (bracketed) to focus mainly on the immediate experience gleaned from the research participants and to ensure that biases do not affect the description of the observations.
- *Intentionality*: It requires the researcher to first describe the lived experiences objectively and then reflect on the description with reference to existing theories about the phenomenon.

Husserl was professor at Freiberg University and had a student called Martin Heidegger (Spinnelli 2005). Heidegger developed his own strand of the philosophy; hermeneutic (interpretive) phenomenology (Spinnelli 2005), which departed in key ways from Husserl’s descriptive phenomenology. According to Heidegger, the researcher exists alongside the phenomena and the essences and cannot be separated from the essence-identification process. This would have to be considered by the researcher throughout the phenomenological process. It is not feasible, as Husserl proposed, to “bracket off” the researcher from his/her/their worldview and chosen methods of exploring and identifying the essence of a phenomenon, according to Heidegger, who claimed instead that a researcher cannot explore phenomena to discover their essences while remaining neutral or detached from it (Smith, Flowers et al., 2009).

I selected hermeneutic (interpretative) phenomenology as the most suitable approach for this study because my exploration of the lived experiences of the research participants was not aimed at describing these experiences as an end in itself, but rather to gain deeper insights into those experiences in order to conceptualise, through my own interpretation of the data, core elements of a support system required to support self-advocacy efforts by people with intellectual disability. Of the two phenomenological approaches, the hermeneutic perspective fitted well with my perspective that in my role as researcher I bring my own beliefs, history, culture experiences to the research endeavour, and that I am not able to remove the potential impact of my own worldview from my understanding and interpretation of the data I collect, but have to be aware of , and manage the potential impact of my own thoughts and feelings through rigorous research methods, in order to comprehend and relate the participants' lived experience in a trustworthy manner. This approach also allowed me to clarify my positionality as a researcher within the research process, knowing and understanding how my experiences and biases may contribute towards the research process.

2.2.3.1 Positionality of the researcher

Positionality describes an individual's world view and the position they adopt about a research task and its social and political context (Holmes, 2020). It is about where the researcher is coming from, their assumptions about human nature and assumptions about the way we interact with our environment and relate to it (Bahari, 2010; Holmes, 2020). These are informed by an individual's values and beliefs that are shaped by their political allegiance, religious faith, gender, sexuality, historical and geographical location, ethnicity, race, social class, and status, and (dis) abilities and so on (Holmes, 2020). Positionality statements are an important tool for being cognisant of our perspectives, beliefs, and underlying assumptions that we bring to the work we do in academia (Bahari, 2010). By assessing our biases and individual privileges, we can ensure our work is well-informed, intentional, and respectful towards participants.

My positionality statement:

I am young black South African woman. I had a challenging up-bringing in a disadvantaged community that lacked basic resources and I am now privileged to belong in the middle-class. I am a social worker, experienced with working with marginalised communities, including people with intellectual and developmental disabilities. I am passionate about giving back and serving marginalised people who are from similar communities as the one I grew up in. I believe that true empowerment lies in capacity building and inclusive citizenship. I have elected to conduct a study about self-advocacy by people with intellectual disability to learn more about their experiences and how I can be more inclusive in my role as a researcher and social worker. My own experiences have without a doubt shaped my view of the world, and therefore this positionality statement is an attempt to become aware of my own biases so I might eliminate them. By including this positionality statement in this research, I am admitting that this research study was not entirely objective, but that my background gave me a particular lens through which I saw the phenomena under investigation.

2.2.4 Data collection methods

The primary data collection method in phenomenological research are in-depth interviews (Frechette, Bitzas, Aubry, Kilpatrick & Lavoie-Tremblay (2020). Interviews are ideal to elicit experienced meaning, however, they may be insufficient to uncover phenomenon in a Heideggerian sense (Paley, 2014). Thus, this approach suggests the use of multiple data collection methods, known as method triangulation (Frechette et al., 2020). In this study., I used multiple data collection methods, including a scoping literature review, semi-structured interviews and focus group discussions.

According to Munn, Peters, Stern, Tufanaru, McArthur and Aromataris (2018, p.2) “scoping reviews are useful for examining emerging evidence when it is still unclear what other, more specific questions can be posed and valuably addressed by a more precise systematic review. They can report on the types of evidence that address and inform practice in the field and the way the research has been conducted. The general purpose for conducting scoping reviews is to identify and map the available evidence”. The scoping review methods used for this study were informed by the Preferred Reporting Items for Systematic Review and Meta-Analysis for scoping reviews (PRISMA-ScR) guidelines (Appendix 1). Eligibility included studies on conceptual/theoretical frameworks for self-advocacy for people with disabilities (including intellectual disability and other developmental disabilities) published between 1 January 2000 and December 2020. A detailed methodology used for the scoping review is outlined in Chapter Three.

De Vos et al., (2011, p. 351) mention that semi-structured interviews are used "to gain a detailed picture of a participant's beliefs about, or perceptions, or accounts of, a particular topic. The method gives the researcher and participant much more flexibility". Semi-structured interviews were used to document and understand the views of parents, carers/supporters, people with intellectual disability, policy makers/implementers and service managers/providers from the perspective of their lived experience of the phenomena of the study. This data collection method providing me with an opportunity to gain in-depth and meaningful data on the participant's views or perceptions (De Vos et al., 2011; Wilson & MacLean, 2011), in this instance, their views about the known opportunities for and barriers to self-advocacy for people with intellectual disability within policymaking and implementation processes in South Africa.

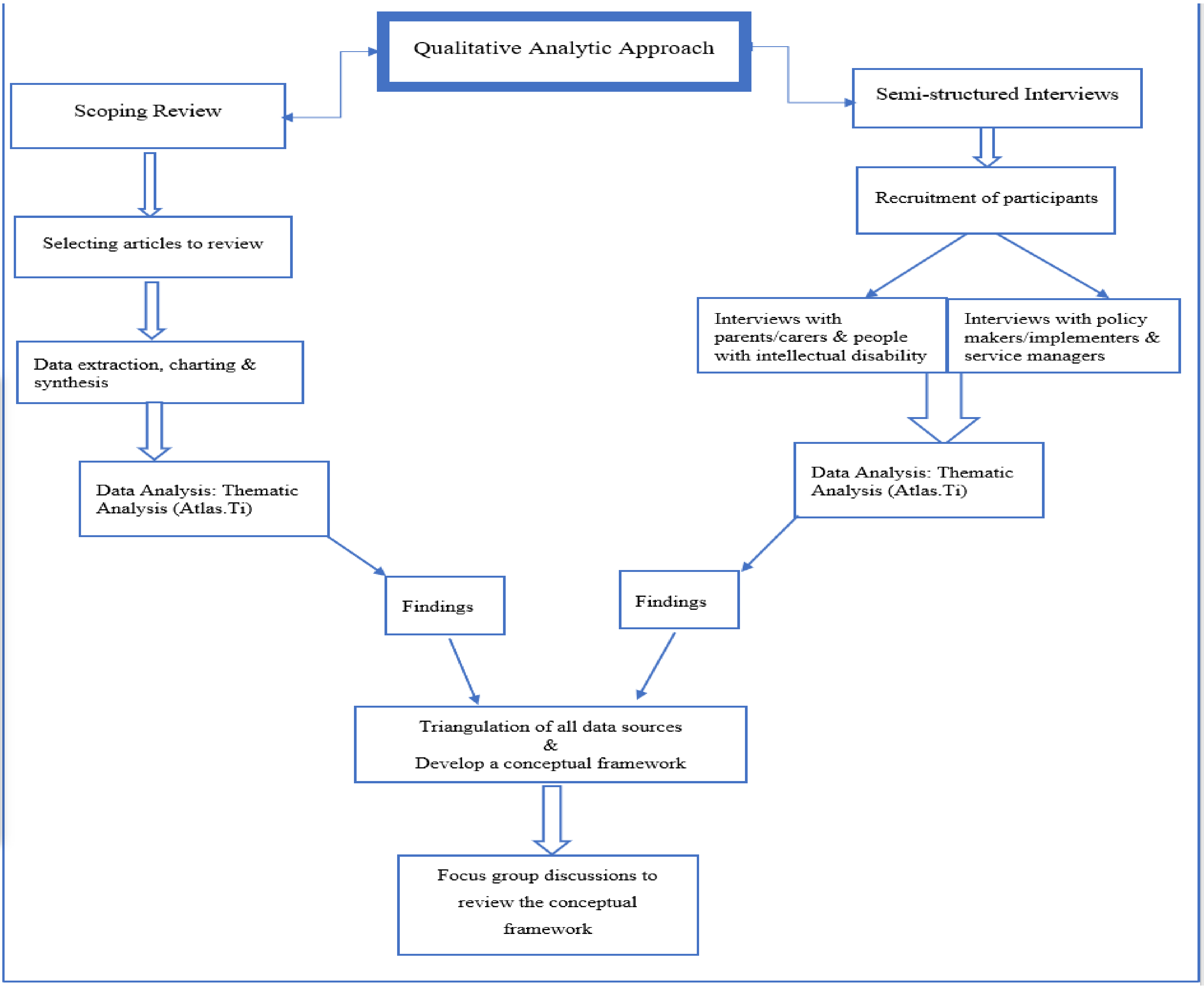
I am qualified social worker experienced with working with people with intellectual and developmental disability and their families. I am well versed in qualitative research and have experience in engaging in interviews with people with intellectual disability and their families, thus, capable of listening to and appropriately exploring the views of eliciting data from the participants. I am bilingual, a native isiXhosa speaker and fluent English speaker. I was able to conduct interviews in isiXhosa when participants were not comfortable with speaking English, as well as conducting interviews in English. In addition, the study is supported by a supervisor with experience in working as a clinical psychologist with people with intellectual disability. The combined experience of the supervisor and myself provided an environment for rich data to be elicited.

Focus groups were also used as a data collection method in this study. De Vos et al., (2011) mention that focus groups are a means of better understanding how people feel or think about an issue, product or service in a group context. They can also provide the researcher with participant feedback on how and whether they have captured participants views authentically, in interpreting the data which participants have provided, as was done in this study to establish whether the conceptual framework developed was a "true" reflection of participant views. Participants were selected because they have certain characteristics in common that relate to the topic of the focus group (De Vos et al., 2011, p. 360).

These three data collection methods were triangulated to deepen understanding of the research questions and to develop a conceptual framework which echoed the perspectives of participants in the research. Figure 4 illustrates the research design flow chart.

Figure 4

Research design flow chart



2.3 Study participants

A total of 25 SSIs were conducted. This study used criterion sampling, where I selected participants based on identified characteristics (McMillan et al., 2016), as outlined below under 2.3.1. Snowballing was also used to identify people with intellectual disability involved in self-advocacy groups in local NPOs (Palinkas et al., 2015). Two NPOs (herein referred to as NPO A and NPO B) which support, advocate for and provide capacity development opportunities for self-advocacy by people with intellectual disability were approached. In addition, an organisation that helps place people with intellectual and developmental disability to enter the job market in the Western Cape, and an educational organisation which provides people with intellectual disability with educational, life-skills and job skills training in the province were also approached to recruit participants with intellectual disability and other key informants. These are relatively small organisations, which have been anonymised to avoid identifying any of the participants.

A formal letter to request permission was sent to each organisation’s Director/Chief Executive Officer (CEO). The requests were reviewed, and a formal response was received indicating whether permission had been granted or not. Only the first two organisations listed above granted permission to conduct the study. Thereafter, the organisations’ assistance to recruit participants for the semi-structured interviews was sought.

Parents, carers, supporters and people with intellectual disability were informed about the study via distribution of information sheets outlining the study’s aims and intentions through each organisation’s usual communication strategies. One organisation (NPO A) provided a list of parents and carers of people with intellectual disability who responded to the call for participation, alongside a list of self-advocates with intellectual disability who expressed interest in participating in the study. NPO B provided a list of supporters of people with intellectual disability who were also interested in participating in the study. Supporters of people with intellectual disability working at these organisations were approached to assist the researcher with a request to support participants with intellectual disability to prepare for the interviews.

Policy makers/implementers and service managers/providers were recruited through their respective departments. The four national and provincial departments within the social cluster (health, social development, basic and higher education) were approached for formal permission to interview officials within these departments. Officials were purposefully sampled and approached to participate in the study. Once permissions were obtained from the relevant departments managers of group homes, educational centres for adults with intellectual disability, as well as support groups and community organisations were approached to request permission to advertise and recruit participants for the study within their organisations. Service providers and/or managers from nursing, social work, psychology, occupational therapy and medicine, representatives from professional associations, as well as NGOs and DPOs were included.

2.3.1 Eligibility criteria

Participants with intellectual disability eligible for selection were:

- Older than 18 years of age with intellectual disability.
- Able to understand the research study aims and their participation in the study (see informed consent procedures, Appendix 7).
- Able to communicate verbally in English, Afrikaans or IsiXhosa.
- Willing and able to participate in individual interviews and/or focus groups.
- Not experiencing an episode of mental and emotional distress at the time of the interview.
- Able to be fully informed of and understand the nature and purpose of the interview and confidentiality of information given during the interview.
- Able to participate voluntarily (no pressure to take part) and aware that withdrawal was possible or rescheduling if (s)he was not able to proceed.

The above requirements for participation excluded people with intellectual disability who are not able verbalise their thoughts and comment on the focus of the study. Engagement in the study required certain capabilities, as described above. People with intellectual disability who do not have the capacity for this kind of participation would require the support of advocates who speak on their behalf, and as this study is about self-advocacy, the researcher restricted the study participants with intellectual disability to those who are able to speak for themselves.

Parents and carers/supporters eligible for selection were:

- The primary caregiver of one or more people with intellectual disability.
- Supporters of one or more people with intellectual disability.
- Able to understand the research study aims and their participation in the study (see informed consent procedures, Appendix 7).
- Able to communicate verbally in English, Afrikaans or IsiXhosa.

2.4 Data collection

All interviews were conducted online via Zoom and WhatsApp calls. This was done due to the strict Covid-19 regulations in place at the time of the study. I am based in Cape Town and some participants, particularly, policy makers and service managers were based in Johannesburg (more than 1600km away), thus I could not ask for face-to-face interviews because of the Covid-19 travelling restrictions. NPO A had a very strict policy on research involving their staff and self-advocates, and during Covid-19 no physical or face-to-face interviews were allowed between self-advocates with intellectual disability and researchers. Similarly, NPO B had similarly strict policies. Both these policies aligned well with Covid - 19 procedures in place for student research at the University of Cape Town, and ethical approval was obtained for the study with these provisions in place. Thus, all the SSIs were conducted online.

People with intellectual disability were reasonably accommodated through simple, easy-to-read information sheets and consent forms. These were read and explained to them by their job coaches/supporters. Thereafter, informed consent was obtained from all the participants and confidentiality assured by removal of identifying material from interviews. The informed consent forms used for the study are included in the appendices (Appendix 7).

2.4.1. Interview schedules

The SSI guides were mapped from the research questions, informed by the literature review and were developed by the researcher (BT). The two interview schedules for participants with intellectual disability and for parents/carers/supporters are included in the appendices as Appendix 9 and 10.

The SSIs with participants with intellectual disability, parents/carers and supporters covered the following generic areas:

- What is self-advocacy and what it means to participants.
- Self-advocacy by people with intellectual disability.
- Opportunities for self-advocacy.
- Barriers to self-advocacy.
- Skills needed for people with intellectual disability to be able to self-advocate.
- Existing support structures for people with intellectual disability.

Thirteen interviews were conducted in English and two were conducted in isiXhosa, an indigenous language. Interviews were recorded on a voice recorder with participants' permission. English interviews were transcribed verbatim by an English-speaking transcriber. The isiXhosa interviews were translated to English by the researcher as a native isiXhosa speaker and transcribed verbatim.

I followed the same process for SSI guides for policy makers/implementers and service managers/providers. The interview schedules were similar for both groups of participants and are included in the appendices (Appendix 11).

The SSIs with policy makers/implementers and service managers/providers covered the following generic areas:

- What is self-advocacy and what it means to participants.
- The need for self-advocacy by people with intellectual disability in policy processes.
- Opportunities for self-advocacy in policy.
- Barriers to self-advocacy.
- Reasonable accommodations for people with intellectual disability.
- Establishing and developing existing support structures for people with intellectual disability.

All 10 interviews were conducted in English and were recorded with each participant's permission. Interviews were transcribed verbatim by an English-speaking transcriber.

2.5. Data analysis

Data were analysed using the Framework method, a structured form of thematic analysis within which thematic analysis of the data is guided by an initial coding framework, with new themes added as the researcher analysed the data iteratively (Ritchie & Spencer, 1994). The approach identifies commonalities and differences in qualitative data, before focusing on relationships between different parts of the data, thereby seeking to draw descriptive and/or explanatory conclusions clustered around themes (Gale et al., 2013; Ritchie & Spencer, 2013). The process comprises seven stages: transcription, familiarisation, coding, developing a working analytical framework, applying the analytical framework, charting data into the framework matrix and interpreting the data (Gale et al., 2013).

The Framework method can use both deductive and inductive types of qualitative analysis consecutively (Gale et al., 2013; Ward et al., 2013). Initially, in this approach, using a deductive approach, codes were pre-selected based on the specifics of the research question, previous literature reviewed and familiarisation with the data and then, using the inductive approach, themes were generated from the interview data that were meticulously coded through open (unrestricted) coding, followed by refining the preliminary themes, for example, adding new themes or sub-themes which I identified from the data, reframing original themes as sub-themes where overarching themes were identified as indicating data relationships not reflected in the preliminary coding frame (Gale et al., 2013; Swallow et al., 2003).

In line with Gale et al.'s process described above, I developed a preliminary coding frame based on key concepts in conceptual frameworks on self-advocacy identified in the scoping review (Cook, 2017; Owen, 2016; Test, Fowler, Wood, et al., 2005) as well as key themes on self-advocacy that emerged from the scoping review.

2.5.1 Transcription

From the interview's audio recordings, the researcher, together with a professional transcriber, transcribed the data verbatim. This was a good opportunity for the researcher to become immersed in the data (Gale et al., 2013).

2.5.2 Familiarisation

The researcher also read through the interview transcripts several times to familiarise herself with the data and to identify potential themes within the data for inclusion in the preliminary coding frame. During interviews the researcher used explorative comments and prompts, paraphrasing and summative statements to check whether she was correctly understanding participants' responses. Notes were also taken after each interview on possible themes which were raised by participants. Participants responses to these questions and summary statements and the field notes were also helpful in the researcher's quest to "stay with" participants views during this familiarisation stage and the coding which followed.

2.5.3 Coding, developing and applying a working analytical framework

Transcripts of the interviews were loaded into ATLAS.TI. ti software (version 9.1.7). Data in the transcripts were then coded against the themes and sub-themes created in the preliminary coding frame. Codes were grouped together into categories, which were then clearly defined. This formed a working analytical framework. There were several iterations of the analytical framework before no new additional codes were identified. Under each category there were codes labelled as "other" in order to avoid ignoring data that did not fit. Where a new theme or sub-theme emerged from this detailed coding of the transcripts which had not been captured in the initial coding frame, this theme or sub-theme was added to the coding frame in an interactive process. An example of a coding frame, a code forest/tree has been attached as Appendix 14.

2.5.4 Charting and interpreting data

The data were summarised by category from each transcript and charted into spreadsheets, then later reduced into themes with careful reflection on the data in order to avoid distorting the original meaning of the data. The identified themes were reviewed and refined, and checked if they reflected distinct themes and sub-themes related to the focus of the study. Data captured in each theme were reviewed and interpreted in a manner that ensured that they reflected a coherent story contributing to the study focus.

The research findings are outlined in Chapters Three, Four and Five. Chapter Six outlines the triangulation of all the findings and describes the process of developing the conceptual framework for self-advocacy by people with intellectual disability. The focus groups constellated to review the draft conceptual framework are also highlighted in Chapter Six.

2.6 Ethical Considerations

Ethical approval (Appendix 19) was obtained from the University of Cape Town's Faculty of Health Sciences Research Ethics Committee of the University of Cape Town (HREC no. 019/2021). Permission was also sought from various government departments to conduct interviews with officials in those departments. This study adhered to the guidelines of ethical considerations outlined in the Declaration of Helsinki (World Medical Association, 2013).

2.6.1 Potential risks of participating in the study

There was no physical risk and no significant emotional risk in this study. In the unlikely event that questions and discussions might have evoked any discomfort, I intended to address these concerns in the context of the interviews, group discussions and advocacy activities in a non- judgmental manner. Although this was planned for, there was no such occurrence during the data collection process.

2.6.2 Confidentiality

All data collected was securely stored, the names of the participants were protected at all times, as each participant was assigned a code ensuring that no private information was shared. The audio recordings were transferred and stored in password protected laptop and google drive (for backup) and only I, the transcriber and supervisor had access to these recordings. The transcriber signed a confidentiality agreement prior to receiving data from the study.

2.6.3 Informed consent procedures

Each participant was briefed and told why they are being asked to participate in the study and was given an information sheet explaining the purpose of the study and how the data would be used, such as for submission as a thesis, presentation at conferences and publication. Informed consent was obtained from the participants themselves, as only adults were included as participants.

2.6.4 Considerations of rigour in qualitative research

Norman and King (2020) mention that for qualitative research to have merit it must be believable and be truthful. Researchers need to employ methods for promoting trustworthiness and demonstrate how a qualitative study meets standard conventions for trustworthiness so that the work might serve the needs of those who are consumers of that research (Norman & King, 2020). Within the hermeneutic frame I have adopted, these measures are vitally important for me to regulate the impact of my own perspectives and potential biases in understanding and interpreting the data, in order to remain as close to the participants originally intended views as possible. The section below demonstrates how I ensured the trustworthiness of this study.

Confirmability: This refers to the degree to which the results of the analysis process would be similar if conducted by other researchers (Anney, 2014). The scoping review was conducted by three people to reduce researcher bias in inclusion and exclusion of studies.

Credibility: This relates to the confidence that can be assumed regarding whether the research findings represent a realistic interpretation of the original data (Anney, 2014). This was addressed as follows: support and guidance from my supervisor and review meetings with an advisory committee set up to provide academic and other advisory input to the conduct of the three sub-studies within the overall study of which this thesis was one sub-study. Members of the committee included two self-advocates with intellectual disability, their supporter, a representative of an NGO who worked in the area of self-advocacy support to people with intellectual disability, an experienced disability researcher and a clinical researcher who works as a psychologist in the field of intellectual disability.

I journaled the research process and my reactivity to these processes in order to ensure reflexivity. The hermeneutic approach emphasizes the significance of reflexivity during the process. According to Creswell (2007) reflexivity is a process in which researchers are conscious of and reflective about the ways in which their questions, methods and subject position might impact on the data or the psychological knowledge produced in a study. My reflexivity helped in interpreting the meanings discovered and added value to those interpretations. Focus groups provided an opportunity to review my interpretation of findings to address potential researcher bias.

Dependability: Involves an assessment of the quality of the processes for integrating data to ensure that it has been done in a consistent way. It establishes the research study's findings as consistent and repeatable and is an assessment of the quality of the processes of data collection, data analysis, and theory generation, ensuring that it has been conducted in a dependable way (Lincoln & Guba, 1985; Anney, 2014). This was achieved through an audit trail, where I accounted for all the research decisions and activities (Anney, 2014).

Transferability: This refers to the extent to which procedures and findings can be reviewed to assess utility for use in other contexts (Anney, 2014). The use of thick descriptions provided a detailed view of the research context, settings, timeframe, participants and procedures have been used to address this in this thesis.

2.7 Chapter Conclusion

This chapter described the procedures used to conduct the study. The study adopted a qualitative research method, which utilised an interpretative phenomenological approach to underpin the research design. The research participants included people with intellectual disabilities and their parents, carers and supporters, policy makers/implementers and service managers. A scoping review and semi-structured interviews were used to collect data, as well as focus group discussions to review the trustworthiness of the developed conceptual framework. The data analysis was explained as well as the strategies implemented to ensure the trustworthiness and rigour of the study. Ethical considerations that were made during the study were also highlighted.

CHAPTER THREE

SCOPING REVIEW

3.1 Introduction

According to Munn et al. (2018), "scoping reviews are useful for examining emerging evidence when it is still unclear what other, more specific questions can be posed and valuably addressed by a more precise systematic review. They can report on the types of evidence that address and inform practice in the field and the way the research has been conducted. The general purpose for conducting scoping reviews is to identify and map the available evidence" (p. 2).

A scoping review of literature was conducted to identify key concepts relevant to empowering direct policy participation by people with intellectual disability, including the identification of other relevant conceptual frameworks for self-advocacy which may be available to inform the focus of this study. This study's conceptual framework will aim to provide a guide to service providers, families, policy developers and administrators, researchers, NGOs and DPOs when planning policy-related work including people with intellectual disability, developing effective self-advocacy strategies, and other consultations with people with intellectual disability during policies development.

The preliminary review of the literature outlined in the introductory chapter indicated a paucity in literature regarding conceptual frameworks for self-advocacy for people with intellectual disability. From this brief review only one conceptual framework of self-advocacy was found. Test, Fowler, Wood, et al. (2005) developed a conceptual framework of self-advocacy for people with disabilities. Using this framework as the sole framework to guide the development of a framework for the focus of the present study was not be optimal, as it focuses on overall disabilities, is located within the educational teaching space and focuses on an individual level of self-advocacy, whereas this study aimed to develop a conceptual framework to self-advocacy specifically for people with intellectual disability at the policy level in the South African context.

3.2 Scoping Review Question and Sub-Objectives

The research question for the scoping literature review is: *What do we know about conceptual frameworks to support self-advocacy by people with intellectual disability?*

The literature review was carried out with the following sub-objectives in mind:

- To identify existing conceptual frameworks/models for self-advocacy by people with disabilities, including intellectual and developmental disability.
- To identify methods used to develop conceptual frameworks for self-advocacy by people with disabilities, including intellectual disability.
- To identify barriers to, and opportunities for, self-advocacy by people with intellectual disability in social and health-related public and service development processes.

3.3 Methods

Although this scoping review did not require ethical clearance, it is based on literature sought for a research study that obtained ethical clearance from the University of Cape Town's Faculty of Health Sciences Research Ethics Committee (HREC no. 019/2021). The Preferred Reporting Items for Systematic Review and Meta-Analysis for scoping reviews (PRISMA-ScR) guidelines was used to conduct the scoping review (Appendix 1). The following eligibility criteria was followed:

The inclusion criteria:

- Studies about conceptual or theoretical frameworks/models of self-advocacy for people with disabilities.
- Studies about conceptual or theoretical frameworks/models of self-advocacy for adults with intellectual disability.
- Studies describing data-based (quantitative or qualitative) interventions or components of interventions intended to promote self-advocacy for people with disabilities and intellectual disability.
- Studies published in peer-reviewed journals.
- Studies published in English.
- Studies published between 1 January 2000 and December 2020.

Exclusion criteria:

- Studies not addressing conceptual frameworks/models for self-advocacy.
- Studies not addressing interventions/components of intervention to support self-advocacy
- Studies which do not address people with disabilities and/or intellectual and developmental disability.
- Studies on children with intellectual disability.

The following databases were searched for relevant papers: Ebscohost (Academic Search Premier, Africa-Wide, MEDLINE, Pubmed, CINAHL and Science Direct), Web of Science and Scopus using Medical Subject Heading (MeSH) terms (or equivalent terms) for published peer-review journal articles relevant to the particular review. MeSH terms were finalised with input from the university librarian. Included studies focused on adults with intellectual disability, studies on self-advocacy related to municipal, provincial and national level policy and service development processes, and studies that focus on theoretical or conceptual frameworks for self-advocacy.

I was assisted by the librarian to refine the search terms, we looked at the focus of the study and listed the key terms to use when searching for the literature to conduct the scoping review. Key concepts (i.e., self-advocacy, conceptual frameworks, people with intellectual disability, barriers and opportunities for self-advocacy) of the study were explored. Thereafter, the synonyms of these concepts were also applied because in some studies, wording could be different. We also considered previously acceptable terms that are no longer used in literature, such as retardation or mental handicap, and other alternative words like learning disability and developmental disability instead of intellectual disability.

Peters, Marnie et al. (2020) mention that the process of evidence screening, and selection is usually conducted by a minimum of two reviewers, and any disagreements should be resolved by either consensus or with a third reviewer. The scoping review was conducted by three people, the researcher (BT) and other two colleagues from the University of Free State (MX) and Tshwane University of Technology (NN). The purpose of this was to reduce bias on inclusion and exclusion of studies and to increase reliability. In this study the third reviewer

(MX) exited the study due to personal reasons after we had completed the final list of inclusion at the abstract review stage.

Sourced articles (Appendix 2) were reviewed by title and abstract by the three reviewers. Full text articles (Appendix 3) were then reviewed by BT and NN using inclusion and exclusion criteria to derive the final list for inclusion (Appendix 4). Each included article was read several times by BT and NN, extracting the findings and entering these on the standard data extraction forms. Although quality assessment is not a requirement for scoping reviews, as inclusion of all relevant articles provides the broader overview of available literature which is the focus of a scoping review (Munn et al., 2018; Peters et al., 2020), the papers were reviewed for quality to bring further rigour to the process. Critical Appraisal Skills Programme (CASP, 2022) tools were used for quality assessment of the included studies.

3.3.1 Search terms

The following search terms were employed for the literature review:

Table 3.1

Scoping review search terms

“Conceptual framework” OR “Theoretical frameworks” OR “Models”
AND “Advocacy” OR “Self-Advocacy” OR “Self-determination” OR “Personal autonomy”
AND “Policy” OR “Social Policy” OR “Health Policy” OR “Policy participation” OR “Policy engagement” OR “Policy Inclusion”
AND “Barriers” OR “Challenges” OR “Difficulties”
AND “Opportunities” OR “Chances” OR “Prospects”
AND “Adult” OR “Elder” OR “Middle Aged” OR “Young Adult”
AND “Disability” OR “disabilities” OR (intellectual disability) OR (intellectual disabilities) OR (developmental disability) OR (developmental disabilities) OR (learning disability) OR (learning disabilities) OR (mental retardation) OR (mental handicap)

3.4 Results

By following PRISMA-ScR guidelines, 168 articles were identified overall, and 66 articles were removed because they were duplicates and did not address conceptual frameworks or self-advocacy for people with disabilities or intellectual disability. The total of 102 articles were found to be suitable for further review for this study. These articles were assessed by title and abstracts by the reviewers. This process was repeated twice in order to ensure rigour for this study. From the first abstract review, 61 articles were selected, and after the second review 40 articles were selected for full-text review. After full-text review 21 articles were excluded. Studies were excluded because they either did not address conceptual or theoretical frameworks for self-advocacy, they did not address participation for and barriers to self-advocacy, they were studies about professionals advocating on behalf of people with intellectual disability, and they were studies about children with intellectual disability.

The reviewers agreed to include 19 articles. One additional article was found on the reference list of one of the reviewed articles, thus making a total of 20 included studies based on the inclusion criteria. The 20 articles were included because they are studies about conceptual frameworks for self-advocacy by people with disabilities, they described interventions intending to promote self-advocacy by people with intellectual disability and they were about adults with intellectual disability. Figure 5 below illustrates the process followed to select studies to be included in this scoping review.

3.4.1 Characteristics of included articles

The included papers (*n* = 20) are summarised in Table 2.3 in reference to alphabetically ordered first author and date, study location, title, study design, phenomenon of interest and outcome. Studies made use of quantitative (*n* = 2), qualitative (*n* = 17) and mixed-methods (*n* = 1) designs. Of the 20 studies, nine studies addressed intellectual disability only and 11 studies addressed disabilities in general. None of these studies included people with disabilities (i.e., intellectual and or learning disabilities) in the study design and during the implementation of the research process.

Figure 5

Selection Process

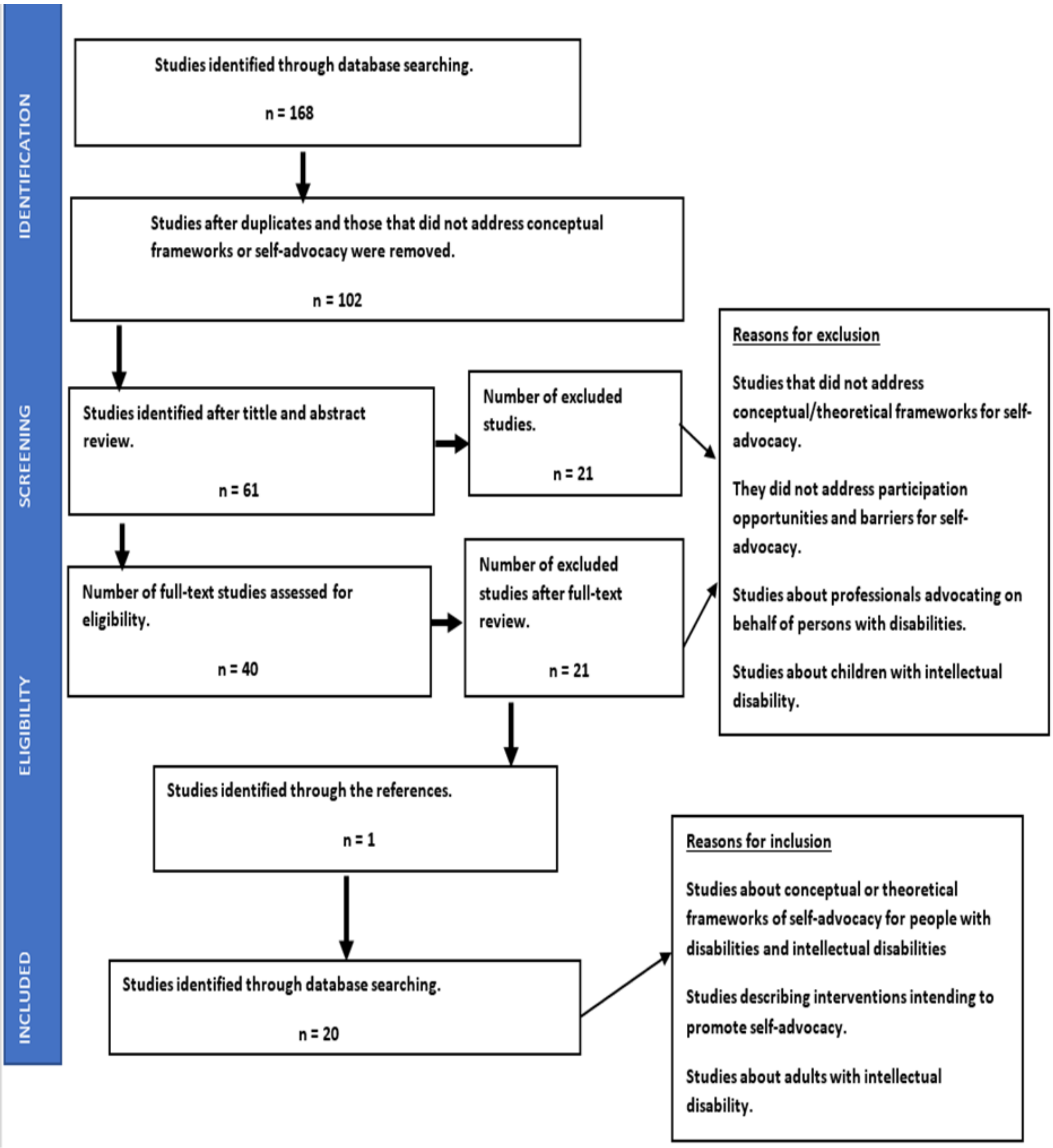


Table 3.2

Characteristics of Selected Studies

First Author & Date	Study Location	Title of Paper	Study Design	Phenomenon of Interest	Outcomes
Azzopardi, A. (2000)	Malta	A case study of a parents' self-advocacy group in Malta: The concepts of 'inclusion, exclusion and disabling barriers' are analysed in the relationship that parents have with professionals.	Qualitative (literature review, own experiences, document review questionnaire)	Self-advocacy and advocacy by parents of people with disabilities	Parents of disabled children provide each other with support within the group that is extensively involved in self-advocacy and is starting an activist approach to issues.
Balint-Langel, K. (2019)	United States of America	Using a Computer-Based Strategy to Teach Self-Advocacy Skills to Middle School Students with Disabilities.	Quantitative (pre- and post-test experimental design)	Improving self-advocacy skills of middle school students with mild and moderate disabilities	Post-test results showed a significant positive difference for students in the treatment group compared to the wait-list control group for the Self-Advocacy Self-Report.
Bigby, C. (2014)	United Kingdom, New Zealand and Australia	Conceptualizing inclusive research with people with intellectual disability.	Qualitative (literature review)	Inclusive research for people with intellectual disability	A strong self-advocacy movement is identified as one of the conditions necessary for inclusive research to flourish.
Cook, A. (2020)	United States of America	Using an inclusive therapeutic theatre production to teach self-advocacy skills in young people with disabilities.	Quantitative (The therapeutic theatre intervention)	Therapeutic theatre intervention for learning self-advocacy skills in people with disabilities	Increased assertiveness, a component of self-advocacy because of the therapeutic theatre production.

Cook, A. L. (2017)	United States of America	Employing a social justice framework to promote postsecondary transition for students with intellectual disability.	Qualitative (literature review)	Conceptual framework: The Multicultural and Social Justice Counselling Competencies (MSJCC)	Increased equity and access to inclusive Post-Secondary Education and postsecondary transition planning for students with Intellectual disability.
Fisher, M. H. (2020)	United States of America	Applying the self-determination theory to develop a school-to-work peer mentoring programme to promote social inclusion.	Qualitative (Semi-structured Interviews and Focus Group Discussion)	Social inclusion for people with intellectual and developmental disabilities	The peer mentoring programme helps in building self-advocacy skills.
Fiedler, C. R. (2007)	United States of America	Self-advocacy instruction: Bridging the research-to-practice gap.	Qualitative (interviews and case studies)	Enhancing self-advocacy skills of students with disabilities	The students expressed strong sentiments regarding self-advocacy. Students with disabilities could be supported in exercising self-advocacy skills with a minimal investment of time and resources.
Frawley, P. (2011)	Australia	Inclusion in political and public life: The experiences of people with intellectual disability on government disability advisory bodies in Australia.	Qualitative (Interviews and observations)	Social inclusion in political and public life of people with intellectual disability on government disability advisory bodies	The political perspective of members with intellectual disability varied, but all had a background in self-advocacy. They found the work hard but rewarding and encountered both practical and intangible obstacles to participation.
Grove, N. (2015)	United Kingdom	Finding the sparkle: Storytelling in the lives of people with learning disabilities.	Qualitative (Story sharing and Interviews)	Self-Advocacy through storytelling	Story sharing has been found to promote increases in communication, participation, relationship building and decision-making.
Islam, M. R (2015)	Kuala Lumpur, Malaysia	Advocacy for Empowerment: A Case of the Learning-Disabled People in Malaysia.	Qualitative (Case study, focus group discussions, and documentations surveys)	Advocacy and empowerment	Advocacy is a powerful tool towards empowerment at individual, family, and community levels for the learning-disabled people.

Johnson, K. (2014)	Ireland and Australia	Inclusive research: Making a difference to policy and legislation.	Qualitative (life stories and focus groups)	Inclusion of people with intellectual disability in policy and legislation	The outcomes of the research included the development of workshops for people with intellectual disability, families and service providers, the production of three short films of the stories narrated by members of the advisory group, and the research led to a change in government policy.
Kimball, E. W. (2016)	United States of America	College students with disabilities redefine activism: Self-advocacy, storytelling, and collective action.	Qualitative (Semi-structured Interviews)	Self-Advocacy of students with disabilities	Activism manifested in a range of behaviours that fit into different themes. The main theme shows students learned basic advocacy skills from parents early in life.
Landmark, L. J. (2017)	United States of America	Experiences of Disability Advocates and Self-Advocates in Texas.	Qualitative (Surveys, case study and interviews) or volunteers, individuals without disabilities, and then family members	Advocacy and self-advocacy for people with disabilities	The results indicated that disability advocates and self-advocates rely most on other individuals with disabilities to assist them in advocacy efforts, followed by advocacy staff.
Nonnemacher, S. (2011)	United States of America	“I'm Supposed to be in Charge": Self-Advocates' perspectives on their self-determination support needs.	Qualitative (in-depth semi-structured interviews)	Self-Advocacy for people with intellectual disability	Participants described self-determination in terms of speaking out for themselves, being in charge, making decisions, and having control over the things they want.
Owen, A., (2016)	United States of America	Nominal Group Technique: An accessible and interactive method for conceptualizing the sexual self-advocacy of adults with intellectual and developmental disabilities.	Qualitative (Participatory Action Research method, Nominal Group Technique)	Conceptual framework for sexuality self-advocacy for people with intellectual disability	Interdependence is a core aspect of self-determination for people with IDD because they often rely on other people in their lives to provide support so they can enact their self-determination.

Pfeifer, M. A. (2020)	United States of America	Speaking up: A model of self-advocacy for STEM undergraduates with ADHD and/or specific learning disabilities.	Mixed method (Semi-structured Interviews and Survey)	Conceptual Framework for self-advocacy	A development of a revised model of self-advocacy for students with ADHD/Learning disability.
Roberts, E. L. (2016)	United States of America	Review of Practices That Promote Self-Advocacy for Students with Disabilities.	Qualitative (literature review)	Test's Conceptual framework for self-advocacy for students with disabilities	The reviewed practices taught self-advocacy skills through published curricula, peer tutoring, writing strategies, employment skills training, transition planning involvement, direct instruction, college-based transition programmes, a weeklong programme, and supporting students to lead their IEP meetings.
Test, D. W. (2005)	United States of America	A content and methodological review of self-advocacy intervention studies.	Qualitative (A Content and Methodological Review of Self-Advocacy)	Conceptual Framework for self-advocacy	Studies indicated that participants demonstrated self-advocacy skills in new situations and expressed satisfaction with instruction.
Test, D. W. (2005)	United States of America	A Conceptual Framework of Self-Advocacy for Students with Disabilities.	Qualitative (literature review and interviews)	Conceptual Framework for self-advocacy for people with disabilities	By analysing and differentiating the components that make up self-advocacy, students, parents, teachers, and service providers may be better able to understand the concept and to identify self-advocacy goals for individual students.
Tideman, M. (2015)	Sweden	Young people with intellectual disability--the role of self-advocacy in a transformed Swedish welfare system.	Qualitative (in-depth interviews)	Self-Advocacy for people with intellectual disability	Findings suggest that participation in self-advocacy groups opens up members for increasing health and well-being through new roles and identities, and it strengthens their control over everyday life. Support is still needed, however, but in new ways; otherwise, the restrictions of the institutions will simply be reconstructed in the new welfare system.

3.5 Data Analysis and Synthesis

The next stage included data extraction, each article being read several times, extracting the empirical findings and entering these on the standard data extraction form, where key items of information obtained from the reviewed articles were captured. Our data extraction approach recorded information about the process of each conceptual/theoretical framework or intervention included in the review so that its outcome is contextualized and more understandable to readers (Arksey & O'Malley, 2005; Peters et al., 2020).

Data extraction forms for qualitative studies (Appendix 5) used SPIDER (Sample, Phenomenon of Interest, Design, Evaluation, Research type) and for quantitative studies (Appendix 6) used PICOS (Population, Intervention, Comparison, Outcome, Study design) elements, respectively (Cooke et al., 2012). The forms were developed by the two reviewers, to capture relevant data from included studies, for example: Authors' name(s), date of publication, name of the publishing journal, purpose of the study and context of the study, sample and methods used, findings including theoretical understanding of and conceptual frameworks for self-advocacy, strategies employed and impact of self-advocacy. Table 3.3 and Table 3.4 are examples of the data extraction sheets.

Table 3.3

Examples of Data Extraction Form for Qualitative Studies (SPIDER)

First author	Sample and setting	Phenomenon of interest	Design	Evaluation	Research type
Fisher, M. (2020)	n=31 USA	Conceptual Framework for Social Inclusion	Semi-structured Interviews and Focus Group Discussion	The peer mentoring programme helps in building self-advocacy skills	Qualitative
Pfeifer, M. A. (2020)	n=25 USA	Conceptual Framework for Self-Advocacy	Semi-Structured Interviews and Survey	A development of a revised model of self-advocacy for students with ADHD/Learning disability	Mixed method

Table 3.4

Examples of Data Extraction Form for Quantitative Studies (PICOS)

First author	Population & setting	Intervention, comparison, and/or effect size	Outcome	Study design
Cook, A. (2020)	n=15 USA	The therapeutic theatre intervention for participants with disabilities was used as the pre- and post-test measure. The participants scored significantly higher in the post-test (M = .88, SD = .92) than in the pre-test t (12) = (3.48), p = 0.005.	Increased assertiveness, a component of self-advocacy because of the therapeutic theatre production.	Quantitative (Drama Therapy Role Play Intervention)
Balint-Langel, K. (2019)	n=19 USA	A pre- and post-test experimental design with random assignment to treatment and wait-list control groups was employed to investigate changes in student participation and level of self-determination.	Post-test results showed a significant positive difference for students in the treatment group compared to the wait-list control group for the Self-Advocacy Self-Report.	Quantitative

A data synthesis approach outlined in Ritchie and Spencer (1994) was then used to conduct the data synthesis. Ritchie and Spencer (1994) describe a technique for synthesizing and interpreting qualitative data by sifting, charting and sorting material according to key issues and themes. In line with this approach, the process followed in this review was as follows: I charted data from the first two articles on the data extraction form, the second reviewer (NN) conducted a quality assurance check to ensure that the data was properly charted. It is suggested that the review team become familiar with the source results and trial the extraction form on two or three studies to ensure all relevant results are extracted (Peters et al., 2020). I then charted data from the rest of the remaining articles and NN continued with quality assurance.

Data were synthesized and analysed thematically; this was done through the aid of the ATLAS.ti software. The deductive thematic analysis approach was used, where I had preliminary codes and themes that were identified during the data charting process. Braun and Clarke (2006) mention that a deductive approach involves coming to the data with some preconceived themes you expect to find reflected there, based on theory or existing knowledge. This approach comprised of six stages:

familiarisation, generation of initial codes, searching for themes, reviewing and defining themes, writing up (Braun & Clarke, 2006; Maguire & Delahunt, 2017).

I uploaded the articles on ATLAS.ti ti, read them several times to gain an overall impression of the emerging themes. Each article was coded for themes embedded in the empirical findings and the authors' discussion of the findings. Each article was read, and I logged similar ideas under themes which had emerged from previously coded articles, and new ideas were logged under new themes. The ideas logged under the initial themes were reviewed several times, with the articles consulted again when necessary to clearly identify and refine the core ideas, similarities, differences and dilemmas emerging within and across the articles.

3.6 Identified Themes

The data synthesis process identified 10 sub-themes. These were then integrated into four main themes (Table 3.5). During the data synthesis process, it was evident that one paper can produce more than one theme, thus, there was an overlap of themes. The first main theme speaks to self-advocacy ($n=9$) and addresses how people with intellectual disability view this concept, methods or programmes that have been used to teach self-advocacy, and skills learnt through self-advocacy. The second theme speaks to the conceptual/theoretical frameworks used for self-advocacy by people with disabilities ($n=5$) and addresses the development and components of the framework, its implementation, and its outcomes or impacts. Thirdly, inclusive citizenship ($n = 6$) speaks to the opportunities for and barriers for self-advocacy by people with disabilities (including intellectual disability). Finally, the fourth theme highlights the overall experiences of self-advocates ($n=6$), these include the positive and negative experiences of being a self-advocate with disabilities.

Table 3.5

Themes and Sub-Themes from the Scoping Review

Theme	Sub-themes	Papers from which themes emerged
Self-advocacy	People with disabilities' views on self-advocacy. Methods or programmes for teaching self-advocacy. Skills learnt through self-advocacy.	Owen et al. (2016) Nonnemacher & Bambara (2011) Balint-Langel et al. (2019) Cook (2020) Fiedler (2007) Grove (2015) Islam & Cojocaru (2015) Kimball et al. (2016) Roberts et al. (2016)
Conceptual/theoretical Frameworks	Methods used for developing the framework. Implementation of the framework. Outcomes/impacts of the framework.	Cook (2017) Owen et al. (2016) Pfeifer et al. (2020) Test, Fowler, Wood, et al. (2005) Test, Fowler, Brewer, et al. (2005)
Inclusive citizenship	Opportunities for participation in society. Barriers to participation in society.	Azzopardi (2000) Johnson et al. (2014) Kimball et al. (2016) Landmark et al. (2017) Fisher (2020) Frawley & Bigby (2011)
Experiences of Self-advocates	Positive (being heard, having an influence, meaningful contributions). Negative (stigma, not being acknowledged, adding numbers).	Bigby et al. (2014) Frawley & Bigby (2011) Islam & Cojocaru (2015) Johnson et al. (2014) Nonnemacher & Bambara (2011) Tideman & Svensson (2015)

Below, we elaborate on the themes identified in Table 3.5:

3.6.1 Self-advocacy

One well-accepted definition of self-advocacy is the “ability to assertively state wants, needs and rights, determine and pursue needed supports, and conduct your own affairs” (Nonnemacher & Bambara, 2011, p. 328). Self-advocacy, with the key components identified relating to self-determination, assertiveness, confidence and decision-making. Petri et al. (2017), for example, define self-advocacy as the ability to speak on behalf of oneself, motivating for one’s needs verbally or in writing, using pictures or gestures.

Similarly, several authors (Azzopardi, 2000; Goodley, 2005; Nonnemacher & Bambara, 2011) highlight that self-advocacy is about ensuring that people with intellectual disability can have a say about issues important to them, and it is also concerned with building their individual and collective capacity. People with intellectual disability and disabilities at large describe or view self-advocacy in various ways, mostly based on their experiences.

3.6.1.1 People with disabilities’ view on self-advocacy

People with intellectual and developmental disabilities (IDD) involved in self-advocacy movements describe self-advocacy as independent groups of people with disabilities working together for justice by helping each other take charge of their lives and fight discrimination (Bigby et al., 2014). The concept of self-advocacy has also been defined by people with IDD as the ability to speak up for their rights and getting the information and support to increase their consent capacity.

In a study conducted by Owen et al. (2016), one self-advocate with intellectual disability mentioned that “self-advocacy teaches us how to make decisions and choices that affect our lives so we can be more independent. It also teaches us about our rights, but along with learning about our rights we learn responsibilities” (p. 176). Similarly, other self-advocates with intellectual disability highlighted the importance of support (Owen et al., 2016; Tideman, & Svensson, 2015), and that it is through supportive systems that they learn about self-advocacy and building their confidence. Self confidence in these groups is seen as one of the key components for self-advocacy. Furthermore, people with intellectual disability view interdependence as a core aspect of self-determination because they often rely on other people in their lives to provide support so they can enact their self-determination (Owen et al., 2016; Wehmeyer, 1998). These supports can be informal or formal, such as skills building programmes.

3.6.1.2 Programmes for teaching self-advocacy and skills learnt by self-advocates

Self-determination and self-advocacy are mostly viewed as one construct and are defined as encompassing the ability to make your own decisions, being able to solve problems, set goals and take the initiative to accomplish those goals (Balint-Langel et al., 2019, p. 1). Without self-determination skills, people with disabilities may rely on other adults to make crucial decisions regarding their lives and goals (Balint-Langel et al., 2019). There have been a great number of practices developed to effectively support people with disabilities to develop self-advocacy skills. Three reviewed papers discussed various strategies to develop people with disabilities' self-advocacy skills and self-determination capabilities; these will be discussed below.

3.6.1.2.1 A computer-based strategy to develop self-advocacy skills (Balint-Langel et al., 2019)

Self-Advocacy Strategy (SAS) is a research-based self-determination intervention that prepares students with disabilities to become active participants in meetings (Balint-Langel et al., 2019). This strategy can be delivered through various methods of instruction (i.e., live teacher instruction or computer-assisted instruction). The computer-based instruction was developed to minimise teacher instruction and increase independence among students when learning self-determination skills (Balint-Langel et al., 2019; Lancaster et al., 2002).

The computer-based programme that teaches self-advocacy skills included six lessons: Introduction, SHARE behaviours (a set of social skills necessary for effective communication in a variety of educational and professional meetings), Inventory, PLAN steps, Conferences and Review (Balint-Langel et al., 2019). Table 3.6 below summarises the lessons taught in this programme.

Table 3.6

Lesson Structure

Name of the lesson	Purpose	Process	Competence measurement
Introduction	To provide an overview of the computer-based strategy.	Learn and define self-advocacy, critical skills to develop self-advocacy and discuss the benefits of this strategy.	Students take a quiz where they will have to obtain 80%, when scores are lower students retake the quiz until they meet this criterion.
SHARE behaviours	To describe and demonstrate SHARE behaviours: Sit up straight, Have a pleasant tone of voice, Activate your thinking, Relax, and Engage in eye communication.	Instructors described and modelled each behaviour and students watched the demonstration.	Students take a quiz over the SHARE behaviours.
Inventory	To record learning strengths; areas to improve or learn, goals, and interests; and choices.	Students create an inventory list pertaining to their needs. Within each of the identified areas, students identify their strengths, areas to improve upon, and future goals.	N/A
PLAN steps	Teach students The PLAN steps: (a) Provide your inventory information, (b) Listen and respond, (c) Ask questions, and (d) Name your goals.	Students watch video clips of student instructors using the PLAN steps.	Students take a quiz over these steps.
Conferences	To provide feedback on the learnt behaviours and steps.	Students evaluate instructors applying the SHARE behaviours and the PLAN steps in different meetings and contexts.	Students provide feedback.
Review	To provide a general overview of the strategy.	Students participate in two role-play activities (i.e., simulations of educational meetings) with the instructor.	Role play indicates students' competence or lack thereof.

In this study, participants were grouped into two groups, the wait-list control group and treatment group. During treatment intervention, students in the wait-list control group attended their regularly scheduled classes. The control group received intervention after the treatment group completed the generalisation phase (Balint-Langel et al., 2019). The overall findings indicated that post-test results showed a significant positive difference for students in the treatment group compared to the wait-list control group for the self-advocacy self-report.

The majority of the students (57%) in the treatment group used an overall pleasant tone of voice and displayed eye contact for the majority of the time during the meetings. Therefore, the majority of students in the treatment group successfully applied the SHARE behaviours in a different setting (i.e., informal educational meetings) and with a different person (i.e., special education teachers).

3.6.1.2.2 Inclusive therapeutic theatre production for young people with disabilities (Cook, 2020)

This quantitative pilot study utilised an inclusive therapeutic theatre production for young people with disabilities to establish if involvement in the production could affect self-advocacy skills, specifically assertiveness. The population of this organisation includes people with physical, developmental and intellectual disabilities. It also comprises of people with mental health disorders such as anxiety, depression and suicidal ideation, and medical illnesses such as Traumatic Brain Injury, stroke and cancer (Cook, 2020).

The study employed a pre-post design with the Drama Therapy Role Play Intervention (DTRPI). Data were gathered from cast members taking part in a therapeutic theatre production. The production served as the intervention for this study. The main theme of the production was how self-advocacy could be used to better one’s life and the lives of people in one’s community. The participants attended 15 rehearsals over five weeks, each lasting approximately one-and-a-half hours.

Self-advocacy was introduced as a topic to the cast, first through the script and then through an explanation of the concept and discussions during the rehearsal process. Self-advocacy was talked about in non-research-oriented terms through accessible language because participants had varying cognitive levels. The assessment instrument, the DTRPI, was used as a pre- and post-measure for this study because it provides a tool to evaluate assertiveness levels in populations with disabilities

(Cook, 2020). Though not a perfect match for the current study's population, the DTRPI was the preferred choice of instrument based on its test-retest validity, its use with disabilities populations, and its inter-rater reliability score (Cook, 2020).

An overall pre-/post-test agreement of 92.5% was calculated for the assertiveness variable, as assertiveness was the main variable being measured (Cook, 2020). The participants' change score (M = .88, SD = .92) indicated a statistically significant difference from the pre- to post-test scores on assertiveness (t(12) = (3.48), p = (0.005). These results indicated that the therapeutic theatre intervention and its components of educational information and discussion facilitation focused on self-advocacy may have strengthened participants' assertiveness levels when advocating for themselves.

3.6.1.2.3 Finding the sparkle: Storytelling in the lives of people with learning disabilities (Grove, 2015)

The ability to tell a story, whether personal or fictional, is a skill which can enable people to build a sense of identity, friendship, community and self-advocacy (Grove, 2015). Storytelling, therefore, is widely recognised as an important tool for enhancing quality of life. Narrating is a cognitive, linguistic and social task involving general knowledge about events. Life-stories are people's accounts of their past experiences as told to another person or persons at various points in time (Grove, 2015).

The training course was developed with the aim of developing the skills of storytelling (Grove, 2009). The course ran one day a week for terms of ten weeks over two years, and followed a structured sequence, addressing different aspects of story. Each week, there was an opportunity for students to tell a story, either independently or collaboratively. These included: themes and symbols of myths and legends, the collection of personal stories, work on specific narrative skills, and the development of a sense of group identity (Grove, 2009, 2015).

The stories that were explored involved some legends about disability, yielding insights into cultural history, and those featuring characters and situations to which the students might relate. Interviews with the participants during the project revealed that what they valued about the course were the opportunities to go out, meet new people and perform or teach, the sense of being part of a strong and friendly group, gains in confidence and an enjoyment of stories (Grove, 2015).

Overall, the storytellers learnt to advocate for themselves and others, they developed confidence and assertiveness, which are identified as key components to self-advocacy (Grove, 2015). These programmes have contributed to teaching self-advocacy skills and improving the skills that self-advocates already possessed. It is evident from the literature that learnt self-advocacy skills require regular practice and application. Programmes such as story-sharing have been found to promote increased communication, participation, relationship building and decision-making, especially when setting time aside for small regular gatherings where both staff and service users can develop and practise their skills (Grove, 2015).

Islam and Cojocaru (2015) also note that through self-advocacy people with disabilities learn the right to self-determination, to speak out and be heard, the right to make choices, the right to services, consumer control, and citizenship. The authors go on to mention that involvement in a self-advocacy group is an effective way to train people with learning disabilities to become more independent (Islam & Cojocaru, 2015). Thus, self-advocacy groups have provided people with learning disabilities with opportunities to develop independence and leadership skills.

3.6.2 Conceptual/theoretical frameworks

This second theme discusses the conceptual/theoretical frameworks used for self-advocacy by people with disabilities that were identified from the scoping review. Of the five studies that addressed conceptual frameworks for self-advocacy for people with disabilities, only three frameworks were identified.

The conceptual framework by Test, Fowler, Wood, and colleagues (2005) was developed with the purpose of guiding teachers, students, families, administrators and researchers when planning instruction, developing effective instructional strategies and evaluating student performance (Test, Fowler, Wood, et al., 2005). This framework was developed for the school or education setting, where students with disabilities can use the key components to advocate for themselves and others. The second conceptual framework (Multicultural Social Justice Counselling Competencies) was developed with the primary focus on the counselling professionals. The components of this framework are to help guide counselling advocacy and interventions (Cook, 2017). The third conceptual framework is a more practical framework that includes the participation of people with intellectual disability. This framework was developed to equip people with intellectual disability to advocate for their sexual rights (Owen et al., 2016). Table 3.7 is a summary of the conceptual frameworks, while Table 3.8 illustrates the cross-cutting themes within the components of these frameworks.

Table 3.7

Summary of Conceptual Frameworks

Conceptual framework	**Author & date**	**Purpose of the framework**	**Targeted population**	**Methods used to develop the framework**	**Components of the framework**
Conceptual framework of self-advocacy	Test, Fowler, Wood, Brewer and Eddy (2005)	To use as a guide for teachers, families, students, administrators, and researchers when planning instruction, developing effective instructional strategies, and evaluating student performance.	Students with disabilities	Literature review and stakeholders’ engagement	- Knowledge of self - Knowledge of rights - Communication - Leadership
Multicultural and social justice counselling competencies	Cook (2017)	To help students with intellectual disability transition to post-secondary education through applying a framework of advocacy.	Counselling professionals	Literature review and engaging counselling professionals.	- Self-awareness - Client worldview - Counselling relationship - Counselling advocacy and interventions
Conceptual framework for sexuality self-advocacy for adults with intellectual and developmental disabilities	Owen, Arnold, Friedman and Sandman (2016)	To enable and equip people with intellectual disability to advocate for their sexual rights.	People with intellectual and developmental disabilities	Participatory Action Research method and Nominal Group Technique	- Self-determination - Interdependence

Table 3.8

Cross-Cutting Themes of the Conceptual Frameworks

Conceptual framework	**Components of the framework**	**Correlation of key components**				
		Support systems	**Self-knowledge**	**Worldview**	**Self-advocacy skills**	**Public policy advocacy**
Conceptual framework of self-advocacy	Knowledge of self		**X**			
	Knowledge of rights			**X**		
	Communication				**X**	
	Leadership					**X**
Multicultural and social justice counselling competencies	Self-awareness		**X**			
	Client worldview			**X**		
	Counselling relationship	**X**				
	Counselling advocacy and interventions					**X**
Conceptual framework for sexuality self-advocacy for people with intellectual disabilities	Self-determination				**X**	
	Interdependence	**X**				

3.6.2.1 Framework 1: Conceptual framework of self-advocacy

Test, Fowler, Wood, et al. (2005) developed a conceptual framework of self-advocacy for people with disabilities. This framework was developed through the review of literature and engagement of stakeholders (i.e., people with disabilities, researchers, teachers, parents and curriculum developers in the areas of self-determination and self-advocacy).

According to Test, Fowler, Wood, et al. (2005), the conceptual framework is comprised of four components, including knowledge of self, knowledge of rights, communication, and leadership. “Knowledge of self and knowledge of rights are viewed as the foundations of self-advocacy because it is necessary for individuals to understand and know themselves before they can tell others what they want” (Test, Fowler, Wood, et al., 2005, p. 45). The third component that is critical to self-advocacy is the ability to “communicate information effectively with others through negotiation, assertiveness, and problem solving in individual and group situations of one’s knowledge of self and rights” (Test, Fowler, Wood, et al., 2005, p. 45). Leadership, as the fourth component, “enables a person to move from individual self-advocacy to advocating for others as a group of individuals with common concerns. Individuals learn about their own strengths and needs and how to express themselves regarding their needs and preferences before developing advocacy skills for a group of individuals with similar needs and preferences” (Test, Fowler, Wood, et al., 2005, p. 45).

The authors go on to say that one does not necessarily need to engage in the leadership component of the conceptual framework to become a successful self-advocate, as leadership includes other aspects, such as the awareness of the common needs of others, working with others, group dynamics, and responsibilities. The conceptual framework developed by Test, Fowler, Wood, et al. (2005) is illustrated in Figure 3 (see section **1.8.2 Conceptual frameworks for self-advocacy**).

Test, Fowler, Wood, et al. (2005, p. 51) mention that this conceptual framework was developed to be used as a guide for teachers, families, students, administrators, and researchers when planning instruction, developing effective instructional strategies, and evaluating student performance. The authors further mention that this conceptual framework can be improved, and more frameworks could be derived from it. The authors note that this framework provides a starting point and a point of departure for more advanced self-advocacy frameworks (Test, Fowler, Wood, et al., 2005).

Pfeifer et al. (2020) used Test, Fowler, Wood, et al.’s conceptual framework to characterise the self-advocacy experiences of students with Attention-Deficit/Hyperactivity Disorder (ADHD) and Specific Learning Disorder (SLD) in undergraduate students. From this study there was evidence of all components of Test, Fowler, Wood, et al.’s conceptual framework of self-advocacy and the authors operationalise each based on the participants' experiences. They identified novel components of self-advocacy for students with ADHD/SLD in undergraduate courses, including knowledge of learning contexts and knowledge of accommodations and the process to obtain them, as well as a novel self-advocacy behaviour and filling gaps. Thus, students demonstrated their capacity to take action to mitigate perceived limitations within their context (Pfeifer et al., 2020).

3.6.2.2 Framework 2: Multicultural and Social Justice Counselling Competencies

According to Cook (2017), Multicultural and Social Justice Counselling Competencies (MSJCC) build from the Multicultural Counselling Competencies (MCC) developed by Sue et al. (1992), and recently updated by Ratts and colleagues (2015), have been adopted to support the needs and strengths of developing youth, including young adults with intellectual disability (Cook, 2017; Ratts et al., 2016; Sue et al., 1992).

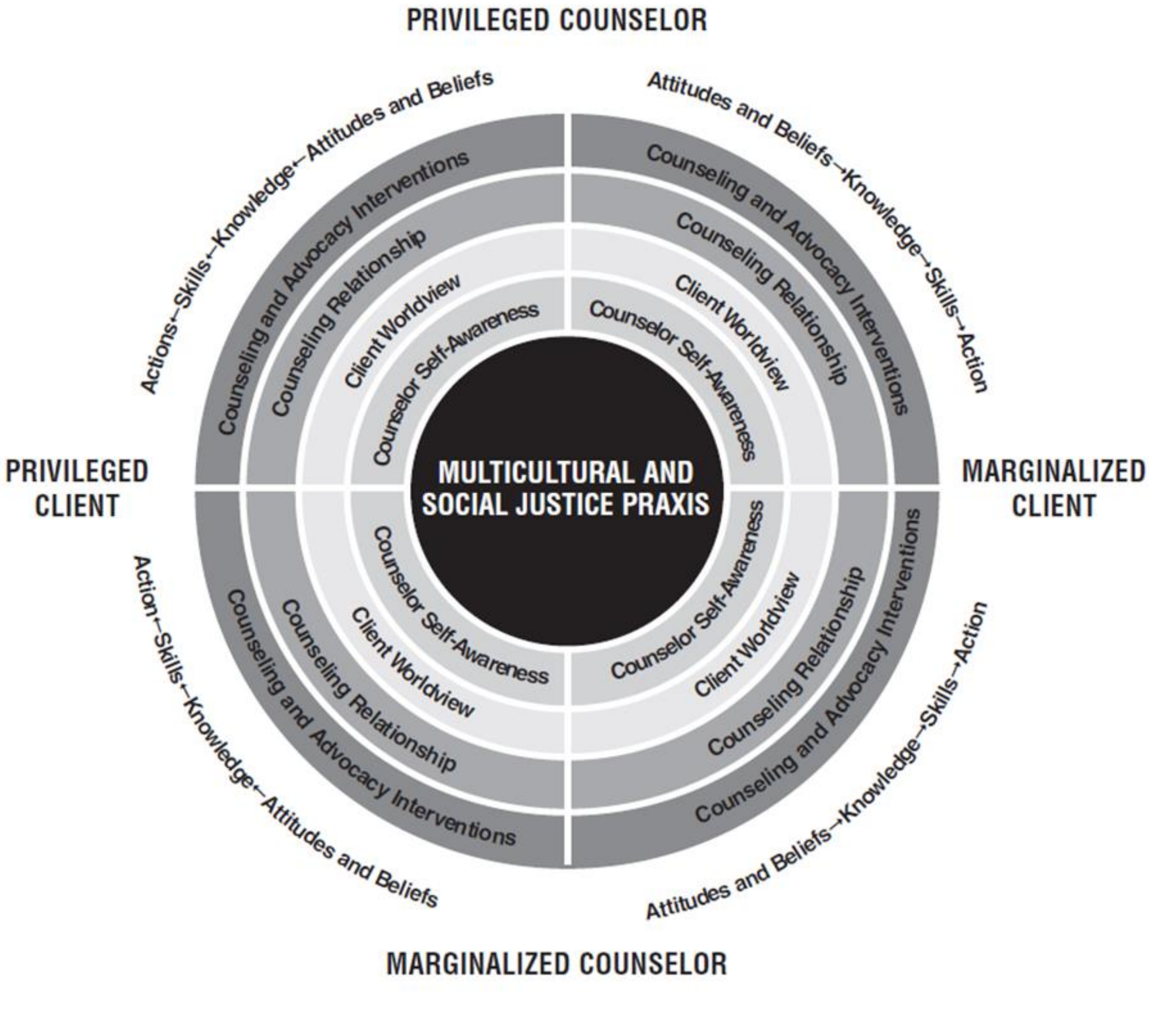
The MSJCC were developed due to the growing need to update the MCC. A committee was commissioned to update the MCC to reflect a more inclusive and broader understanding of culture and diversity that encompasses the intersection of identities and to better address the expanding role of professional counsellors to include individual counselling and social justice advocacy (Ratts et al., 2016). This process involved a literature review of relevant multicultural competency literature, engaging in discussions with other professions regarding their multicultural competency documents, identifying strengths and gaps within the original MCC document, and obtaining feedback from the American Counselling Association (ACA) and the Association for Multicultural Counselling and Development (AMCD) members and leaders through professional electronic mailing lists and focus groups conducted at the ACA national conference (Cook, 2017; Ratts et al., 2015). Upon the acceptance and endorsement of the MSJCC, the original MCC document was replaced. The term "social justice" was incorporated into the title of the revised competencies to reflect the growing changes in society (Nassar-McMillan, 2014; Ratts et al., 2016).

There are four components of the MSJCC's development and practice: (a) self-awareness, (b) client worldview, (c) counselling relationship, and (d) counselling advocacy and interventions. These components are relevant to building knowledge and acquiring a social justice orientation in ways that inform counselling practice that is relevant to specific community- and population-based needs and strengths of youth with intellectual disability (Cook, 2017; Hays et al., 2007). These four components are crucial for advocacy and teaching self-advocacy to people with intellectual disability. Figure 6 below illustrates the MSJCC framework.

Figure 6

Multicultural and Social Justice Counselling Competencies Framework

(Source: Ratts et al. (2015, p. 4)



The first three components (self-awareness, client worldview and counselling relationship) of this framework are developmental competencies: attitudes and beliefs, knowledge, skills and action (Ratts et al., 2016). Counsellors must firstly strive to become aware of their values, beliefs, and biases. This internal awareness then extends to counsellors' understanding of clients' worldviews and, subsequently, the ways in which culture, power, privilege, and oppression influence the counselling relationship (Cook, 2017). In turn, this entire process enables counsellors to collaborate with their clients in determining interventions and strategies that are multiculturally responsive and that promote social justice through advocacy (Cook, 2017; Ratts et al., 2015, 2016).

The fourth component (counselling advocacy and interventions) integrates the socioecological perspective to address person and environment interactions. This perspective is similar to Bronfenbrenner's ecological systems theory (Bronfenbrenner, 1994). This theory suggests there are multiple factors, both internal and external, that interconnect to impact an individual's development (Cook, 2017). Counselling advocacy and interventions are considered across various dimensions, including, intrapersonal, interpersonal, institutional, community, public policy and international/global levels (Cook, 2017; Ratts et al., 2016).

Overall, the MSJCC framework provides a link between multicultural and social justice competence, which has implications for counsellor advocacy. It integrates advocacy as a necessary aspect of multicultural and social justice competence (Cook, 2017). Therefore, counsellors should seek to refine their understanding of social justice and advocacy related to working with culturally diverse clients and communities (i.e., people with disabilities).

3.6.2.3 Framework 3: Conceptual framework for sexuality self-advocacy for people with intellectual disability: The Nominal Group Technique

Many advances have been made regarding the quality of life of people with IDD, including increased access to community services, supported employment, and the growth of the Self-Advocacy Movement. However, people with IDD are still often perceived as both hypersexual and asexual, stripped of their identities as sexual beings, and viewed as lacking capacity to consent to sexual relationships (Murphy and O'Callaghan, 2004; Owen et al., 2016). Additionally, because of power imbalances, people with IDD must often advocate regarding their sexuality, forcing them to engage with other people, particularly those in authority, in ways that non-disabled people do not experience (Owen et al., 2016). Owen et al. (2016) emphasise that sexual self-advocacy is an important concept to develop and apply to policy and practice because it provides opportunities to address relational and structural power inequalities.

This study provides a conceptualisation of sexual self-advocacy, a view of sexuality formulated by adults with IDD that is closely tied to the values of the Self-Advocacy Movement. Participatory Action Research (PAR) method and Nominal Group Technique (NGT) were used as methods of gaining insight from adults with IDD. The topic of sexual self-advocacy is important to people with IDD (Owen et al., 2016). This exploratory study asked people with IDD what sexual self-advocacy meant to them. Many aspects of this research design, including the conceptual framework, method, and data analysis, were guided by the core themes of the Self-Advocacy Movement, including self-determination and interdependence (Owen et al., 2016).

The process of conceptualising sexual self-advocacy was completed during an all-day community research forum in Chicago. The community research forum was planned collaboratively with the research team. On the day of the forum, self-advocates participated in activities about sexual self-advocacy, nominal group technique, and a closing circle process. The activities included relationship and safety role-playing scenarios in addition to a short presentation on the sexual bill of rights for people with disabilities. These activities aimed to educate self-advocates and to ensure that they understood the question asked during the nominal group technique (NGT).

This technique (NGT) was introduced as a time for everyone to share their ideas and then discuss those ideas as a group. During the NGT, participants were asked: “What does sexual self-advocacy mean to you?”. During the initial brainstorming period, which lasted about seven minutes, participants wrote down or drew their responses, with assistance from support people if necessary. The support people were given specific instructions not to influence the responses of the participants, but to merely support participants in writing down their ideas (Owen et al., 2016).

All participants shared their ideas, examples of participants’ responses include, “Being comfortable with other people”, “Respect others’ girlfriends about sex” and “I have the right to have my opinions.… I have the right to have privacy when I want”. After all participants had shared their ideas, participants were presented with the themes and asked if they agreed with the themes and if anything was missing. Participants added a few more ideas but agreed that the themes were valid.

In the final step, participants ranked their top three themes. Participants were given three sticker dots to use in voting and they could vote multiple times on one theme or spread their votes among the themes. Once the facilitator and several assistants had tallied the votes, the top-ranked themes were announced. The theme with the most votes was “my choices” (Owen et al., 2016, pp. 179–180). From the feedback given during the circle process, after the nominal group technique, several participants experienced a sense of accomplishment at the end.

3.6.3 Inclusive citizenship

Inclusion is perceived as a fundamental principle to social understanding and respect (Azzopardi, 2000). It is about a community for all, where the individual is seen as a whole. Inclusion is not an abstract concept but a policy discourse that has different interpretations depending on the historical context. Rowland (2004) mentions that the expression “nothing about us, without us” should be upheld when addressing issues concerning people with disabilities, this expression emphasising self-representation and empowerment.

3.6.3.1 Opportunities for participation

In line with the tenth sustainable developmental goal, Landmark et al. (2017) mention that in the US, different States provide opportunities for self-advocacy by individuals with disabilities in the most integrated setting as is appropriate. Advocates’ and self-advocates’ voices have an important place in discussions about community-based services and supports. Self-advocacy is used as a mechanism for social inclusion, providing a sense of belonging, social connections and occupation (Goodley, 2005; Landmark et al., 2017). Caldwell (2010) further highlights that participating in self-advocacy is personally transformative for people with intellectual disability.

Frawley and Bigby (2011) mention that in most high-income countries there are support structures put in place for people with intellectual disability to be able to participate fully in communities through self-advocacy. This is also done in self-advocacy group settings where people with intellectual disability receive individualised support for their specific needs

(Caldwell, 2010; Frawley & Bigby, 2011). Additionally, people with disabilities and their family members have opportunities to advocate for accessibility causes, and community-based services and healthcare.

Furthermore, most self-advocacy groups are an important source of support in creating opportunities for people with an intellectual disability to contribute, and with the confidence to do so. Support elements, such as support for accessing information, developing knowledge relevant to the participation, engaging in the processes of the participatory body, forming relationships, and direct skill development are most common in self-advocacy groups. However, the most common type of support is often individualised, and is usually provided by support workers external to advisory bodies (Frawley & Bigby, 2011).

One example of individualised support for people with intellectual disability is captured in the study conducted by Fisher et al. (2020). This study reported a model for a peer mentoring programme between individuals with IDD attending a school-to-work transition programme housed at a large, public university. Mentors were undergraduate students without disabilities attending the university and mentees were students with IDD. The goal of this programme was to help both individuals with and without IDD maintain social connections and have a greater sense of community when transitioning from high school to the community environment. The mentees said they enjoyed the peer mentoring programme because it helped integrate into the community with same-age peers and build their confidence when trying new activities. Additionally, several mentees said they socialise more with people in general now because they feel confident in using and applying the skills that they learned with their peer mentor during the programme (Fisher et al., 2020).

Similarly, a study conducted by Kimball et al. (2016) highlights that some opportunities are created by colleges and universities when partnering with kindergarten–Grade 12 (K–12) schools for tutoring and mentoring programmes. This creates potential collaborations in cultivating and supporting students with disabilities. Kimball et al. (2016) further mention that despite participants in their study seeming to have parents who taught them to self-advocate, this might not be a reality for all students with disabilities. Some people with disabilities often experience barriers towards their participation, thus limiting them from inclusive citizenship.

3.6.3.2 Barriers to participation

People with intellectual disability often experience tangible and intangible barriers when participating in society, particularly with their involvement in policy development or advisory bodies (Frawley & Bigby, 2011). These barriers include systemic barriers, negative attitudes and exclusion by society for people with disabilities (Retief & Letšosa, 2018). Moreover, the social model of disability highlights ableist social and environmental factors in society as the most common barriers to participation for people with disabilities (Oliver, 1990; Retief & Letšosa, 2018). Bigby et al. (2014), for example, mention that people with intellectual disability still are not treated as equal citizens, their rights are violated, with stigma playing a significant role in the violation of their human rights (Bigby et al., 2014; Lund, 2016).

A review of the South African literature by Kleintjes et al. (2020) further highlights a lack of inclusion of people with intellectual disability in policy, treatment and support-service decisions in this context. Furthermore, parents and family members of people with disabilities also experience a number of barriers that prevent them from advocating for their loved ones and supporting them to advocate for themselves in policy processes. Literature highlights that in some instances service providers often do not afford parents the opportunity to advocate for their children with disabilities (Azzopardi, 2000; Islam & Cojocaru, 2015).

On the other hand, another noticeable barrier is parents’ mindsets regarding disability and self-advocacy. Some parents are generally unaware of the self-advocacy concept, tending to depend on others to advocate for their children (Islam & Cojocaru, 2015). Independence of people with intellectual disability from parents and families seems more difficult because of the mindset of parents or guardians, some finding it difficult to support their child’s involvement in self-advocacy and/or self-advocacy groups (Azzopardi, 2000; Islam & Cojocaru, 2015; Lan, 2007). Therefore, more effort should be made to educate parents and guardians on self-advocacy. The right information and life stories will help parents to see the relevance of self-advocacy groups.

3.6.4 Experiences of self-advocates

Participation in an advisory capacity is the most common way people with intellectual disability are included in research and policy-making (Frawley & Bigby, 2011; Grant & Ramcharan, 2007). With this approach they are seen as “experts by experience” who should be called on to prioritize, design, advise on and disseminate research. Participants in a study conducted by Grant and Ramcharan (2007) mentioned that “we will make a difference if we are there” (p. 8). Participants with intellectual disability are also commonly sole or joint authors of research publications (Bigby et al., 2014). According to Islam and Cojocaru (2015), evidence suggests that the quality of life of people with disabilities, and of the broader community, improves when people with disabilities actively voice their concerns and participate in decision-making processes.

3.6.4.1 Positive experiences

Literature indicates that self-advocacy organisations play a significant role in helping people with disabilities speak on their own behalf concerning the proper design and implementation of policy, legislation and strategies which ensure their full participation in social, economic, cultural and political life (Islam & Cojocaru, 2015). When met with great support, people with disabilities thrive in these groups and they become the voices of the voiceless.

This is quite evident in the study by Nonnemacher and Bambara (2011), where nine self-advocates spoke positively about support staff who encouraged them to initiate choice-making by presenting options and exposing them to new experiences. Three self-advocates described specific examples of staff providing them with opportunities to make frequent, daily choices in their homes, speaking at length about support staff providing them with options for meals. Although these choice opportunities seemed minor in comparison to making decisions about employment and living situations, they were nonetheless important to these self-advocates (Nonnemacher & Bambara, 2011).

Self-advocates with intellectual disability become active members of research teams and advisory committees when they receive all the necessary support that they require. A study conducted by Johnson et al. (2014) reveals that self-advocates with intellectual disability who were part of a research team were involved in designing the best ways to access possible contributors, solving ethical problems, developing interview questions, analysing the life stories, speaking about the study to the media, and they took part in developing resources for the workshops. Two of the self-advocates became members of the committee established to change government policies (Johnson et al., 2014). However, it becomes very challenging for self-advocates when they do not have the necessary support and reasonable accommodations. This leads to them having negative experiences that could have implications for their involvement in advisory and self-advocacy groups.

3.6.4.2 Negative experiences

Bigby et al. (2014) mention that some self-advocates are thrown in the deep end and are set up for failure. Failure to adequately support self-advocates who are invited to act in an advisory capacity can leave people recalling contributing little and feeling disempowered. Frawley and Bigby (2011) also revealed that some self-advocates with intellectual disability feel ill-prepared for their role in terms of their own education or the expectations others held about their membership. Most self-advocates spoke about the practical difficulties they encountered that stemmed from the way the advisory bodies conducted business. The issues raised were long meetings; the failure to translate agendas, minutes, and other documents into simple and easy-to-read English; and being inadequately briefed on the issues to be discussed at meetings (Frawley & Bigby, 2011; Bigby et al., 2014).

Some self-advocates highlighted more intangible difficulties they encountered in participating in the advisory bodies and felt dissatisfied with their performance or influence as members. Their feelings were often associated with the way they felt they were perceived by other members or staff. One self-advocate, for example, "felt other members did not actively engage her in conversations at meetings, that people spoke over her at meetings.She believed that others had expected her, as a participant with an intellectual disability, to be passive and silent" (Frawley & Bigby, 2011, p. 33). Some self-advocates do not feel respected by other members, and they expressed feelings of being regarded as less capable and competent than other members.

Nonnemacher and Bambara's (2011) study highlighted that some self-advocates relayed numerous instances where their opportunities to express self-determination were impeded by support staff who made decisions for them. Support staff control over decision-making extended beyond daily choices and often pre-empted opportunities for self-advocates to decide where to work and live and with whom. Two self-advocates also expressed dismay about their support staff changing their employment without consulting them (Nonnemacher & Bambara, 2011).

Furthermore, support staff tend to have control over personal spending money, resulting in the self-advocates either not having direct access to their money or having to ask support staff for daily spending money. This was a significant barrier to self-determination for a number of self-advocates (Nonnemacher & Bambara, 2011; Tideman & Svensson, 2015). These sort of practices by support staff can have long-term effects on the lives of self-advocates. The support staff attitudes and actions at the micro-level of self-advocacy will in turn also impact on the likelihood of their being open to exposing people they are supporting to meaningfully participate in self-advocacy groups or advisory bodies at the macro-level.

3.7 Discussion

This study addresses a relatively under-researched area, providing a scoping review of studies which have explored conceptual frameworks for self-advocacy by people with disabilities, including intellectual disability. The literature reviewed makes it clear that there are no conceptual frameworks for self-advocacy specifically for people with intellectual disability, even more so in the African context. None of the included studies are from South Africa or any other African country, this is indicative of the gap in literature that this current study intends to fill. The findings further highlight the barriers to self-advocacy and support the assertion that the inclusion of people with disabilities in society should be upheld when addressing issues concerning them. This puts more emphasis on self-representation and empowerment (Landmark et al., 2017; Rowland, 2004).

3.7.1 Self-advocacy for people with intellectual disability

According to Roberts, Ju, et al. (2016), there have been a great number of practices developed to effectively support people with disabilities to develop self-advocacy skills. Many of these practices have also been empirically tested for their efficiency as part of the quest for best practices and evidence-based practices. Consequently, a significant number of studies have been produced to provide empirical support for certain practices. The scientific approaches to these inquiries, however, vary a great deal.

The results elaborate numerous ways people with intellectual disability advocate for themselves and their rights. Grove (2015), for example, highlights storytelling as one way that people can self-advocate, and notes how this can contribute towards an understanding of difficult past life events, thereby encouraging an individual’s more profound sense of self and identity. Meininger (2006) concurs by stating that the process of storytelling for people with intellectual disability can be empowering, in that people with intellectual disability relay instances of personal resilience and struggle against acts of discrimination and exclusion through their stories.

In the African context, storytelling is a significant part of *Ubuntu*, it is a strong way in which people within a community strengthen their sense of social cohesion, both in the present and intergenerationally as part of building communities. Storytelling is also potentially an important, accessible way in which people with intellectual disability can self-advocate, as the telling of their stories can be a window to their thoughts, experiences, needs and, by inference and elaboration, their priorities, including their social and health-related priorities. Collective sharing of these stories can also identify common variations in priorities and common priorities which people with intellectual disability may want addressed to improve their quality of life, creating an agenda for change which can be promoted through public self-advocacy efforts, as well as inform the focus of advocacy efforts of supporters.

Kimball et al. (2016) described self-advocacy as a form of activism and note that capability for bringing their views to the table of decision-making is not an inherent capability, but needs to be nurtured from a young age, with opportunity to express and thereby strengthen this capability. Self-representation is a core element, and self-advocacy the tangible vehicle of this, requiring the activation of three overarching behavioural themes. The first main theme speaks to the need for people with disabilities to learn basic advocacy skills from parents early in life (Kimball et al., 2016). The second theme focuses on people with disabilities role-modelling and teaching self-advocacy activism, reducing stigma through education and storytelling, and collective action. The last theme reflects their desires to engage in activism about various topics, not only limited to disability. Kimball et al.’s work brings to our attention that people with disabilities are more than their disabilities and their activist efforts reflect that reality (Kimball et al., 2016). A part of their journey as activists includes coming to understand themselves not just as people with disabilities, but also as people who are more than their disabilities.

3.8 Conceptual Frameworks for Self-Advocacy

It is evident that there is a paucity of conceptual frameworks for self-advocacy. The reviewed literature yielded only three conceptual frameworks for self-advocacy by people with disabilities. Of the three frameworks, one is intended for counselling professionals to assist them in applying advocacy in their work and help people with intellectual disability to self-advocate. These three frameworks do provide insights to inform the question of what is needed to support self-advocacy by people with intellectual disability, and to inform the most suitable method to employ in the development of my own conceptual framework for self-advocacy by people with intellectual disability in South Africa.

3.8.1 Elements to consider in a conceptual framework

3.8.1.1 Self-knowledge

Self-knowledge is crucial in self-advocacy because it is necessary for individuals to understand and know themselves before they can tell others what they want (Test, Fowler, Brewer, et al., 2005). Test, Fowler, Brewer, et al.'s (2005) first component (knowledge to self) is similar to Ratts et al.'s (2015) first component (self-awareness), in that they both speak to one's ability to know who they are, their values, beliefs and biases. The MSJCC does not specifically note "self-awareness, but highlights counsellors", incorporation of empowerment-based theories to address internalised oppression people with intellectual disability may experience (Cook, 2017; Ratts et al., 2016). This can be addressed by building a critical understanding of developing self-determination skills, including, self-awareness, goal setting, and decision-making. These conceptual frameworks note that self-knowledge is crucial in self-advocacy because it is necessary for individuals to understand and know themselves before they can tell others what they want and may be considered foundational to self-advocacy (Goodley, 2005; Mallander et al., 2018).

3.8.1.2 Support systems

Support systems are considered as central to self-advocacy by people with intellectual disability. Cook (2017), for example, emphasises that independence for people with intellectual disability is fostered through relationships, but may more accurately be referring to the need to acknowledge the interdependence in relationships between people and their supporters (Cook, 2017). Ratts et al. (2016) echo this by mentioning that interpersonal interventions incorporate the examination of significant relationships (i.e., family, parents, and friends) to determine how they may be of support or non-support in self-advocacy.

Additionally, interdependence is a core aspect of self-determination for people with intellectual and developmental disabilities because they often rely on other people in their lives to provide support so they can enact their self-determination (Owen et al., 2016; Wehmeyer, 1998).

It is important to explore individual versus family decision-making processes (Andersen & Bigby, 2017), as parents or other supporters' views may not always be aligned to that of the person with intellectual disability, and a risk exists that support may not prioritise their views but rather that of their supporters. This can be done through linking various services that ensure that parents feel understood and supported in the process, while understanding cultural differences and building upon cultural strengths to inform self-advocacy (Bennett & Gallagher, 2013; Cook, 2017). These insights can help support systems and supporters to identify and engage with self-advocates in a manner that enforces individuality and interdependence.

3.8.1.3 Worldview

Test, Fowler, Brewer, et al. (2005) assert that it is a crucial step toward self-advocacy for people with intellectual disability to know about their rights (i.e., personal, community, human service and educational rights), to know their immediate environment and the world at large. Similarly, Cook (2017) highlights the importance of being more attuned to one's worldview and experiences, and to that of others to successfully engage in self-advocacy. This knowledge and understanding will be important for self-advocates and their supporters to think about and plan how best to fashion their messages in collaborating with key community institutional and societal level stakeholders to promote equity and access to participation. Through the involvement and consultation of people with intellectual disability, families and supporters can also learn what is needed to effectively assist them to transition to self-advocacy (Cook, 2017; Ratts et al., 2016).

3.8.1.4 Self-advocacy skills

Once the foundation components of knowledge of self and knowledge of rights are in place, an individual with intellectual disability needs to improve their communication skills in order to convey their needs effectively (Test, Fowler, Brewer, et al., 2005). Communication skill development is considered as a means to promote self-advocacy. Wehmeyer and Shogren (2016) draw attention to assertiveness, negotiation, persuasion and compromise, body language and listening skills as the crucial subcomponents of good and effective communication skills. Self-determination, as noted by Nonnemacher and Bambara (2011), is a by-product of effective communication. It entails people with intellectual disability's ability to make themselves heard about their wants and needs, including both daily decisions and larger goals.

3.8.1.5 Public policy advocacy

Self-advocacy requires one to be knowledgeable of local and national policies and laws affecting them, so that they can advocate for policy change. According to Cook (2017), it is the counsellors' role to keep abreast with local and national policy issues that inform understandings of barriers that people with intellectual disability face, in turn helping them to be well equipped for self-advocacy for their rights (Cook, 2017; Ratts et al., 2016). Finally, Test, Fowler, Brewer, et al. (2005) mention that in order for people with intellectual disability to be able to advocate for themselves at a public policy level, they need to possess leadership skills. Self-advocacy at the system or policy level requires leadership (Martin et al., 1993; Test, Fowler, Brewer, et al., 2005), and self-advocates can use their leadership skills to advocate for other people with disabilities who cannot advocate for themselves.

3.8.2 Methods of developing conceptual frameworks

The first two conceptual frameworks employed the same method in developing the frameworks. This includes an extensive review of literature and the engagement of relevant stakeholders. Test, Fowler, Wood, et al. (2005) reviewed 25 articles pertaining to self-advocacy and then engaged with stakeholders to provide feedback on the draft of the conceptual framework (Test, Fowler, Wood, et al., 2005). Similarly, Ratts et al. (2015) reviewed the MCC framework that was developed by Sue et al. (1992) and based on their review they decided to add the concept of social justice. They reviewed similar literature from other professions regarding the MCC, engaging various stakeholders and associations to adapt and update the MCC framework to the MSJCC framework, which is more centred on social justice advocacy (Cook, 2017; Ratts et al., 2016). Additionally, Owen et al. (2016) used the nominal group technique to engage with people with intellectual disability to understand and conceptualise sexual self-advocacy (Owen et al., 2016). All three methods are suitable to inform the development of my own conceptual framework.

Literature reviews help in gaining insight into what has been done previously and to explore what exists in literature that can be of use, or to highlight the gaps that still need to be filled (Munn et al., 2018). Engaging with stakeholders, particularly, professionals or people who are in the field is as important because this provides more insight on the day-to-day happenings, providing an additional lens to what literature has highlighted. Similarly, participation of people with intellectual and developmental disabilities in this process is highly important. As the saying goes, "*nothing about us, without us*" (Rowland, 2004). As noted in previous studies, the inclusion of people with intellectual disability is of paramount importance; they are experts by experience (Bigby et al., 2014).

Literature on the conceptual frameworks for self-advocacy indicated that self-advocacy for people with intellectual disability is not a one-person project. In order for people with intellectual disability to self-advocate they need support from various people or systems such as families, supporters and professionals. Results from the reviewed literature emphasise that people with disabilities, including intellectual and developmental disabilities, mostly rely on their peers and families in the advocacy process (Landmark et al., 2017). Therefore, interdependence is a crucial component for self-advocacy of people with intellectual disability.

3.8.3 Inclusion of people with intellectual disability

Inclusive citizenship for people with intellectual disability involves participating freely in a particular national space on condition of honouring various rights and duties. However, Capri, Abrahams, et al. (2018) mention that when viewed as a politically "unfit" homogenous group, the political rights of people with intellectual impairment are disabled in cases where individuals have competence and capacity to make political decisions (Capri, Abrahams, et al., 2018). Inclusive citizenship helps to communicate the importance of acceptance of differences among people with intellectual disability (Cook, 2017). Therefore, involvement of people with intellectual disability and their families must be strengthened in order to protect their rights and promote inclusion and access to societal resources.

There must be a shift from advocacy to self-advocacy, that is, the direct inclusion of the voices of people with intellectual disability in these activities. Goal Ten of the SDGs states that inequality within and among countries should be reduced (UN, 2016). This can be done by providing more opportunities for people with intellectual disability to participate in society and reduce the existing barriers to participation.

3.8.3.1 Barriers to and opportunities for participation

The studies highlight individual and structural barriers that hinder people with intellectual disability to participate in society and policy development or implementation processes. These structural, organisational and procedural barriers diminish their personal and social power. These include being restricted to exercise one's rights as citizens, and limited access to the social and economic resources of society which enable autonomy (Frawley & Bigby, 2011). People with intellectual disability often face marginalisation of their voices in policy dialogues (Bigby & Frawley 2010; Lund, 2016). A predominant aspect of the barriers found in literature includes the inability of people with intellectual disability to make their own decisions. Nonnemacher and Bambara (2011), for example, highlight that supporters and parents of people with intellectual disability are often the ones making decisions for them. They are deemed as unfit or incapable of making proper and meaningful decisions.

Results of this review further demonstrate how stigma and marginalisation play a role in people with intellectual disability's capacity to participate in society (Azzopardi, 2000; Bigby et al., 2014; Frawley & Bigby, 2011). People with intellectual disability are usually stigmatised and not afforded full participation. Where they are afforded an opportunity for self-representation, they often do not feel heard and their contributions are not acknowledged (Bigby et al., 2014; Frawley & Bigby, 2011; Tideman & Svensson, 2015). They are seen as incompetent, and people do not see past their impairment. People with intellectual disability are often not afforded an opportunity to be independent from parents and families (Azzopardi, 2000). This is because parents and guardians believe that self-advocacy is more difficult for them, and they do not have the capabilities to participate in self-advocacy.

The results highlight self-advocacy groups and peer mentoring programmes as available opportunities for people with intellectual disability to self-advocate. However, the papers reviewed make it clear that there are insufficient opportunities for people with intellectual disability to participate in society through self-advocacy. In some instances, some people with intellectual disability participate in advisory bodies (Bigby et al., 2014; Fisher et al., 2020; Kimball et al., 2016; Landmark et al., 2017). Literature notes that in order to address the existing barriers more opportunities for self-advocacy need to be created. This can be achieved through involving people with intellectual disability in policy-making and decision-making processes on issues that concern their lives.

Findings from this scoping review indicate the gap that exists in literature regarding self-advocacy by people with intellectual disability in the global south. None of the studies included in this scoping review were from the African continent, thus, indicating a significant gap on what has been done in South Africa and Africa at large. This signifies the importance of the work of the current study in terms of filling the knowledge gap and offering a new insight from a South African perspective.

3.9 Chapter Conclusion

This scoping review investigated available literature about conceptual frameworks for self-advocacy by people with disabilities, including intellectual disability. We incorporated available research evidence in a synopsis of 20 eligible studies, synthesised the literature and identified areas for future investigation. Self-advocacy education is a promising method of improving self-determination, decision-making and inclusive citizenship. However, there is limited evidence of conceptual frameworks on self-advocacy for people with intellectual disability, particularly in the area of the focus of this research, self-advocacy at the public policy-making level, limiting our understanding of how best to conceptualise and implement strategies for supporting self-advocacy in this domain.

CHAPTER FOUR

THE VIEWS OF PARENTS, CARERS AND PEOPLE WITH INTELLECTUAL DISABILITY ABOUT THE OPPORTUNITIES AND BARRIERS TO SELF-ADVOCACY

4.1 Introduction

Given the historical marginalisation and disempowerment of people with intellectual disability, self-advocacy is pertinent (Caldwell, 2010; Goodley, 2005). In high-income countries, self-advocacy movements are well established and people with intellectual disability are involved in policy-making processes and other self-advocacy initiatives (Henderson & Bigby, 2017; Tronto, 2010). Although self-advocacy in these countries is established, there are some challenges that impact the existence and longevity of self-advocacy movements. One major challenge includes budget cuts, as highlighted in Chapter One (Rouse et al., 2022). These challenges have left some self-advocacy movements destitute and some ceased to operate (Rouse et al., 2022).

In South Africa there are very few self-advocacy movements and involvement of people with intellectual disability is still very limited. As noted in Chapter One, there are approximetely six active self-advocacy groups in South Africa, with the SAFMH a leading organisation supporting self-representation of people with intellectual disability (Daniels, 2018). It is, thus, important to strengthen existing self-advocacy initiatives and create more opportunities for self-advocacy in South Africa (Capri, Abrahams, et al., 2018), to ensure the creation of more platforms through which people with intellectual disability's voices will be heard.

The scoping review found that people with intellectual disability have limited opportunities to participate in self-advocacy and policy-making processes. Moreover, they face various barriers that hinder them from becoming self-advocates; these include individual, procedural and structural barriers (Bigby & Frawley 2010; Frawley & Bigby, 2011; Lund, 2016). The purpose of this chapter is to document the views of people with intellectual disability, together with the views of parents and carers/supporters of people with intellectual disability about the local opportunities for and barriers to self-advocacy in South Africa. The strategies to overcome these barriers will also be highlighted

4.2. Study participants

Participants for this section of the study were recruited from NPO A and NPO B, using criterion sampling and snowballing (McMillan et al., 2016; Palinkas et al., 2015). All the participants met the eligibility criteria. Of the 25 SSIs, 15 comprised carers/supporters of people with intellectual disability (n=5), self-advocates with intellectual disability (n=5 and parents of adults with intellectual disability (n=5). NPOs from which self-advocates and parents were recruited generally offer services to people with intellectual disability and their families from low and middle income communities. The list of participants is included in the appendices as Appendix 12.

4.3 Results

Analysis of the interview data using the coding frame initially yielded nine sub-themes, that were then integrated into four main themes. Table 4.1 below reflects all the identified themes from interviews conducted with parents, carers, supporters, people with intellectual disability and other stakeholders. In this chapter the focus will be on the results from the SSIs conducted with people with intellectual disability and parents/carers/supporters.

Table 4.1

Themes and Sub-Themes from Semi-Structured Interviews with People with Intellectual Disability, Parents/Carers and Supporters

Theme	**Sub-Themes**
Understanding self-advocacy by people with intellectual disability in South Africa.	Self-advocacy by people with intellectual disability in South Africa. Experiences of self-advocates.
Inclusion of people with intellectual disability in society.	Opportunities for participation of people with intellectual disability in society. Accessibility of resources.
Barriers to participation.	Challenges experienced by people with intellectual disability. Challenges faced by families and supporters of people with intellectual disability.
Using *Ubuntu*/Interdependence to support self-advocacy by people with intellectual disability.	Skills required by people with intellectual disability to self-advocate. Available support for self-advocacy by people with intellectual disability. Creating an inclusive environment for people with intellectual disability to participate in policy advocacy. Capacity development for various stakeholders.

4.3.1 Identified themes

The first main theme focuses on participants' understanding of self-advocacy by people with intellectual disability in South Africa, documenting the meaning of self-advocacy and its components. The second theme speaks to the barriers for full participation in society by people with intellectual disability, where the challenges faced by people with intellectual disability and their families and/or supporters are discussed. The third theme focuses on the inclusion of people with intellectual disability in society. Finally, the fourth theme highlights the importance of *Ubuntu* in self-advocacy by people with intellectual disability; here the discussion is on supported self-advocacy of people with intellectual disability and the required skills for people with intellectual disability to be able to self-advocate, existing support systems and required reasonable accommodations for a more inclusive environment.

A discussion of the views of the respondents under each theme follows:

4.3.1.1 Understanding self-advocacy for people with intellectual disability in South Africa

One of the main themes from this study's findings is how self-advocacy is understood and what it means for people with intellectual disability and their parents/carers and supporters within the South African context. Although participants define self-advocacy differently, the most common thread is that self-advocacy is about having the ability to speak up for yourself, stand up for your rights and the ability to make your own decision:

[Key: C=Carer; I=Interviewer/researcher; P=Parent; T=Person with intellectual disability]

> ***(I): Can you tell me what you understand about self-advocacy and what does it mean to you****?*
> *(T1): … for me it means that I can talk for myself. When people bully me I can stand up and talk for myself and my friends if someone treats us bad.*
>
> *(P6): Well, I feel that self-advocacy is all about what, and how you feel and think about yourself. Learning to speak up for yourself, making your own decisions. How to inform others about your decisions.… How to inform others about your decisions, basically, to distinguish between whether you are doing the right thing or not.... So,*

> *yeah, uhm, knowing yourself, what your needs are, what you do need and things like that. I would say that.*
>
> *(C1): To my knowledge, I would say that self-advocacy is when you stand up for your rights and you stand up for what you believe, and you take a stand, and you voice your opinion about what you believe to be right.*

Some participants expressed that self-advocacy is not only about being able to speak up for yourself but requires an environment within which speaking up is supported:

> *(C4): … giving people the opportunity to speak for themselves, to acknowledge that they, and everyone has a voice and that everyone has uhm, an opinion and that everybody wants to be able to share their voice…. So to me it really means providing opportunities for people to share what they think, what they want others to know about themselves, what they want people to know about what they think in general, and I think yeah, that's what self-advocacy means to me, it's listening and providing opportunities to listen.*

Some participants noted that people with intellectual disability lack capacity to voice their opinions:

> *(P6): Because they are mentally challenged, people don't take the time to listen. Don't take the time to understand what the person is saying.*
>
> *(T2)*: *Yes, because for them it is, that they can actually talk for themselves, they can protect themselves, and they can stand up for themselves! Because, you know, this time in the world, there are people who don't regard people with disabilities as advocates or don't seem as an advocate to them. So, they can actually tell them, no, I am a person, and I can, I can talk for myself. No one can make decisions for me; I can make my own decisions… Yeah, before, before, I became an advocate, it was like that where people would tell them what to do.*

Other participants gave concrete examples of how opportunities for training and direct participation in projects and processes had strengthened their ability to self-advocate. In some instances, initial experience of and skills development in self-advocacy paved the way to go beyond self-advocacy, to advocating for others with intellectual disability as well:

> ***(I): Do you consider yourself a self-advocate, what kind of self-advocacy have you done?***
> *(T2): Now you see, uhm, I was a self-advocate, I used to be on the, on the (names organisation which offers services and support to people with ID)…. I used to be the chairperson of the training, the training council and I was a representative for the people living with disability on the board of the (names another organisation that offers services and supports to people with ID).*
>
> *(T1): Ok, I started being a self-advocate when I started with the project at (names organisation)…. So, in this project we help people who can't read…. I also learnt to speak up from this programme. Growing up, I wasn't a vocal person. They even know this at home, I was not a person who speaks a lot but ever since I started with this programme, I started speaking with people I didn't know. That's when I saw that I can speak not only for myself but for other people as well.*

Respondents also highlighted the value of having additional assistance from supporters to reflect on and prepare themselves to express their ideas without being misunderstood. Reading assistance for those whose reading skills are limited was mentioned, for example:

> *(T4): Because sometimes then* [redacted] *will help me out with some stuff, if I don't know the words, then he will like, help me. If there is a word that I don't know, then he will read it to me, then he will tell me what the word is…. Miss* [redacted] *helps me, she will tell me uhm, I must read it and then she will help me like, get to the last letter. Say if it is maybe a big word, then Miss* [redacted] *will help me then with the word and I will understand it. When I speak up for myself, I will use, uhm, I will use the word I learnt from Miss* [redacted].

The use of adapted communication methods, such as easy-to-read technology, was also noted as an important reasonable accommodation to promote self-advocacy:

> *(C2): I would say sometimes it's difficult seeing some of the service users struggling to do some certain tasks because of their disabilities. But then when, when you see that they are progressing, that is where I would say you, you see that there's something that the staff of (names organisation) as well as me the supporter, is doing to making progress. Self-advocacy, I would say it is when the service users speak for themselves. Like I was saying, with uh, regarding* [redacted]*, he is doing (the easy-to-read*

> *programme) so through it, they are able to speak for themselves because they are given the pictures, and they are given the words.... And then it's, it is them that have to confirm that this picture, this picture does correspond with the sentence and all of that. So, they advocate for themselves. That is, when you speak for yourself and for others.*

Where people with intellectual disability cannot self-advocate, their supporters, carers and parents advocate on their behalf:

> *(C3): I used to sort of like, advocate for, for people with living with intellectual disabilities and we used to go to court and even in court I mean my role, it was not that hard, it was just to make them, you know, uhm, to feel more comfortable…. I mean I have to be the voice for them, you know? So, what I've discovered you know, working with people, living with disabilities or with intellectual disabilities, that there is a big gap when it comes for them being able to express themselves.*

Some of the respondents highlighted that people with intellectual disability can advocate for others with intellectual disability who may have challenges speaking up for themselves:

> *(P8): You see, my son is a very quiet person. I don't think he is able to speak up for himself…. But his sister, no shame. She also has a learning disability, but she is more vocal. She will fight for him, she's younger than him but she always stands up for him, ever since they were little, she always stood up for her brother. Even now, she's overprotective. In this case I would say that his sister is a self-advocate.*

4.3.1.2 Inclusion of people with intellectual disability in society

When people with intellectual disability were asked about their views and experiences about opportunities for participation, some of the respondents mentioned that protective workshops and organisation-based self-advocacy groups are some of the opportunities available for them to fully participate:

> *(T5):I love to work at this workshop because it helps me out with my disability, because I like using my hands. My disability is more on reading, that's my disability. Yes, if you give me something to do on paper, I won't have to do it. Yes, that's my weakness. That's just my weak … my weakness of it … there's a job I got inside at (names organisation) to train someone else to do their job. Now I'm training someone else to do it. But I, I'm showing him, so he understands how to do it.*

(T2): I started at (names organisation) then a few years later, there was an opportunity that came up, so I was selected to be on the on the training council. So, automatically as you be on the training council and selected to be the chairperson, then you automatically on the board …. and I was a representative for the people living with disability on the board of the (names another organisation).

(I): What do you advocate for when you are advocating for women?
(T1): About the things that happen to women, more especially gender-based violence. Women are being killed, raped and there's a lot of brutality against women…. I normally do advocacy on social media platforms such as Facebook. I haven't done it in the community or other places. I only post using my phone because I don't know of any other platforms or how to advocate at a higher level…. I also met another lady in the community, she would like for me to go with her to schools when I am not working or maybe on Wednesdays. She would like for us to go to schools to tell children about their rights.

There are various settings within which people with intellectual disability can and should be encouraged to speak up for themselves. Participants highlighted these as different opportunities available for self-advocacy by people with intellectual disability. These include opportunities to participate in social groups, school-based programmes that encourage self-advocacy, community groups and religious settings:

(I): Can you think of any opportunities available for participation of people with intellectual disability?
(C4): A few years ago (names organisation) used to run social events for young people with intellectual disability or with autism or young people on the spectrum…. So, they used to do social groups… just creating a space where people can speak about what they wanted to speak about…. I think that there's opportunities for programmes to be done in schools. I think there's opportunities for programmes to be running in church and community groups or religious spaces as well.

(C3): Uhm, if you look at the, the forum… I, I think in Cape Town we do have the (names organisation working with self-advocates). Uhm, so I think yeah, it's, it's a

> *platform whereby you know different professionals are part of it. Uhm yeah, so it's, it's, a forum that actually can be used and can be expanded in terms of inclusion.*

Parents and caregivers also felt that there are a few opportunities for people with intellectual disability to be involved in society and self-advocacy. Some participants recognise the significant gap, there are not many opportunities available, and this proves to be a challenge because it means that more people with intellectual disability are excluded:

> ***(I): Can you think of any opportunities available for participation of people with intellectual disability?***
>
> *(P4): Man, to tell you the truth I, I know of, of something being done, but not enough is being done. The something that is being done is on a minimal level, and it's not too loud. More needs to be done to push the boundaries…. So, I just feel that they can, you know be exposed to more things. To be taught differently, more things. Take you on field trips to different workplaces or to see what happens.*
>
> *(P6): No, there isn't. Apart from the workshop that they attend I don't see, I don't think, well, I haven't heard of any other place that they can go, you know, so I would say no.*
>
> *(C3): Uhm, it's very hard to get uhm, or to find people who are living with an intellectual disability who actually advocate for themselves ... so, it's very rare actually for them to have that platform whereby they can be able to express how they feel and also share their own ideas. It's all about being reliant to the next person ... there's a lack of self-advocacy when it comes to people who are living with intellectual disability.*

When participants were asked about how the opportunities can be created and who should create them, they highlighted that it is community-based organisations and professionals who should create opportunities for people with intellectual disability to self-advocate:

> *(C4): I think schools should create it, I think uhm, professionals in the sector should create it. So, whether you're in private practice or work in a government organisation, I think your, your space of psychologists, social workers, therapists, and allied health professionals, everyone should be working on, you know, if you're*

> *working in the space of mental health, you should be working on creating opportunities for young people to speak up for themselves or to encourage self-advocacy programmes.*
>
> *(C5): I would say going through community or civil society organisations to create awareness could be a good one as well for how to be a self-advocate.*

Most participants were in favour of people with intellectual disability's participation in self-advocacy and mentioned that a lot of opportunities should be created for them. Some participants went on to say that they would encourage people with intellectual disability to become self-advocates*:*

> *(C1): I would just speak to them, encourage them and tell them about the benefits of advocacy and why it's important to stand up for yourself and for other people, and especially for yourself. So should anything go wrong, you know uhm, what to do.*

4.3.1.3 Barriers to participation

People with intellectual disability have their own limitations and weaknesses that are recognised as barriers to self-advocacy. Participants were asked what they consider as barriers to self-advocacy for people with intellectual disability. Some parents highlighted communication challenges as a major barrier for self-advocacy:

> *(P4): Uhm, for me, people with learning disabilities can sometimes not speak for themselves, or they don't have that ability to stand up for themselves or speak for themselves… in different ways and stuff.*
>
> *(P5): I have two children with intellectual disabilities.* [redacted]*, my son, he is 31 years of age, and* [redacted] *my daughter is 28 years of age. Every child, young adult has got his own level of being intellectual disabled. But for instance, you get those that can speak, but both of them, they, they are not on the same level, where they will speak up for themselves. Like him, he, he won't say anything whatever goes wrong, he won't. I will find out by somebody else. She's the one, she will tell me, but it won't be that same day, but I'm waiting on you to speak up.*

Some respondents with intellectual disability shared similar sentiments, that there are internal or individual barriers that impact their ability to self-advocate. These include the lack of communication capacity and limited reading and writing skills:

> *(T4): Sometimes I get very nervous, because I maybe get scared because maybe the next person will laugh me out because I can't read that good, I can only read a little bit and I am afraid to speak up for myself.*
>
> *(T5): There's people who got disability, got disabilities but they don't like speaking up for themself. They always keeping things to themselves. There's a lot of people like that. Uh, go into a state of keeping things, but when you're asking me, not me. Me I can speak for myself and that's why I can fight for the women at the workshop.*

Findings also indicate that people with intellectual disability are not seen and treated as equals to other citizens, and this too proves to be a significant barrier:

> *(T1): I don't think we are treated equally as people without disability. For example, when you have a child with disability, your child is not treated the same as other children. Even children in the community would tease them and sometimes not play with them. That is also not right, because this child didn't choose to have a disability. Only God knows why the child is like that. We are all equal, whether you have a disability or not we are all the same. Every person has their own challenge, whether it's known or not.*

Over and above language and communication barriers that people with intellectual disability experience, they also experience systemic barriers, such as stigma and negative attitudes. They are not seen as "normal" people, they are belittled and infantilised, and are not allowed to make their own decisions:

> *(T3): Uh, before I became a staff member I used to walk from the work to home and where the people sell fish, they used to call us "abnormal" people, but you know, we are not abnormal, we're normal people…. Uh, I don't think they understand what disability and mental illness is and of them some don't have respect, some people don't have respect for people with disabilities.*
>
> *(T2): There's a lot of stigma around it of being belittled. For them, if they see you as a person and they will tell you that no, you must do this, so they expect you, that you*

> *must go follow them. Instead of asking them, do you want to, or don't you want to? Or, or ... do you want me to take, do you want me to decide for you?*
>
> *(C4): People with intellectual disability don't come to restaurants, their families don't take them to movies, they don't take them to social events and community events because there's so much stigma around their diagnosis.*

Another significant barrier to self-advocacy by people with intellectual disability includes being overlooked, excluded and rejected by people in society:

> *(P6): ... sometimes people think that they can walk all over her and bamboozle her because she doesn't know any better and yet, people who are mentally challenged, they do know. They have their own mind, they can speak up, it's just you, the person who's listening, must listen and take heed of what is happening. Don't just brush them off.*
>
> *(P4): But that's the society that, that is rejecting, so to speak, these kind of people and children, because if you can't fit in with the norm, then you're classified as not being normal. But there isn't any provision made for people with disabilities really.... I just feel that people with learning disabilities are being seen, but they're not being heard.*

Some people with intellectual disability are not afforded an opportunity to participate in general activities and learn new skills. People tend to believe that people with intellectual disability are not capable of doing anything. Those who actually do something are sometimes looked down upon, thus resulting in them being excluded from fully participating in society:

> *(P6): They don't think they are able to do some work. Maybe, maybe it's too dangerous. Maybe they feel that mentally challenged people won't be able to handle this so that they don't expose them to it, but I'm sure if they are taught, it can change.*
>
> *(T1): Other people in the community have a way of making you feel down. Even when you do something great, they discourage you and make you feel bad about yourself.*
>
> *(C4): ... we need to stop limiting their opportunities and making assumptions about what they can and can't do.*

These are notable barriers to self-advocacy for people with intellectual disability. However, the findings also show that these barriers can be addressed, and it is everyone's responsibility to address them. Some participants suggested that these barriers can be addressed by including people with intellectual disability in policy-making and implementation processes; where they can be part of decision-making processes, attitudinal change and systemic changes, particularly in government:

> *(P4): It's just that there's such a lot of wrongdoing out there towards people with disability and, and you know, for me personally, you need to start at the ground level first before you make the way up. You can't go to Parliament and say listen this is what, but you don't know what the needs of the people are.*
>
> *(C3): I think it's very important when we are having these multidisciplinary meetings not to forget, you know, including the people who are actually raising uhm, these children or who are looking after these adults who are living with intellectual disabilities…. Uhm yeah, as I've mentioned earlier on, I think it's very important you know, when, when policies are made, these people need to be included and be part of the decision-making, yeah.*
>
> *(C4): I'm at a point where I think the barriers are everybody's responsibility to remove. I think as with many barriers, there needs to be a push from government, there needs to be a push in terms of our social structures…. But then I also think there needs to be a shift in thinking in the professional space of intellectual disability … there are so many things that children and adults with intellectual disability are excluded from that we can't actually consistently just blame government for it because we need an attitudinal change as well as a systemic change.*

4.3.1.4 Using *Ubuntu*/Interdependence to support self-advocacy by people with intellectual disability

People with intellectual disability often need support from those around them. Some participants with intellectual disability indicated that in order for them to become self-advocates they require support with building self-advocacy skills. When asked what people with intellectual disability need to become self-advocates, some participants highlighted some of the personal skills required for self-advocacy, these include communication, assertiveness, confidence, public speaking, and leadership skills, among others:

> ***(I): What do you think people with intellectual disability need to be able to self-advocate?***
>
> *(T1): I would say, the kind of support that would help me to be able to advocate in front of the whole nation. Where I could stand in front of everyone and speak up … Some people like me need to learn to speak up for themselves. I also learnt to speak up from this programme* (*Self-advocacy group*).
>
> *(P6): I feel that she needs self-confidence. She needs more confidence. She needs to be assertive. She needs to believe in herself.*
>
> *(P8): Already, she has shown leadership skills. OK, and that's because somebody believed in her at the workshop. She's got beautiful leadership skills. And she has a team working with her, so that, to me, is wonderful. I feel that more and more people like her need such skills.*

Some participants mentioned that for people with intellectual disability to be able to self-advocate they need to be knowledgeable about their rights and policies pertaining to them and need to be aware of their met and unmet needs:

> *(T5): You know for me, self-advocacy is like standing for your rights whatever someone can't push things on you. Self-advocacy is about knowing your rights and be able to stand up and fight for them.*
>
> *(C1): It is important for them to know policies so that they can be able to know what they are speaking up for. Self-advocates with intellectual disability should be the biggest advocates within mental health and ambassadors for mental health so I think that they should be the ones that are on the forefront fighting for this. They should be out there, you know, going out and going to whoever, Parliament or parliamentary people and saying listen, you need to give us a chance on this, this is my journey I've been on and as you can see, here I am. This is what I've achieved, and this is what I believe that others can achieve too.*

Over and above the required skills and the awareness of rights and policies, participants further highlighted the importance of having supporters and how having support helps with self-advocacy by people with intellectual disability. This support can be from various sources such as family, peers, professionals and organisations:

> *(T3): Uh, from my side, I think they need support because some of them don't, don't, know how to read and write, so they need someone to help them out.*
>
> *(T2): Now you see, uhm, I was a self-advocate, I actually paid the supporter, so the supporter that would now help me with getting my reports ready, that time she was the general manager, she compiled my reports with me, but in a professional way on her laptop, and then she will now sit with me and ask me, now what do I want to say? And then,* [redacted] *was my other supporter, she was actually technically with me in the board meeting, so she was my supporter, and she was also my chauffeur.*

Other participants highlighted the importance of peer-to peer support to promote self-advocacy by people with intellectual disability. Parents and supporters of people with intellectual disability shared how they have seen peer support work and how it has helped with self-advocacy:

> *(P6): She needs people to guide her, just to stand with her and to back her up, then she will actually voice her opinion more…. The person who gives support, it depends on the situation. Like sometimes it would be the parents, but most of the time it will be a peer.*
>
> *(C2): Uh, the peer supporters are there, I would say to comfort others, as a peer-to-peer support, that means, let's say it's you and me, we are having the same disability, so it would be easier for both of us to, to connect on everything and be each other's support systems.*
>
> *(C5): The CEO of the (names organisation that offers peer-to-peer support) is from South Africa, diagnosed with schizophrenia and has received funding to now run a peer network of people with intellectual and psychosocial disabilities to share their lived experience. I would say for other people with intellectual disability who are in the, in a situation like this in South Africa and are looking for a platform to connect with others to understand, also to share their voices to put pressure on government*

> *from a policy perspective perhaps.... About how people with lived experience must be at the forefront of decisions made when it comes to policy, when it comes to programming services and all the rest. I would say a self-advocacy movement like that, so that would be a form of support.*

Additionally, participants felt that people with intellectual disability need supportive and inclusive environments that will enable them to self-advocate and in turn enhance their sense of belonging and their well-being. They highlighted that self-advocacy by people with intellectual disability can be enabled by the existing and potential supportive/inclusive systems, available opportunities for self-advocacy and existing reasonable accommodations. For example, one supporter alluded to the environment of a self-advocacy group at a local NGO which encapsulates most of the things needed for effective self-advocacy by people with intellectual disability:

> *(C1): Uhm, in most of the groups there is uhm, trainees and there is a chairperson to each group. I think there are six groups. The people involved would be our general manager, the (mentions organisation's name) board, as I've mentioned, the chairperson. There would be a supporter, which would be the job coach and then also the seniors of the workshops. They are also part of it so there's a lot of teaching going on there, there's a lot of support, and of course there is a lot of learning for them within those meetings and things. It really helps them a lot, it teaches them about peer pressure, how to support their peers. Then they have a pressure group where they are taught about the different pressures. Then, there's the easy-to-read group, then they have a training committee group where they discuss problems, certain things that arise in the workshop. And then there's a women committee group where they speak about women things that women need. And then of course, there's the training council where they speak about things in general that they need advocacy on.*

A major re-occurring theme throughout the interviews was the importance of having appropriate support systems and inclusive environments in order to become a self-advocate. These environments are the ones where supporters (families, friends, peers, professionals, etc.) of people with intellectual disability are skilled, trained, competent and have an understanding of what intellectual disability is and how it affects individuals:

> *(P6): Not everyone can deal with mentally challenged people. You have to be trained and educated. You have to know, you have to understand, you have to know*

> *psychology and all that, you know? You must be basically able to understand people with intellectual disability. I feel that they have to have some level of education man, and people skills and you know things like that?*
>
> *(C2): Recently we had a training conducted by social workers. Uhm, the training where we were being supported on how to deal with like people with intellectual disability with challenging behaviours. We learnt how to best support them and their parents.*

Most participants mentioned that a platform for increasing the capacity of people with intellectual disabilities is needed for their participation in policy-making and implementation processes, as well as for supporters who require capacity building on effective ways to support people with intellectual disability. Participants mentioned that there is a need for training programmes in advocacy, policy participation and organisational skills, and skills development programmes:

> *(P4): Generally, I think you they need programmes to teach them self-advocacy, the programmes to find out strengths. Then maybe I think, identify in which way we can be able to have different levels of empowerment for different children, different people…. I would think, definitely, they would be able to, to advocate for themselves in places like parliament if they maybe just given a chance, or with the correct programme like I said, and the correct encouragement.*

4.4 Discussion

One of the study's objectives was to document the views of people with intellectual disability together with the views of parents and carers/supporters of people with intellectual disability about the opportunities for and barriers to self-advocacy. The views of these stakeholders captured in this chapter highlight the strategies that can be used to address barriers to policy participation by people with intellectual disability and emphasised the need for more opportunities for participation.

Literature indicates that self-advocacy by people with intellectual disability in South Africa is still in its infancy and is still primarily service provider driven (Daniels, 2018). Findings from this study concur with this. There are very few self-advocacy groups in South Africa, and they are mostly driven by NGOs. The SAFMH, for example, is the leading NGO that spearheads the self-advocacy movement for people with intellectual disability in the country, supporting the statement by Daniels (2018) that self-advocacy in South Africa is service provider driven. Within this organisation, the aim is to support clients, workers and self-advocates to develop the skills they need to self-advocate.

As noted in Chapter One, policy and legislation in South Africa support the involvement of service users in policy-making and implementation processes. This is in line with the global trend of involving “experts by experience” in generating effective research to inform policy and service delievery (Albert & Hurst, 2004; Kleintjes, 2012). Policy participation by people with intellectual disability is widely supported in literature, and participants whose views were documented for this component of this study were also generally in favour of the participation of people with intellectual disability in self-advocacy for policy-related priorities.

Findings from this study, however, confirm that actual participation is still lacking in South Africa. Participants in this study identified several areas of action which could improve inclusion of people with intellectual disability in policy development and implementation processes. These are discussed below in terms of (a) increasing the capacity of people with intellectual disability to participate, and (b) addressing barriers through creating supportive and inclusive environments. The concept of *Ubuntu* is incorporated in each area of action to highlight the significance of interdependence when including people with intellectual disability to participate in policy making processes.

4.4.1 Increasing the capacity of people with intellectual disability to participate

People with intellectual disability have been and still are disempowered when it comes to policy participation (Bigby et al., 2014; Frawley & Bigby, 2011). Their disability is often considered as an inability, they are seen as incompetent regarding participation in policy processes. Findings from the interviews similarly indicate that people with intellectual disability’s rights to participation in policy processes is often hindered by the lack of belief in their abilities and skills, with stigma playing a huge role in the disempowerment of people with intellectual disability. Stigmatising attitudes and beliefs about people with intellectual disability detract from the need to focus attention on building their capacity to contribute to their policy priorities through self-advocacy and to create supportive environments within which they are able to participate freely (Borg & Kristiansen, 2004; WHO, 2003).

In line with the literature, participants in this study were of the opinion that capacity building of people with intellectual disability must be considered in developing opportunities for participation and self-determination (Andersen & Bigby, 2017; Kasmel & Andersen, 2011). Participants with intellectual disability highlighted that they require advocacy skills in order for them to be able to self-advocate. Supporting people with intellectual disability to represent their views in public policy-related processes requires effective and suitable training and skills development of people with intellectual disability. Skills noted by the participants are collectively considered self-determination skills, which are crucial components for self-advocacy. These skills will enable them not only to advocate for their rights to be realised through policy priorities but also to advocate for others.

An important aspect of dispelling stigmatising views of people with intellectual disability as lacking capacity, is to amplify the notion that their need for, and reliance on, support for participation should not necessarily be viewed as a negative attribute, but rather as a part of the nature of human relatedness and relationships. That is to say, that although people may be socialised to value their independence, that independence is embedded in a social and relational environment of support, to a greater or lesser degree, depending on the person and their environment. This worldview is aptly captured by the concept of *Ubuntu*, a philosophy which understands self-determination and empowerment to be a reciprocal process (Mji et al., 2011). As noted in Chapter One, *Ubuntu* can best be described as an African philosophy that places emphasis on interdependence and as being self through others. It is a form of humanism which can be expressed in the phrases, “I am because of who we all are” (Mugumbate & Nyanguru, 2013).

Interdependence is a valued part of *Ubuntu*, where people are seen as needing to rely and depend on each other, rather than experiencing themselves, their talents, actions and achievements as independent of others. The view is in keeping with the findings from the interviews and the scoping review which support the notion that self-advocacy by people with intellectual disability can be achieved through interdependence, where people with intellectual disability can rely on their peers, supporters, families and friends to help them to advocate for their policy priorities as a valued, rather than stigmatising, concept. Furthermore, this interdependent approach supports participants' opinions that creating inclusive environments through reasonable accommodation can enhance one's ability to self-advocate. In order for some to be able to self-advocate they will need or depend on their supporters, initially, periodically or on an ongoing basis, dependent on their personal capabilities. Louw (2003) sees *Ubuntu* as more than just being who you are through others, *Ubuntu* extends to how people relate and rely on others around them.

4.4.2 Addressing systemic barriers through creating supportive and inclusive environments

The findings from the scoping review together with findings from the interviews highlighted individual and systemic barriers, negative attitudes and exclusion by society for people with disabilities (Azzopardi, 2000; Bigby et al., 2014; Frawley & Bigby, 2011) as the significant barriers to self-advocacy. Similar to the findings, the social model of disability mentions that it is systemic barriers, negative attitudes and exclusion by society for people with disabilities that are the disabling factors.

Findings from the interviews concur with the social model of disability, that in order for any meaningful change to happen there should be change in the society, especially diminishing the societal barriers that people with intellectual disability face. In South Africa, there is a lack of inclusion of people with intellectual disability, which, while a worldwide phenomenon (Capri, Abrahams, et al., 2018), this has been exacerbated by the country's long-standing history of colonialism and more recent history of Apartheid discrimination and disempowerment (Capri, Abrahams, et al., 2018; Kleintjes, 2012; Kleintjes et al., 2020). However, as noted earlier, there is a beginning of the development of inclusive initiatives for people with intellectual disability within the NGO sector which can be expanded, and which include self-advocacy groups, participation in advisory boards, and still-limited participation in policy level self-advocacy through ad hoc public protest, written contributions to public policy documents, and participation in policy review and development workshops (SAFMH, 2022).

Participants suggested that the existing systemic barriers could be addressed by creating supportive and inclusive policy environments. This can be done by providing reasonable accommodations such as translating policies into easy-to-read formats, so that they can understand and make meaningful contributions during advocacy processes. Furthermore, participants highlighted the importance of assistance and support by trained supporters through interdependence-based strategy, to enable an inclusive environment for people with intellectual disability. Findings also point out the importance of policy makers, service providers, various professionals NGOs and DPOs as potential allies central to supporting people with intellectual disability's direct involvement in the formulation of policies through the exchange of information, expertise, and tools for policy reform (Kleintjes, 2012).

4.5 Chapter Conclusion

People with intellectual disability are rarely involved in policy development and implementation processes in South Africa. Participation in policy development and implementation processes requires stakeholder, policy, and legislative support, but it is not sufficient for such participation to occur. In order to move support to action, tangible strategies are required. Stigmatising attitudes amongst the general public, by professionals and within public policy need to be replaced with acknowledgment and acceptance of the right of people with intellectual disability to participate in decisions that affect their lives. Their participation capacity should be strengthened through the development of self-advocacy skills and supported exposure to the policy and service development environments. Systemic barriers need to be addressed through the creation of reasonable accommodations that allow for inclusive policy environments. Finally, their supporters need to be capacitated to effectively support and empower people with intellectual disability to become self-advocates.

CHAPTER FIVE

THE VIEWS OF POLICY MAKERS AND SERVICE MANAGERS ABOUT THE OPPORTUNITIES AND BARRIERS TO SELF-ADVOCACY

5.1 Introduction

The purpose of this chapter is to document the views of policy makers, policy implementers and service providers and managers on the need for self-advocacy by people with intellectual disability in social and health-related policy development and implementation processes, opportunities for and barriers they might experience in including their views within the policy context, and strategies to overcome these barriers. The suggested strategies to overcome these barriers will also be highlighted. This study has employed empowerment theory as the theoretical framework, additionally focusing on the concept of *Ubuntu* as the core principle of interdependence.

5.2. Study participants

The total sample and the number of SSIs conducted are highlighted in the previous chapters. Of the 25 participants 10 comprised of policy makers and service managers. Similar to the participants in Chapter Four, participants were selected using criterion sampling. The researcher selected the participants based on identified characteristics (McMillan, 2016). The 10 SSIs were conducted with service managers from the DoH and DBE, and local and National NGOs (n=5). The policy makers (n=5) were from the DHET, DoH and NPO C (a national umbrella body for organisations that support, advocate for and provide capacity development opportunities for self-advocacy by people with intellectual disability). The list of respondents is included in the appendices (Appendix 12).

5.3 Results

The SSIs were guided by the themes present in the interview schedules, these yielding five themes that had 12 sub-themes (see Table 5.1 below). The identified themes in this chapter are from the SSI process conducted with policy makers, implementers, service providers and managers. The two chapters (Chapters Three and Four) were separated because each chapter addresses its study objective. Although the themes that emerged are not entirely different, the participants’ views from these different groups differ somewhat.

Table 5.1

Themes and Sub-Themes from Semi-Structured Interviews with Policy Makers, Implementers, Service Providers and Managers

Theme	**Sub-Themes**
Self-advocacy in policy.	Meaning of self-advocacy from professionals' point of view. Self-advocacy by people with intellectual disability in organisations and government in South Africa.
Inclusion of people with intellectual disability in policy processes.	Opportunities for participation in policy. Creating inclusive policy environments. Accessibility of available resources.
Barriers to participation.	Challenges experienced by people with intellectual disability. Challenges faced or anticipated by policy makers and service managers.
Supported self-advocacy in policy.	Skills needed for self-advocacy by people with intellectual disability. Available support for self-advocacy by people with intellectual disability. Reasonable accommodations for policy participation by people with intellectual disability.
Capacitating service providers and policy makers about intellectual disability.	Train policy makers and service providers/managers about intellectual disability. Funding for self-advocacy training to enable participation.

5.3.1 Identified themes

The first main theme focuses on understanding self-advocacy by people with intellectual disability in policy. The views of stakeholders on the meaning of self-advocacy and its components are documented. The second theme addresses inclusion of people with intellectual disability in policy processes, this section exploring the stakeholders' views about opportunities for participation in policy, creating inclusive policy environments and accessibility of resources. The third theme speaks to the barriers for full participation in policy-making and implementation processes by people with intellectual disability, where the challenges faced by people with intellectual disability and policy makers/service managers are discussed. The fourth theme highlights the importance of supported self-advocacy in policy for people with intellectual disability; here the discussion is on the available support for self-advocacy by people with intellectual disability, existing and possible reasonable accommodations for policy participation by people with intellectual disability and creating an inclusive environment for people with intellectual disability to participate in policy advocacy. Finally, the fifth theme focuses on capacitating service providers and policy makers about intellectual disability; here the stakeholders discuss the need for training policy makers and service providers/managers about intellectual disability and funding for self-advocacy training to enable participation.

Below is a discussion of the views of the respondents under each theme:

5.3.1.1 Self-advocacy in policy

One of the main themes from this group of respondents is about self-advocacy in policy. This looks at how policy makers and service providers/managers define self-advocacy in the context of intellectual disability. When asked about self-advocacy and what it means to them, most participants highlighted that it is about people with intellectual disability having the right to advocate for their constitutional and or human rights, their need to challenge policies that do not support these rights, and their right to advocate for inclusion and participation:

[Key: I=Interviewer/researcher; Pol=Policy makers; S=Service providers]

> ***Interviewer (I): What is self-advocacy and what does it mean to you and in relation to your work?***
> *(Pol5): So, from my work, you know in the field, self-advocacy is a very big part of the work we do. It's also part of the mental health policy framework, you know, the, the ambition for people with psychosocial and intellectual disabilities to grow the ability to be able to advocate for their own rights, their own needs, their own you know, for services, for better realisation of their human rights.*
>
> *(S3): … allowing people to speak for themselves, allowing their authentic voices to be heard by those in power as well as everyone around … so it's a matter of making your voice known as a matter of being able to tell your story, that's how I understand it. And the importance of it for me, is that you know, everyone within the country has a constitutional right to be heard and, and there's a constitutional right to participate in society just like everyone else, more than anything.… And self-advocacy allows people to do that, allows people to participate just like everyone else.*

Other participants defined self-advocacy as an ability to speak up for yourself in a manner that people can understand*:*

> *(Pol1): Self-advocacy means being able to speak for yourself and be able to indicate what you like and what you don't like, what you want, and what you don't want. Or maybe articulate your wishes…. Yes, in a, in a manner that other people can understand and make sense of.*

Some participants defined self-advocacy based on people with intellectual disability's capabilities or lack thereof. They went on to mention that when people with intellectual disability cannot speak up for themselves, professionals ought to do it on their behalf:

> *(Pol4): Self-advocacy is different for people with intellectual disability, it requires you to have an understanding. I think for those as far as possible, when they can understand anything, what is happening to them must be allowed to advocate for themselves. It would be pointless to those who can't speak and understand the platform to participate in self-advocacy.*

> *(S2): … they also don't have the level of competence at times to speak up for themselves, and that's why we as mental health professionals need to be their mouthpiece and we need to speak up for them when they can't do it for themselves.*

Participants were asked if they have worked with self-advocates with intellectual disability and to elaborate on that experience:

> *(Pol5): Yeah, we do. I work at a national level, but many of our mental health societies work at community level. For instance, (names an organisation) that's based there in the Western Cape, so they run a self-advocacy group for people with intellectual and psychosocial disabilities…. I have engaged with self-advocates, our organisation historically had people with intellectual disability who sat on our governance structures to make sure that our work was representative of people with intellectual disabilities, so yeah, I have, I have extensive experience of, of engaging with people with intellectual disabilities in terms of self-advocacy.*

> *(Pol1): Uhm, yes, in a way because we, we do policy for people with disabilities, isn't it? So, but obviously it's, it's a range of disabilities, it's not just people with intellectual disabilities, which means most of the time, those who will speak are those*

who are able to speak and who understand who, who, who are confident enough and can be able to express themselves very well.

(I): Can you please elaborate on your experience of working with self-advocates with intellectual disability.

(Pol5): In March every year it's intellectual disability awareness month so what we would do is we would consult those groups to make sure that the theme that we choose for the month, that they have an input into the theme. Last year we produced a series of advocacy videos, and we got those groups involved to talk about the impact of stigma and discrimination, you know. My role, my work with them is generally on a consultative basis for them as experts with lived experience.

(S5): … what we do is, we advocate, and we work with self-advocates and government to lobby for better mental healthcare policies as well as better mental health financing. We also connect the country on a global stage. We work with other advocacy organisations like United for Global Mental Health, which is based in the UK …

(Pol4): When, I managed the first NPO (a residential facility for people with intellectual disability) we have had systems that promoted self-advocacy, where the residents were able to say what they would like to do and have sessions with them so that they can actually decide on some of it.

5.3.1.2 Inclusion of people with intellectual disability in policy processes

When participants were asked about their views about the inclusion of people with intellectual disability and existing opportunities for participation, some respondents expressed what the inclusion of people with intellectual disability in policy means to them and how it can be attained:

> *(S1): … to be inclusive means that we cannot exclude anybody because of a diagnosis or because of a certain label or certain population. Everybody needs to be included in policy-making processes. Especially people with intellectual disability because they have been excluded for a long time.*

> *(Pol5): … if we are going to include people with intellectual disabilities in the development of policies, let's make sure that when we consult them, it is done in a way that they understand, it doesn't help if you want to consult a person with an intellectual disability, who can't read. It doesn't help if you put a hundred-page document in front of them and say, oh, can I consult you on this? So, and it's not, it's not the person with the intellectual disability's responsibility to make that accessible for themselves.*

Some participants mentioned that when creating opportunities for people with intellectual disability to participate in policy, one must take into consideration a number of things such as their willingness to participate and their ability or lack thereof to participate. They need to be properly inducted so that they can make an informed decision about wanting to participate or not:

> *(Pol5): We must make sure that if we do have people represented on bodies and decision-making structures, even just on a committee, that it's done for the right reasons and that those people are given the opportunity to fully participate and help in the decision-making, and that includes them receiving an adequate induction and training about what it is that they are going to be expected to do on this group so that they can decide if it's something that they want to do. If they don't want to do it, they should be able to say, actually, I don't want to because I feel it's not appropriate, I don't understand it, I don't want, you know, they've got the right to say no.*

When asked about opportunities for policy participation, some respondents mentioned that the departments that they work for do not have opportunities for self-advocacy by people with intellectual disability, while others mentioned that they are still in the process of establishing them:

> ***(I): Can you think of any opportunities for self-advocacy or policy participation available in your department?***
>
> *(Pol1): I will speak for my department, the department of higher education, specifically the TVET [Technical and Vocational Education and Trainingt] colleges. In our department we don't have self-advocacy by people with intellectual disability, hence I was saying the voice of those with intellectual disabilities is, is more than welcome and we will be able to in future, when we review policy, review it in such a way that it accommodates them.*

> *(Pol2): ... we are in the process of establishing disability support units, because not all colleges have these units. We want to ensure that we support our colleges so that they we have disability units at all the colleges. So, there is still quite some work that we still have to do to support colleges to really accommodate students with disabilities.*

Some participants highlighted that there are not many opportunities for participation for people with intellectual disabilities, but some do get invited to review policies. However, not everyone is able to participate, thus making them feel left behind:

> *(Pol1): .... when we developed the policy framework, the disability policy framework for the post-school education and training system, we invited different people and organisations to review this policy, and even though we did, there are those that feel that we left them behind, and they may be if they were there, they would have influenced the policy differently from how it is now.*

Taking into consideration that there are not many opportunities for policy participation, some participants suggested that self-advocacy opportunities should be created at a community level and indicated the importance of supporting persons as well as reasonable accommodations when creating policy participation opportunities:

> *(Pol5): I think there's a real opportunity to say that what we want, we want to see some specific programmes for the development of self-advocacy at community level for people with intellectual disability uhm, taking into consideration the need for support persons or the development of easy-to-read materials and all the other support functions that might be necessary to help people with intellectual disability become self-advocates.*

Participants were asked what is needed to create an inclusive policy environment that will enable and allow people with intellectual disability to self-advocate for their policy priorities. Most participants mentioned that an inclusive policy environment is one that allows for people with intellectual disability to be free to express themselves, their support needs and provide feedback on policies and interventions:

> *(Pol 2): ... it means that really getting feedback from the recipients of all the policies and interventions that we are coming up with and that which recipients have*

> *happened to be, uh, students with disabilities. They also give feedback in terms of the kind of support that they would appreciate if it is provided to them, and so it's really them communicating their needs, where managers create an enabling and inclusive environment that ensures that they are able to perform with the best of their ability.*
>
> *(Pol1): I've mentioned that we need to give them space to speak for themselves. Put them in a room, interview them, talk to them, let them express themselves as much as they can. Let them write down if possible, what they would like to see happening in a particular environment, whether it's in the health sector or it's in the education institution or it's in the workplace or wherever.*
>
> *(S3): An inclusive environment is where people with intellectual disabilities are able to say how would they like to see things taking shape so that their views are taken into consideration when decisions are made in organisations. It need not be a once-off meeting because, like everybody else, their needs change, their aspirations change. Their feelings and thinking are controlled by what they see or what they experience, and so from time to time they need to be engaged. Believe me, I strongly believe that it will go a long way into boosting their confidence.*

Some policy environments are inclusive of people with intellectual disability. However, in some instances they are included for token representation. They are chosen to be participants because it is required by law or for funding reasons. Some respondents elaborated on this by mentioning the following:

> *(Pol5): You find that you might have people with intellectual disability or psychosocial disability sitting on a group because it's required by some mandate and actually, those people sit there not because they have specific expertise, but it's a box ticking exercise so that whoever is facilitating the group can afterwards say, oh, great, we had somebody with an intellectual disability sitting on our group, let's tick the box, we've been inclusive. When you speak to that person afterwards, they have no idea what was discussed, what their role is.*
>
> *(S4): When people with intellectual disabilities are put into let's say a board or an executive committee or something like that, a decision-making body, they are not told about personal liabilities involved, so let's say, that group needs to assume*

responsibility for the finances of an organisation or group, that person of the intellectual disability might not know that they are personally liable for certain decisions that are being made. They are put in these positions as token participants so that they can get funding, without them knowing what the role entails, they're being strong-armed into sitting on this group, but they don't understand the ramifications if their groups' decisions go wrong, then they are going to be held liable. They are just put there for token representation.

5.3.1.3 Barriers to participation

There are various barriers that hinder people with intellectual disability from becoming self-advocates. These barriers are identified by participants as individual, procedural and systemic or structural barriers. Some respondents highlighted individual barriers, such as lack of communication skills, low self-esteem, and the inability of knowing what they want and what they would want to advocate for.

> ***(I): What do you consider as barriers to self-advocacy for people with developmental disabilities?***
>
> *(S4): I consider communication issues as barriers and then I think about the people around the person with intellectual disability, if they are not trained to understand to get beyond the communication barriers, then that's a huge barrier.*
>
> *(Pol3): ... they are, I'm sorry to say this, but let me say, they have low self-confidence, and their self-esteem has been affected in a way that they have too much self-doubt in themselves. This becomes a barrier when it comes to self-advocacy, I don't think they can speak up for themselves when they have low self-esteem.*
>
> *(Pol1): What I would consider to be a barrier, is they're not understanding what their needs are, for example, in higher education, we deal with, and say for example, funding for people with disabilities for their studies, tuition fees and also assistive devices and maybe, stipends for pocket money, you know, travel, toiletries and things like that. If this person does not know what their reasonable accommodation needs are, it may be very difficult for them to advocate for themselves.*

Some participants highlighted the personal challenges and lack of certain capabilities of people with intellectual disability. They highlighted that it could be more challenging for people whose intellectual disability is more prominent than others to participate in self-advocacy at a policy level:

> *(Pol4): Some people with severe and profound intellectual disability won't be able to speak up for themselves at the policy level. They may have communication challenges that will not allow them to speak up for themselves let alone understanding what the policy says.*
>
> *(Pol5):… somebody with an intellectual disability with a very low level of functioning, self-advocacy might just mean being able to tell somebody that they're able to feed themselves, or brush their own teeth, or tie their own shoelaces…. Or, you know, to be able to ask not to be touched in a certain way. Yeah, so I think self-advocacy is something that we often talk about it represents a homogeneous group of people with similar needs but I think it's a very broad concept that requires one to have certain capabilities.*
>
> *(S1): When we talk about self-advocacy, we need to look at the person's capabilities. You can't expect a person with severe or profound, even moderate intellectual disability to advocate at that level. Especially, with these kinds of issues, we know that this could be a challenge for them. Some can speak up for themselves at home, they can say this is the kind of t-shirt I want, this is the food I want to eat. But that's as far as it goes for them you know.*

Stigma is one of the most common barriers for self-advocacy by people with intellectual disability. All respondents mentioned that stigma and society's negative attitudes are the barriers that hinder people with intellectual disability from participating in society and in policy-making processes:

> *(S1): I think the biggest barriers is that they are not being taken seriously. There's still the perception, that they don't really know what they want, or they don't understand the world around them and uhm, therefore they can't speak for themselves.*

> *(Pol4): Well, systemic barriers such as an environment that is not ready to include people with disabilities. The truth is, people with disabilities in general, and mostly people with intellectual disabilities, struggle with stigma … if people within the environment are not prepared to have the right attitude towards them, that could contribute towards being a barrier to them.*

Some respondents mentioned that people with intellectual disability are often stigmatised in society because most people are ignorant and do not want to celebrate people's differences and acknowledge people with intellectual disability's constitutional rights:

> *(Pol3): Ignorance from the society is an issue, the lack of recognition that differences should be celebrated but more than anything you know, the, the constitutional rights of people to be seen, recognised and participate just like everyone else is not a responsibility of government, it's a personal responsibility that we as a human nature, should take seriously. I think that's one of the major barriers.*

Family structures are also considered as barriers to self-advocacy for people with intellectual disability:

> *(Pol5): One of the things that I've observed as a barrier to advocacy over the years is, you know, often people with intellectual disability if they're adults, they've come from a family where they've always been highly dependent on the family. The family have spoken for them, have made all their decisions for them, and now all of a sudden, we are empowering them, and we're teaching them about, you know, the right and the ability and the responsibility to self-advocate … all of a sudden, this person starts standing up for themselves, they're being regarded as obstructive and disrespectful or you know, adversarial in the home environment and you know, the families might not like the idea of self-advocacy and I think that's something we really need to think about is you don't just teach a person self-advocacy in a bubble.*

> *(S4): I think families who are not sufficiently trained, or again, equipped properly, they too won't take the time to advocate for their human rights, they won't have time to teach their children self-advocacy because they're so busy dealing with the other things.*

Another recognisable barrier to self-advocacy by people with intellectual disability is the lack of access to self-advocacy programmes, the inaccessibility of platforms where they can fully participate as citizens and the lack of support:

> *(Pol3): It starts with issues of accessibility. Students with disabilities, especially those with intellectual disabilities often don't have access to institutions of higher learning. If they struggle with getting an education, how much more with being given access to participate in policy processes.*
>
> *(S2): Some colleges are unable to offer support to different types of disabilities, so this becomes a huge barrier when students want to advocate for themselves because there is no one there to support them or is equipped to provide that needed support.*
>
> *(Pol5): If I, as a service provider or government official, want to consult somebody with intellectual disability on a certain policy, I need to make sure that that documentation or the content is accessible for the person I want to consult. So when presenting the information I should have done my homework and I should have made it accessible to them, and I should make sure that not just the content, but also the process is inclusive and respectful and, and that I truly give them the opportunity to give input.*

Over and above the challenges experienced by people with intellectual disability, policy makers/implementers and service managers experience challenges that could be barriers to self-advocacy by people with intellectual disability. These barriers include lack of understanding intellectual disability by professionals, lack of consequences for policy makers and service providers who stigmatise people with disabilities and lack of reasonable accommodations.

> ***(I): What do you consider as barriers to self-advocacy by people with intellectual disability in policy-making, review or implementation processes?***
> *(Pol5): I do think that professionals not really understanding intellectual disability and their needs is a problem when it comes to policy-making processes. Somebody sitting in a government office somewhere might need to consult a person with an intellectual disability and draft a memo and send it to them while those people might*

> *not be able to read you know, or they might be really vulnerable and there might be safeguarding issues that need to be taken into account because you know of abuse.*
>
> *(S3): I think that we have created a society that does not cater to individuals who have disabilities, there is no efficient system that caters to them. I also think there are no consequences, there are no consequences for not listening to people that are living with disability. So, whether they advocate or they don't advocate, policy makers are not fined, policy makers are not questioned, policy makers not put on the podium and asked why they don't have people with disabilities speaking for themselves, why don't they have a self-advocacy, you know a programme that ensures that you hear the voices of those with ID [intellectual disability].*
>
> *(S4): We have not been trained to communicate with people with intellectual disability who struggle with communication skills, and I think that's a huge barrier.*

The participants identified the above barriers but further made suggestions on how these barriers can be addressed and who needs to address them. It is not only the role of people with intellectual disability, but it is also the role of the community, policy makers, service managers and the government to play a part in addressing the barriers in order to improve policy participation of people with intellectual disability:

> ***(I): How do you think these barriers can be addressed? And, who needs to address them?***
> *(S4): With regards to communication barriers, where they aren't able to communicate, or for those with communication deficits, their caregivers need to be their voices, or people who know them well. But at the same time, to kind of have that balance where and if at all possible, you try to give that person a voice, an opportunity to voice their needs and their wants and their views.*
>
> *(Pol3): I'm thinking about issues self-advocacy goes, I believe that people with intellectual disability need to be capacitated to advocate for themselves.... Their confidence needs to be boosted for them to be able to stand up there and advocate for themselves, for them to be out there and be able to advocate for other people with disabilities.*

Some participants mentioned that breaking down and addressing stigmas in the community could go a long way to addressing barriers that hinder people with intellectual disability from advocating for themselves:

> *(Pol1): Yes, this stigma is caused by our attitudes. So, if we can remove all that, make everybody in the environment understand that everybody has got the right to dignity and respect, and be treated in a way that says, I recognise you as a fellow human being, that will assist a lot in breaking down these barriers.*

Some participants suggested that these barriers can be addressed by being inclusive in communities and in government sectors. Including people with intellectual disability in policy-making and implementation processes through self-advocacy, and also teaching people with intellectual disability about what inclusion entails:

> *(Pol5): I think with the review of the mental health policy framework that is on the cards, and that's actually very overdue, I think it's a really good opportunity for people with intellectual disability to be included because in the previous policy framework there was a move towards trying to develop self-advocacy, but I don't think enough was really done to really flesh out what are we talking about when it comes to self-advocacy and how do we want it to happen? What I'd like to see is, in a mental health policy framework, I'd like to see some specific mentions about intellectual disability.*
>
> *(S1): I think there's a real opportunity for some specific programmes for the development of self-advocacy at community level for people with intellectual disability, taking into consideration the need to support persons or the development of easy-to-read materials and all the other support functions that might be necessary in including people with intellectual disability in self-advocacy.*
>
> *(Pol3): People with intellectual disability need to understand issues of inclusion. What are we talking about when we talk about is inclusion, why is it important for them to be included and for them to be able to access these policy spaces, acquire skills and for them to be supported accordingly to succeed equally, be given equal opportunities despite the differences and their disabilities?*

One respondent mentioned the importance of inclusive research as a way to address barriers. Having people with intellectual disability participate in research as part of the research team and as participants is another way of addressing barriers to self-advocacy by people with intellectual disability:

> *(S4): Well, on an individual level as a clinician (service manager) and researcher, I think it's important for me to do inclusive research. Inclusive in that I have a person with intellectual disability on my research advisory committee, but I'm also including them as a participant. I think that's another way that I can reinforce the message that people with intellectual disability should be speaking for themselves in terms of service needs. I believe that going to Parliament together with my group will be another way to address these barriers.*

Some respondents highlighted that barriers can be addressed by upskilling themselves as professionals to better understand and communicate with people with intellectual disability:

> *(S2): ... like I just mentioned, for me that would be the one barrier that I would want to break, to have proper understanding on how to engage with the person with intellectual disability and then also to upskill myself on how to manage and how to communicate and how to access the people who have intellectual disability.*

5.3.1.4 Supported self-advocacy in policy

When asked what people with intellectual disability need to become self-advocates, some participants highlighted that they require support with building self-advocacy skills that will in turn help them navigate the policy space:

> ***(I): What do you think people with intellectual disability need in order for them to become self-advocates, or what do you think they need for successful self-advocacy?***
> *(Pol1): .... I'm saying if they are able to express themselves, if they know what they want, I think it would work out better. Remember, people with disabilities say nothing for us without us, and having their voice I think would make a big difference in terms of us understanding what their needs are and what their aspirations are, and I think it would also make policy-making much easier, because the truth is, even though we, we develop policy on disabilities, there are those with certain disabilities who may feel left out.*

> *(Pol3): …. develop their communication skills, their reasoning skills, and develop them to understand that their, their disability doesn't inhibit them to participate in society like any other person. To capacitate them to create opportunities for themselves to penetrate systems where they will be heard and enjoy their rights like any other person. This will help them get recognition and be put on boards, to speak their minds, speak about their challenges and for them to be engaged in developing strategies to address these challenges at a policy level.*

Some participants mentioned that people with intellectual disability often need support from those around them in order for them to become self-advocates; the support is often provided by NGOs/NPOs:

> *(Pol5): …. there are some really good models of self-advocacy such as the one provided by (names an organisation that provides self-advocacy groups). I think their model is probably the best model that I've seen for self-advocacy in South Africa. Where they support people, but they also recognised that there's a need to cut the apron strings at a certain point and, and to be able to let people function independently and make their own decisions.*
>
> *(S5): There's an organisation that gives access to people with intellectual disability that cannot stand up for themselves, who can't articulate themselves; they speak up for their clients. They are the advocacy team for the intellectual disability. So, we need to have more organisations that that are accessible for people who cannot articulate whatever injustice they are experiencing.*

At a societal level, NGOs provide advocacy services or teach people with intellectual disability self-advocacy and provide them with an environment where they can practice self-advocacy. However, some participants mentioned the importance of families in self-advocacy by people with intellectual disability:

> *(Pol5): … it takes a village to raise a child. It's not just mum and dad, but it's uncle and aunt, it's brothers and sisters, it's neighbours, it's that community setup that we often find in South African communities. I think that self-advocacy efforts, especially when we're talking about people with intellectual disability, all these people I mentioned should be involved to make it a success. It is irresponsible to teach them*

> *self-advocacy without looking at their wider context. We need to teach them self-advocacy and then send them back home to people who know about and support it.*
>
> *(S4):. So, I think when we are looking at developing self-advocacy, we need to look at more holistic approaches, to look at empowering the whole family to create interdependence. Self-advocacy is not one size fits all, one person with an intellectual disability might be from a supportive family and the other from a family against speaking up for yourself. We need to look at each person individually when we're talking about self-advocacy to make sure that as professionals, when we are teaching people to self-advocate we include important role players in their lives who will support them as self-advocates.*

Some participants mentioned the importance of support when teaching or empowering people with intellectual disability to self-advocate. They emphasised the importance of having long-term support because this is a lifelong journey and is different for every person:

> *(Pol4): We want to empower them, we want to impart skills and knowledge on them, but it is not the same for every person. For one person to become empowered, it might take a few training sessions, or you know, a few discussions or whatever. For another person to become empowered, it might take years of hand holding and supporting them. Empowerment is a journey that we all embark on and when it comes to people with intellectual disability or any other vulnerable groups, they need people to walk with them side by side.*
>
> *(S3): … there needs to be a recognition that we need to support them until they tell us that they don't need our support anymore. Let's not throw a bunch of information their way and say, OK, now you know what self-advocacy is about, off you go, go and self-advocate. I think that's counterproductive, and I think it's quite irresponsible. We need to recognise that everybody is an individual and unique and that their empowerment journey towards becoming self-advocates is going to be unique and different.*

Participants further highlighted the importance of having supporters and how this helps with self-advocacy by people with intellectual disability. A re-occurring theme throughout the interviews was the importance of having support persons to help them navigate and self-advocate in the policy space; according to the participants supporters could be professionals or peers:

> *(Pol2): One example I can give about a supporter is a former student with a disability, who is also a self-advocate and advocates for the needs of students with disabilities, the ones who are coming after her. She speaks about her experiences, how she was supported and how she supports others, and makes recommendations in terms of how to strengthen and improve that support.*
>
> *(Pol5): I'm going to use (names an organisation) as an example because that's the body that we work with the most when it comes to intellectual disability and consulting groups about policies, they would make available support persons for the person with intellectual disability to help them. For instance, if there's translation work or if there's complicated subject matter that might be discussed that the person might not grasp or that they might struggle with, then there will be a support person to help them interpret the information and make clear what's being asked and help them to articulate themselves in a way that is helpful for the conversation if they need that support.*

When asked about supported self-advocacy, some participants highlighted that in some instances people with intellectual disability's views are overshadowed by their supporters' views, where the supporter speaks for the person with intellectual disability without listening to what their views are first. Thus, it is important for supporters to know what their role entails and not overstep:

> *(Pol5): When a support person is present, they need to make sure that they understand their role is not to answer for the person, but to help the person respond in their way, in their words, bringing across the message that they would want to articulate. What you'll sometimes find is that a support person, and I've encountered this over the years in different settings, not just within our organisation. Where you have a support person perhaps just because they are passionate about what's being discussed, but you'll often find that the supports a person starts answering the questions you know, instead of the person with intellectual disability actually answering. So, you'll find that you end up actually speaking to the support person and you have to say actually, hang on, is this your answer or is it the person that you are supporting's answer?*

Participants highlighted the importance of providing reasonable accommodations for policy participation by people with intellectual disability. These are measures put in place to help support people with intellectual disability to self-advocate, including easy-to-read materials, assistive devices, qualified personnel, and creating an enabling environment:

> *(Pol5): .... I think it's very important that there are support structures put in place to help people with intellectual disability self-advocate. These include things like the easy-to-read methodologies, and I think that's a wonderful way of supporting people with intellectual disability to engage with subject matter.*
>
> *(Pol2): We've got to ensure that we prepare first so that by the time they are here, we are able to give them the necessary support, and part of that preparation at times involves getting the necessary learning materials, getting the necessary assistive devices, ensuring that you've got personnel who are capacitated to cater for students with a certain nature of disability.*
>
> *(Pol1): ... for example, we create a standardised environment for them, an enabling environment for participation. Where we make sure that everything is in place for them to fully participate in policy processes. We also ask questions like, what is it that you would like to see happening to make you feel accommodated?*

5.3.1.5 Capacitating service providers and policy makers about intellectual disability

Some participants highlighted the need for opportunities for training and development to strengthen their knowledge on intellectual disability. This will help them know how to interact with people with intellectual disability during policy processes and it will also equip them to help provide suitable environments for self-advocacy in policy-making and review processes:

> *(Pol2): I'll be honest to say I have limited knowledge about intellectual disabilities, this is because I have not interacted much with people with intellectual disability in the policy setting. I would really benefit from more training programmes about intellectual disabilities. Although I have interacted with a couple of people, but I can really benefit from learning more so that I can do better. I speak for my colleagues as well.*

> *(Pol5): Policy makers, service providers and consultants in the mental health sector need to familiarise themselves with intellectual disability and understand the target group that they are going to consult or work with. It is up to the person wanting to do the consultation to, like I said, to make sure that they do their homework and that they understand the client group and who they're going to be working with. And that safeguarding measures are put in place and that consultations are done respectfully and in a way that is inclusive and that respects the person, safeguards their human rights.*

Another crucial point raised by participants in relation to training is the component of creating awareness and bridging the knowledge gap on intellectual disability:

> *(Pol1): ... creating awareness about intellectual disabilities helps bridge the knowledge gap in our communities, especially in our institutions. This goes with ensuring that we educate the entire student body as well as support staff, and really creating an environment where they are really accepted.*

Funding for self-advocacy training to enable participation is required of different government departments. This will ensure that the different stakeholders are capacitated by qualified and experienced people or organisations that work with people with intellectual disability. Participants highlighted this as one of the things that would equip them to better assist self-advocates and create an enabling environment for self-advocacy in policy:

> *(Pol3): The National Office needs to make funding available for us to get proper training from qualified people who know what needs to be done and what programmes do they think are relevant. The National Office need to bring resources, resources in terms of funding, that mostly covers infrastructure, human resources and, and other things that need to be done. Funding to bring experts in areas of intellectual disability and self-advocacy.*

> *(Pol1): I believe that student support services managers are not experts or disability managers in colleges are not experts in issues of disabilities, especially because we have diverse disabilities. So we have people and organisations out there who have expertise in various disabilities who can be brought into the institutions to come and assist us with better understanding of intellectual disability. They can also assist*

> *students with disabilities with self-advocacy skills. All of this requires money and that is why these programmes should be on the mandate for funding.*

5.4 Discussion

One of the study's objectives was to document the views of policy makers, policy implementers and service providers and managers on the need for self-advocacy by people with intellectual disability in social and health-related policy development and implementation processes. To explore the opportunities for, and barriers they might experience in including their views within the policy context, and strategies to overcome these barriers. This was done for the purpose of informing the development of the conceptual framework.

Interview findings concur with the scoping review findings that people with intellectual disability should be included in decision-making processes to have a say in issues affecting them (Perkins, 2010; Petri et al., 2017). People with intellectual disability have the same rights as any other person, this means that just like everyone they have the right to have an input on the decisions made that affect or concern them. The social and human rights models of disability agree with the interview findings by acknowledging disability as a natural part of human diversity, that people with disabilities should be respected and supported, and their impairments not used as an excuse to restrict their rights (Korolkova & Anthony, 2016). Decisions made about and for people with disabilities should always be person-centred (Degener, 2014, 2017). The empowerment theory further emphasises the importance of uplifting vulnerable groups in society to gain greater access to, and control over, societal resources and are afforded democratic participation in the life of their community (Perkins & Zimmerman, 1995).

The interview findings suggest that barriers to self-advocacy by people with intellectual disability are the personal impediments (including lack of communication skills, lack of capacity to understand complex information, not knowing their needs and support needs, and lack of confidence). The barriers to self-advocacy also include barriers in society, these include stigma, negative attitudes, lack of access to resources and information, lack of inclusive policy and policy makers' lack of understanding of intellectual disability. This implies that in considering barriers to participation requires attention to these main areas, individual barriers, procedural and structural barriers. Personal barriers identified by the findings, such as communication deficits, lack of confidence, and inadequate decision-making skills can be addressed by capacitating people with intellectual disability with communication skills and supported decision-making. By breaking down these barriers people with intellectual disability get a chance to full participation in society.

Findings from the interviews identified communication deficits as one of the major barriers to self-advocacy by people with intellectual disability. Participants and literature mention that some people with intellectual disability often struggle with communication skills (Adnams, 2010), thus it becomes challenging for them to express themselves and speak up for themselves. Hence, the participants in this study suggested that people with intellectual disability who struggle with communication should be capacitated with communication skills that will enable them to advocate for themselves. These skills need to be taught by qualified people who will also provide them with support. The scoping review concurs with these findings by stating that it is important that people with intellectual disability are supported to improve their communication skills in order to convey their needs and wants effectively (Nonnemacher & Bambara, 2011; Test et al., 2005; Wehmeyer & Lawrence, 1995). Communication skills development is considered as a means to promote self-advocacy in policy.

Additionally, findings highlighted that there are people with intellectual disability whose disability is too prominent for them to meaningfully engage in policy-making. Like everyone else, people with intellectual disability differ in their capabilities, and depending on their capabilities they will need different levels of support. Some people may have personal constraints which are overcome with reasonable accommodations, others may not be able to participate themselves, but would be individuals who would need their families and other supporters to represent their views, that is, to advocate for their needs and rights (Gilmartin & Slevin, 2010; Kilpatrick, 2021). Others may be able to self-represent at other levels, such as personal care, within their homes, schools and other less complex settings, but may not be able to do so in the policy arena.

There are people with intellectual disability who can self-advocate, with support, training and experience, who have not in the past been allowed to self-represent at policy level. This has been happening for far too long, where people with intellectual disability were seen as not able to self-represent. This is a main argument of stigmatising people with intellectual disability, where all people with intellectual disability are categorised as people who are unable to participate. Other significant barriers highlighted by the findings are policy makers' lack of understanding of intellectual disability, and people with intellectual disability's lack of access to participate in policy environments. These findings echo the ideas of the social model, that it is society that disables people by excluding them from full participation (Oliver, 2004; Retief & Letšosa, 2018). Findings highlight that the barriers should be addressed in a way that is centred on societal change instead of on individual adjustment (Degener, 2017). Participants suggested that the existing systemic, structural and procedural barriers could be addressed by creating inclusive policy environments and promoting supported self-advocacy.

The South African White Paper on Integrated National Disability Strategy aims to ensure that disability issues are integrated in all governmental policies, strategies, planning and programmes (Republic of South Africa, 1997). This policy mentions that people with disabilities should enjoy equal access to fundamental rights, removing barriers and creating inclusive environments. In some instances, government departments have built on this inclusive approach within their implementation strategies. While policies indicate that there is support for participation, there is a significant gap between the policy directives and the implementation of supportive practice and resourcing to ensure that opportunities are available for people with intellectual disability to participate in policy processes.

Participants of this study are supportive of the policy directives and offered suggestions for how these opportunities can be created. That is, by creating mechanisms for voluntary participation of people with intellectual disability, where they are not coerced to participate and can express themselves as best as they can and are afforded meaningful participation rather than be included for token representation. Notions supported by Frawley and Bigby (2011) who note that the key element in providing inclusive environments is to allow participants to join voluntarily, thereafter providing support in different forms. This support can include providing access to information, knowledge development, engaging in processes, forming relationships with stakeholders, and skill development (Andersen & Bigby, 2015; Caldwell et al., 2009; Frawely & Bigby, 2011). Similarly, Concannon (2005) highlights that an inclusive policy environment is one that gives people with intellectual disability power to participate in order to avoid tokenism, where people with intellectual disability are present but not participating.

This involves acknowledging how invisible but powerful policy maker negative attitudes, stigma and lack of knowledge contribute to this situation (Johnson et al., 2014; Landmark et al., 2017). As noted by participants of this study, there must be capacity building for policy makers and service managers, where they can learn more about intellectual disability and ways in which they can accommodate them to fully participate during policy consultation processes. Participants' suggestions of how they can be capacitated are in keeping with current literature on the topic, and include skills building, awareness and training on how to provide reasonable accommodations to people with intellectual disability.

5.4.1 Supported self-advocacy through interdependence

There are various supports that the participants suggested, these included supporters such as their family and/or friends, organisations working with people with intellectual disability, trained support persons and access to reasonable accommodations. Participants views are supported by the scoping review literature which indicate that self-advocacy for people with intellectual disability is not a one-person project, rather people with intellectual disability need support from various people or systems such as families, supporters, peers and professionals (Landmark et al., 2017; Roberts et al., 2016). Therefore, interdependence is a crucial component for self-advocacy of people with intellectual disability.

Interdependence is an integral part of empowerment, the empowerment theory suggests that empowerment is an interaction between the individual and their community towards change with a long timeframe, in terms of significant social and political change (Kasmel & Andersen, 2011; Laverack & Wallerstein, 2001). This supports what the participants and the scoping review have highlighted about the importance of the community and government supporting self-advocates with intellectual disability towards meaningful change in government policy or legislation.

Similarly, the concept of *Ubuntu* highlights the importance of inter-connectedness of people having an impact in societal change. An interdependent community is one in which individuals can only discover who they are through others, while recognising the distinctive identity of individuals (Breed & Semenya, 2015; Ewuoso & Hall, 2019; Murithi, 2007;

Ngubane-Mokiwa, 2018). The concept of *Ubuntu* is beautifully captured by the participant who noted that raising and training a child is a task for the community. These findings show that effective and meaningful self-advocacy can be achieved through interdependence, where people with intellectual disability can rely on their peers, supporters, families and friends to help them to advocate for their policy priorities.

5.5 Chapter Conclusion

Improving policy participation of people with intellectual disability will need the involvement of a range of support services, systems, and role-players. These include policy makers, funders, NGOs, support persons and families and/friends. There must be a shift in role-players' stigmatising attitudes, where they move from ignorance to acceptance and provide supportive self-advocacy spaces for people with intellectual disability. The views of these stakeholders highlight the strategies that can be used to create suitable policy environments that improve policy participation by people with intellectual disability. Findings further reinforce the importance of supported self-advocacy and the importance of providing reasonable accommodations to aid self-advocacy by people with intellectual disability. A challenge for policymakers is to understand further the conditions that enable independent self-advocacy to flourish in the policy environments. This involves questions about how best to develop capacity to ensure skilled support is available to self-advocates, how to deliver core funding that ensures continuity of support, and how can these initiatives be implemented in ways which are sustainable.

CHAPTER SIX

DEVELOPMENT OF A CONCEPTUAL FRAMEWORK FOR SELF-ADVOCACY

6.1 Introduction

The purpose of this chapter is to describe how the conceptual framework for self-advocacy by people with intellectual disability was developed, to describe the components of the framework and to discuss the framework. This study's conceptual framework describes what is needed to help people with intellectual disability participate and advocate for their social and health-related policy priorities in South Africa. It addresses the question of what the opportunities for, and barriers to, self-advocacy by people with intellectual disability are, in social and health-related public policy and service development processes. The framework highlights strategies that can be implemented to address these barriers and create more opportunities for self-advocacy in policy participation.

6.2 Method

The conceptual framework was developed by reviewing approaches used to in creating similar frameworks. The first framework that was reviewed focused on strengthening the participation of people with psychosocial disability and carer involvement in the National Institute for Mental Health England (NIMHE), an organisation attached to the National Health Service in the United Kingdom (UK) (HASCAS, 2005), which was disbanded in March 2011 (Robotham &Ackerman, 2011). This framework was identified through the preliminary overview of the literature conducted to inform the development of the research protocol for this study.

Three additional frameworks were identified during the more rigorous literature search conducted for the scoping review. The framework by Owen et al. (2016) was not used when developing the conceptual framework, as the core methodology used was a group technique, whereas the other two frameworks' methodologies were more in line with requirements needed for this study's process of developing the conceptual framework. The remaining two frameworks identified by the scoping review, which were used to inform the development of the framework for the current study, are the self-advocacy framework by Test, Fowler, Wood, et al. (2005), and the multi-cultural and social justice counselling competencies by Cook (2017). These were detailed in Chapter Three on the scoping review. All three frameworks’ approaches were considered in deriving a process to develop this study’s conceptual framework.

Table 6.1 below summarises the processes followed in the consulted frameworks and the process I followed to develop the conceptual framework for this study. Thereafter, a detailed description of the process is outlined.

Table 6.1

Process of Development of the Conceptual Framework

Process of developing a conceptual framework	Reviewed Frameworks		
	HASCAS, 2005	**Conceptual framework for self-advocacy (Test, Fowler, Wood, et al., 2005)**	**MCSJCC (Cook, 2017)**
Scoping review: - To identify existing conceptual frameworks for self-advocacy, strategies to support self-advocacy and methods of developing conceptual frameworks (objective 1). - To identify principles and strategies to support participation. - To assess legislative, policy and stakeholder support for participation.	- Literature scan to identify key issues, principles, and good practice. - Reviewing NIHME strategy in relation to service user and carer involvement.	- Extensive literature review of 20 articles pertaining to self-advocacy.	- Review of the MCC framework that was developed by Sue et al. (1992). - Review of similar literature from other professions regarding the MCC.
Semi-structured interviews: - To identify stakeholder conceptual understanding of self-advocacy and their views on barriers and opportunities for self-advocacy and how to address these. - To document stakeholder views on current participation and support for participation. - To document policy makers, implementers and service providers' views on the need for self-advocacy by people with intellectual disability in social and health-related policy development and implementation processes.	- Collecting information on what users/carers are currently involved in. - Focused interviews with NIMHE stakeholders to identify difficulties and strengths in user/carer involvement. - Questionnaire to programme leads in NIHME current involvement arrangements. - Focus groups with users and carers to explore issues raised in the above process.	- Engagement of relevant stakeholders.	- Engagement of various stakeholders and associations to adapt and update the MCC framework to the MSJCC framework.

	- Attending meetings of existing NIMHE networks. - Questionnaire to service users and carers on MindLink mailing list/invitations to national organisations to comment.		
Drafting of the conceptual framework: - Triangulation by researcher of all data sources to draft conceptual framework. - Translation to the easy-to-read format by Cape Mental Health easy-to-read consultation group comprised of advisors with intellectual disability and supporters.	- Drafting of the framework with assistance of user/carer reference group and expert consultation.		
Consultation to finalise draft conceptual framework: - Review of Draft 1 via focus group discussions. - Consultation with study advisory group presentation and discussion of framework Draft 1 to clarify areas of uncertainty in the drafting. - Review of conceptual framework through two focus group discussions with policy makers, service managers, parents and supporters of people with intellectual disability and two individual meetings with people with intellectual disability. - Researcher’s incorporation of feedback from stakeholders into the final version of the framework.	- Consultation: Wide circulation of background report and framework for two months, and incorporation of comments to finalise framework.	- Engagement of stakeholders to provide feedback on the draft of the conceptual framework.	- Engagement of stakeholders to provide feedback on the framework.

6.2.1 Data collection to inform the components of the framework

Data collection was carried out similarly to the methods employed in the three frameworks listed in Table 6.1 above (Cook, 2017; HASCAS, 2005; Test, Fowler, Wood, et al., 2005). The HASCAS (2005) process collected data through literature scan, interviews and focus groups were conducted with NIMHE stakeholders to identify difficulties and strengths in user/carer involvement (HASCAS, 2005). Test, Fowler, Wood, et al. (2005) conducted an extensive literature review of 20 articles pertaining to self-advocacy and engaged with relevant stakeholders for their inputs (Test, Fowler, Wood, et al., 2005). Similarly, Cook (2017) reviewed the MCC framework that was developed by Sue et al. (1992) and later updated by Ratts and colleagues (2015). Thereafter, a literature review of relevant multicultural competency literature was conducted, followed by discussions with other professions regarding their multicultural competency documents, identifying strengths and gaps within the original MCC document, and obtaining feedback from different stakeholders (Cook, 2017; Ratts et al., 2015).

This study collected data by means of a scoping review and SSIs with different stakeholders and policy makers, as well as service managers, as highlighted in Chapters Two to Four. The scoping review was conducted to identify key concepts relevant to empowering direct policy participation by people with intellectual disability, including the identification of other relevant conceptual frameworks for self-advocacy which were used to inform the focus of this study. The scoping review identified 168 articles and after a rigorous inclusion and exclusion process, 20 articles were included and reviewed. The scoping review identified available strategies to support self-advocacy and methods of developing conceptual frameworks, and it identified principles and strategies to support participation and assessed legislative, policy and stakeholder support for participation.

The SSIs were conducted with five groups of stakeholders, the first group comprising of people with intellectual disability, the second group including their parents, and the third group including carers and supporters. The fourth and fifth groups were made up of policy makers/implementers and service managers respectively. The SSIs were conducted to address objectives two and three of this study. From the interviews, the views of participants regarding self-advocacy and opportunities for and barriers to participation in policy processes were documented, as well as the suggested strategies to address these barriers and create more opportunities for participation. Detailed findings from the SSIs are discussed in Chapters Three and Four.

6.2.2 Data analysis: Triangulation of all data sources

This section summarises the findings of the study regarding the opportunities for, and barriers to, self-advocacy by people with intellectual disability. It examines how the findings in each chapter relate to and differ from each other. This provides an opportunity to triangulate the results from different data sources (scoping review and SSIs), in the pursuit of answering the research question. Data were triangulated by examining the themes that emerged from each data source, then comparing the findings and exploring the relationships between the themes and sub-themes.

From the scoping review, four themes emerged, (a) understanding of self-advocacy, (b) conceptual/theoretical frameworks used for self-advocacy by people with disabilities, (c) inclusive citizenship, and (d) experiences of self-advocates. From SSIs with the participant groups, there were common and different perspectives of stakeholders on the themes that emerged, as discussed in the previous chapters. Moreover, the overall themes that emerged from the SSIs were (a) meaning of self-advocacy for people with intellectual disability, (b) barriers to full participation, (c) opportunities for self-advocacy participation, (d) inclusion of people with intellectual disability in society, (e) *Ubuntu*/Interdependence (supported self-advocacy) in self-advocacy by people with intellectual disability, and (f) capacitating service providers and policy makers about intellectual disability. Table 6.2 below shows how these themes were connected across the data sources.

Table 6.2

Relating Themes Across Data Sources

Themes	**Data Source**		
	Scoping Review	**SSI with parents, supporters & people with ID**	**SSI with policy makers and service managers**
Meaning of self-advocacy	√	√	√
Conceptual/theoretical frameworks	√		
Inclusive citizenship	√	√	√
Experiences of self-advocates	√	√	
Barriers to full participation	√	√	√
Opportunities for self-advocacy participation	√	√	√
Inclusion of people with intellectual disability in society	√	√	√
Ubuntu/Interdependence (supported self-advocacy)	√	√	√
Capacitating building	√	√	√

After identifying the notable similarities and differences within the themes across all data sources, I interpreted the themes according to how they relate to or answer the research question, "What are the opportunities for, and barriers to, self-advocacy by people with intellectual disability in social and health-related policy?". I looked at the themes and interrogated them regarding which part of the research question they answer, asking myself the following questions:

Which of these themes:

- Explain the meaning of self-advocacy by people with intellectual disability?
- Indicate what is needed by people with intellectual disability in order to self-advocate at a policy level?
- Show the available opportunities for self-advocacy?
- Show what can be done to create opportunities for self-advocacy by people with intellectual disability?
- Identify the barriers to self-advocacy by people with intellectual disability?
- Suggest strategies for addressing these barriers?

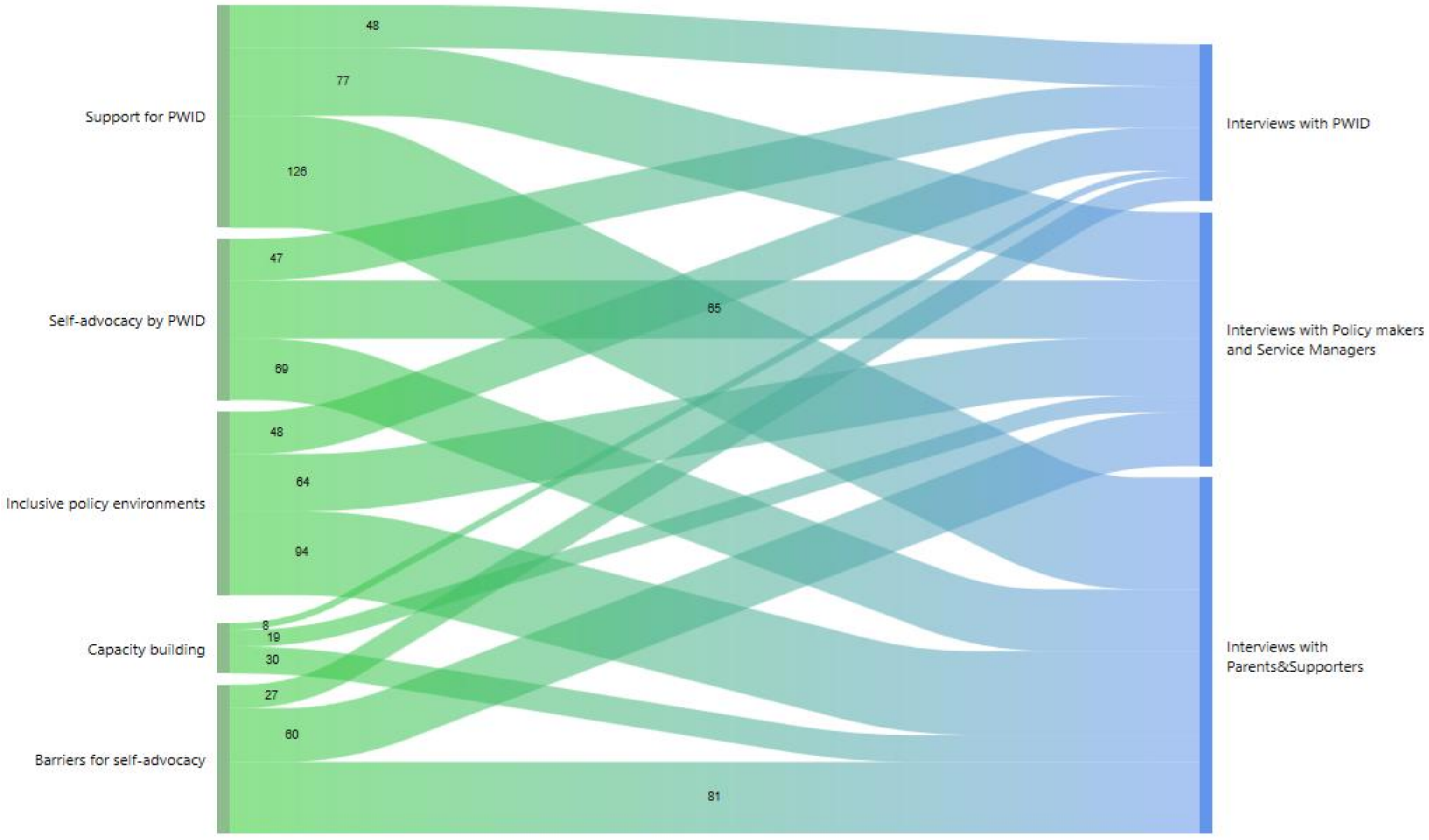
- Explain how people with intellectual disability can be included in self-advocacy at a policy level?

I grouped the themes according to how they answered these questions and categorised them into five groups according to their meanings. The categories were (a) self-advocacy by people with intellectual disability, (b) support for people with intellectual disability, (c) barriers to self-advocacy, (d) inclusive policy environments, and (e) capacity building. These categories helped in extracting and developing the key components for the conceptual framework to guide self-advocacy by people with intellectual disability within a policy and service development context in South Africa.

Figure 7 below illustrates these categories in relation to the participant groups. The numbers within the categories indicate the frequencies of the codes and themes within these categories in relation to the participant groups. The majority (n=251) of codes from all participant groups highlighted the importance of support for people with intellectual disability when advocating for themselves in policy. The second most frequent category of codes (n=206) highlighted the importance of having inclusive policy environments and how these can be achieved. Following was the category that highlighted the meaning of self-advocacy by people with intellectual disability (n=181). This comprised themes that indicated what is needed by people with intellectual disability in order to self-advocate. The fourth category (n=168) highlighted the barriers to self-advocacy and the suggested strategies to address these barriers. The category with the least number of codes (n=57) indicated the importance of capacity building of people with intellectual disability, as well as capacity building of policy makers, parents and supporters of people with intellectual disability.

Figure 7

Categorised Themes



6.3 Summary of the Findings of the Study

This study's findings were grouped into themes, each triangulated and categorised based on their meaning. The five categories stated above will be discussed in this section, as well as the process of extracting the key components of the conceptual framework. Data pertaining to the opportunities for, and barriers to, self-advocacy were triangulated in a manner that sought to answer the research question. It was through understanding the meanings drawn from data sources and the incorporation of the suggested strategies to addressing the identified barriers as well as creating self-advocacy opportunities that the conceptual framework was developed.

6.3.1 Self-advocacy by people with intellectual disability

Data in this category were triangulated to extract the meaning of self-advocacy, to determine the required self-advocacy skills for people with intellectual disability to participate meaningfully in policy-making processes, and the different self-advocacy strategies that people with intellectual disability can employ when advocating for their rights in policy-related initiatives. Self-advocacy has been defined by people with intellectual disability as the ability to speak up for their rights and getting the information and support needed to enhance their meaningful understanding of procedures and issues under discussion, and their freedom to respond from an informed perspective. It enables people with intellectual disability to make their own decisions about their needs and wants, to know what they value, and it allows them to speak out and be heard about their rights.

Self-advocacy literature emphasises that self-advocacy is about knowing what and how you feel or think about yourself and your needs and informing others about your decisions related to your self-knowledge and needs, and available options for meeting these (Grove, 2015; Islam & Cojocaru, 2015). Self-advocacy, as defined by participants in this study, is about people with intellectual disability having the right to advocate for their constitutional and/or human rights, their needs to challenge policies that do not support these rights and advocate for inclusion and participation. From these definitions of self-advocacy, it was determined that self-advocacy is about knowing how to speak up for yourself, knowing your rights and advocating accordingly and knowing who you are as a person, what you stand for, what your needs and wants are and speaking up about them.

Additionally, the findings in this category highlighted the necessary things that people with intellectual disability need to have and know in order for them to be able to advocate for themselves in policy. These included self-advocacy skills, the knowledge of their strengths, and areas in which they might require support. The required self-advocacy skills included self-confidence, communication skills, assertiveness, decision-making skills, public speaking, and leadership skills. Self-confidence is seen as one of the key skills for self-advocacy. Other necessary skills that the findings highlighted included reading and writing. Although, many people with intellectual disability may have difficulties in read complex material or relate to complex ideas in the written form, findings indicate that there should be alternative supports to reading and writing for people with intellectual disability.

Some parents, when defining self-advocacy, were doubtful about their children's self-advocacy skills and capabilities. These sentiments were also shared by some policy makers, who highlighted their lack of confidence in people with intellectual disability's capabilities to self-advocate. However, findings suggest that in instances where people with intellectual disability lack the necessary self-advocacy skills, rather than excluding them, people with intellectual disability need to be capacitated with these skills. Such skills include making use of alternative communication methods suitable for individuals with intellectual disability and employing alternative self-advocacy methods such as storytelling. Storytelling has been found to promote self-advocacy by people with intellectual disability. It allows for people to share their stories in the best way they know how. It also allows for increased communication, participation, relationship building and decision-making (Grove, 2015). People with intellectual disability can share their stories on how a certain policy impacts their lives and further make recommendations on that specific policy.

When people with intellectual disability need additional support to acquire new skills, other supports may contribute to supporting participation and helping them when engaging with policy documents. These include the provision of memory support, explanation, simplification, encouragement, emotional support, recording, and preparation, as discussed later in this chapter.

6.3.2 Support for people with intellectual disability

In this category, data were triangulated to determine available support for people with intellectual disability in self-advocacy. This category focused on support systems, peer-to-peer support, supported self-advocacy by parents and professionals, empowerment of people with intellectual disability, their access to resources and services, existing opportunities for self-advocacy, and reasonable accommodations put in place to help people with intellectual disability participate in self-advocacy.

Interviews with participants in this study and findings of the scoping review emphasised the importance of support when engaging in self-advocacy. Findings highlighted interdependence as a core aspect of self-advocacy by people with intellectual disability because they often rely on other people in their lives to provide support so that they can enact their self-determination (Owen et al., 2016; Tideman & Svensson, 2015). Furthermore, these findings highlighted the significance of having support when preparing to participate in self-advocacy, having someone to share their ideas with and being able to express themselves without judgement prior to participating in self-advocacy, particularly in policy environments.

Where people with intellectual disability require support with speaking up for themselves, the findings from both the scoping review and interviews indicated that people with intellectual disability need to be empowered in ways that will equip them to be able to self-advocate. The importance of having someone, such as a family member, peer, or support personnel, to help them co-present their ideas was highlighted. The term “co-presentation” in this study is understood to be when the person with intellectual disability works with their supporter to co-construct ideas to be presented in a manner that is easy for the person with intellectual disability. For example, when people with intellectual disability need support with public speaking skills, they might make a video together with their supporter where they read off their speech to the camera and have that shown to policy makers. The co-presentation of ideas needs to be done in a manner that fully reflects the self-advocate’s ideas and not the ideas of those supporting them.

When exploring available opportunities for self-advocacy the scoping review indicated that there are few opportunities for people with intellectual disability to participate in society through self-advocacy (Bigby et al., 2014; Kimball et al., 2016). Findings from the interviews concur with literature, highlighting that the only known opportunities available for self-advocacy by people with intellectual disability in South Africa are those run by organisations working with people with IDDs. Where people with intellectual disability are not affiliated with these organisations, they usually do not have a platform from which to participate in self-advocacy and their exposure to self-advocacy is very limited. Literature from the scoping review also highlights self-advocacy groups and peer mentoring programmes as the most available opportunities through which people with intellectual disability can self-advocate (Fisher et al., 2020; Frawley & Bigby, 2011).

In fewer instances, some people with intellectual disability participate on advisory bodies (Bigby et al., 2014). In this study, for example, where project advisory members included two self-advocates with intellectual disability, training was provided by their supporter in the purpose and roles of advisory group members. There were pre-meeting preparations of documents to be discussed at these meetings, as well as the availability of a dedicated supporter at the actual advisory meeting to assist with participation by advisors to the project. However, some findings from the scoping review and from the interviews indicate that some people with intellectual disability who participate in advisory bodies are often included as token participants (Bigby et al., 2014; Fisher et al., 2020; Frawley & Bigby, 2011; Kimball et al., 2016; Landmark et al., 2017). Literature further suggests that the selection process should not be solely based on their status as a person with intellectual disability but on their views and goals for participating as a member of society (Frawley & Bigby, 2011). Tokenism can also be addressed by allowing for voluntary participation, where people with intellectual disability are not coerced to participate because of their disability status but are well-informed about what their participation entails and understand their goals for participating..

Opportunities for self-advocacy in society are limited, as noted in the scoping review, that in order to address the existing barriers more opportunities for self-advocacy need to be created (Caldwell, 2010; Frawley & Bigby, 2011). This includes the development of contextually appropriate self-advocacy programmes in communities with the help of support personnel and other supportive structures. These include support for accessing information, developing knowledge relevant to the participation, engaging in the processes of the participatory body, forming relationships, peer-to-peer mentoring, direct skill development and individualised support for their specific needs (Caldwell, 2010; Fisher et al., 2020; Frawley & Bigby, 2011).

Findings further suggest that inequality can be reduced by creating more opportunities that enhance and ensure participation and self-representation of people with intellectual disability. This can be done by eliminating laws that discriminate against people with intellectual disability, eliminating policies and practices that are not inclusive of people with intellectual disability, and promoting appropriate legislation and policies that are more inclusive and promote their rights (Frawley & Bigby, 2011; Pfeifer, 2020). This can also be achieved through involving people with intellectual disability in policy-making and decision-making processes on issues that concern their lives so that their views, based on first-hand experience, can be captured along with those of other stakeholders who do not have the perspective of the lived experience of people with intellectual disability.

6.3.3 Barriers to self-advocacy

This category focused on challenges experienced by people with intellectual disability and their families, challenges experienced by self-advocates with intellectual disability based on their experiences, exclusion of people with intellectual disability in society, limitations set by parents and professionals on people with intellectual disability, stigma, and negative attitudes, as well as suggestions for addressing these barriers.

Findings highlighted individual, procedural and structural barriers as the main hindrances for people with intellectual disability's participation in society and policy development or implementation processes. Individual barriers noted by the scoping review and by the participants refer to the individual limitations, such as impediments in language and communication skills, inability to read or write, lack of confidence or assertiveness and inability to speak up for themselves. In addition to individual barriers, findings from the scoping review as well as findings from the interviews noted that people with intellectual disability are often overlooked, belittled and infantilised, and are usually not allowed to make their own decisions.

Interviews with some parents indicate that there is a common belief that people with intellectual disability are not capable of doing anything and are not afforded opportunities to participate in policy-related activities and learn new skills. Those who are able to do things are looked down upon and excluded from fully participating in society. Similarly, findings from the scoping review indicate that people with intellectual disability are sometimes restricted to exercise their rights as citizens and have limited access to the social and economic resources of society which enable autonomy (Frawley & Bigby, 2011). Findings from the interviews conducted with policy makers further highlighted other barriers such as policy makers' lack of understanding of intellectual disability, their lack of knowledge of how to include people with intellectual disability when developing or implementing policy, and people with intellectual disability's lack of access to participate in policy processes.

Another notable aspect of the barriers found by the scoping review includes the restriction of encouragement and practice of capacity of people with intellectual disability to be able to make their own decisions. Literature in the scoping review mentions that supporters and parents of people with intellectual disability are often the ones making decisions for them.

They are deemed unfit or incapable of making proper and meaningful decisions, thus not giving them the opportunity to be independent from parents and families (Azzopardi, 2000; Nonnemacher & Bambara, 2011). In such instances, the findings from both the scoping review and semi-structured interviews suggest that there should be supported decision-making, where parents and supporters help people with intellectual disability explore available options, and potential problem areas so that they have information to help them make their own decisions without being coerced (Kohn, Blumenthal & Campbell, 2013).

Some parents and policy makers share similar views regarding the barriers to self-advocacy by people with intellectual disability. There is a common belief that self-advocacy is too difficult for some people with intellectual disability, and they do not have the capabilities to participate in self-advocacy. This may be true for people whose disability is too prominent, who may experience difficulties with advocating in complex settings, such as the policy environment. In those instances, the scoping review and semi-structured interview findings suggest that there should be advocacy instead of self-advocacy, where advocacy is done by peers with intellectual disability who are self-advocates, family members or other supporters.

6.3.4 Inclusive policy environments

This category explored the inclusion of people with intellectual disability in society, particularly within the policy space. Findings from both the scoping review and the semi-structured interviews indicate that it is everyone’s responsibility to play a role in addressing barriers and creating opportunities for self-advocacy. Findings from the semi-structured interviews suggest that it is the responsibility of supporters, family members, service providers and policy makers to ensure that people with intellectual disability are included in policy processes.

According to findings from the SSIs, the policy environment in South Africa is not inclusive of people with intellectual disability as they are usually not invited to participate in policy processes. This was indicated by a few self-advocates with intellectual disability who mentioned that they are usually not included to participate in policy-making and implementation processes. Similarly, some policy makers mentioned that when inviting people to comment on policies, people with intellectual disability are usually not invited to provide input, thus being left behind. These policy makers cited as main reasons for exclusion that they are not well versed with intellectual disability, and they do not know how to provide reasonable accommodations for people with intellectual disability in policy environments. On the other hand, some parents cited a different reason for exclusion of people with intellectual disability. They indicated that people with intellectual disability are not included in the policy environment because they lack the capabilities to advocate in such complex environments and that they are comfortable with their children advocating in less complex settings such as their everyday environment.

Some policy makers and a few supporters of people with intellectual disability mentioned that inclusive policy environments can be created to allow for meaningful participation by people with intellectual disability. These environments should be inclusive in a manner that allows for self-advocates to be free to express themselves fully without judgement and not feel that they are incapable of advocating for themselves. A few service managers mentioned that in order for meaningful participation to happen, policy makers should take into consideration people with intellectual disability's willingness to participate and allow for them to freely stop participating in these processes when they no longer want to. These environments should allow for people with intellectual disability to express what their support needs are and should promote individualised support for self-advocacy, based on their specific needs. Moreover, findings from the scoping review highlighted that an inclusive policy environment is where people with intellectual disability are able to say how they would like to see things proceed so that their views are taken into consideration when policies are made.

In order for policy environments to be inclusive, findings from both the scoping review and interviews emphasise the importance of putting reasonable accommodations in place. In cases where self-advocates struggle with voicing their ideas, accommodations should be put in place to support alternative methods of communication. This could be through writing down their ideas or even using pictures to convey their views, ideas and needs. Where people with intellectual disability need support with reading or writing, findings from the interviews suggest that policy documents should be translated into easy-to-read and understandable formats, and supporters should help in simplifying complex policy documents to promote understanding.

Findings from the interviews and scoping review show that in order to achieve inclusive policy environments, peer-to-peer support should be fostered. Furthermore, findings suggest that inclusive policy environments can be achieved through allowing participation by people with intellectual disability to experience the power and opportunity to organise which is possible through self-advocacy groups, community-based groups and local organisations.

6.3.5 Capacity building

This area focused on the necessary things required for self-advocacy by people with intellectual disability. These include skills building for meaningful self-advocacy, training and development of supporters of people with intellectual disability, as well as capacity building of policy makers and service managers regarding intellectual disability in order for them to create inclusive policy environments. Findings from the scoping review and interviews indicated that training and direct participation of people with intellectual disability in policy-making projects and processes strengthens their ability to self-advocate. This includes self-advocacy skills development.

Similarly, findings note the importance of training policy makers and service managers about intellectual disability. This will capacitate them regarding how to best interact with people with intellectual disability and will equip them with the necessary skills required to support people with intellectual disability during policy-making processes. This can be done through awareness building and training policy makers and service managers regarding reasonable accommodations and how to provide these within policy environments so that participation by people with intellectual disability can be improved.

6.4 The Conceptual Framework for Self-advocacy by People with Intellectual Disability

The framework is derived from strategies recommended for creating and improving policy participation by people with intellectual disability in Chapters Two to Four. The framework is underpinned by both the empowerment theory and the concept of *Ubuntu*. From the triangulated data, the first draft of the conceptual framework was developed and is illustrated as Figure 8. The conceptual framework was developed by breaking down each of the five categories emanating from the study findings and elucidating the underlying meanings in each category. The first element of the conceptual framework was developed by looking at the first two categories, namely self-advocacy by people with intellectual disability and support for people with intellectual disability. Here I asked these questions:

- What does self-advocacy mean?
- What is needed for people with intellectual disability to self-advocate?

- What do they need to know in order to be self-advocates?
- What do they need to have in order for them to self-advocate in policy?

Thereafter, I explored the last three categories, including policy environment and capacity building, and the identified barriers to self-advocacy and the suggested strategies for addressing these barriers. I incorporated them with the available opportunities for self-advocacy to develop the second element. These answered the following questions:

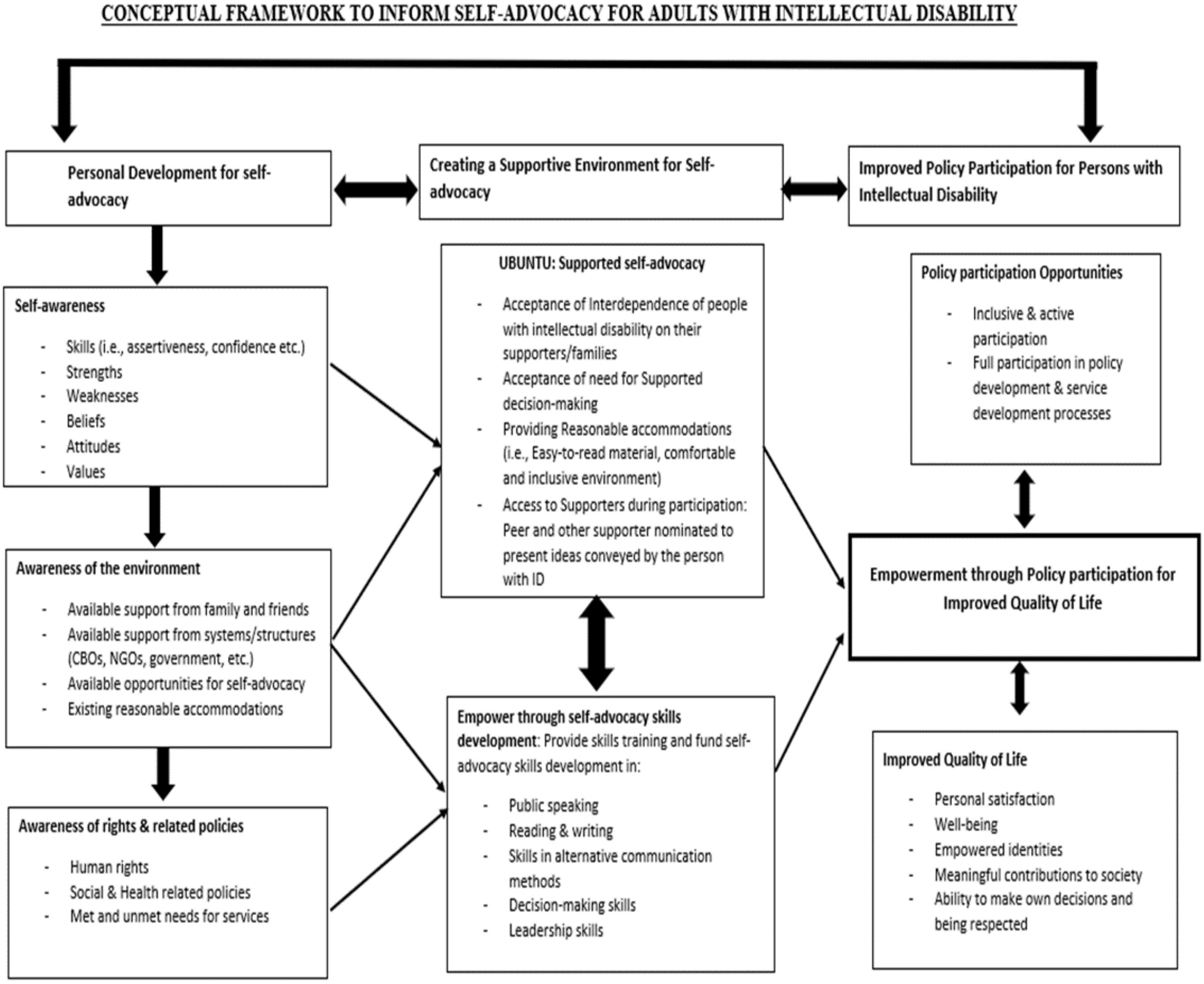
- How can an inclusive policy environment be created?
- Who must create it?
- What should they do?
- If people with intellectual disability lack what has been identified in the first element, what should be done?
- What do they need to participate meaningfully in policy?
- What kind of support do they need to self-advocate in policy?
- Who should provide this support?
- What is the role of *Ubuntu* and Empowerment?

The third element of the framework was developed by exploring what is needed to ensure that there are improved policy participation opportunities for people with intellectual disability. This was done by answering the following questions:

- Is policy participation inclusive of people with intellectual disability?
- Are they allowed to fully participate in policy?
- What does policy participation mean to them?
- Does policy participation empower them?
- Will policy participation improve their lives? If so, how?

Figure 8

First Draft of the Conceptual Framework



6.4.1 Process of reviewing and finalising the conceptual framework

The conceptual framework was reviewed by 10 stakeholders including two people with intellectual disability, three parents/supporters and five policy makers and service managers, recruited from all who participated in the SSIs. The review group is listed in Appendix 13. At the end of the SSIs all participants were asked if they would like to participate in focus group discussions where they would review the conceptual framework. Those who wished to participate were noted down and consent forms for focus group discussions were sent to them to peruse and sign. Of the 25 participants, 19 indicated that they were keen to participate in focus groups. However, when they were later contacted to make arrangements for the focus group discussions, only 10 participants availed themselves to participate in the review process and other participants did not respond when they were contacted.

The conceptual framework was initially reviewed by the group of policy makers and service managers. This was done to get their professional input and to examine if the conceptual framework is practical enough for them to use in the policy environment. The second focus group discussion with parents/carers and supporters was scheduled to be conducted after the first one, however, due to participants' unavailability and clashing time-schedules, it had to be arranged for a later date when they were all available.

The third group with people with intellectual disability was scheduled to be conducted after the conceptual framework had been converted into an easy-to-read format (Appendix 18), so that they could understand what the conceptual framework is about and allow for them to have meaningful contributions to the framework. Although the review with people with intellectual disability was planned to be a focus group, this was not possible for the following reasons:

- The organisation through which participants were recruited did not permit face-to face meetings with participants due to Covid-19 regulations.
- I had to schedule an online focus group session via Zoom.
- Participants were available on different dates; I could not establish a suitable time to schedule the focus group for all to attend.

Due to these reasons, the review process with people with intellectual disability happened individually with the help of their supporters. Below are the questions posed to the reviewers (policy makers/implementers, service managers, parents and supports):

- Do you think this document shows what we spoke about in our last meeting about what people with intellectual disability need to speak up for themselves? If not, what is missing?
- Does this document show everything that is needed to be done to encourage people with intellectual disability to speak up for themselves in policy or when they speak up about the laws affecting their lives? If not, what is missing?
- Is this document clear and do you think it can be used for people with intellectual disability? If not, what would you change?

- Do you have something else to say or add, which we have not previously spoken about?

Draft 1 of the conceptual framework was reviewed by the first group comprised of policy makers and service managers. The conceptual framework was presented to the group and each element was broken down and explained in detail. After the presentation the participants were given an opportunity to ask questions and make comments. The questions listed above were asked of participants as they commented on the conceptual framework. The questions asked by the participants were answered to provide clarity, and in addition to that, participants were probed for more comments pertaining to the framework and its practicality. Table 6.3 below summarises the main comments made by this group of reviewers pertaining to the conceptual framework.

Reviewers in this group suggested that the language used in the conceptual framework should be positive and affirming, that there should be a component stating that people with intellectual disability need to be aware of their rights and policies pertaining to those rights. Additionally, participants agreed on the importance of supported self-advocacy, but they suggested that there should be a section on the framework that speaks to the capacitation of supporters and policy makers/service managers. They mentioned the importance of having qualified and experienced people to train policy makers and service managers regarding intellectual disability so that they can create an inclusive policy environment. In addition to this, participants suggested that there should be a mention of funding of programmes that support people with intellectual disability to self-advocate in policy environments. The critical feedback was edited into the initial document to arrive at the final version of the conceptual framework.

Table 6.3

Reviewers' (Policy Makers and Service Managers) Comments on the Conceptual Framework

Elements of the Conceptual Framework	Reviewers' Comments
Personal Development for Self-Advocacy	- *If you look at self-awareness you know the aspiration of people having assertiveness, recognising their strength, weaknesses, beliefs, values, attitude. I think these are important tools that people with intellectual disability need to have when they want to advocate for their rights.* - *the sense of self of who I am and where I am at, and where my need is, should be also a skill that we should be developing for self-advocacy because I can only speak for what my needs and wants are if I can identify as to who I am and where I'm at. And I think a lot of times that is even difficult for people to understand that you know. It starts here and only then I can ask for the things that can support me to get where I want to be. So, I see in your self-awareness, in your first column, you've got all of those that I think it is still a skill, a self-advocacy skill, that has to be developed in the individual to empower them.* - *for people who lack self-awareness, I don't think it should mean that we can't expose them to see in what capacity they can still contribute and how much of self-awareness they actually have, and also how they can express themselves. I think a lot of the times we restrict people because we think that they lack self-awareness, we need to create means for people to express their own view based on their self-awareness.* - *I see on the 1st column, where you are talking about the awareness of the environment, talking about families and friends, about Government NGOs. I completely agree with that, these places and government are crucial to creating spaces for self-advocacy.* - *they need to understand that they also have human rights that need to be protected and promoted, your framework it addresses those issues of making sure that people with disabilities are capacitated, including those that would be expected to give support to people with*

	- *intellectual disabilities towards making sure that they are being given that space to be able to advocate for themselves because from what I have learned is that, issues of advocacy, they are not only limited to people with mild or moderate disability but to most of the people with disabilities.*
	- *I think that maybe should be added in that people with disability need to be aware of their rights and what policies support those rights, and that the policy is there to service them and that they have an active role to play in making the policy or developing the policy as well.*
	- *It was just a comment to say that perhaps in the spirit of empowerment and in trying to build confidence, that when talking about the development of self-advocacy, we don't refer to people's weaknesses, because it is quite a negative term. Perhaps, we can rather refer to strengths and areas for development or something like that so that we don't imply to people that they are weak, because again, they there might be people who have faced stigma and discrimination and exclusion for all their lives, and they have been told that they are useless and weak, and I think if we try and put them through a process of self-assessment and we say, okay, identify your weaknesses. I don't know it might be triggering for people and I would suggest that we maybe use positive language all the way through yes, that is just a suggestion, that is just language, but I think it might be worth just considering that.*
Creating a Supportive Environment for Self-Advocacy	- *Mine is on the issue of awareness of the environment. I think since being in this space, I have learned that policies are saying we should create inclusive environments, but unfortunately the environment that we live in at this stage in this country are not conducive even though we have policies, and, at the end of the day I always say issues of disability no matter which disability, it is not only issue that affects a certain group. It should be everybody's business to make sure that the environment is inclusive.*
	- *I am particularly drawn to the section that addresses how those without disabilities can partake in making sure that the people with intellectual disabilities are given the necessary support to be able to advocate for themselves. Because my understanding is that policies are there, they are talking, but we don't have enough people to support those that don't have the ability to read and interpret and be able to review and understand what needs to be done in policy by people with disabilities.*

- *Policies are in place, but we are still trying to come up with programmes and also the financial support to make sure that people with disabilities are included in the sector and the sector is accommodative, but I think the challenge also lies with the changing of the mindset of those who are expected to implement what needs to be done. I think we should not shy away from … I would not shy away from the fact that we are aware that people with disabilities need to be included, there needs to be a conducive environment for them, their rights need to be protected like any other citizens.*

- *But it takes a lot of work and a lot of support and capacity development, and I guess what I am saying is, this does not spontaneously just happen. There needs to be a lot of resources put into this kind of support by people that really know what they are doing. So absolutely, you know, brilliant skills to develop, but I think within the conceptual framework there needs to be a recognition that these things need to be resourced and you need service providers like occupational therapists and social workers and those kinds of people to help with the development of these kinds of skills because often you are talking about people that have been marginalised their whole lives and they have never had the opportunity to develop any kind of these skills.*

- *I wanted to highlight that we are saying yes, we need to capacitate these people and support them, but those who are supposed to give that support if they are not capacitated also, there is no way that they would be able to give the necessary support, or maybe the relevant support. What I learned is that the country is also still lacking in terms of specialised skills that we need in our policy space to be able to support people with intellectual disability.*

- *I think there's just a lot that needs to be done for us to automatically at the end of the day to be able to support and maybe help our people with disabilities who are able to advocate for themselves, who are able to talk for their rights and we have people on their side who are able to support them with the right skills and who are also willing. Because for me I think for one to be able to be in the space of people with disabilities and to be able to support them, you need to be self-aware first and also be able to understand what people with disabilities are going through. Until then, I don't think some people will still be doing it as a work to be compensated rather than doing it for the support and promotion of the human rights of people with disabilities.*

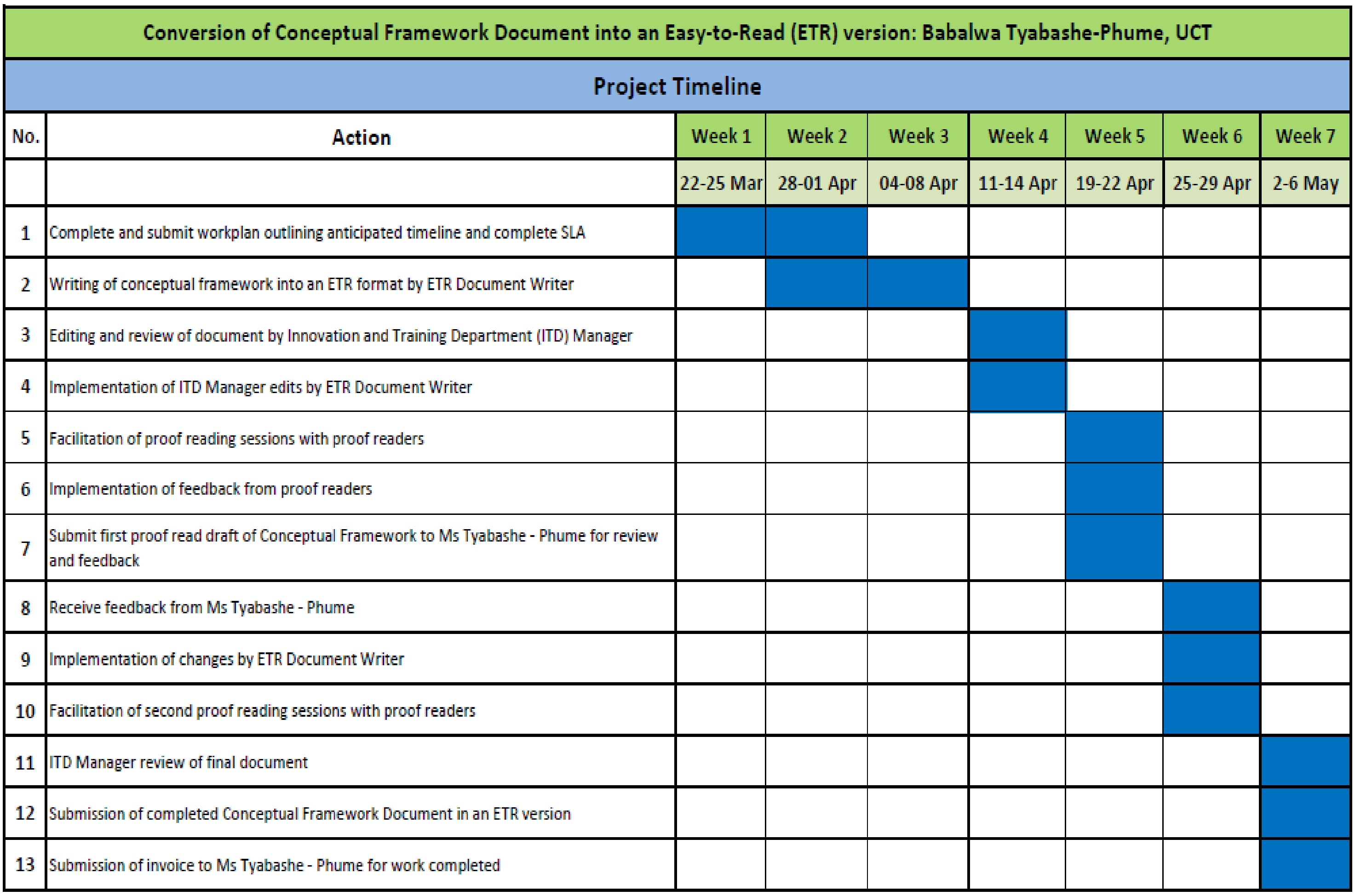
	- *Another point I wanted to make is that we need more funding, we need funding to train people to be able to support people with intellectual disability. We need funding for such programmes and also we need trained people to come to the policy space to train us as well about intellectual disability so that we know how to work with people with intellectual disability when we consult them about policies. This will make the process run smoothly and help us all to be on the same page.*
Improved policy participation for people with intellectual disability	- *As we make policies, we really need to make sure that we give people with intellectual disability a chance to advocate for their rights. They need to have a space where they can feel like they are making a difference by what they are saying. This will be beneficial to other people with disabilities at large. They will know that they have a space in policy environments where they can make meaningful contributions and that their voices are heard.* - *Like I said before and during our interview, we need to invite more people with intellectual disability to review policies and we need to consult them more. You know, their contributions can go a long way in developing policies. When we know what they have to say about their rights it will make our jobs easier, it will make things easy for everyone actually. Just like we invite people without disabilities to comment on policies, we should make sure that people with intellectual disability are invited as well, for representation, you know.* - *It is important that people with intellectual disability's voice is heard and that their ideas are included in policies, so that we know clearly what they need and not provide them with services that we think they need without having them saying it. If we don't give them that chance, we won't know what they want and instead make assumptions about what their needs are.*

It is worth mentioning that participants with intellectual disability could not review the first draft of the conceptual framework due to the delay in the translation of the original version into easy-to-read format. This process took longer than stipulated on the agreed timeframes that were given at the beginning of the translation process. The finalised version of the conceptual framework (Appendix 16) was then sent to Cape Mental Health to be converted into an easy-to-read format for use with participants with intellectual disability (Appendix 18). Cape Mental Health (2021), the oldest mental health society in South Africa, and one of a network of such NGOs in South Africa, offers document writer training and translation services for easy-to-read.

Figure 9 below illustrates the process undertaken by Cape Mental Health in translating the conceptual framework into an easy-to-read format. The conceptual framework was translated by adhering to the Inclusion Europe standards (Inclusion Europe, 2017), an organisation for and by people with intellectual disability. Easy-to-read is all about writing with people with intellectual disability and not for them (Cape Mental Health, 2022), hence this translation process included people with intellectual disability as proof-readers.

Figure 9

Process for Conversion of the Conceptual Framework into Easy- To- Read format



Conversion of Conceptual Framework Document into an Easy-to-Read (ETR) version: Babalwa Tyabashe-Phume, UCT

Project Timeline

No.	Action	Week 1	Week 2	Week 3	Week 4	Week 5	Week 6	Week 7
		22-25 Mar	28-01 Apr	04-08 Apr	11-14 Apr	19-22 Apr	25-29 Apr	2-6 May
1	Complete and submit workplan outlining anticipated timeline and complete SLA	■	■					
2	Writing of conceptual framework into an ETR format by ETR Document Writer		■	■				
3	Editing and review of document by Innovation and Training Department (ITD) Manager				■			
4	Implementation of ITD Manager edits by ETR Document Writer				■			
5	Facilitation of proof reading sessions with proof readers					■		
6	Implementation of feedback from proof readers					■		
7	Submit first proof read draft of Conceptual Framework to Ms Tyabashe - Phume for review and feedback					■		
8	Receive feedback from Ms Tyabashe - Phume						■	
9	Implementation of changes by ETR Document Writer						■	
10	Facilitation of second proof reading sessions with proof readers						■	
11	ITD Manager review of final document							■
12	Submission of completed Conceptual Framework Document in an ETR version							■
13	Submission of invoice to Ms Tyabashe - Phume for work completed							■

Prior to the translation process I met with the document writer and the Innovation and Training Department (ITD) Manager to discuss the conceptual framework and to provide clarity on its purpose and the components of the framework. Thereafter, the translation process started. The document writer translated the conceptual framework into an easy-to-read booklet, then it was reviewed and edited by the ITD manager. Subsequently, changes made by the manager were implemented in the document. Step five of the translation process involved people with intellectual disability as proofreaders of the document. During the proofreading process a team of people with intellectual disability (four proofreaders) checked the conceptual framework and gave feedback to the document writer regarding what they found easy or confusing. They helped the document writer to make changes to the document so that it can be easy to read and understand (see Appendix 17 for the proofreading process).

The document was then sent back for me to review and provide feedback. Upon receiving the document, I noticed that the essence of the conceptual framework was not sufficiently captured, so I arranged a meeting with the document writer to clarify and provide further input. My input was implemented in the document and the second proofreading process started. It is noteworthy that, during the feedback meeting with the document writer, it was mentioned that the proofreaders highlighted that this is a very important document, it is practical, and it can be used in various settings, and they think that they will benefit from it. The feedback from the proofreaders was implemented in the document, then the document was sent back for review. My supervisor and I reviewed and edited the document, then sent it back to Cape Mental Health for finalisation with the proofreaders with intellectual disability. The final easy-to-read conceptual framework booklet (Appendix 18) was then sent back to us.

Once the document was received, I arranged for the review meetings with the participants with intellectual disability. Participants with intellectual disability did not review the conceptual framework in a group setting but reviewed it individually with the help of their supporters. This was due to the reasons mentioned above. A week prior to the meetings with the participants with intellectual disability I sent the easy-to-read booklet of the conceptual framework to the supporters of the participants with intellectual disability, who supported them during the SSIs, and I had meetings with them individually to provide a brief presentation of the booklet and answered their questions regarding the framework. This was done so that the supporters would have enough time to prepare the participants with intellectual disability for the discussion, for them to think about the questions and suggestions that they might have. The supporters were asked to introduce the questions that were going to be asked so that they could assist them in thinking about what they might want to say in providing feedback on the conceptual framework. The questions were adapted into easy-to-read for people with intellectual disability.

The review process with participants with intellectual disability was conducted via Zoom with the help of their supporters. I presented the conceptual framework to the participants as written on the easy-to-read booklet, then I invited them to comment on the framework prior to asking them the following questions:

- I would like to know if what we spoke about in our interview about what you need to speak up for yourself was written in this document? If not, what did I forget to write?
- Do you agree or disagree that these things will help you as a person with intellectual disability to speak up for your rights to government? If you disagree, what do you think will help you?
- Does this document talk about all the things that are needed when helping people with intellectual disability speak up for themselves when the government makes policies? If not, what did I forget to write?
- Is this document clear and do you think you can use it when you want to speak up for yourself? If not, what would you change?
- Do you have any other comments you wish to make?

Storytelling was identified as a key vehicle for policy input by people with intellectual disability, as noted in earlier chapters. It was interesting to see that these reviewers' responses to the questions also drew very much on their personal experience to reference their policy-related comments to the conceptual framework. These reviewers' story-based feedback did not include suggestions for new elements or deletion of any included elements to the framework, but rather supported and elaborated on some components captured in various elements of the framework, for the most part, by commenting on these elements from the perspectives of their own experiences, as summarised in Table 6.4 below which captures quotations from the two participants.

Table 6.4

Reviewers' (People with Intellectual Disability) Comments on the Conceptual Framework

Elements of the Conceptual Framework	Reviewers' comments
Personal Development for Self-Advocacy	**Self-awareness:** *People must have more say in everything, you can't always have people with normal abilities and a person with disabilities is not there. Maybe they can also be the same, maybe they can do the same physical thing the same way as that person but they are only struggling with speaking up. If they learn it, they can get it more better, if they learn the how to speak to people and all that.* **Awareness of rights and related policies:** *So, like, you know, the government decides that they will give us, us people with disability the SASSA grant. So, they say they will give people with disabilities a grant of this money, but now they do not ask us, like maybe to say how much money do we think we will need for the grant that we think will be enough. Like they just decide for us and it's not nice man, it's like now I have to buy things, for like taking care for myself but the money is not enough. It would be nice that when they make these rules they like, they think about us, like you know, ask us how much we need for the month before they just make that decision.* ***(Interviewer): Do you think that this document will help you when you want to speak up for yourself about these things to government?*** *Yes, yes, this document will help me be able now to say when the government, maybe they are trying to decide how much to give us and then they ask us, I will be able to you know, speak up for myself and other people with disability to say this is how much we need. Not to ask for a lot of money but to ask for money that will be enough for us.*
Creating a Supportive Environment for Self-Advocacy	**Empower through self-advocacy skills development:** *Like me, I'm learning how to speak to people, and I speak a lot now to everyone, before I wasn't like that, I was a person that would just keep quiet. Now it helps me, now I'm outspoken person now.*

Sometimes I get very nervous, because I maybe get scared because maybe the next person will laugh me out because I can't read that good, I can only read a little bit and I am afraid to speak up for myself.

Sometimes I get very scared to speak up, I don't know why if someone asked me to say something like in the group, then I get very shy and then after that I spoke very soft. It's only that, Miss. Uh, I am shy and can't actually read so lekker (well). If someone can help me maybe read, and then I won't be shy anymore, like maybe to read something or stuff like that. Then someone can help me. It's alright, because sometimes it's better to speak up because then Mr. Y will help me out with some stuff, if I don't know the words, then he will like, help me. If there is a word that I don't know, then he will read it to me, then he will tell me what is the word. Yes, Miss C also help me. If she, if she maybe make a copy of something like this document, then she tell me uhm, I must read it and then she help me like, to read the words and help me understand some big words.

(Interviewer): Was this document difficult for you to read?
No, it is just some big words I didn't understand, by number 11, that of government part I didn't know what that was but Miss C explain to me and now I know and understand. The pictures helped me a lot, when I was reading mos, you know and not understand, I will look at the picture and try to see what is happening there then I read and say oh, I now understand what they are talking about here.

<u>Empower through supported self-advocacy:</u>
That's true, people who make policies also need to give us more chances to let them know what we need, like they must give us a chance to speak up, you know for ourselves.
We need people to help the people with disabilities and intellectual disabilities, to speak up for their rights. If you can't have people like that, maybe that person got more skills than the other person who have a disability. That's how I look at it, that way you can't choose only one who doesn't have a disability, we choose both, so they both can help people with intellectual disability to speak up for themselves.

(Commenting on his supportive role for new self-advocates) Me, I'm working now at the moment, more people coming in every time to us, they don't know the job, but we train them to show them a job, but they do sometimes better than what I do … and I feel, hey, this I'm proud about it. That that person did something better, he's learning the job more, and he'll give me sometimes, I know we must put this way, let's try it this way, I say, okay let's try it, sometimes it helps. Sometimes it doesn't help. You don't know how far it goes and then. That's it, that's what I do.

Improved Policy Participation for People with Intellectual Disability	*I am working here at the workshop, so most of the times I speak up for others. They come to me and tell me their problems, then I go tell Mr. X, so now I can speak up more for other people. It makes me feel like I'm doing something right for another person.* *We were in the women committee mos, ne? so me and the other girls come here and speak, when I sit here and us guys have a meeting, we talk mos about issues that we have. Like sometimes like, the girls like, they'll ask that they want like, say maybe like bins or something like that. Or, say maybe like, they told me like, they actually wanted new toilets because as they say, you must stand in lines. Because that is what the girls want now. And then they tell me like, say like maybe they want like, pads and things like that, like for the girls and whatever. Then I must tell Mr. Y that the girls want pads and things like that. Then I go to Mr. Y and then I ask him now tell me like, the girls need things like that. And then now the girls even got more bins also in the toilet and now there's more toilets for the girls. That makes me feel good because now I speak up for the girls and now I feel like I make a difference because we have more toilets.*

The second focus group comprised of parents and supporters of people with intellectual disability and took place after the review process with the participants with intellectual disability. This group reviewed the second draft of the conceptual framework. They did not review the first draft due to their unavailability on the proposed dates, as they had clashing schedules that did not allow them to participate in the scheduled review process. These participants were only available after the comments of the policy makers and participants with intellectual disability had been incorporated into the conceptual framework, so that it seemed best to then ask them to comment on the second and final draft of the conceptual framework.

Their input was valuable even though they did not add or suggest removal of any elements of the framework, but rather mentioned that the conceptual framework is practical and that it will be a useful tool for self-advocacy. As mentioned earlier in this chapter, some parents were doubtful about their children’s capabilities to self-advocate in a policy setting. One parent who was part of the review group mentioned during the individual interviews that they are comfortable when their child self-advocates in their immediate environment but did not think that they would be able to participate in self-advocacy at a policy level. However, after reviewing the conceptual framework, this parent mentioned that they are now comfortable in knowing that their child will receive the support they require when they participate in self-advocacy in policy. Table 6.5 below summarises the views from this particular group on the conceptual framework with supportive quotations from the participants.

Table 6.5

Reviewers'(Parents and Supporters) Comments on the Conceptual Framework

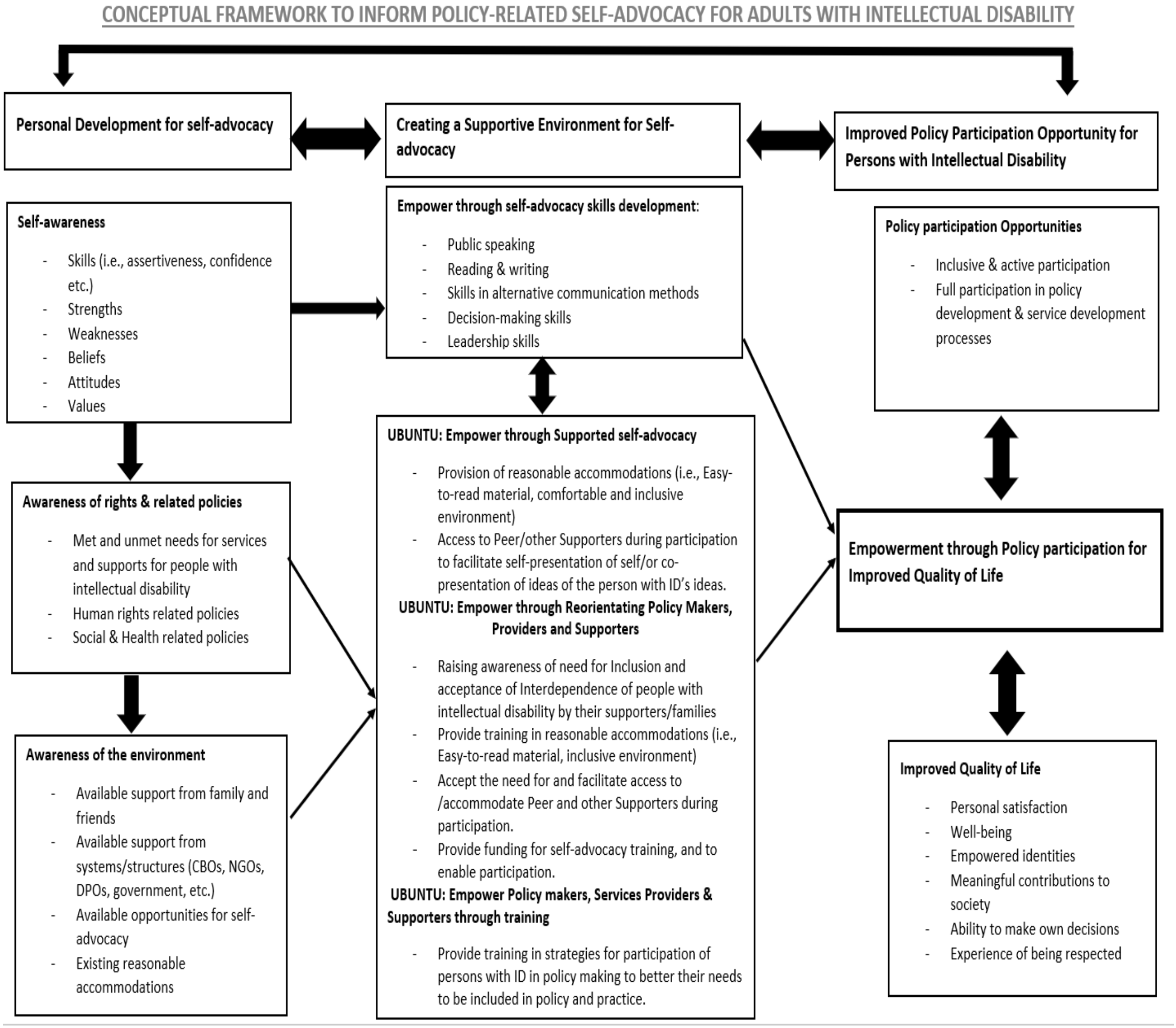
Summary	Supporting quotations
Participants mentioned that their views were properly captured in the conceptual framework and that these will benefit people with intellectual disability in their self-advocacy efforts. They went on to mention that even the things that they might have not thought about before are captured in the framework and this has helped them realise the potential benefits of this conceptual framework.	***Interviewer (I): Are your views on what is required by people with intellectual disability to self-advocate properly captured in this conceptual framework? If not, what is missing?*** - *For me there's nothing missing, but I can just share that if we could use this document here at the workshop, a lot of our service users (people with intellectual disability) would benefit from it. So, I think yes, it is a great tool to have.* - *Yes, I think so. Everything is properly captured here and there's some things that I didn't even think about. You know the part about rights and policies, for me that is not something that I would think my child needs to know about because I didn't think that it would help him with anything. You know in society they are not treated with respect already even if they have rights, their rights are not taken into consideration so I thought it is me as a parent who must know these things and speak up for him. But now I see, it is important for him also to know about them so that he can speak up, you know.* - *I see some of the things I mentioned during our interview here, I see that you translated them properly in a way that they will be of benefit to people with intellectual disability and in their self-advocacy.*
They mentioned that this is a great starting point for people with intellectual disability to advocate for their social and health policy priorities and it can be developed into something better in the future. They felt that the study's conceptual framework is a useful tool to be used in policy spaces.	***(I): Does the conceptual framework address all the relevant strategies which need to be considered in promoting self-advocacy by people with intellectual disability in policy development? If not, what is missing?*** - *I think it is a good basis to start off with and to work from in the absence of not having anything as such as yet, and I think it can develop into something much better in the future, but for now we have something to start with.* - *I just echo what the other speakers have said. I think it is a good place to start and with, some further tweaking and testing, and I think yes, it is definitely useful to have. Like I said before and during our interview, we need to encourage more people with intellectual disability to participate in policy spaces. You know, their contributions can go a long way in developing policies. As organisations we need to implement these strategies to encourage and support them when they want to advocate for their rights.* - *We can promote self-advocacy by creating more awareness in our communities, this is not only my job as a parent but the government must employ people to teach people in communities about intellectual disability. This will make it easier for our children when they do self-advocacy, when people know about their disability they will understand them and take time to listen to them.*

They agreed that this conceptual framework is clear and practical enough to be used with people with intellectual disability. They emphasised the importance of supported self-advocacy and mentioned that it is the most practical component of the framework because people with intellectual disability often need people to support them. They further mentioned that it is crucial for support persons to be skilled and well equipped to support people with intellectual disability.	***(I): Is the conceptual framework clear and practical enough? If not, what would you change?*** - *Yes, it is practical, I would have disagreed if you mentioned that people with intellectual disability can go to government by themselves and speak about policies without any help. People with intellectual disability need help with most of the things, it's not like they can't do anything for themselves, but they need help here and there. I am glad that you also mentioned it here that even with self-advocacy in policy spaces they will need help.* *I didn't think or believe that my child can do self-advocacy in big places, I though he is alright talking for himself at the workshop or at home, but now I see that with the right support he can do that. I am not saying I know everything, but I know that if my child were to advocate for themselves in policy, they will definitely need some help, especially with reading the policy documents with big words. What I am saying is that I strongly agree with the part about support for people with intellectual disabilities.* - *As a supporter of people with intellectual disability, I agree with what you said about Ubuntu. Our service users usually rely on me to help them navigate a lot of things, especially things that they are not familiar with. It takes time to build this kind of relationship, you must have the right skills and patience for you to provide support to people with intellectual disability. So, for them to be self-advocates and speak up for their rights they need someone with these qualities or people that they trust like their family members or friends to give them that support. So, that for me is what Ubuntu is about.* - *For me, the most important part of this framework is the part about support. It shows the steps and the things needed by people with intellectual disability to help them self-advocate. This part shows what we need to do as people to help them self-advocate. People with intellectual disability need things to be put in place to assist them with self-advocacy. Like you mentioned, reasonable accommodations must be put in place, for example, policy documents must be written in easy-to-read so that they understand what they are advocating for or against. This for me is very practical. It is also my role as a supporter to make sure that the policy space is user friendly for them and that when they speak up they are comfortable and know exactly what they want to say without feeling intimidated.*

The key elements of the final version of the conceptual framework are depicted in Figure 10 and discussed below.

Figure 10

Finalised Conceptual Framework



6.5 Discussion of the Key Elements of the Conceptual Framework

The framework comprises three interactive elements: Personal Development for Self-Advocacy, Creating a Supportive Environment for Self-Advocacy, and Improved Policy Participation Opportunities for People with Intellectual Disability. Personal development will be discussed first then discussion moves from left to right in Figure 10, to describe the remaining elements which make up each of the three aspects of the framework, and how they are related to each other.

6.5.1 Personal development for self-advocacy

The main contention of this element of the conceptual framework is that in order for people with intellectual disability to self-advocate they will require self-development as an essential element to facilitate their participation in self-advocacy in policy processes. This element comprises three sub-elements, self-awareness, awareness of rights and related policies, and awareness of the environment.

The self-awareness sub-element of the framework relates to the capacity to know who you are, your values, beliefs and biases. Self-awareness is about having knowledge about who you are, knowing your strengths and challenges in different settings and knowing what helps you thrive (Cook, 2017; Ratts et al., 2016; Test, Fowler, Wood, et al., 2005). It involves being able to recognize and speak to the impact that intellectual disability has on you academically, socially, and emotionally (Balint-Langel et al., 2019). Being self-aware entails having knowledge about what you believe about the world, and about knowing what you believe to be right or wrong. You also need to know your attitudes, how you think and feel about things, know your values, and know the things that are important to you. Self-awareness is the ability to tune into your feelings, thoughts, and actions and being able to recognise how other people see them. Having self-awareness means that one understands that how one sees oneself may be different from how others see you.

Self-awareness supports knowledge about what personal, interpersonal and environmental capacities and skills people with intellectual disability already have, those that need improvement or need to be developed to achieve personal goals. Self-knowledge is crucial in self-advocacy because it is necessary for individuals to understand and know themselves before they can tell others what they want. Some adults with intellectual disability struggle with self-awareness and need help in developing it. On the other hand, others have self-awareness, but there is still a need for more development of this awareness (Balint-Langel et al., 2019; Cook, 2020). The scoping review and the findings from the interviews mention that people with intellectual disability need to be empowered and provided with the necessary support to improve their self-awareness.

The second sub-element of the framework focuses on people with intellectual disability’s need to be aware of their rights and related policies. The ability to know about your rights and what government policies say about these rights is crucial for self-advocacy (Cook, 2017; Test, Fowler, Wood, et al., 2005). This sub-element speaks to the need to teach people with intellectual disability about their rights and the policies that support the attainment of those rights. Knowledge about their human rights means that they will be aware when their rights are being infringed, and they can advocate for themselves accordingly. In addition to this, they need to be aware of their met and unmet service needs, where they will be cognisant of the services they are entitled to and whether or not these services are adequately provided for them. When there is a gap in service delivery, and they are aware of it, they can advocate for their service needs that are unmet. Additionally, they can advocate for their support needs.

Finally, this sub-element mentions the awareness of social and health-related policies. People with intellectual disability need to know how the government includes their health and social needs. These relate to, for example, basic things such as enough food, safe water and sanitation, work, SASSA grants, education, training to work, housing, freedom of expression, freedom to participate in legislation, and make political choices, as enshrined in the Bill of Rights in the South African Constitution (Republic of South Africa, 1996). When people with intellectual disability know what their rights are and what policies say regarding their rights, they will know when there is an infringement of their rights, thus enabling them to make informed decisions when they advocate for themselves.

The third sub-element of the framework focuses on the awareness of the environment. Literature supports this be stating that it is crucial for people with intellectual disability to be aware of and know their environment and the world at large (Cook, 2017; Test, Fowler, Wood, et al., 2005). This includes their support systems, such as family, friends and peers. It also includes other support systems within their communities, such as local organisations working with people with intellectual disability and organisations led by people with disabilities. For example, places they can go to have their voices heard, where they can participate in self-advocacy groups, and where they can give their opinions on policies that are being written.

In South Africa, organisations are still limited but there are organisations, such as the WCFID, which provides training to service organisations working with people with intellectual disability and advocates for the rights of people with intellectual disability (WCFID, 2022), and the SAFMH (2022), the latter being a national umbrella organisation of affiliated mental health societies within the nine provinces of the country and other affiliated organisations working with people with intellectual and psychosocial disability. However, work to support self-advocacy initiatives are variously developed in individual organisations at the time of writing this thesis, with most still at the early stages of this work.

When developing self-advocacy initiatives by people with intellectual disability a great deal can be learnt from the global north's history of self-advocacy. An important issue for example, are lessons to be learnt from this history about organising for self-advocacy, that is, how best to support and capacitate people with intellectual disability in South Africa to consider the issue of spearheading their own self-advocacy movements (Ledger & Tilley, 2006). Experiences from countries where such organisation has already been in place for some time, suggest that moving to more formal organisation of self -advocacy forums can foster a sense of ownership about self-advocacy initiatives as experts by experience. What can also be learnt and implemented by self-advocates in South Africa is the concerted efforts of mobilisation, where people with intellectual disability work together to create their own self-advocacy organisations with the help of their supporters. This would need to be considered along with some of the difficulties experienced by existing self-advocacy organisations, such as access to funding, and the nature of support to experts by experience within these organisations (Ledger & Tilley, 2006; Rouse et al., 2022). Further research would assist in addressing this for local implementation.

People with intellectual disability need to be aware of the larger environment, including governmental structures and available opportunities for self-advocacy within government sectors. When opportunities for self-advocacy are available for people with intellectual disability there must be reasonable accommodations put in place to help support their self-advocacy efforts, as indicated by findings from both the scoping review and interviews. Reasonable accommodations are the changes within the environment that need to be put in place to help people with intellectual disability self-advocate. They are ways in which people and places in the environment are enabled to help people with intellectual disability to be self-advocates and provide inputs to government policies towards meaningful change. Examples of reasonable accommodations are when people with intellectual disability are accompanied by people that will support them to self-advocate, provided with easy-to-read policy documents, and making policy environments conducive for self-advocates with intellectual disability to provide their input. Overall, it is important for people with intellectual disability to be self-aware, have knowledge about their rights and related policies, and have a broad awareness of their environment and support structures therein.

6.5.2 Creating a supportive environment for self-advocacy

The development of the sub-elements noted above in section 6.6.1 need concerted effort, and the second element of this framework comprises the complementary societal level responses needed to enable individual level components of the sub-elements described above. The main contention of the second element of the framework is that empowerment of people with intellectual disability as essential to their participation in self-advocacy in policy processes. The framework posits that in order for people with intellectual disability to fully participate in self-advocacy they require empowerment through two main sub-elements: (a) the creation of self-advocacy skills development opportunities, and (b) the establishment of the support network within which self-advocacy can take place. The sub-element of supported self-advocacy has an additional sub-component which speaks to reorientating and training policy makers, service providers and supporters. In essence, people with intellectual disability's full participation in policy process can be achieved through the creation of supportive environments that will be accommodative and enable them to advocate for themselves. This second element of this conceptual framework looks at how families, supporters, service managers and providers, and policy makers can support people with intellectual disability's self-advocacy in policy.

6.5.3 Empowerment through self-advocacy skills development

Findings indicate that for people with intellectual disability to self-advocate they need self-advocacy skills. Where these are lacking, they need to be taught and capacitated with these skills. These skills are essential in equipping them with practical tools to make themselves heard about their rights, needs and wants (Nonnemacher & Bambara, 2011). It will help people with intellectual disability to advocate for their rights if they can be empowered by others to learn self-advocacy skills. Empowerment in this regard refers to when people with intellectual disability are supported to learn skills pertaining to self-advocacy.

Findings from both the scoping review and interviews indicated that the necessary skills needed for self-advocacy are public speaking, reading and writing, skills in alternative communication methods, decision-making skills and leadership skills. Some people with intellectual disability struggle with speaking in public or in front of people who they are not familiar with. Therefore, they will require relevant support from a supporter, family member or friend to practice and thus improve at advocating for themselves. For people with intellectual disability who cannot read or write, they can ask a supporter to write down their ideas for them. They can request that information be written in an easy-to-read format and learn to use alternative communication methods, such as using pictures, record videos or audios, and story-sharing to convey their ideas, or advocate for themselves.

Additionally, people with intellectual disability need to be equipped with decision-making skills and supported in their decision-making. They can request help from a supporter or family member to help them think through their ideas so that they can make informed decisions about what they will choose to say or do as a self-advocate. Additionally, findings indicated that self-advocacy by people with intellectual disability requires leadership skills. Leadership skills entail that they need to be aware of the common needs of others, working with others, and have interest in and the ability to speak up for other people with intellectual disability who cannot speak for themselves, that is, to both self-advocate and to advocate on behalf of others.

6.5.3.1 *UBUNTU*: Empower through supported self-advocacy

The findings identify support systems as important enablers of policy participation for people with intellectual disability and this is outlined in several of the chapters in this study. This sub-element of this framework is grounded in the concept of *Ubuntu*. Connectedness to and the need for support from others is a basic element of human nature, whether living with intellectual disability or not. The interconnectedness of people within society is the essence of this sub-element, meaning in the instance of the focus of this study, that people with intellectual disability should be able to rely on people around them when they want to self-advocate. Supported self-advocacy entails the interdependence of people with intellectual disability relative to their supporters and family or friends. When people support people with intellectual disability it helps them feel empowered.

Ubuntu ensures that each person in an interaction is supporting the other to be their full selves, not overshadowing or dominating one or the other, hence, true support of people with intellectual disability self-advocating must ensure that the views expressed are their own, not the supporters or family members' decisions about what is best for them. Parents and supporters' views on what they need are their own perspectives, and they will need insight into this, in order to be able to allow and support the person with intellectual disability to express their own views on what they want and need. This, however, could be a difficult task for supporters and parents who are accustomed to speaking on their behalf or wanting to protect them.

Through *Ubuntu*, people with intellectual disability can be empowered by receiving support in areas they find difficult, such as having policy documents written in easy-to-read format for ease of understanding. It is through *Ubuntu* that policy makers, service providers, supporters, family and friends can be encouraged to create a comfortable and inclusive policy environment. This will empower people with intellectual disability to feel comfortable and supported in advocating for themselves in policy environments. Furthermore, *Ubuntu* ensures access to peer and other supporters during participation to facilitate self-presentation, or co-presentation, of ideas of people with intellectual disability. Fisher et al. (2020) emphasise the importance of peer support in the promotion of self-advocacy by people with intellectual disability. Peer support benefits both the individual receiving the support and the person giving it. The benefits of peer support include an increased sense of well-being, increased confidence and learning skills, and greater connectedness (Fisher et al., 2020). Subsequently, policy environments should allow for self-advocates with intellectual disability and their peers to participate in policy while making accommodations for them to bring along a support person to help them share their ideas.

6.5.3.2 UBUNTU: Empower through reorientation and training policy makers, service providers and supporters

The last two components of this sub-element encompass the findings that indicate the empowerment of people with intellectual disability through reorientating policy makers, service providers and supporters on intellectual disability and their needs within the policy context. This sub-element also focuses on the training of policy makers, service providers and supporters about intellectual disability, and training in ways in which they can create inclusive policy environments that allow meaningful participation by people with intellectual disability. Firstly, the sub-element on reorientation focuses on the importance of raising awareness of the need for inclusion and acceptance of the rights of people with intellectual disability and their supporters and families, to participate, and be supported to do so along with other citizens who have other disabilities or are not disabled. In this regard, people with intellectual disability can be empowered by policy makers' efforts by raising awareness about the important role they can play in including people with intellectual disability in policy environments.

This empowerment can be attained through providing training on how to give the right reasonable accommodations for people with intellectual disability, such as writing important information in easy-to-read documents, accommodating the use of supporters in policy-making processes, and making policy environments inclusive and accessible to people with intellectual disability. *Ubuntu* in this component emphasises that in order for empowerment of people with intellectual disability to happen, policy makers need to accept that people with intellectual disability need to have access to peer and other support during policy participation, and therefore, policy actors and processes should facilitate this. In addition to these, people with intellectual disability and their supporters should be provided with funding in order to support self-advocacy (Rouse et al., 2022). Funding will be needed to enable participation in self-advocacy training and the provision of training in strategies for participation of people with intellectual disability in policy-making, thus ensuring the inclusion of their needs in policies and practice.

6.5.4 Policy participation opportunities for people with intellectual disability

The first element in the framework focuses on *self-advocates*' awareness, orientation to, capabilities for and interest in participating in self-advocacy. The second element focuses on the awareness of, attitudes toward, capabilities and training needs for, and willingness of *potential supporters* to work with self-advocates with intellectual disability to enter and participate in policy-making spaces. The third element of this conceptual framework focuses on the importance of a concerted effort to ensure that there are *actual policy participation opportunities* which will permit inclusive participation of people with intellectual disability and that the experience of engaging in these opportunities is life-enhancing, both personally, but also in terms of the impact of that participation on influencing policy outcomes for people to support the quality of life of people with intellectual disability.

That is, the framework captures participants' views that there should be two primary foci of policy participation. Firstly, to provide input to these policies to inform improved quality of life for people with intellectual disability by obtaining and including their views on what policies should support to observe their rights and needs. Secondly, to support empowerment of people with intellectual disability through the very act of participation – including them on par with other citizens – as well as acting on their input to ensure outcomes of their participation results in tangible improvements in their lives.

The framework contends that, at the political level, people with intellectual disability should be given meaningful – not token – opportunities to actively engage more with the democratic systems of the state. However, currently in South Africa people with intellectual disability do not participate equally in the democratic systems. For example, they are not allowed to vote or run for election (Capri & Swartz, 2018). People with intellectual disability are excluded from participating in elections because they are regarded as being of unsound mind (Capri & Swartz, 2018; Combrinck, 2014) and thus, political equality for people with intellectual disability is denied (Kleintjes et al., 2020). Goal Sixteen of the SDGs calls for non-discriminatory laws and policies that are inclusive of people with disabilities (UN, 2016). Findings from this study suggest ways in which people with intellectual disability can be included to participate in electoral and other political processes.

Suggestions from participants further indicate that this can be achieved by policy makers' efforts in ensuring that people with intellectual disability are included when the people of South Africa are asked to participate in commenting on or reviewing different policy documents. Care should be taken to ensure that people (and their organisations) invited to meetings to work on writing or commenting on drafts of new policies should include people with intellectual disability and their supporters. Participants' responses spoke to the fact that when people with intellectual disability are actively involved in policy participation, there will be a positive impact that will potentially improve their quality of life. They will experience feelings of being respected, treated with dignity, experience personal satisfaction and empowered identities through the ability to voice their perspectives and make their own decisions, and through experiencing the conviction that their efforts contribute meaningfully to their lives and the lives of others with intellectual disability.

6.6 Chapter Conclusion

The fourth objective of this study was to develop a conceptual framework for self-advocacy of people with intellectual disability, to help them participate and advocate for their social and health-related policy priorities in South Africa. This chapter demonstrated and discussed the process of developing the conceptual framework. The findings of the study highlight strategies that can be implemented to address these barriers and create more opportunities for self-advocacy in policy participation. They further call for a widening of perceptions about what is required to enable people with intellectual disability to empower themselves, and to be supported to participate as citizens, and service users.

CHAPTER SEVEN

DISCUSSION AND CONCLUSION

7.1 Introduction

The aim of this study was to develop a conceptual framework that will support people with intellectual disability to self-advocate for inclusion of their priorities in social and health-related policy in South Africa. This study has addressed the question: What are the opportunities for, and barriers to, self-advocacy by people with intellectual disability in social and health-related public policy and service development processes?

The objectives were:

- To conduct a scoping literature review of conceptual frameworks for self-advocacy.
- To explore the views of parents, carers, and people with intellectual disability about the opportunities for, and barriers to, self-advocacy and strategies to overcome these barriers.
- To explore and understand the views of policy makers, policy implementers and service providers and managers on the need for self-advocacy by people with intellectual disability in social and health-related policy development and implementation processes, opportunities for, and barriers they might experience in, including their views within the policy context, and strategies to overcome these barriers.
- To develop a conceptual framework to guide self-advocacy for people with intellectual disability within a policy and service development context in South Africa.

In this chapter, a discussion of the main findings and conclusions drawn from this study will be unpacked in relation to the study’s objectives. Thereafter, the study’s contributions will be highlighted, as well as the study’s limitations together with recommendations for further research.

7.2 Main Findings and Conclusions Drawn from the Study

> *Umntu Ngumntu Ngabantu! – A person is a person because of other people; We are human only through the humanity of others.*
>
> *– Ubuntu: An African Philosophy*

Ubuntu is an African philosophy that emphasises interconnectedness among members of society. In this study, *Ubuntu* is a call for supported self-advocacy for people with intellectual disability. At the core of *Ubuntu* is interdependence, where people rely on each other for self-determination and empowerment. Findings from this study have demonstrated how self-advocacy by people with intellectual disability can be achieved through interdependence. This section provides a discussion of the key findings through the theoretical lens of the empowerment theory in the context of *Ubuntu*. Additionally, the social model of disability together with the human rights model of disability will be incorporated in this discussion. Empowerment in the context of *Ubuntu* is a reciprocal, ongoing process centred in personal and community development, involving mutual respect, and group participation. It is a process through which people lacking an equal share of valued resources gain greater access to and control over those resources; or a process by which people gain control over their lives, and democratic participation in the life of their community (Kasu, 2021; Perkins & Zimmerman, 1995). In this chapter, I will offer insights into how people with intellectual disability can be empowered through self-advocacy and how they can be empowered to self-advocate in policy.

The social model of disability views disability as a socially produced injustice that can be challenged and eliminated through radical social change. It highlights that people are not disabled by their impairments but by the barriers they face in society (Lawson & Beckett, 2021; Oliver, 2013). Structural and procedural barriers that hinder self-advocacy by people with intellectual disability need to be addressed in order for people with intellectual disability to be able to fully participate in civic life, including participation in policy-related processes. Furthermore, the human rights model of disability recognises disability as a natural part of human diversity and that people with disability have the same rights as everyone else in society (Degener, 2014). Therefore, people with intellectual disability have the right to participate in policy processes through self-advocacy. In this chapter, I discuss the rights of people with intellectual disability and how they are infringed by societal barriers. Strategies to address these barriers to self-advocacy by people with intellectual disability will be outlined and I will further discuss the suggested strategies for creating opportunities for self-advocacy by people with intellectual disability.

7.2.1 Barriers to and opportunities for participation

This study's findings indicate the lack of opportunities for self-advocacy by people with intellectual disability in South Africa and further highlight the existing barriers to self-advocacy. The findings provide suggestions of how to create more opportunities whilst addressing the existing barriers to self-advocacy. The social model of disability posits that in order for any meaningful change to happen there should be change in society, especially diminishing societal barriers that people with intellectual disability face (Oliver, 1990, 2013; Shakespeare, 2010). Findings from the scoping review and the SSIs highlighted individual, procedural, systemic barriers, negative attitudes and exclusion of people with disabilities by society as significant barriers to self-advocacy. This is in keeping with the social model of disability which asserts that systemic barriers, negative attitudes and exclusion by society for people with disabilities are the disabling factors (Retief & Letšosa, 2018; Shakespeare, 2010).

These structural, organisational and procedural barriers diminish the personal and social power of people with disabilities. These include being restricted in exercising one's rights as citizens, limited access to the social and economic resources of society which enable autonomy, and marginalisation of their voices in policy dialogues (Frawley & Bigby, 2011; Lund, 2016). The social model mandates the removal of barriers, the enforcement of antidiscrimination legislation, and diminishing social oppression (Shakespeare, 2010). This model is concerned with addressing the barriers to participation experienced by people with disabilities as a result of various ableist social and environmental factors in society (Du Plessis, 2013; Oliver, 2013; Retief & Letšosa, 2018). Findings from this study concur with the social model of disability, that in order for any meaningful change to happen there should be change in society, especially diminishing the societal barriers that people with intellectual disability face.

The findings further highlighted that some people with intellectual disability are seen as unable to make their own decisions due to personal impairments and inconducive environments; supporters and parents of people with intellectual disability are often the ones making decisions (Nonnemacher & Bambara, 2011). They are often not afforded an opportunity to optimally exercise their capabilities independently where they are able to do so, supported by parents and families only if and when necessary (Azzopardi, 2000). However, the human rights model asserts that people with disabilities have the right to make decisions affecting them; they should be placed at the centre in the process of decision-making and should be allowed to make their own decisions themselves (Degener, 2014; Degener & Quinn, 2002). For people with intellectual disability who may lack decision-making skills, literature suggests decision-making training, supported decision-making, as well as shared decision-making (Bach & Kerczner, 2010; Sullivan & Heng, 2018).

People with intellectual disability can be trained to make their own decisions, this training being individualised based on the person's needs and their decision-making capabilities. Where their capabilities for independent decision-making may not sufficiently be assisted by developmentally appropriate opportunity for decision-making improvement as a life-long journey or by targeted training, Sullivan and Heng (2018) suggest that there should be supported decision-making. This refers to when a person with intellectual disability appoints a person they trust to make decisions on their behalf by entering into an agreement with family members or other supporters. However, the findings do not agree with this form of decision-making because it still takes the decision-making power away from the person with intellectual disability and gives it to other people.

Instead, the findings support shared decision-making as a better alternative for people with intellectual disability, along a continuum of capability for this. Shared decision-making is when people with intellectual disability are supported to consider different options before making a decision (Sullivan & Heng, 2018). This study's conceptual framework lists shared decision-making as one of the ways in which people with intellectual disability can be empowered in order to self-advocate in policy development processes.

The scoping review further demonstrates how stigma and marginalisation play a role in people with intellectual disability's capacity to participate in society. People with intellectual disability are usually stigmatised and not afforded full participation. Where they are afforded an opportunity for self-representation, they often do not feel heard and their contributions are not acknowledged (Azzopardi, 2000; Bigby et al., 2014; Frawley & Bigby, 2011; Tideman & Svensson, 2015). They are seen as incompetent, and people usually do not see past their impairments. Focusing only on impairments overshadows individual competencies, lowers expectations for new learning, and reinforces unequal power relations (Capri, Abrahams, et al., 2018; Pillay 2012). The denial of people with intellectual disability's capabilities legitimises discrimination and reinforces social prejudice.

Similarly, findings from the interviews conducted with policy makers/implementers revealed their lack of understanding of intellectual disability and lack of knowledge regarding how to create policy participation opportunities for people with intellectual disability in policy processes as significant barriers. These findings echo the ideas of the social model, that it is the society that disables people by excluding them from full participation (Oliver, 2013; Retief & Letšosa, 2018). Capri, Abrahams, et al. (2018) mention that it is people working in policy that disable impaired individuals by shaping environments that restrict participation and confine options and choices or obstruct the right to a humane life. Findings suggest that these could be addressed by reorientating policy makers about intellectual disability and issues affecting them, training them on how to provide the right reasonable accommodations for people with intellectual disability to participate in policy. Engagement with policy makers familiar with this environment can also provide support for organisations, informal supporters and self-advocates in understanding what might be needed to offer effective training and lobby for appropriate accommodations. This will not only mitigate these barriers but will create more inclusive policy environments that promote full participation of people with intellectual disability.

Currently, the findings show that there are few opportunities for self-advocacy by people with intellectual disability in South Africa. Internationally these include self-advocacy groups, advisory bodies and peer mentoring programmes (Bigby et al., 2014; Fisher et al., 2020; Kimball et al., 2016; Landmark et al., 2017), with only the first one, and very limited examples of the second, in evidence in NGOs' work to address existing barriers to self-advocacy. Goal Ten of the SDGs states that inequality within countries can be reduced by creating opportunities for social, economic and political inclusion of all, irrespective of age, sex, disability, race, ethnicity, origin, religion or economic or other status (UN, 2016). Therefore, inequality can be reduced by creating more opportunities that enhance and ensure participation and self-representation of people with intellectual disability, to address social, economic and political agendas of people with intellectual disability along with other citizens who have redress through such engagements.

Furthermore, inequality in policy can be achieved through the elimination of discriminatory laws, policies and practices and promoting appropriate legislation and policies. There needs to be dedicated disability legislation that could help to improve intersectoral policies aimed at service delivery (Kleintjes et al., 2020). Similarly, Capri, Abrahams, et al. (2018) call for a Vulnerable Persons Act that can help prevent harm and reduce the risk of abuse or neglect to people with intellectual disability. This will also address infantilisation and the isolation of people with intellectual disability that perpetuates discrimination and their exclusion in general society, and in policy processes in particular.

7.2.2 Empowerment through creating inclusive policy environments

There appears to be a significant gap in the opportunities available for people with intellectual disability's participation in policy within the different government departments, according to the findings of this study. Even where openness to participation is observed, consciousness of the need to action this in policy participation may be absent, for reasons detailed in the previous chapter. The Mental Health Policy Framework and Strategic Plan 2014-2020 (DoH, 2012), for example, explicitly mentions that service development and delivery in South Africa should aim to build user capacity to return to, sustain and participate in satisfying roles of their choice in their community. It also asserts that people with intellectual and psychosocial disabilities should be given equal opportunities and reasonable accommodation to ensure full participation in society, where they can speak out about the infringement of their rights (DoH, 2012).

Findings from this study on policy participation concur with the Mental Health Policy Framework's sentiments on inclusion and the right to voice regarding social issues which impact on their lives, in this instance at the level of policy environments. At the level of implementation of these sentiments, however, much work needs to be done to actualise these principles of inclusion. Policy participation consultations which were held in 2012 to inform the finalisation of this policy framework included some representation of people with psychosocial disability and a few with intellectual disability, included as a part of a mental health NGO's chosen delegation to the invitation to participate. Participants, however, felt their participation to be tokenistic as no reasonable accommodations were put in place for them to ensure meaningful participation (Marais et al., 2020). Inclusive policy environments can be created by preparing people with intellectual disability for policy participation, and empowering people with intellectual disability to self-advocate through supported self-advocacy.

7.2.3 Preparing people with intellectual disability for policy participation

Findings from this study indicate that people with intellectual disability's rights to participate in policy processes may be hindered by the lack of belief in their abilities and skills. In order for people with intellectual disability to be able to self-advocate they require preparation in a form of empowerment, where their self-advocacy skills are developed, thus enabling them to advocate for themselves. Self-advocacy skills can enable people to build a sense of identity, friendship, community and self-determination (Balint-Langel et al., 2019; Grove, 2015). Self-advocacy skills, as noted in the preceding chapters, are collectively considered self-determination skills. Therefore, self-advocacy skills-building should be considered when preparing people with intellectual disability to participate in self-advocacy.

Preparing people with intellectual disability for participation requires that supportive systems are put in place and for support personnel to be involved in this process (Roberts et al., 2016). These are the key people who will help in preparing people with intellectual disability for participation, therefore their support is crucial for self-advocacy by people with intellectual disability. These support systems are made up of community members with formal and unofficial authority positions who can act as allies to advance the interests of people with intellectual disability, NGOs that work with people with intellectual disability, and allies (friends, peers and family members). In line with the human rights and social inclusion perspectives, support persons are the key role-players in the South African community who can provide support to the participation of people with intellectual disability in policy development and provide support through brokering interventions that will provide them with the opportunity and capacity for self-representation or supported decision-making (Burns 2009; Minkowitz 2006).

In addition to the actions that these role-players can take within their assigned roles and organisations, there is a need to create more inclusive policy spaces and strengthen collaborations with existing disability structures, and the peer-led forums for people with intellectual disability. People with intellectual disability and their allies should also strengthen their engagement with organisations such as the South African Human Rights Commission to transform policies and practices which infringe on the human rights of people with intellectual disability. Furthermore, people with intellectual disability and their allies should actively engage with government departments within the social cluster that are responsible for overseeing the creation and execution of government programs and policies that pertain to women, children, and people with disabilities in order to advance their needs and priorities on the agenda of the government.

Findings further suggest that when people with intellectual disability are actively involved in policy participation, they will have an improved quality of life, where they will experience personal satisfaction and have empowered identities through the ability of making their own decisions. Kosciulek (2005) mentions that an improved quality of life requires that a person has control and choice within the environment (social and political) and can assert this in the pursuit of meeting their needs and aspirations. Participants with intellectual disability in this study felt that policy participation will mean that they are making meaningful contributions to society and will get to experience respect and dignity. With active policy participation there will be a shift (Kleintjes, 2012); this shift is central to enabling people with intellectual disability to move from being an observer in deliberations about their lives, to central, valued role-players within the policy development environment.

7.3 Contributions of the Study

This study has several contributions which will be discussed below.

7.3.1 Contributions to existing knowledge in the field

To my knowledge, this is the first study that examines the opportunities for, and barriers to, policy participation of people with intellectual disability in the South African context. Specific contributions of the study are listed below.

(a) The study provides a scoping literature review on key concepts relevant to empowering direct policy participation by people with intellectual disability, including the identification of other relevant conceptual frameworks for self-advocacy which informed the focus of this study. The review found that there are no conceptual frameworks for self-advocacy specifically for people with intellectual disability, including in the African context. The findings further highlight the barriers to self-advocacy and support the assertion that the inclusion of people with disabilities in society should be upheld when addressing issues concerning them. This puts more emphasis on self-representation and empowerment.

(b) The study provides a novel exploration of the opinions of people with intellectual disability, including advocates and non-advocates regarding self-advocacy for their policy priorities in South Africa.

(c) Given the degree to which people with intellectual disability are marginalised in society, the study provides a detailed, meaningful examination of their participation in policy processes, highlighting many of the mechanisms of their marginalisation in policy level spaces for engagement.

(d) The study identifies several strategies which stakeholders can implement to strengthen the participation of people with intellectual disability in social and health policy processes.

(e) The study findings bring attention to the fact that while there are contextual differences to the experiences of people with intellectual disability in the South African context, their disempowerment, exclusion, and their striving for empowerment and respect for their rights, is fundamentally the same as that experienced by people with intellectual disability elsewhere in the world.

(f) The study synthesised the findings into a conceptual framework to inform policy-related self-advocacy for adults with intellectual disability.

(g) The conceptual framework has been converted into an easy-to-read booklet that can be used to explore self-advocacy with people with intellectual disability, and it will also work as a guide for those who wish to participate in self-advocacy for their policy-related priorities.

7.4 Limitations of the Study and Recommendations for Further Research.

The study has several limitations that are acknowledged below.

7.4.1 Qualitative research methodology

7.4.1.1 The scoping review

There are several limitations to the scoping review. We aimed to discover conceptual frameworks to support self-advocacy by people with intellectual disability. However, it was beyond the scope of this review to include work on conceptual frameworks for self-advocacy for people with intellectual disability that has not been published in peer-reviewed journals. Non-peer reviewed work available from websites hosted by peer organisations of people with intellectual disability, conference proceedings, work published in books, and unpublished reports were not consulted in the review, potentially limiting the range of views which could be accessed from the available data. Only articles published in English were included in the review and relevant work published in other languages may have been omitted.

The review is based on limited data from only 20 published articles, many of which were conducted in high-income countries, with none conducted within the African context. Another limitation is that the thematic data analysis was conducted by one reviewer and my subjective analysis of the data might have been influenced by my involvement in the themes which emerged from the other data sources. However, reflexivity helped me in interpreting the themes identified added value to those interpretations. Regular consultations with my supervisor and quarterly consultations with the advisory committee assisted me to be objective, redefine and make sense of the themes as I analysed the data. Finally, focus groups provided an opportunity to review my interpretation of findings to address potential researcher bias. Results are limited by the sample of selected studies and findings may not be representative of experiences of all self-advocates.

7.4.1.2 Sample for the interviews

The research findings are based on a very limited sample. The study focussed on adults with intellectual disability, excluding children and adolescents, and people with other developmental disabilities, narrowing the range of perspectives tapped from the broader community. The sample from the government departments was very limited, in that there were no participants from the Department of Social Development and the Department of Women, Youth and People with Disabilities. These departments are at the centre of service provision for people with disabilities in South Africa, therefore narrowing the perspectives of policy makers and service managers. The results of the study may therefore not be representative of the views of all relevant parties, South Africans in general, including all South Africans living with intellectual disability.

7.4.1.3 Instrumentation

The structured nature of the topic guides and interview schedules may have influenced the similarity of categories of findings across the stakeholder groups. On the other hand, my familiarity with the schedules did allow me to let the participants take the lead in spontaneously exploring areas of enquiry, which they did, with further enquiry from me focusing on areas not addressed by the respondent, as the interview unfolded. The literature review, conducted using a different methodology and data source, still yielded findings which were congruent with the findings of the SSIs.

7.4.1.4 Focus group discussions

It was my intention to conduct three focus group discussions with five participants in each from different stakeholders' groups. However, due to the Covid-19 regulations set by the organisations where participants with intellectual disability were recruited from, no face-to-face contact was allowed. Secondly, only two participants were available to review the conceptual framework. Additionally, several parents and carers of people with intellectual disability were not available to participate in the review of the conceptual framework, hence only three participants from this group reviewed the framework, thereby limiting the perspectives and suggestions of ways to improve this framework. It may be useful, after the study, to engage more widely with stakeholders to review the framework to obtain greater input, which may improve the utility of the framework for stakeholders wishing to action its elements. This may also yield a stronger indication of whether the framework resonates with more participants' views.

7.5 Further Research

The limitations of this study can be addressed by expanding the enquiry to include the following areas:

(a) A more comprehensive review of the literature, including unpublished grey literature, may provide a wider range of perspectives on the topic than was possible in the current review, which may inform further development of the conceptual framework.

(b) Research focused on policy development processes specific to the roles of stakeholders at the provincial and local implementation levels may uncover other viable implementation strategies to engage people with intellectual disability.

(c) Obtaining the views of a wider, more representative range of South Africans with intellectual disability, including the views of children and adolescents, and people with other developmental disabilities.

(d) Obtaining views from a wider range of policy makers and service managers from various government departments and not limited to only those in the social cluster.

(e) Intervention studies would assist in determining whether implementation of the identified strategies are feasible and improve the participation of people with intellectual disability in policy environments, and under what conditions.

(f) Research required to further explore the elements of the framework, and to evaluate the feasibility of implementing the conceptual framework, may include:

- *Self-awareness and knowledge of their rights and related policies*: For example, does self-awareness and knowledge of rights and policies in relation to these rights improve self-advocacy by people with intellectual disability?
- *Awareness of the environment*: For example, does their awareness of the environment help them get more involved in policy participation?
- *Self-advocacy skills building*: For example, does advocacy skills training improve the work of self-advocates with intellectual disability in participating in policy environments? Are there factors which influence people with intellectual disability to take on the work of being self-advocates for those who are non-advocates?
- *Supported self-advocacy:* For example, are the support systems put in place helping people with intellectual disability advocate for their policy-related priorities? What models of organisation for self-advocacy would be most useful in the South African context?
- *Reorientation and training of policy makers:* For example, does reorientating and training policy makers and service managers/providers add to the value system suggested in the framework that result in increased policy participation of people with intellectual disability?
- *Improved quality of life:* For example, does participation in self-advocacy in policy environments result in improved quality of life and a greater sense of empowerment in people with intellectual disability?

7.5.1 Studies which assess the impact of policy participation on policy outcomes

Further studies could be conducted to evaluate opportunities for participation, to assess whether participation results in the acceptance of the views of people with intellectual disability in policies. While interventions may result in increased participation by people with intellectual disability, participation in policy processes does not necessarily result in increased acceptance of the priorities of participants in actual policy directions (Kleintjes, 2012; McColl & Boyce, 2003). Studies included in the scoping review make only brief reference to the impact of the participation of people with intellectual disability in policy on actual outcomes for policy directions. Similarly, participants from South Africa have had limited opportunities to participate in actual policy development and implementation initiatives, and further research is required to evaluate the impact of people with intellectual disability's participation in actual policy processes, to add to the limited research available in this area (Marais et al., 2020).

7.6 Conclusion

The removal of barriers to policy participation requires more inclusive environments. There should be greater opportunities for people with intellectual disability to become involved in the development of policies and services aimed at improving for their well-being, and a broadening of the settings of their participation, beyond the mental health service settings, to community and civil society settings, including that of civic engagement which can impact on policy-making processes. There is a great need to address stigma and exclusionary attitudes which affect people with intellectual disability. The recommendations of this dissertation, made in respect of policy participation, must be considered in contexts beyond the narrow focus of this dissertation, to the overall social environment within which people with intellectual disability live.

Overall, the conceptual framework highlights what is needed for people with intellectual disability to participate in self-advocacy for their policy priorities. It also highlights practical changes which need to be made to actively include people with intellectual disability in policy processes. The elements of the framework provide a breakdown of what individuals need in order to become self-advocates and further demonstrate what needs to be done by policy makers, service providers and supporters to create an inclusive policy environment for people with intellectual disability, thus making it possible for them to participate as self-advocates in policy environments. The framework further demonstrates the importance of concerted efforts to ensure that there are policy participation opportunities which will permit inclusive participation of people with intellectual disability.

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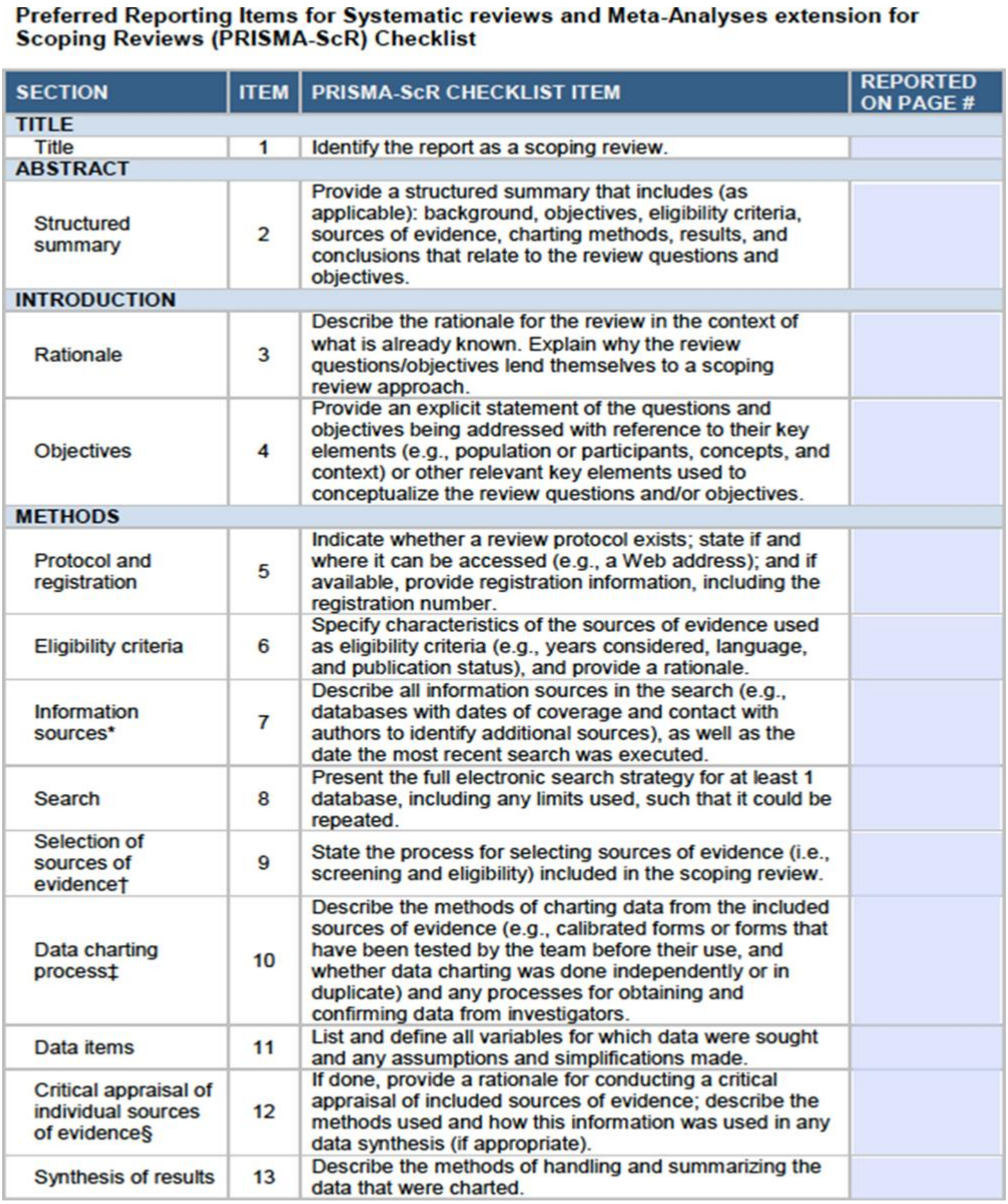
APPENDICES

Appendix 1: PRISMA Guidelines



Preferred Reporting Items for Systematic reviews and Meta-Analyses extension for Scoping Reviews (PRISMA-ScR) Checklist

SECTION	ITEM	PRISMA-ScR CHECKLIST ITEM	REPORTED ON PAGE #
TITLE			
Title	1	Identify the report as a scoping review.	
ABSTRACT			
Structured summary	2	Provide a structured summary that includes (as applicable): background, objectives, eligibility criteria, sources of evidence, charting methods, results, and conclusions that relate to the review questions and objectives.	
INTRODUCTION			
Rationale	3	Describe the rationale for the review in the context of what is already known. Explain why the review questions/objectives lend themselves to a scoping review approach.	
Objectives	4	Provide an explicit statement of the questions and objectives being addressed with reference to their key elements (e.g., population or participants, concepts, and context) or other relevant key elements used to conceptualize the review questions and/or objectives.	
METHODS			
Protocol and registration	5	Indicate whether a review protocol exists; state if and where it can be accessed (e.g., a Web address); and if available, provide registration information, including the registration number.	
Eligibility criteria	6	Specify characteristics of the sources of evidence used as eligibility criteria (e.g., years considered, language, and publication status), and provide a rationale.	
Information sources*	7	Describe all information sources in the search (e.g., databases with dates of coverage and contact with authors to identify additional sources), as well as the date the most recent search was executed.	
Search	8	Present the full electronic search strategy for at least 1 database, including any limits used, such that it could be repeated.	
Selection of sources of evidence†	9	State the process for selecting sources of evidence (i.e., screening and eligibility) included in the scoping review.	
Data charting process‡	10	Describe the methods of charting data from the included sources of evidence (e.g., calibrated forms or forms that have been tested by the team before their use, and whether data charting was done independently or in duplicate) and any processes for obtaining and confirming data from investigators.	
Data items	11	List and define all variables for which data were sought and any assumptions and simplifications made.	
Critical appraisal of individual sources of evidence§	12	If done, provide a rationale for conducting a critical appraisal of included sources of evidence; describe the methods used and how this information was used in any data synthesis (if appropriate).	
Synthesis of results	13	Describe the methods of handling and summarizing the data that were charted.	

Appendix 2: List of Sourced Articles for the Scoping Review

Author	Year	Title of paper	Journal
Abayneh, S. Lempp, H. Alem, A. Kohrt, B. A. Fekadu, A. Hanlon, C.	2020	Developing a Theory of Change model of service user and caregiver involvement in mental health system strengthening in primary health care in rural Ethiopia.	International Journal of Mental Health Systems 14(1).
Arvidsson, P. Granlund, M. Thyberg, M.	2008	Factors related to self-fated participation in adolescents and adults with mild intellectual disability - A systematic literature review.	Journal of Applied Research in Intellectual Disabilities 21(3): 277-291.
Auger, C., Leduc, E., Labbé, D., Guay, C., Fillion, B., Bottari, C., Swaine, B.	2014	Mobile applications for participation at the shopping mall: Content analysis and usability for people with physical disabilities and communication or cognitive limitations.	Int J Environ Res Public Health 11(12): 12777-12794.
Azzopardi, A.	2000	A case study of a parents' self-advocacy group in Malta: The concepts of 'inclusion, exclusion and disabling barriers' are analysed in the relationship that parents have with professionals.	Disability & Society 15(7): 1065-1072.
Balint-Langel, K. Woods-Groves, S. Rodgers, D. B. Rila, A. Riden, B. S.	2019	Using a Computer-Based Strategy to Teach Self-Advocacy Skills to Middle School Students With Disabilities.	Journal of Special Education Technology.
Beighton, C., Victor, C., Carey, I. M., Hosking, F., DeWilde, S., Cook, D., G.Manners, P., Harris, T.	2019	‘I'm sure we made it a better study…’: Experiences of adults with intellectual disabilities and parent carers of patient and public involvement in a health research study.	J Intellect Disabil 23(1): 78-96.
Bigby, Christine Anderson, Sian Cameron, Nadine	2018	Identifying conceptualizations and theories of change embedded in interventions to facilitate community participation for people with intellectual disability: A scoping review.	Journal of Applied Research in Intellectual Disabilities 31(2): 165-180.
Bigby, Christine Frawley, Patsie Ramcharan, Paul	2014	Conceptualizing inclusive research with people with intellectual disability.	Journal of applied research in intellectual disabilities : JARID 27(1): 3-12.

Boyd, K. Diepstra, H. Elbard, K. Hamdani, Y. Lunsky, Y.	2018	Consumer inclusion: Experience of patients with intellectual and developmental disabilities informs primary care.	Canadian Fam Physician 64(Suppl 2): S8-S11.
Brolin, R., Brunt, D., Rask, M., Syrén, S., Sandgren, A.	2016	Striving for meaning-Life in supported housing for people with psychiatric disabilities.	Int J Qual Stud Health Well-being 11: 31249
Burke, Eilish Pyle, Melissa Machin, Karen Varese, Filippo Morrison, Anthony P.	2019	The effects of peer support on empowerment, self-efficacy, and internalized stigma: A narrative synthesis and meta-analysis.	Stigma and Health 4(3): 337-356.
Callus, A. M.	2019	Being an inclusive researcher: Seeking questions, raising answers.	Disability & Society 34(7-8): 1241-1263.
Capri, Charlotte Abrahams, Lameze McKenzie, Judith Coetzee, Ockert Mkabile, Siyabulela Saptouw, Manuel Hooper, Andrew Smith, Peter Adnams, Colleen Swartz, Leslie	2018	Intellectual disability rights and inclusive citizenship in South Africa: What can a scoping review tell us?	African Journal of Disability 7(1): N.PAG-N.PAG.
Cattaneo, L. B. and A. R. Chapman	2010	The process of empowerment: A model for use in research and practice.	American Psychologist 65(7): 646-659.
Chapman, R. and L. Tilley	2013	"Exploring the Ethical Underpinnings of Self-advocacy Support for Intellectually Disabled Adults.	Ethics & Social Welfare 7(3): 257-271.
Collins, G. and J. A. Wolter	2018	Facilitating postsecondary transition and promoting academic success through language/literacy-based self-determination strategies.	Language, Speech, and Hearing Services in Schools 49(2): 176-188.
Cone, A. A.	2000	Self-advocacy group advisor activities and their impact/relation to self-advocacy group development.	International Journal of Disability, Development and Education 47(2): 137-154.

Cone, A. A.	2001	Self-reported training needs and training issues of advisors to self-advocacy groups for people with mental retardation.	Mental Retardation 39(1): 1-10.
Cook, A.	2020	Using an inclusive therapeutic theatre production to teach self-advocacy skills in young people with disabilities.	Arts in Psychotherapy 71.
Cook, A. L.	2017	Employing a social justice framework to promote postsecondary transition for students with intellectual disability.	International Journal for Educational and Vocational Guidance 17(3): 311-328.
D’Eloia, M. H. and P. Price	2018	Sense of belonging: Is inclusion the answer?	Sport in Society 21(1): 91-105
Di Lorito, C., Bosco, A., Birt, L., Hassiotis, A.	2018	Co-research with adults with intellectual disability: A systematic review.	Journal of Applied Research in Intellectual Disabilities 31(5): 669-686.
Dirth, T. P. and N. R. Branscombe	2018	The social identity approach to disability: Bridging disability studies and psychological science.	Psychological Bulletin 144(12): 1300-1324.
Dowling, S. Williams, V. Webb, J. Gall, M. Worrall, D.	2019	Managing relational autonomy in interactions: People with intellectual disabilities.	Journal of Appl Res Intellect Disabil 32(5): 1058-1066.
Fiedler, C. R. and J. E. Danneker	2007	Self-advocacy instruction: Bridging the research-to-practice gap.	Focus on Exceptional Children 39(8): 1-20.
Fisher, Marisa H. Athamanah, Lindsay S. Sung, Connie Josol, Cynde Katherine	2020	Applying the self-determination theory to develop a school-to-work peer mentoring programme to promote social inclusion.	Journal of applied research in intellectual disabilities : JARID 33(2): 296-309.
Frawley, P. and C. Bigby	2011	Inclusion in political and public life: The experiences of people with intellectual disability on government disability advisory bodies in Australia.	Journal of Intellectual & Developmental Disability 36(1): 27-38.
Garrison-Wade, D. F. and J. P. Lehmann	2009	A conceptual framework for understanding students’ with disabilities transition to community college.	Community College Journal of Research and Practice 33(5): 415-443.
Gibson, B. E., King, G., Teachman, G., Mistry, B., Hamdani, Y.	2017	Assembling activity/setting participation with disabled young people.	Sociol Health Illn 39(4): 497-512.

Gillespie-Lynch, K. Bublitz, D. Donachie, A. Wong, V. Brooks, P. J. D'Onofrio, J.	2017	For a long time our voices have been hushed": Using student perspectives to develop supports for neurodiverse college students." Frontiers in Psychology 8	International Journal of Environmental Research and Public Health 15(4).
Goldberg, Caren B. Clark, Mark A. Henley, Amy B.	2011	"Speaking up: a conceptual model of voice responses following the unfair treatment of others in non-union settings."	Human Resource Management 50(1): 75-94.
Gooding, Piers, Arstein-Kerslake, Anna, Flynn, Eilionoir	2015	Assistive technology as support for the exercise of legal capacity.	International Review of Law, Computers & Technology 29(2/3): 245-265
Gosse, L. Griffiths, D. Owen, F. Feldman, M.	2017	Impact of an Individualized Planning Approach on Personal Outcomes and Supports for People with Intellectual Disabilities.	Journal of Policy and Practice in Intellectual Disabilities 14(3): 198-204.
Grove, N.	2015	Finding the sparkle: Storytelling in the lives of people with learning disabilities.	Tizard Learning Disability Review 20(1): 29-36.
Halperin, I. Shupac, A. Morad, M. Merrick, J.	2005	Health policy for people with intellectual disability: Experiences from Israel.	Scientific World Journal 5: 71-92.
Hollomotz, A.	2014	Are We Valuing People's Choices Now? Restrictions to Mundane Choices Made by Adults with Learning Difficulties.	British Journal of Social Work 44(2): 234-251.
Hung-Chih, L.	2005	The Self-Determination for Youth with Intellectual Disabilities in Taiwan.	International Journal of Diversity in Organisations, Communities & Nations 5(1): 1-16.
Islam, M. R. and S. Cojocaru.	2015	Advocacy for Empowerment: A Case of the Learning Disabled People in Malaysia.	Revista de Cercetare si Interventie Sociala 50: 38-52.

Jetha, A. Shaw, R. Sinden, A. R. Mahood, Q. Gignac, M. A. McColl, M. A. Martin Ginis, K. A.	2019	Work-focused interventions that promote the labour market transition of young adults with chronic disabling health conditions: A systematic review.	Occup Environ Med 76(3): 189-198.
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Karr, V. L.	2011	A life of Quality: Informing the UN Convention on the Rights of People with Disabilities.	Journal of Disability Policy Studies 22(2): 67-82.
Kenny, A. and M. Power	2018	Social inclusion and intellectual disability in Ireland: Social inclusion co-ordinators' perspectives on barriers and opportunities.	Scottish Journal of Residential Child Care 17(4): 1-23.
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Kimball, Ezekiel W. Moore, Adam Vaccaro, Annemarie Troiano, Peter F. Newman, Barbara M.	2016	College students with disabilities redefine activism: Self-advocacy, storytelling, and collective action.	Journal of Diversity in Higher Education 9(3): 245-260.
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			Research and Public Health 15(4).
Kramer, J. M., Hwang, I., T., Helfrich, C. A., Samuel, P. S., Carrellas, A.	2018	Evaluating the Social Validity of Project TEAM: A Problem-Solving Intervention to Teach Transition Age Youth with Developmental Disabilities to Resolve Environmental Barriers.	International Journal of Disability, Development and Education 65(1): 57-75.
Kritsotaki, D.	2016	Turning Private Concerns into Public Issues: Mental Retardation and the Parents' Movement in Post-war Greece, c. 1950-80.	Journal of Social History 49(4), 982–998
Landmark, L. J., Zhang, D., Ju, S., McVey, T. C., Ji, M. Y.	2017	Experiences of Disability Advocates and Self-Advocates in Texas.	Journal of Disability Policy Studies 27(4): 203-211.
Landmark, L. J. Zhang, D. Ju, S. McVey, T. C. Ji, M. Y.	2017	Experiences of Disability Advocates and Self-Advocates in Texas.	Journal of Disability Policy Studies 27(4): 203-211.
Lorenzo, T., van Pletzen, E., Booyens, M.	2015	Determining the competences of community-based workers for disability-inclusive development in rural areas of South Africa, Botswana and Malawi.	Rural Remote Health 15(2): 2919.
Marks, B. Sisirak, J. Magallanes, R. Krok, K. Donohue-Chase, D.	2019	Effectiveness of a Health Messages peer-to-peer program for people with intellectual and developmental disabilities.	Intellectual and Developmental Disabilities 57(3): 242-258.
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McDonald, K. E., Conroy, N. E., Kim, C. I., LoBraico, E. J., Prather, E. M., Olick, R. S.	2016	Is Safety in the Eye of the Beholder? Safeguards in Research With Adults With Intellectual Disability.	J Empir Res Hum Res Ethics 11(5): 424-438.
McDonald, K. E. Conroy, N. E. Olick, R. S.	2018	A quantitative study of attitudes toward the research participation of adults with intellectual disability: Do stakeholders agree?	Disabil Health J 11(3): 345-350.

McDonald, K. E. and C. B. Key	2008	How the Powerful Decide: Access to Research Participation by those at the Margins.	American Journal of Community Psychology 42(1/2): 79-93.
McPherson, L.,Ware, R., S., Carrington, S., Lennox, N.	2017	Enhancing Self-Determination in Health: Results of an RCT of the Ask Project, a School-Based Intervention for Adolescents with Intellectual Disability.	Journal of Applied Research in Intellectual Disabilities 30(2): 360-370.
Mead, Shery Hilton, David Curtis, Laurie	2001	Peer support: A theoretical perspective.	Psychiatric Rehabilitation Journal 25(2): 134-141.
Mikołajczyk-Lerman, G. and M. Potoczna	2019	Enhancing Autonomy through the Occupational Engagement of Adults with Intellectual Disabilities: Supported Employment Model Applied by the Polish Association for People with Intellectual Disabilities (Branch in Zgierz).	Przeglad Socjologii Jakosciowej 15(4): 184-203.
Mumbardó-Adam, CristinaVicente Sánchez, Eva Simó-Pinatella, David Coma Roselló, Teresa	2020	Understanding practitioners' needs in supporting self-determination in people with intellectual disability.	Professional Psychology: Research and Practice 51(4): 341-351.
Nevala, N. Pehkonen, I. Teittinen, A. Vesala, H. T. Pörtfors, P. Anttila, H.	2019	The Effectiveness of Rehabilitation Interventions on the Employment and Functioning of People with Intellectual Disabilities: A Systematic Review.	J Occup Rehabil 29(4): 773-802.
Nonnemacher, S. L. and L. M. Bambara	2011	"I'm Supposed to be in Charge": Self-Advocates' perspectives on their self-determination support needs.	Intellectual and Developmental Disabilities 49(5): 327-340.
Owen, Aleksa Arnold, Katie Friedman, Carli Sandman, Linda	2016	Nominal Group Technique: An accessible and interactive method for conceptualizing the sexual self-advocacy of adults with intellectual and developmental disabilities.	Qualitative Social Work 15(2): 175-189.
Pfeifer, M. A., Reiter, E. M., Hendrickson, M. K., Stanton, J. D.	2020	Speaking up: A model of self-advocacy for STEM undergraduates with ADHD and/or specific learning disabilities.	International Journal of STEM Education 7(1).
Pfister, A., Georgi-Tscherry, P., Berger, F., Studer, M.	2020	Participation of adults with cognitive, physical, or psychiatric impairments in family of origin and intimate relationships: A grounded theory study.	BMC Public Health 20(1): 642.
Pogach, D.	2019	Supported Decision-Making for Older Adults with Age-Related Cognitive Decline: A comparison of policy and procedure around supported decision-making for people with intellectual disabilities, and for people with age-related cognitive decline.	Generations 43(4): 87-93.
Potvin, L. A., Fulford, C., Ouellette-Kuntz, H., Cobigo, V.	2019	What adults with intellectual and developmental disabilities say they need to access annual health examinations: System navigation support and person-centred care.	Can Fam Physician 65(Suppl 1): S47-s52.

Quinn, A. and M. Otteson	2019	Strengthening the Voice of Those with Mental Health Issues: A Community Approach to Developing a Mental Health Identification System.	Social Work 64(3): 216-223.
Racino, J. A.	2002	Community Integration and Statewide Systems Change: Qualitative Evaluation Research in Community Life and Disability.	Journal of Health & Social Policy 14(3): 1-26.
Rezaul Islam, M. and S. Cojocaru	2015	Advocacy for empowerment: A case of the learning disabled people in Malaysia.	Revista de Cercetare si Interventie Sociala 50(September): 38-52.
Roberts, E. L. Ju, S. Zhang, D.	2016	Review of Practices That Promote Self-Advocacy for Students With Disabilities.	Journal of Disability Policy Studies 26(4): 209-220.
Robinson, Sally Fisher, Karen R. Strike, Robert	2014	Participatory and Inclusive Approaches to Disability Program Evaluation.	Australian Social Work 67(4): 495-508.
Roets, Griet, Reinaart, Rosa, Adams, Marie, Van Hove, Geert	2008	Looking at lived experiences of self-advocacy through gendered eyes: Becoming femme fatale with/out 'learning difficulties'.	Gender & Education 20(1): 15-29.
Scheffers, F. Moonen, X. van Vugt, E.	2020	External sources promoting resilience in adults with intellectual disabilities: A systematic literature review.	J Intellect Disabil: 1744629520961942.
Schmidt, E. K. Faieta, J. Tanner, K.	2020	Scoping Review of Self-Advocacy Education Interventions to Improve Care.	OTJR Occupation, Participation and Health 40(1): 50-56.
Schoffstall, S. Cawthon, S. W. Tarantolo-Leppo, R. H. Wendel, E.	2015	Developing Consumer and System-Level Readiness for Effective Self-Advocacy: Perspectives from Vocational Rehabilitation Counselors Working With Deaf and Hard of Hearing Individuals in Post-Secondary Settings.	Journal of Developmental and Physical Disabilities 27(4): 533-555.
Shogren, Karrie A.Wehmeyer, Michael L.Buchanan, Cindy L.Lopez, Shane J.	2006	The Application of Positive Psychology and Self-Determination to Research in Intellectual Disability: A Content Analysis of 30 Years of Literature.	Research & Practice for People with Severe Disabilities 31(4): 338-345.
Sniatecki, J. L. Pelz, J. A. Gates, T. G.	2018	Human Rights Advocacy for Students with Disabilities: Challenging Stigma and Promoting Opportunity in Social Work Education.	Journal of Human Rights and Social Work 3(4): 183-190.
Sprague, J. and J. Hayes	2000	Self-determination and empowerment: A feminist standpoint analysis of talk about disability.	American Journal of Community Psychology 28(5): 671-695.

Stylianos, S. and V. Kehyayan	2012	Advocacy: Critical component in a comprehensive mental health system.	American Journal of Orthopsychiatry 82(1): 115-120.
Sullivan, W. F., Heng, J., Salvador-Carulla, L., Lukersmith, S., Casson, I.	2018	Approaches to primary care of adults with intellectual and developmental disabilities: Importance of frameworks for guidelines.	Can Fam Physician 64(Suppl 2): S5-S7.
Tanis, E. S. Palmer, S. Wehmeyer, M. Davies, D. K. Stock, S. E. Lobb, K. Bishop, B.	2012	Self-report computer-based survey of technology use by people with intellectual and developmental disabilities.	Intellect Dev Disabil 50(1): 53-68.
Test, D. W. Fowler, C. H. Brewer, D. M. Wood, W. M.	2005	A content and methodological review of self-advocacy intervention studies.	Exceptional Children 72(1): 101-125.
Test, David W.Fowler, Catherine H.Wood, Wendy M.Brewer, Denise M.Eddy, Steven	2005	A Conceptual Framework of Self-Advocacy for Students with Disabilities.	Remedial and Special Education 26(1): 43-54.
Tideman, M. and O. Svensson	2015	Young people with intellectual disability--the role of self-advocacy in a transformed Swedish welfare system.	Int J Qual Stud Health Well-being 10: 25100.
Triguero-Mas, M. Anguelovski, I. Cirac-Claveras, J. Connolly, J. Vazquez, A. Urgell-Plaza, F. Cardona-Giralt, N. Sanyé-Mengual, E. Alonso, J. Cole, H.	2020	"Quality of Life Benefits of Urban Rooftop Gardening for People With Intellectual Disabilities or Mental Health Disorders.	Prev Chronic Dis 17: E126.
Turner, G. W. and B. Crane	2016	Sexually Silenced No More, Adults with Learning Disabilities Speak Up: A Call to Action for Social Work to Frame Sexual Voice as a Social Justice Issue."	British Journal of Social Work 46(8): 2300-2317.

Vaccaro, A. Daly-Cano, M. Newman, B. M.	2015	A sense of belonging among college students with disabilities: An emergent theoretical model.	Journal of College Student Development 56(7): 670-686.
van Diemen, T., Craig, A., van Nes, I. J. W., Stolwijk-Swuste, J. M., Geertzen, J. H. B., Middleton, J., Post, M. W. M.	2020	Enhancing our conceptual understanding of state and trait self-efficacy by correlational analysis of four self-efficacy scales in people with spinal cord injury.	BMC Psychol 8(1): 108.
van Wingerden, E. Sterkenburg, P. S. Wouda, M.	2018	Improving empathy and self-efficacy in caregivers of people with intellectual disabilities, using m-learning (HiSense APP-ID): Study protocol for a randomized controlled trial."	Trials 19(1): 400.
Vergunst, R.Swartz, L.Hem, K. G.Eide, A. H.Mannan, H.MacLachlan, M.Mji, G.Braathen, S. H.Schneider, M.	2017	Access to health care for people with disabilities in rural South Africa.	BMC Health Serv Res 17(1): 741.
Vergunst, R. Swartz, L. Mji, G. MacLachlan, M. Mannan, H.	2015	'You must carry your wheelchair'--barriers to accessing healthcare in a South African rural area .	Glob Health Action 8: 29003
Visagie, S., Eide, A. H., Dyrstad, K., Mannan, H., Swartz, L., Schneider, M., Mji, G., Munthali, A., Khogali, M., van Rooy, G., Hem, K. G., MacLachlan, M.	2017	Factors related to environmental barriers experienced by people with and without disabilities in diverse African settings.	PLoS One 12(10): e0186342
Weber, Stephanie Smith, Jennifer Ayers, Kara Gerhardt, Jane	2020	Fostering disability advocates: A framework for training future leaders through interprofessional education.	Psychological Services 17(S1): 120-127.
Wehmeyer, M. L.	2004	Self-determination and the empowerment of people with disabilities.	American Rehabilitation 28(1): 22-29.
Wehmeyer, M. L.	2020	The Importance of Self-Determination to the Quality of Life of People with Intellectual Disability: A Perspective.	Int J Environ Res Public Health 17(19).
White, Keeley Flanagan, Tara D. Nadig, Aparna	2018	Examining the Relationship Between Self-Determination and Quality of Life in Young Adults with Autism Spectrum Disorder.	Journal of Developmental & Physical Disabilities 30(6): 735-754.

Wilson, S. McKenzie, K. Quayle, E. Murray, G.	2014	A systematic review of interventions to promote social support and parenting skills in parents with an intellectual disability.	Child: Care, Health & Development 40(1): 7-19.
Yoma, S. M.	2019	[User participation in public policies of mental health: an integrative review].	Cien Saude Colet 24(7): 2499-2512.
Zhang, Dalun Walker, Jessica M. Leal, Dianey R. Landmark, Leena Jo Katsiyannis, Antonis	2019	A Call to Society for Supported Decision-Making: Theoretical and Legal Reasoning.	Journal of Child & Family Studies 28(7): 1803-1814.

Appendix 3: Articles for Full Text Review

Author	Year	Title of paper
Auger, C. Leduc, E. Labbé, D. Guay, C. Fillion, B. Bottari, C. Swaine, B.	2014	Mobile applications for participation at the shopping mall: content analysis and usability for people with physical disabilities and communication or cognitive limitations.
Azzopardi, A.	2000	A case study of a parents' self-advocacy group in Malta: The concepts of 'inclusion, exclusion and disabling barriers' are analysed in the relationship that parents have with professionals.
Balint-Langel, K. Woods-Groves, S. Rodgers, D. B. Rila, A. Riden, B. S.	2019	Using a Computer-Based Strategy to Teach Self-Advocacy Skills to Middle School Students With Disabilities.
Bigby, C. Frawley, P. Ramcharan, P.	2014	Conceptualizing inclusive research with people with intellectual disability.
Boyd, K. Diepstra, H. Elbard, K. Hamdani, Y. Lunsky, Y.	2018	Consumer inclusion: Experience of patients with intellectual and developmental disabilities informs primary care.
Callus, A.M.	2019	Being an inclusive researcher: Seeking questions, raising answers.

Capri, C. Abrahams, L. McKenzie, J. Coetzee, O. Mkabile, S. Saptouw, M. Hooper, A. Smith, P. Adnams, C. Swartz, L.	2018	Intellectual disability rights and inclusive citizenship in South Africa: What can a scoping review tell us?
Chapman, R. and L. Tilley	2013	Exploring the Ethical Underpinnings of Self-advocacy Support for Intellectually Disabled Adults.
Collins, G. and J. A. Wolter	2018	Facilitating postsecondary transition and promoting academic success through language/literacy-based self-determination strategies.
Cone, A. A.	2000	Self-advocacy group advisor activities and their impact/relation to self-advocacy group development.
Cone, A. A.	2001	Self-reported training needs and training issues of advisors to self-advocacy groups for people with mental retardation.
Cook, A.	2020	Using an inclusive therapeutic theatre production to teach self-advocacy skills in young people with disabilities.
Cook, A. L.	2017	Employing a social justice framework to promote postsecondary transition for students with intellectual disability.
Fiedler, C. R. and J. E. Danneker	2007	Self-advocacy instruction: Bridging the research-to-practice gap.
Fisher, Marisa H. Athamanah, Lindsay S. Sung, Connie Josol, Cynde Katherine	2020	Applying the self-determination theory to develop a school-to-work peer mentoring programme to promote social inclusion.

Frawley, P. and C. Bigby	2011	Inclusion in political and public life: The experiences of people with intellectual disability on government disability advisory bodies in Australia.
Garrison-Wade, D. F. and J. P. Lehmann	2009	A conceptual framework for understanding students' with disabilities transition to community college.
Gibson, B. E. King, G. Teachman, G. Mistry, B. Hamdani, Y.	2017	Assembling activity/setting participation with disabled young people.
Gillespie-Lynch, K. Bublitz, D. Donachie, A. Wong, V. Brooks, P. J. D'Onofrio, J.	2017	"For a long time our voices have been hushed": Using student perspectives to develop supports for neurodiverse college students.
Gosse, L. Griffiths, D. Owen, F. Feldman, M.	2017	Impact of an Individualized Planning Approach on Personal Outcomes and Supports for People with Intellectual Disabilities.
Grove, N.	2015	Finding the sparkle: storytelling in the lives of people with learning disabilities.
Islam, M. R. and S. Cojocaru .	2015	Advocacy for Empowerment: A Case of the Learning Disabled People in Malaysia.
Karr, V. L.	2011	A life of Quality: Informing the UN Convention on the Rights of People with Disabilities.

Kimball, Ezekiel W. Moore, Adam Vaccaro, Annemarie Troiano, Peter F. Newman, Barbara M.	2016	College students with disabilities redefine activism: Self-advocacy, storytelling, and collective action.
Kotzer, E. and M. Margalit	2007	Perception of competence: Risk and protective predictors following an e-self-advocacy intervention for adolescents with learning disabilities.
Landmark, L. J. Zhang, D. Ju, S. McVey, T. C. Ji, M. Y.	2017	Experiences of Disability Advocates and Self-Advocates in Texas.
McPherson, L. Ware, R. S. Carrington, S. Lennox, N.	2017	Enhancing Self-Determination in Health: Results of an RCT of the Ask Project, a School-Based Intervention for Adolescents with Intellectual Disability.
Nonnemacher, S. L. and L. M. Bambara	2011	"I'm Supposed to be in Charge": Self-Advocates' perspectives on their self-determination support needs.
Owen, Aleksa Arnold, Katie Friedman, Carli Sandman, Linda	2016	Nominal Group Technique: An accessible and interactive method for conceptualizing the sexual self-advocacy of adults with intellectual and developmental disabilities.
Pfeifer, M. A. Reiter, E. M. Hendrickson, M. K. Stanton, J. D.	2020	Speaking up: A model of self-advocacy for STEM undergraduates with ADHD and/or specific learning disabilities.
Rezaul Islam, M. and S. Cojocaru	2015	Advocacy for empowerment: A case of the learning disabled people in Malaysia.

Roberts, E. L. Ju, S. Zhang, D.	2016	Review of Practices That Promote Self-Advocacy for Students With Disabilities.
Schmidt, E. K. Faieta, J. Tanner, K.	2020	Scoping Review of Self-Advocacy Education Interventions to Improve Care.
Sniatecki, J. L. Pelz, J. A. Gates, T. G.	2018	Human Rights Advocacy for Students with Disabilities: Challenging Stigma and Promoting Opportunity in Social Work Education.
Stylianos, S. and V. Kehyayan	2012	Advocacy: Critical component in a comprehensive mental health system.
Test, David W. Fowler, Catherine H. Wood, Wendy M. Brewer, Denise M. Eddy, Steven	2005	A Conceptual Framework of Self-Advocacy for Students with Disabilities.
Tideman, M. and O. Svensson	2015	Young people with intellectual disability--the role of self-advocacy in a transformed Swedish welfare system.
Weber, Stephanie Smith, Jennifer Ayers, Kara Gerhardt, Jane	2020	Fostering disability advocates: A framework for training future leaders through interprofessional education.
Zhang, Dalun Walker, Jessica M. Leal, Dianey R. Landmark, Leena Jo Katsiyannis, Antonis	2019	A Call to Society for Supported Decision-Making: Theoretical and Legal Reasoning.

Test, D. W. Fowler, C. H. Brewer, D. M. Wood, W. M.	2005	A content and methodological review of self-advocacy intervention studies.

Appendix 4: Included Articles

First Author & Date	Title of paper
Azzopardi, A. (2000)	A case study of a parents' self-advocacy group in Malta: The concepts of 'inclusion, exclusion and disabling barriers' are analysed in the relationship that parents have with professionals.
Balint-Langel, K. (2019)	Using a Computer-Based Strategy to Teach Self-Advocacy Skills to Middle School Students with Disabilities.
Bigby, C. (2014)	Conceptualizing inclusive research with people with intellectual disability.
Cook, A. (2020)	Using an inclusive therapeutic theatre production to teach self-advocacy skills in young people with disabilities.
Cook, A. L. (2017)	Employing a social justice framework to promote postsecondary transition for students with intellectual disability.
Fisher, M. H. (2020)	Applying the self-determination theory to develop a school-to-work peer mentoring programme to promote social inclusion.
Fiedler, C. R. (2007)	Self-advocacy instruction: Bridging the research-to-practice gap.
Frawley, P. (2011)	Inclusion in political and public life: The experiences of people with intellectual disability on government disability advisory bodies in Australia.
Grove, N. (2015)	Finding the sparkle: Storytelling in the lives of people with learning disabilities.
Islam, M. R (2015)	Advocacy for Empowerment: A Case of the Learning-Disabled People in Malaysia.
Johnson, K. (2014)	Inclusive research: Making a difference to policy and legislation
Kimball, E. W. (2016)	College students with disabilities redefine activism: Self-advocacy, storytelling, and collective action.
Landmark, L. J. (2017)	Experiences of Disability Advocates and Self-Advocates in Texas.
Nonnemacher, S. (2011)	“I'm Supposed to be in Charge”: Self-Advocates' perspectives on their self-determination support needs.
Owen, A., (2016)	Nominal Group Technique: An accessible and interactive method for conceptualizing the sexual self-advocacy of adults with intellectual and developmental disabilities.

Pfeifer, M. A. (2020)	Speaking up: A model of self-advocacy for STEM undergraduates with ADHD and/or specific learning disabilities.
Roberts, E. L. (2016)	Review of Practices That Promote Self-Advocacy for Students with Disabilities.
Test, D. W. (2005)	A content and methodological review of self-advocacy intervention studies.
Test, D. W. (2005).	A Conceptual Framework of Self-Advocacy for Students with Disabilities.
Tideman, M (2015)	Young people with intellectual disability--the role of self-advocacy in a transformed Swedish welfare system.

Appendix 5: Data Extraction Form for Qualitative Studies (SPIDER)

First author	Sample and setting	Phenomenon of interest	Design	Evaluation	Qualitative
Azzopardi, A. (2000)	n=66 Malta	Self-advocacy and advocacy by parents of people with disabilities	Literature review, personal experiences and involvement with the Parents' Society, documentation review and a questionnaire	The Parents' Society perceive 'inclusion' as a fundamental principle to social understanding and respect. It is about a community for all, a society that is ready to groom away its disrespect, where the individual (against individualism) is seen as a whole	Qualitative
Bigby, C. (2014)	number of reviewed studies was not specified. UK, New Zealand & Australia	Inclusive research for people with intellectual disability	Peer literature review	A strong self-advocacy movement is identified as one of the conditions necessary for inclusive research to flourish.	Qualitative
Cook, A. L. (2017)	n=66 USA	The Multicultural and Social Justice Counseling Competencies Framework	Literature review	Increased assertiveness, a component of self-advocacy because of the therapeutic theatre production.	Qualitative
Fisher, M. (2020)	n=31 USA	Conceptual Framework for Social Inclusion	Semi-structured Interviews and Focus Group Discussion	The peer mentoring programme helps in building self-advocacy skills	Qualitative
Frawley, P. (2011)	n=21 Australia	Social inclusion in political and public life of people with intellectual disability on government disability advisory bodies	In-depth interviews, observation, and document analysis	The political perspective of members with intellectual disability varied, but all had a background in self-advocacy. They found the work hard but rewarding and encountered both practical and intangible obstacles to participation	Qualitative

Grove, N. (2015)	n=8 residential homes and 1 day centre UK	Self-Advocacy through storytelling	Story sharing and interviews	Story sharing has been found to promote increases in communication, participation, relationship building and decision-making.	Qualitative
Islam, M. R. (2015)	n=12 Malaysia	Advocacy and empowerment	In-depth case study, focus group discussions (FGDs), and documentation survey.	Advocacy is a powerful tool towards empowerment at individual, family, and community levels for the Learning-Disabled people.	Qualitative
Kimball, E. W. (2016)	n=59 USA	Self-Advocacy of students with disabilities.	Semi-structured interviews	Activism manifested in a range of behaviours that fit into different themes. The main theme shows students learned basic advocacy skills from parents early in life.	Qualitative
Landmark, L. J. (2017)	n=113 USA	Advocacy and self-advocacy for people with disabilities	Surveys, case study and interviews	The results indicated that disability advocates and self-advocates rely most on other individuals with disabilities to assist them in advocacy efforts, followed by advocacy staff.	Qualitative
Nonnemacher, S. L. (2011)	n=10 USA	Self-Advocacy for people with disabilities	In-depth semi-structured interviews	Participants described self-determination in terms of speaking out for themselves, being in charge, making decisions, and having control over the things they want.	Qualitative
Owen, A. (2016)	n=35 USA	Conceptual framework for sexuality self-advocacy for people with intellectual disability	Participatory Action Research method, Nominal Group Technique	Interdependence is a core aspect of self-determination for people with IDD because they often rely on other people in their lives to provide support so they can enact their self-determination.	Qualitative

Pfeifer, M. A. (2020)	n=25 USA	Conceptual Framework for self-advocacy	Semi-structured Interviews and Survey	A development of a revised model of self-advocacy for students with ADHD/Learning disability	Qualitative
Roberts, E. L. (2016)	n=18 articles USA	Test's Conceptual framework for self-advocacy for students with disabilities	Literature review	The reviewed practices taught self-advocacy skills through published curricula, peer tutoring, writing strategies, employment skills training, transition planning involvement, direct instruction, college-based transition programmes, a weeklong programme, and supporting students to lead their IEP meetings.	Qualitative
Test, D. W. (2005)	n=25 articles USA	Conceptual Framework for self-advocacy	Literature review and Interviews	Studies indicated that participants demonstrated self-advocacy skills in new situations and expressed satisfaction with instruction.	Qualitative
Test, D. W. (2005)	n=20 articles USA	Conceptual Framework for self-advocacy for people with disabilities	A Content and Methodological Review of Self-Advocacy	By analysing and differentiating the components that make up self-advocacy, students, parents, teachers, and service providers may be better able to understand the concept and to identify self-advocacy goals for individual students.	Qualitative
Tideman, M. (2015)	n=12 Sweden	Self-Advocacy for people with intellectual disabilities	In-depth Interviews over 10 years	Findings suggest that participation in self-advocacy groups opens up members for increasing health and well-being through new roles and identities, and it strengthens their control over everyday life. Support is still needed, however, but in new ways; otherwise, the restrictions of the institutions will simply be reconstructed in the new welfare system.	Qualitative

Johnson, K. (2014)	n=45 Ireland & Australia	Inclusion of people with disabilities in policy and legislation	Interviews	The outcomes of the research included the development of workshops for people with intellectual disabilities, families and service providers, the production of three short films of the stories narrated by members of the advisory group, and the research led to a change in government policy.	Qualitative

Appendix 6: Data Extraction Form for Quantitative Studies (PICOS)

First author	Population, & setting	Intervention, comparison, and/or effect size	Outcome	Study design
Cook, A. (2020)	n=15 USA	The therapeutic theatre intervention for participants with disabilities was used as the pre- and post-test measure. The participants scored significantly higher in the post-test (M = .88, SD = .92) than in the pre-test t (12) = (3.48), p = 0.005.	Increased assertiveness, a component of self-advocacy because of the therapeutic theatre production.	Quantitative (Drama Therapy Role Play Intervention)
Balint-Langel, K. (2019)	n=19 USA	A pre- and post-test experimental design with random assignment to treatment and wait-list control groups was employed to investigate changes in student participation and level of self-determination.	Post-test results showed a significant positive difference for students in the treatment group compared to the wait-list control group for the Self-Advocacy Self-Report.	Quantitative

Appendix 7: Informed Consent

University of Cape Town • iYunivesithi yaseKapa • Universiteit van Kaapstad

INFORMED CONSENT FORM FOR RESEARCH PARTICIPANTS

Research study about Self Advocacy by People with Intellectual Disability

Why are we doing this research? This research will look at what will help people with intellectual disability self-advocate to government for services and supports they need to live a quality life. Self-advocacy is about speaking up for yourself to tell people who make decisions that affect you to include your needs in their actions and plans so that you can live a quality life amongst others in your community. This can include government plans that affect your life.

How will you take part in the research?

The steps we will take in the research are:

1. I will conduct an interview with you that will take place in any venue you are comfortable with, with the help of the person you trust /supporter.
2. The interviews will take 30 minutes to an hour.
3. The interviews will be recorded so that we can type up exactly what you said so we don't make any misunderstand what you have said to us.
4. After a few months, I will set up the group meeting with you to share what I have found as well as find out what you think of the findings, if you agreed to that. Lastly the results will be put in a report to share our findings of our research study with others.

Why have you been asked to take part?

You have been asked to participate in this research because we would like to improve our understanding of whether people with Intellectual Disability like yourself would be interested in self advocacy, and what things you would like government to include in their plans that affect you.

Will your participation in the research study be kept confidential?

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

What will happen to the results?

The results or findings will be put in a thesis report to the University of Cape Town. The results will be seen by three research supervisors, the person who types up our reports and the examiners. The report may be read by future students or by other researchers and interested people. I also plan to write up these findings into an article to be published, and to present the findings at research meetings or conferences. I will also draw up easy-to-read brochures to share with organisations who are interested in supporting people with Intellectual disability to self-advocate for their rights and needs. We will write policy briefs to government to share your ideas on how they can include the ideas of people with intellectual disability in writing and working on their plans to improve the lives of people in South Africa.

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

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

What are the possible disadvantages of taking part?

As a researcher I do not see any negative impact of 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 or wrong answers. You are welcome to tell me if there are any questions you do not want to answer or find upsetting.

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

Taking part in this research study is done so on a voluntary basis. You do not have to participate. If you do agree to take part but choose later that you do not want to anymore that is also okay. Refusing to take part in the study will not affect your position with me or anyone else.

What if I have questions?

If you have any questions, you can contact me at a later stage:

Babalwa Tyabashe-Phume	Tybbab001@myuct.ac.za	0825506818

or my supervisor, Prof. Sharon Kleintjes (+27 21404 2166, sr.kleintjes@uct.ac.za), Department of Psychiatry and Mental Health, University of Cape Town, Private Bag Rondebosch, 7700.

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

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

I agree to participate in this study: ____
Date: _______________________________

I agree that the interviews can be recorded__________________________________
Date: _______________________________

Appendix 8: Focus Group Informed Consent Form

FOCUS GROUP CONFIDENTIALITY BINDING & CONSENT FORM

Research study about Self Advocacy by People with intellectual disability

The study has been described to me in language that I understand. My questions about the study have been answered I understand what my participation will involve, and I agree to participate of my own choice and free will. I understand that my identity will not be disclosed to anyone by the researchers. I understand that I may withdraw from the study at any time without giving a reason and without fear of negative consequences or loss of benefits.

I hereby give consent to participate in the study. I agree to uphold the confidentiality of the discussions in the focus group by not disclosing the identity of other participants or any aspects of their contributions to members outside of the group.

Participant's name……………………………………….
Participant's signature………………………………….
Date………………………

Appendix 9: Semi-Structured Interviews Topic Guides for People with Intellectual Disability

Topic Guides:

Please tell me a little about yourself:

- a. Home life
    - i. Age, education
    - ii. Who you live with -family, children (including ages)?
    - iii. Employment
    - iv. Interests/activities during a typical week

1. Can you please tell me what you understand about self-advocacy?
    - a. What does self-advocacy mean to you?
    - b. Do you consider yourself as a self-advocate?
        - i. If yes, please tell me about your experience as a self-advocate with ID
        - ii. When did you become a self-advocate?
        - iii. What made you decide to become a self-advocate?
            - Probe for reasons
        - iv. What kind of support do you get or need as a self-advocate?
            - Probe more about existing support systems
    - c. If no to (b), would you like to be a self-advocate?
        - i. If yes, what do you think you need to become a self-advocate?
        - ii. What skills do you think you need to acquire, improve, or learn to become a self-advocate?
        - iii. If no, probe for reasons
    - d. Do you know of any self-advocates with ID?
        - i. If yes, who are they?
            - Do you interact with them?
            - Probe for more information
        - ii. If no, would you like to know them?
            - Probe for reasons
2. What do you consider as barriers to self-advocacy for people with ID?
    - a. Have you experienced these barriers?
        - i. If yes, probe for details

        ii. If no, do you know of someone with ID who experienced them?
            - If yes, probe for more details

    b. How can these barriers be addressed?
        i. Who needs to address them?
            - Probe

        ii. What can you contribute to address these barriers?
            - Probe

3. Can you think of any opportunities available for self-advocacy for people with intellectual disability?
    a. What are existing opportunities for self-advocacy?
        - Probe

    b. Who should create opportunities for self-advocacy for people with intellectual disability?
        - Probe

    c. Given the opportunity would you encourage other people with intellectual disability to become self-advocates?
        i. If yes, probe for ways or strategies or suggestions
        ii. If no, probe for reasons

4. After speaking about self-advocacy is there anything you want to add that this interview has made you think about? Or something you want to mention?

End

- Reiterate confidentially, “I just want to remind you again that everything we have discussed here will remain between me, the research team on this study and yourself (and supporter if present). No outside person will have access to this information, and your name will not be on any of the publications and reports that will be written about this study.”
- I am going to leave the information sheet I read to you at the beginning of this session with you so that you can read it again in your own time. If any other questions or concerns should come up after this interview, please feel free to contact me or send me a “please call me” or “WhatsApp message” on 082 550 6818.

Thank you….

Appendix 10: Semi-Structured Interviews Topic Guides for Parents or Carers of People with Intellectual Disability

Topic Guides:

Please tell me a little about yourself:

Home life

- v. Age, education
- vi. Who you live with – family, children (including ages)?
- vii. Employment
- viii. Interests/activities during a typical week

Can you please tell me what you understand about self-advocacy?

- a. What does self-advocacy mean to you?
- b. Do you consider your child/person in your care a self-advocate?
    - i. If yes, please tell me about more
    - ii. When did they become a self-advocate?
    - iii. What made them decide to become a self-advocate?
        - Probe for reasons
    - iv. What kind of support do you give them, or you think they need as a self-advocate?
        - Probe more about existing support systems
- c. If no to (b), would you like them to be a self-advocate?
    - i. If yes, what do you think they need to become a self-advocate?
    - ii. What skills do you think they need to acquire, improve, or learn to become a self-advocate?
    - iii. If no, probe for reasons
- d. Do you know of any self-advocates with ID?
    - i. If yes, who are they?
        - Do you or your child/person in your care interact with them?
        - Probe for more information
    - ii. If no, would you like to know them?
        - Probe for reasons

What do you consider as barriers to self-advocacy for people with ID?

- a. Have you or your child/person in your care experienced these barriers?

        iii. If yes, probe for details
        iv. If no, do you know of someone with ID who has experienced them?
            - If yes, probe for more details
    b. How can these barriers be addressed?
        i. Who needs to address them?
            - Probe
        ii. What can you contribute to address these barriers?
            - Probe

Can you think of any opportunities available for self-advocacy for people with intellectual disability?

    c. What are existing opportunities for self-advocacy?
            - Probe
    d. Who should create opportunities for self-advocacy for people with intellectual disability?
            - Probe
    e. Given the opportunity would you encourage other people with intellectual disability to become self-advocates?
        i. If yes, probe for ways or strategies or suggestions
        ii. If no, probe for reasons

After speaking about self-advocacy is there anything you want to add that this interview has made you think about? Or something you want to mention?

End

- Reiterate confidentially, “I just want to remind you again that everything we have discussed here will remain between me, the research team on this study and yourself (and supporter if present). No outside person will have access to this information, and your name will not be on any of the publications and reports that will be written about this study.”
- I am going to leave the information sheet I read to you at the beginning of this session with you so that you can read it again in your own time. If any other questions or concerns should come up after this interview, please feel free to contact me or send me a “please call me” or “WhatsApp message” on 082 550 6818.

Thank you…

Appendix 11: Semi-Structured Interviews Topic Guides for Policy Makers, Policy Implementers and Service Providers/Managers

Topic Guides:

Please tell me a little about yourself:

Home life Age, education

Employment/Position at work

Can you please tell me what you understand about self-advocacy?

a. What does self-advocacy mean to you?
b. Do you know of any self-advocates?
c. Have you engaged or worked with self-advocate(s) with intellectual disability in the field?

- if yes
    i. Please tell me about your experience with working with them
    ii. What kind of support have you given them?
    iii. Are there other support systems available for self-advocates?
- Probe
- If no
    i. Would you like to engage or work with them?
- Please elaborate

d. Do you think there is a need for self-advocacy by people with intellectual disability in policy development and implementation processes?

- Probe for reasons

e. What do you consider as barriers to self-advocacy for people with intellectual disability?

- Probe for details

f. How can these barriers be addressed?
    i. Who needs to address them?
        - Probe
    ii. What can you contribute to address these barriers?
        - Probe

g. Can you think of any opportunities available for self-advocacy for people with intellectual disability?
    a. What are existing opportunities for self-advocacy?
        - Probe
    b. Who should create opportunities for self-advocacy for people with intellectual disability?
        - Probe
    c. Given the opportunity would you encourage other people with intellectual disability to become self-advocates?
        i. If yes, probe for ways or strategies or suggestions
        ii. If no, probe for reasons

After speaking about self-advocacy is there anything you want to add that this interview has made you think about? Or something you want to mention?

End

- Reiterate confidentially, “I just want to remind you again that everything we have discussed here will remain between me, the research team on this study and yourself (and supporter if present). No outside person will have access to this information, and your name will not be on any of the publications and reports that will be written about this study.”
- I am going to leave the information sheet I read to you at the beginning of this session with you so that you can read it again in your own time. If any other questions or concerns should come up after this interview, please feel free to contact me or send me a “please call me” or “WhatsApp message” on 082 550 6818.

Thank you….

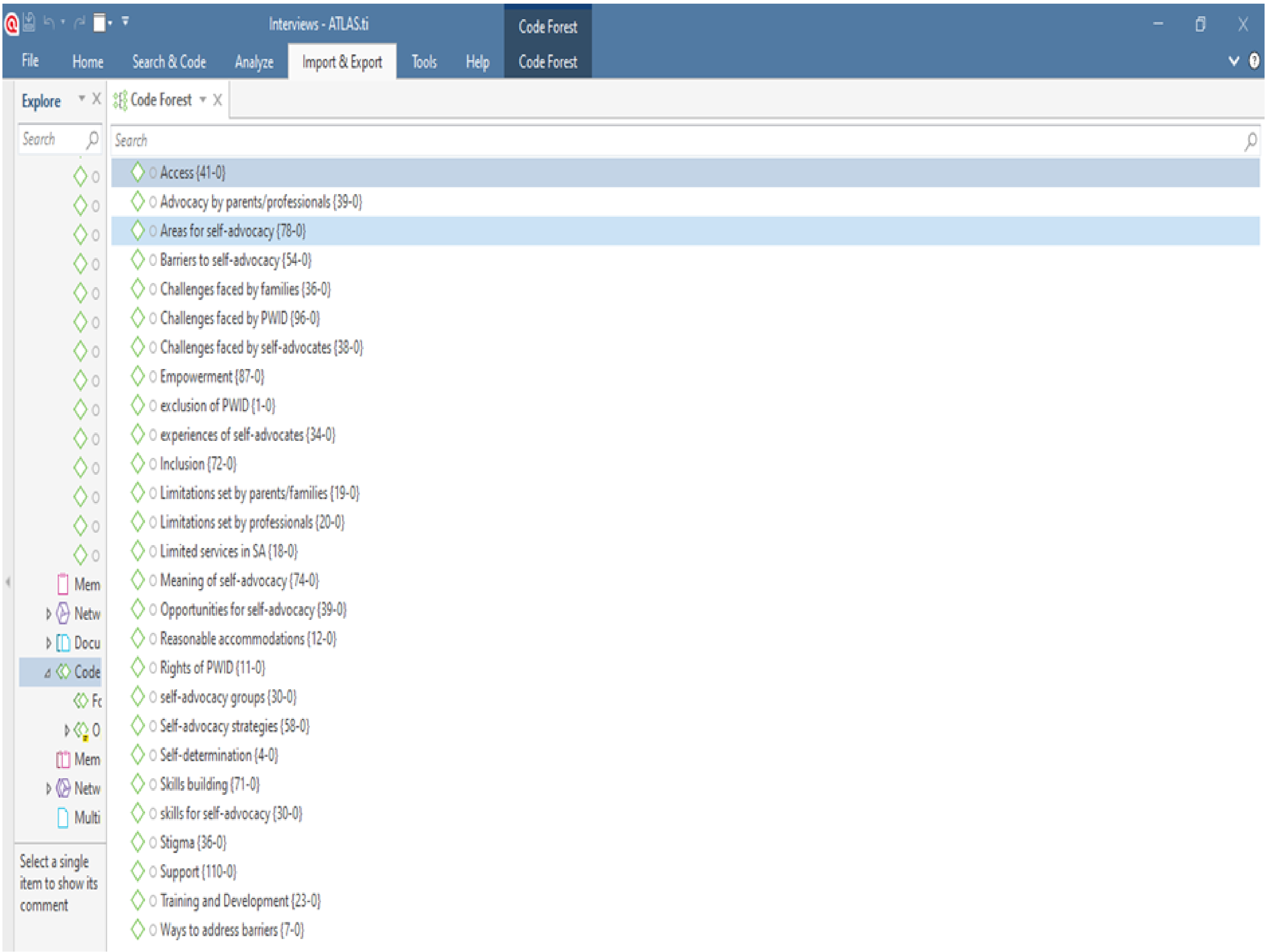
Appendix 12: List of Participants

National and Provincial Policy Makers	
1.	Policy maker from the National Department of Higher Education and Training
2.	Policy maker from the Gauteng Province Department of Higher Education Training
3.	Policy maker from the Western Cape Province Department of Higher Education and Training
4.	Policy maker from SA Federation for Mental Health
5.	Policy maker from the Western Cape Province Department of Health
Service Managers	
1.	Head of Department from the Western Cape Province Department of Basic Education
2.	Head of the Psychiatry Unit in one of the hospitals in the Western Cape Province
3.	Director of NPO working with people with intellectual and other developmental disabilities
4.	Senior Psychologist/Manager at a Psychiatric Hospital
5.	Service manager at SA Federation for Mental Health
Self-Advocates	
1.	Self-advocate from NPO B
2.	Former self-advocate from NPO B
3.	Self-advocate from NPO A
4.	Self-advocate from NPO A
5.	Self-advocate from NPO A
Parents and Carers	
1.	Parent of a self-advocate with intellectual disability
2.	Parent of an adult with intellectual disability
3.	Parent of an adult with intellectual disability
4.	Carer of an adult with intellectual disability
5.	Carer of a self-advocate with intellectual disability
Supporters	
1.	Supporter of people with intellectual disability
2.	Supporter of self-advocates with intellectual disability
3.	Supporter of self-advocates with intellectual disability
4.	Supporter of self-advocates with intellectual disability
5.	Supporter of people with intellectual disability

Appendix 13: List of Reviewers

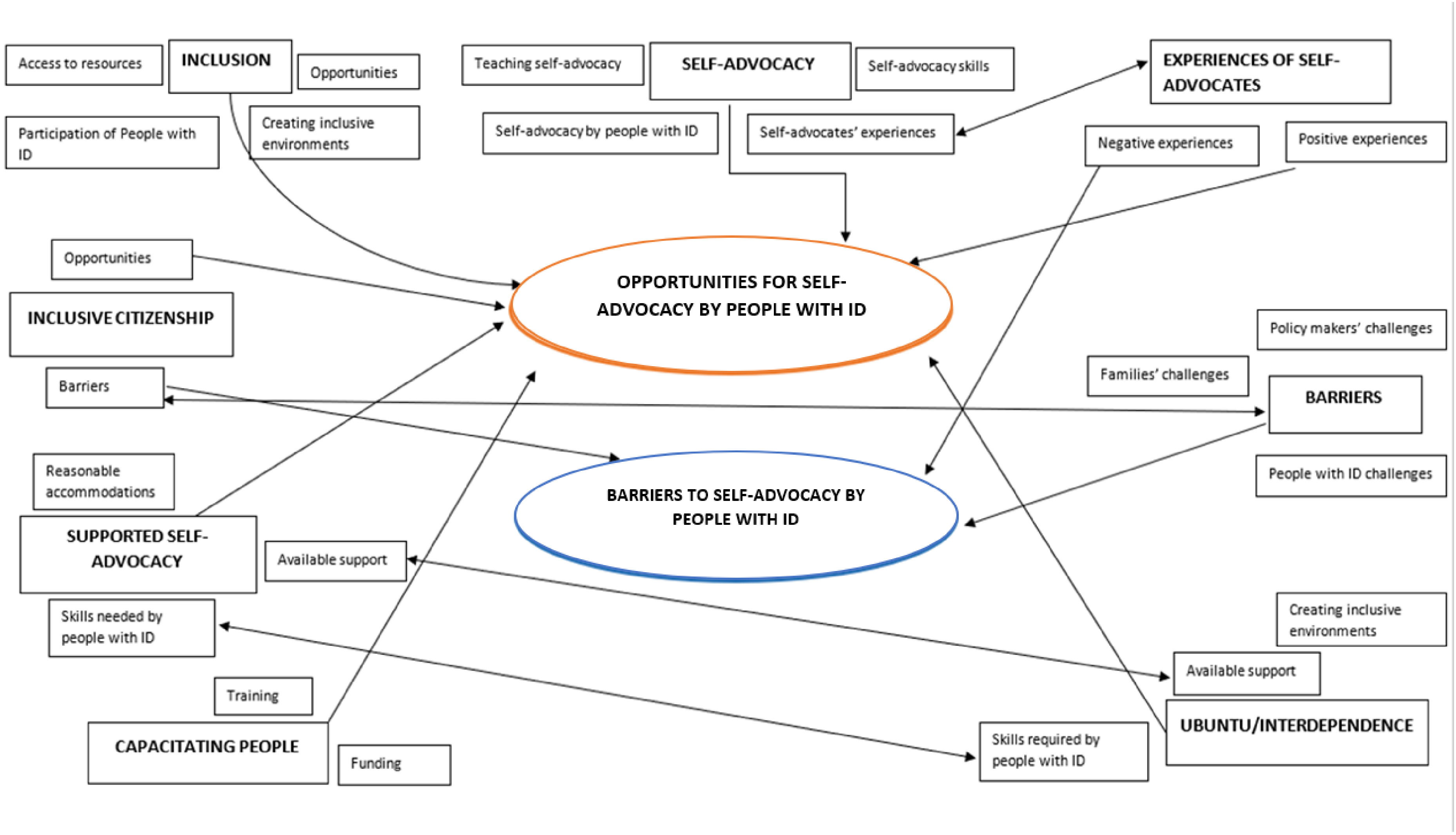
National and Provincial Policy Makers & Service Managers	
1.	Policy maker from the National Department of Higher Education and Training
2.	Service manager at SA Federation for Mental Health
3.	Director of NPO working with people with intellectual and other developmental disabilities
4.	Policy maker from SA Federation for Mental Health
5.	Head of Department from the Western Cape Province Department of Basic Education
Self-Advocates	
1.	Self-advocate from NPO A
2.	Self-advocate from NPO A
Parents, Carers & Supporters	
1.	Parent of a self-advocate with intellectual disability
2.	Supporter of self-advocates with intellectual disability
3.	Supporter of self-advocates with intellectual disability

Appendix 14: Code Forest/Tree



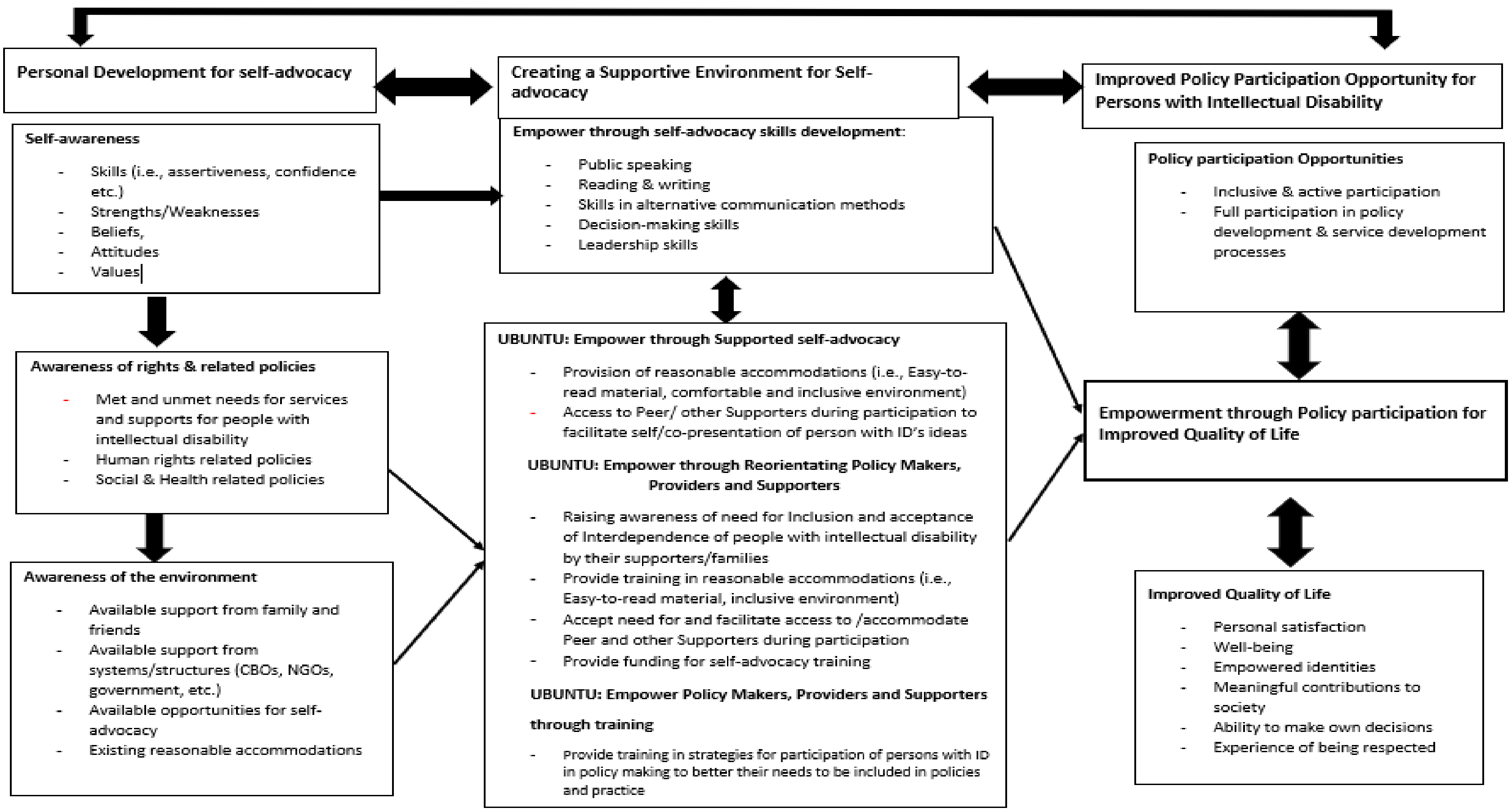
○ Access {41-0}
○ Advocacy by parents/professionals {39-0}
○ Areas for self-advocacy {78-0}
○ Barriers to self-advocacy {54-0}
○ Challenges faced by families {36-0}
○ Challenges faced by PWID {96-0}
○ Challenges faced by self-advocates {38-0}
○ Empowerment {87-0}
○ exclusion of PWID {1-0}
○ experiences of self-advocates {34-0}
○ Inclusion {72-0}
○ Limitations set by parents/families {19-0}
○ Limitations set by professionals {20-0}
○ Limited services in SA {18-0}
○ Meaning of self-advocacy {74-0}
○ Opportunities for self-advocacy {39-0}
○ Reasonable accommodations {12-0}
○ Rights of PWID {11-0}
○ self-advocacy groups {30-0}
○ Self-advocacy strategies {58-0}
○ Self-determination {4-0}
○ Skills building {71-0}
○ skills for self-advocacy {30-0}
○ Stigma {36-0}
○ Support {110-0}
○ Training and Development {23-0}
○ Ways to address barriers {7-0}

Appendix 15: Data Triangulation and the Cross-Cutting Themes and Sub-Themes



Appendix 16: Conceptual Framework to Inform Policy-Related Self-Advocacy for Adults with Intellectual Disability

CONCEPTUAL FRAMEWORK TO INFORM POLICY-RELATED SELF-ADVOCACY FOR ADULTS WITH INTELLECTUAL DISABILITY



Personal Development for self-advocacy

Self-awareness

- Skills (i.e., assertiveness, confidence etc.)
- Strengths/Weaknesses
- Beliefs,
- Attitudes
- Values

Awareness of rights & related policies

- Met and unmet needs for services and supports for people with intellectual disability
- Human rights related policies
- Social & Health related policies

Awareness of the environment

- Available support from family and friends
- Available support from systems/structures (CBOs, NGOs, government, etc.)
- Available opportunities for self-advocacy
- Existing reasonable accommodations

Creating a Supportive Environment for Self-advocacy

Empower through self-advocacy skills development:

- Public speaking
- Reading & writing
- Skills in alternative communication methods
- Decision-making skills
- Leadership skills

UBUNTU: Empower through Supported self-advocacy

- Provision of reasonable accommodations (i.e., Easy-to-read material, comfortable and inclusive environment)
- Access to Peer/ other Supporters during participation to facilitate self/co-presentation of person with ID's ideas

UBUNTU: Empower through Reorientating Policy Makers, Providers and Supporters

- Raising awareness of need for Inclusion and acceptance of Interdependence of people with intellectual disability by their supporters/families
- Provide training in reasonable accommodations (i.e., Easy-to-read material, inclusive environment)
- Accept need for and facilitate access to /accommodate Peer and other Supporters during participation
- Provide funding for self-advocacy training

UBUNTU: Empower Policy Makers, Providers and Supporters through training

- Provide training in strategies for participation of persons with ID in policy making to better their needs to be included in policies and practice

Improved Policy Participation Opportunity for Persons with Intellectual Disability

Policy participation Opportunities

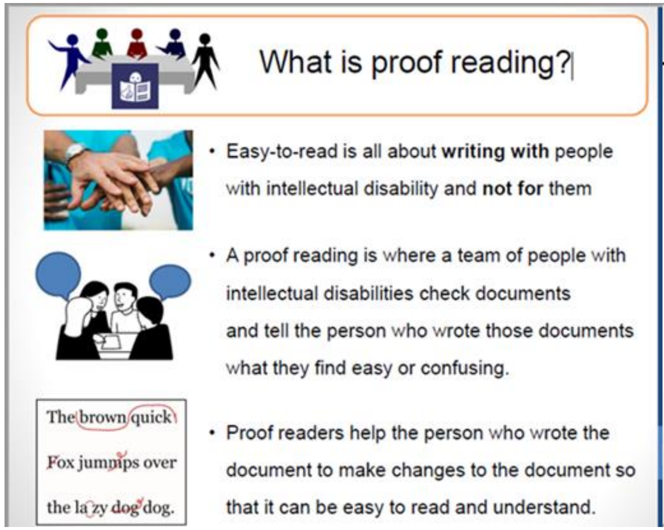
- Inclusive & active participation
- Full participation in policy development & service development processes

Empowerment through Policy participation for Improved Quality of Life

Improved Quality of Life

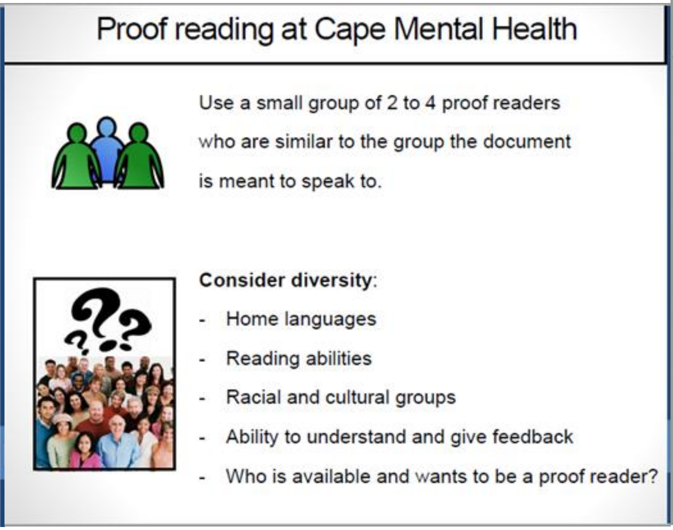
- Personal satisfaction
- Well-being
- Empowered identities
- Meaningful contributions to society
- Ability to make own decisions
- Experience of being respected

Appendix 17: Cape Mental Health Proofreading Process



What is proof reading?

- Easy-to-read is all about **writing with** people with intellectual disability and **not for** them
- A proof reading is where a team of people with intellectual disabilities check documents and tell the person who wrote those documents what they find easy or confusing.
- Proof readers help the person who wrote the document to make changes to the document so that it can be easy to read and understand.

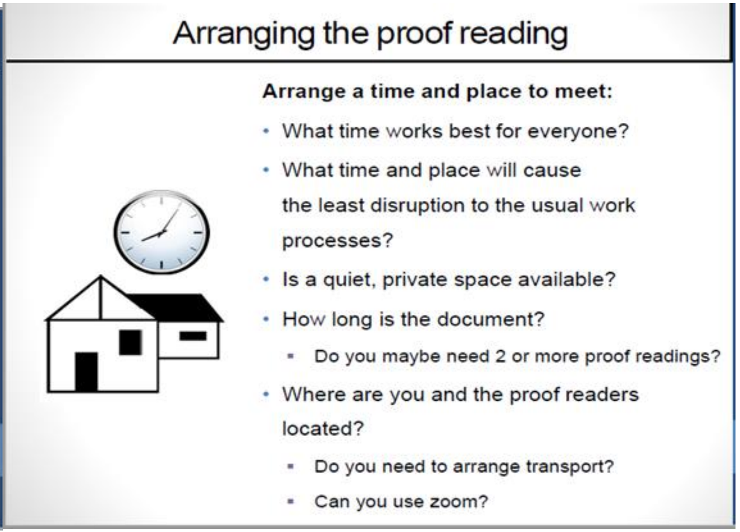


Proof reading at Cape Mental Health

Use a small group of 2 to 4 proof readers who are similar to the group the document is meant to speak to.

Consider diversity:

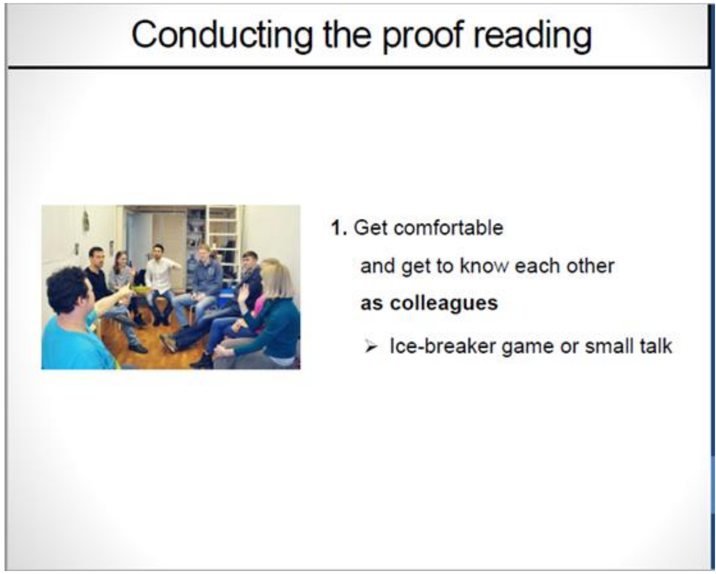
- Home languages
- Reading abilities
- Racial and cultural groups
- Ability to understand and give feedback
- Who is available and wants to be a proof reader?



Arranging the proof reading

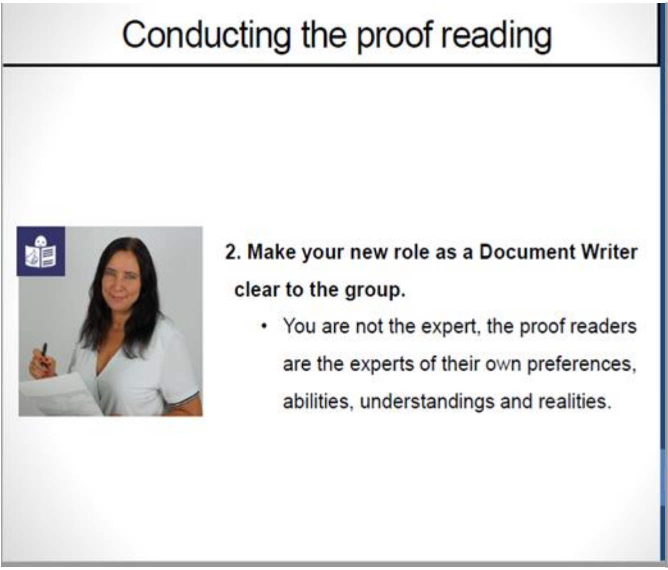
Arrange a time and place to meet:

- What time works best for everyone?
- What time and place will cause the least disruption to the usual work processes?
- Is a quiet, private space available?
- How long is the document?
  - Do you maybe need 2 or more proof readings?
- Where are you and the proof readers located?
  - Do you need to arrange transport?
  - Can you use zoom?



Conducting the proof reading

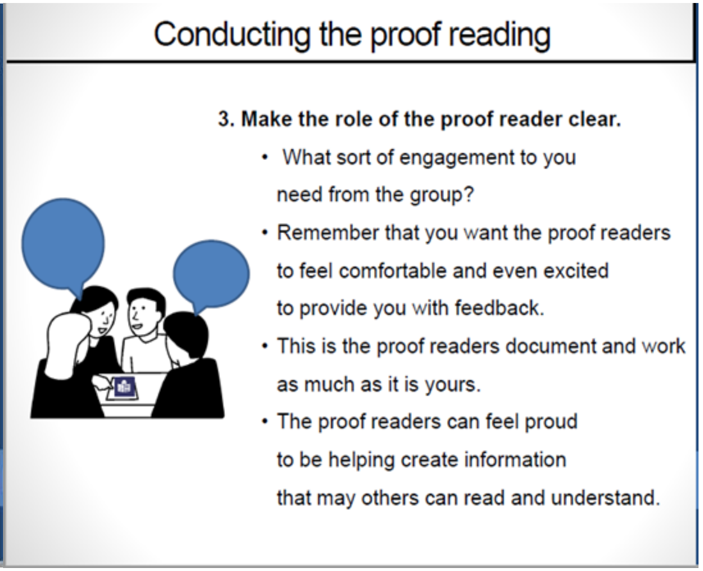
1. Get comfortable and get to know each other **as colleagues**
   - Ice-breaker game or small talk



Conducting the proof reading

2. Make your new role as a Document Writer clear to the group.

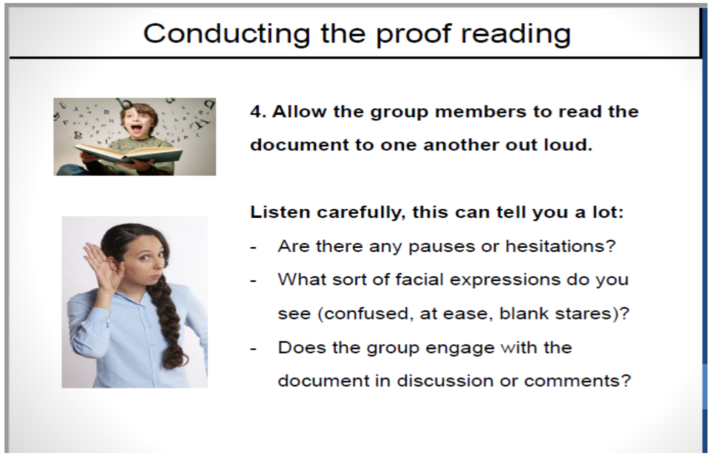
- You are not the expert, the proof readers are the experts of their own preferences, abilities, understandings and realities.



Conducting the proof reading

3. Make the role of the proof reader clear.

- What sort of engagement to you need from the group?
- Remember that you want the proof readers to feel comfortable and even excited to provide you with feedback.
- This is the proof readers document and work as much as it is yours.
- The proof readers can feel proud to be helping create information that may others can read and understand.

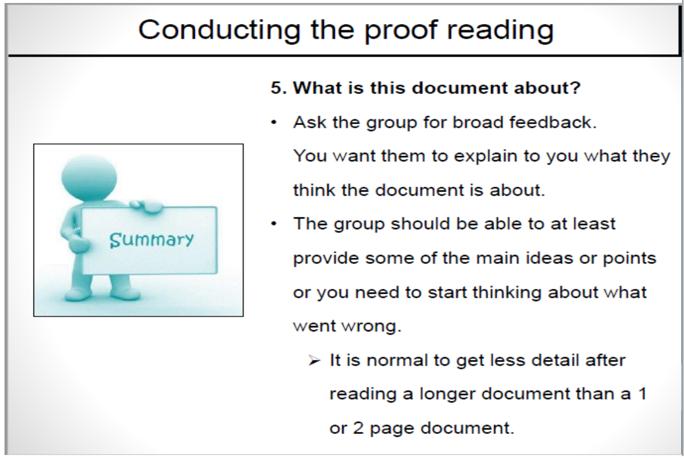


Conducting the proof reading

4. Allow the group members to read the document to one another out loud.

Listen carefully, this can tell you a lot:

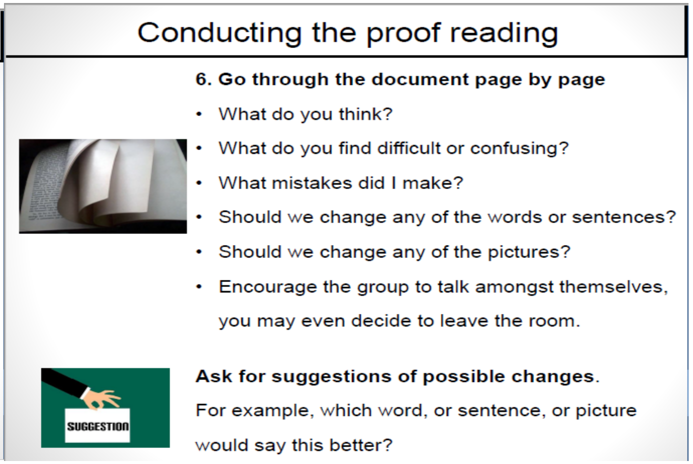
- Are there any pauses or hesitations?
- What sort of facial expressions do you see (confused, at ease, blank stares)?
- Does the group engage with the document in discussion or comments?



Conducting the proof reading

5. What is this document about?

- Ask the group for broad feedback. You want them to explain to you what they think the document is about.
- The group should be able to at least provide some of the main ideas or points or you need to start thinking about what went wrong.
  - It is normal to get less detail after reading a longer document than a 1 or 2 page document.

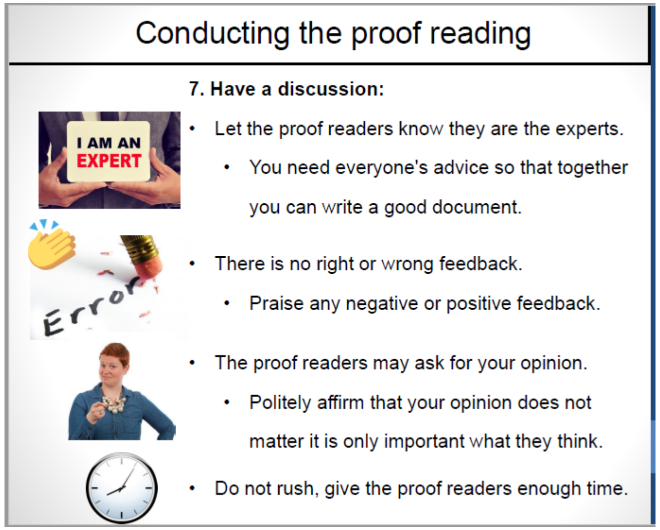


Conducting the proof reading

6. Go through the document page by page

- What do you think?
- What do you find difficult or confusing?
- What mistakes did I make?
- Should we change any of the words or sentences?
- Should we change any of the pictures?
- Encourage the group to talk amongst themselves, you may even decide to leave the room.

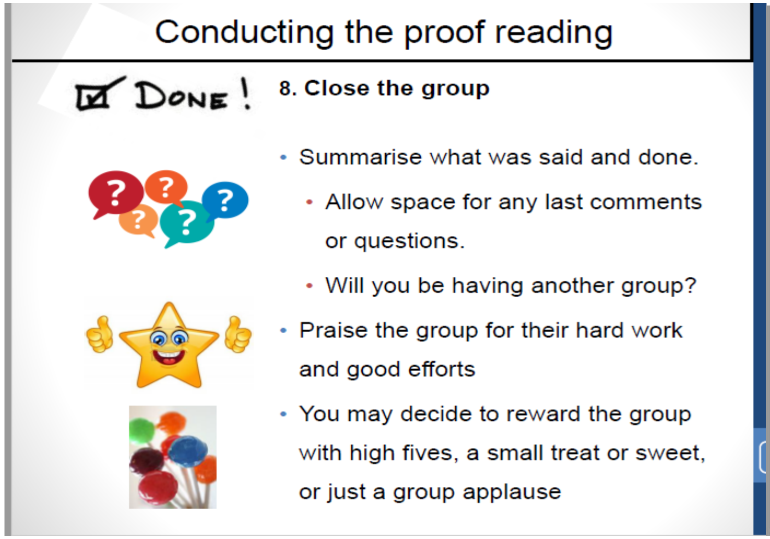
Ask for suggestions of possible changes. For example, which word, or sentence, or picture would say this better?



Conducting the proof reading

7. Have a discussion:

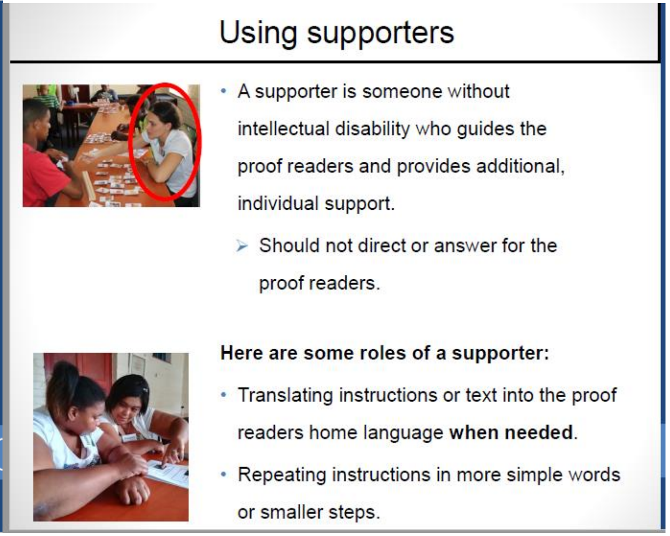
- Let the proof readers know they are the experts.
  - You need everyone's advice so that together you can write a good document.
- There is no right or wrong feedback.
  - Praise any negative or positive feedback.
- The proof readers may ask for your opinion.
  - Politely affirm that your opinion does not matter it is only important what they think.
- Do not rush, give the proof readers enough time.



Conducting the proof reading

8. Close the group

- Summarise what was said and done.
  - Allow space for any last comments or questions.
  - Will you be having another group?
- Praise the group for their hard work and good efforts
- You may decide to reward the group with high fives, a small treat or sweet, or just a group applause



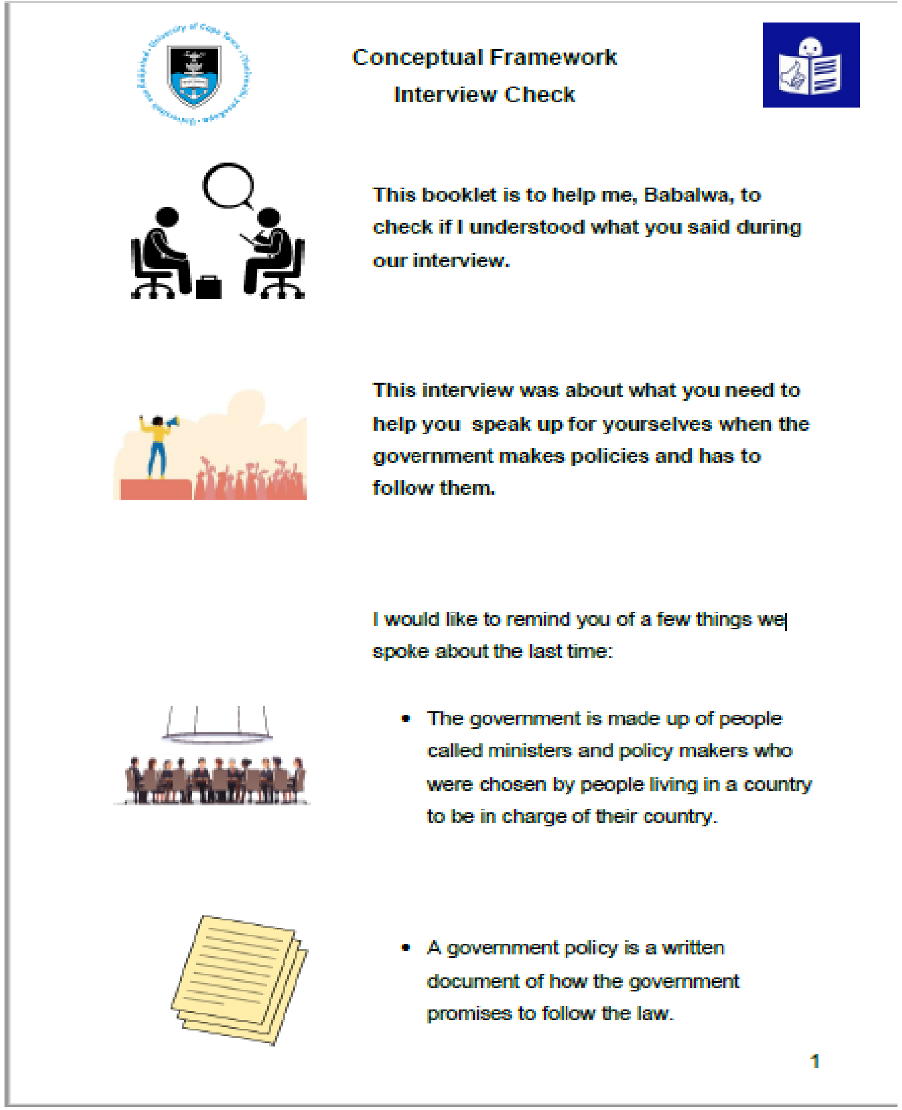
Using supporters

- A supporter is someone without intellectual disability who guides the proof readers and provides additional, individual support.
  - Should not direct or answer for the proof readers.

Here are some roles of a supporter:

- Translating instructions or text into the proof readers home language **when needed**.
- Repeating instructions in more simple words or smaller steps.

Appendix 18: Easy-to-Read Conceptual Framework



Conceptual Framework
Interview Check

This booklet is to help me, Babalwa, to check if I understood what you said during our interview.

This interview was about what you need to help you speak up for yourselves when the government makes policies and has to follow them.

I would like to remind you of a few things we spoke about the last time:

- The government is made up of people called ministers and policy makers who were chosen by people living in a country to be in charge of their country.

- A government policy is a written document of how the government promises to follow the law.

1

- Many of the laws speak about what the government are going to do to protect your rights as a human being and make sure your basic needs are met.

- Basic needs are things that people need so that they can live.
  Basic needs include things like somewhere safe to live, access to food and the right to education and to get a job.

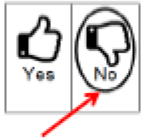
When the policies and the actions of the government do not support your rights or provide these basic needs, you also have the right to **speak up.**

You need to let the government know that you want them to include in your rights and basic needs in the work they do for all the people in the country.

If you speak up for the rights of other people with intellectual disability, you are called an **advocate.**

2

If you speak up for your own rights as a person with intellectual disability, you are called a **self-advocate.**



I am going to ask you if you agree or disagree with all the things I have written below.
I want to know if you agree or disagree that these things will help you as a person with intellectual disability to advocate for your rights to government?

1. It will help me to advocate for my rights to government if I can learn to know who I am as a person, know what I believe and know what I need to live a good life.
   Knowing all of these things about myself is called being **self-aware.**

To be self-aware, I need to know things about myself, for example:

- I need to know what **skills** I have.
  Skills are things I have learnt and am good at doing.

- I need to know what I am **not good at doing** and what I need help with.

- I need to be **confident** in myself.
  This means that I feel free and able to share my ideas with others.

I need to know what I believe about the world, my family, my friends, my neighbours and about what is right or wrong.
These are called my **beliefs**.

- I need to know how I think and feel about things.
  These are called **attitudes.**

- I need to know what things are important to me like having a family, being independent and telling the truth.

These are called **values.**

2. It will help me to advocate for my rights to government if I know what my rights are and what **government policies** say about my rights as a person with intellectual disability.

If I know about what government policies say, then I will also know when people are not following the policies properly to help people with intellectual disability.

I will then be able to raise my voice and tell the government to do their jobs better.

For example, I need to know if government policies say enough about:

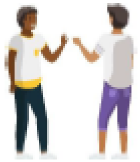
- How they will help me to get all the services I need?

- How will the government help me with getting the support I need to be fully part of society?

- How will they make sure that my human rights are respected?

- How the government will include my health needs and my social needs? These are things such as enough food, safe water and toilets, work, SASSA grants, education, training to work, housing and other needs.

3. It will help me to advocate for my rights to government as a self-advocate if I know about the world around me.
   The world around me is called the **environment.**



My environment includes all the things and people around me, such as;

- My family and my friends.

- Organisations that help people with intellectual disability.

- Places where I can go and get my voice heard as a self-advocate.
  For example, I can go to self-advocacy groups at organisations like Cape Mental Health and the Western Cape Forum for Intellectual Disability or I can give my opinion on policies that are being written.

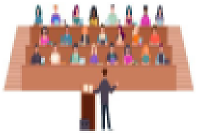
- There are changes that can be made to make it easier for me to give my opinion as a person with intellectual disability when government makes policies.
  These changes are called **reasonable accommodations.**

An example of a reasonable accommodation is when they give me a person that will support me to self-advocate.

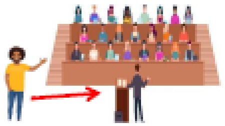
Reasonable accommodations are ways in which people and places in my environment are allowed to help me to be a self advocate and change government policies.
We will say more about this below.

1. It will help me to advocate for my rights to government if I can be supported by others to learn self-advocacy skills.
   When someone is supported to learn new things we call this **empowerment**.

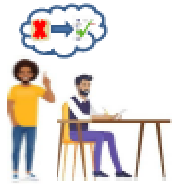
These are examples of self-advocacy skills I will need,



- Speaking to lots of people that I do not know when they are altogether in a room or on the screen.
  This is called **public speaking.**



If I am not good at public speaking, I will need help from a supporter, family member or friend to practice to get better at speaking up for myself or I can tell them what I want to say so they can tell government about my ideas for what government must include in their policies.



- **Reading and writing.**
  If I cannot read or write, I can ask a supporter to write down my ideas for me.

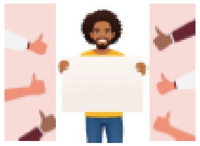
- **Using different ways to get my message to people.**
  For example, I can learn to use pictures, like the ones in this booklet, to tell government and other people what I need.

- **Making decisions for myself and other people who have intellectual disability.**
  I can ask for help from a supporter or family member to help me think through my ideas so I can make decisions about what I will choose to say or do as a self-advocate

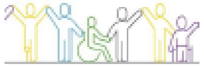
- Becoming a leader that other people with intellectual disability can learn from and listen to.

A leader is someone who can guide the group of people with intellectual disability.

Being a leader will mean that I could speak up for other people with intellectual disability who cannot speak for themselves.



2. It will help me to advocate for my rights to government if other people care about me and respect me as a person.



They show me respect when they help me to be part of our community and to take part in all community activities.

This acceptance, respect and being included is called **Ubuntu.**

Ubuntu is an African belief that means 'I am because of who we all are'.

This means that we are all connected.
If I want to speak up for myself, the people around me will support me.

When I cannot speak up for myself, I can choose someone that I trust to add my ideas to what others are saying.

When people support me, it helps me believe in my own power.

Helping someone to believe in their own power is called **Empowerment**.
This is part of the spirit of Ubuntu.

Through Ubuntu, some of the ways that I can be empowered are:

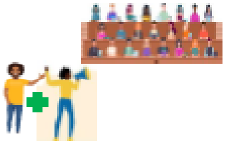
- Support me in areas I find difficult, such as having policy documents written in Easy-to-Read so I can understand them and know what to say.

- I would need to feel comfortable and supported to speak up for myself wherever I am.

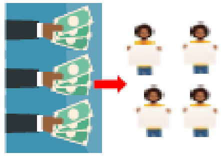
- Making sure other self-advocates are also invited to take part (my peers) and that I can bring someone along whom I trust to help me share my ideas (my supporter).

3. **It will help me to advocate for my rights to government if the people who make the policies, organisations that provide services and supporters can empower me by:**
   - Raising awareness of the need for including people with intellectual disability because we are all connected to one another.

   - Providing training on how to give the right reasonable accommodations for people with intellectual disability, such as writing important information in Easy-to-Read.



   - Understand that I may need help from other people to be a self-advocate and allow me to bring my supporter, family member or friend to places where I want to self-advocate.

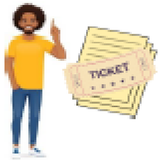


- Give money for training people with intellectual disabilities to be self-advocates.

Learning more about myself, getting to know what can support me, and getting support from others to help me self advocate for policy change is not enough.

To be a self-advocate, people who make the policies also need to give me more chances to let them know what I want in the policies.

1. It will help me to advocate for my rights to government if they make sure that people with intellectual disability are included when the people of South Africa are asked to give their ideas about different policies.



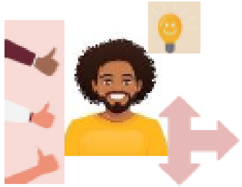
2. It will help me to advocate for my rights to government if policy makers make sure people with intellectual disability like me are on the list of people they invite to meetings they organise to work on writing new policies.

Why is it so important that my voice is heard and my ideas are included in government policies or promises they write down to protect my rights?

When I take part in making policies, it **empowers** me.
To be empowered is important to people like me because it helps us feel connected to everyone else in our communities.
We feel like we belong.

When my needs are included in policies, it can improve my life by making sure I get services that I can enjoy, just like other people do.

When I get to take part in making decisions, it makes me feel like I can **help my community and myself**, and that what I do and say is important.



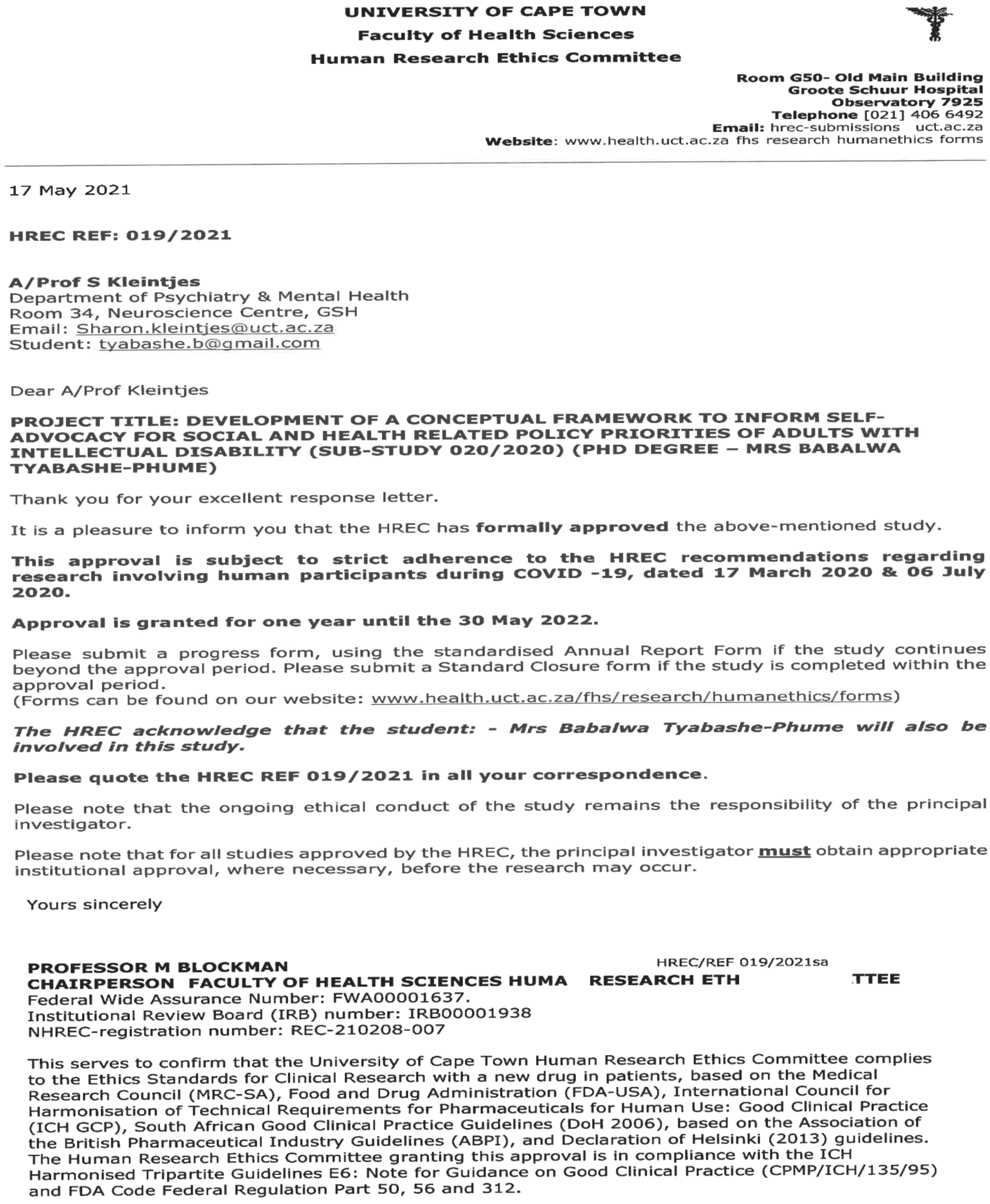
Helping my community and myself can help me in these ways,

- I feel that people respect me.
- I feel good about my life.
- I can make my own decisions.

This document was proof read by:

- Gabriel Lekeur
- Jeremiah Kasper
- Anathi Ngcwangu
- Kurt Pretorius

Appendix 19: Ethical Clearance



UNIVERSITY OF CAPE TOWN
Faculty of Health Sciences
Human Research Ethics Committee

Room G50- Old Main Building
Groote Schuur Hospital
Observatory 7925
Telephone [021] 406 6492
Email: hrec-submissions uct.ac.za
Website: www.health.uct.ac.za fhs research humanethics forms

17 May 2021

HREC REF: 019/2021

A/Prof S Kleintjes
Department of Psychiatry & Mental Health
Room 34, Neuroscience Centre, GSH
Email: Sharon.kleintjes@uct.ac.za
Student: tyabashe.b@gmail.com

Dear A/Prof Kleintjes

PROJECT TITLE: DEVELOPMENT OF A CONCEPTUAL FRAMEWORK TO INFORM SELF-ADVOCACY FOR SOCIAL AND HEALTH RELATED POLICY PRIORITIES OF ADULTS WITH INTELLECTUAL DISABILITY (SUB-STUDY 020/2020) (PHD DEGREE – MRS BABALWA TYABASHE-PHUME)

Thank you for your excellent response letter.

It is a pleasure to inform you that the HREC has **formally approved** the above-mentioned study.

This approval is subject to strict adherence to the HREC recommendations regarding research involving human participants during COVID -19, dated 17 March 2020 & 06 July 2020.

Approval is granted for one year until the 30 May 2022.

Please submit a progress form, using the standardised Annual Report Form if the study continues beyond the approval period. Please submit a Standard Closure form if the study is completed within the approval period.
(Forms can be found on our website: www.health.uct.ac.za/fhs/research/humanethics/forms)

The HREC acknowledge that the student: - Mrs Babalwa Tyabashe-Phume will also be involved in this study.

Please quote the HREC REF 019/2021 in all your correspondence.

Please note that the ongoing ethical conduct of the study remains the responsibility of the principal investigator.

Please note that for all studies approved by the HREC, the principal investigator **must** obtain appropriate institutional approval, where necessary, before the research may occur.

Yours sincerely

HREC/REF 019/2021sa

PROFESSOR M BLOCKMAN
CHAIRPERSON FACULTY OF HEALTH SCIENCES HUMA RESEARCH ETH TTEE
Federal Wide Assurance Number: FWA00001637.
Institutional Review Board (IRB) number: IRB00001938
NHREC-registration number: REC-210208-007

This serves to confirm that the University of Cape Town Human Research Ethics Committee complies to the Ethics Standards for Clinical Research with a new drug in patients, based on the Medical Research Council (MRC-SA), Food and Drug Administration (FDA-USA), International Council for Harmonisation of Technical Requirements for Pharmaceuticals for Human Use: Good Clinical Practice (ICH GCP), South African Good Clinical Practice Guidelines (DoH 2006), based on the Association of the British Pharmaceutical Industry Guidelines (ABPI), and Declaration of Helsinki (2013) guidelines. The Human Research Ethics Committee granting this approval is in compliance with the ICH Harmonised Tripartite Guidelines E6: Note for Guidance on Good Clinical Practice (CPMP/ICH/135/95) and FDA Code Federal Regulation Part 50, 56 and 312.