Strategies for People with Intellectual Disability to Engage in Social Policy-Related Self-Advocacy in South Africa

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Abstract

Aim: This study investigated strategies for people with intellectual disability to self-advocate for inclusion of their priorities in social policy processes in South Africa. **Method:** Self-advocacy strategies were identified through a scoping literature review, a review of self-advocacy toolkits and semi-structured interviews with people with intellectual disability and other stakeholders working at non-governmental and disabled people's organisations. The data were triangulated to identify common strategies which can best support self-advocacy for people with intellectual disability. In addition, these findings informed the development of a local self-advocacy toolkit which was reviewed by a group of young adults with intellectual disability. The toolkit provides an evidence-based compilation of strategies for self advocacy that can be used by self -advocates with intellectual disability and their supporters in the local context. **Results:** Data triangulation identified three core strategies for self-advocacy, specifically, (1) strategies for in-person self-representation in public spaces, (2) written communication strategies, and (3) engagement through social and other forms of media. These were incorporated into the self-advocacy toolkit. The experiential review of the toolkit yielded positive feedback from participants. As part of the experiential review, participants related to the idea of social media advocacy by choosing to produce a video as their self-advocacy activity, aimed at sharing their perspectives on the way they experience society and social policy. **Discussion:** Inclusion of people with intellectual disability in civic and political life is crucial and will only be achieved if self-advocates are accepted into the policy-making arena. Strategies are available for people with intellectual disability to challenge the status quo of society in which prejudice and stigma continue to impact on their inclusion in social discourse. By using these self-advocacy strategies, people with intellectual disability can have a say in policy decisions which impact on their lives. **Conclusion**: Self-advocacy to enhance policy participation can promote the inclusion of the voices of people with intellectual disability to influence public social policy decisions. Adopting strategies which enable the inclusion of the voices of people with intellectual disability in civic activities holds potential for diversifying perspectives brought to public participation in policy development and implementation, which is currently primarily the domain of citizens without disability.

Keywords: Intellectual disability, self-advocacy, human rights, participation, policy, inclusion

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Self-advocacy is hard. Being the nail that stands up above the rest may invite the hammer. But without standing tall, without discomfort, no growth can occur, and so, we have to be brave.

"I now see that owning our story and loving ourselves through that process is the bravest thing that we will ever do" – Brené Brown

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Chapter One

Introduction

This chapter will provide a background and context to the importance of the area of study. It defines key concepts used, provides a brief account of origins of the self-advocacy movement and an overview of self-advocacy for people with intellectual disability. It then proposes the reasons for undertaking the current study, states the research question and outlines the aims and objectives of the study.

Introduction

On the 27th of August 2020, a young, 16-year-old boy with Down Syndrome, Nathaniel Julius, was murdered in the Gauteng province of South Africa.

“He had biscuits in his hands, he was eating”, said the residents and witnesses of this brutal murder. This young person was killed, shot in the chest when he was unable to answer questions from the police about why he was out on the street during strict lockdown conditions during the first year of the Covid-19 pandemic in South Africa. His body was thrown into the back of a police van and taken to hospital where he died. According to his uncle, who cut his hair hours before his death, “He can’t talk at all, so when he sees me he says ‘C…cut’. After I cut his hair he went on to his Mom and said 'Mooi' (nice)” (retrieved from multiple sources, such as https://ewn.co.za/2020/08/28/nathaniel-julius-family-saps-trying-to-cover-up-his-cold-blooded-murder). In a social media post about Nathaniel Julius, written by KeeptheEnergy, it was claimed that, “due to his condition, he was unable to speak clearly (and that is why he was murdered)”.

According to recent news statements, the case made substantial and significant progress with the testimonials of 23 witnesses. However, it was brought to a sudden halt when the presiding Judge, Ramarumo Monama, passed away in early 2022. The three officers are facing charges ranging from murder to defeating the ends of justice, to which they have pleaded not guilty. Due to one of the legal representatives for the accused being unavailable owing to personal reasons, the court agreed to postpone once more, with the new date set for 3 October 2022 (https://www.thesouthafrican.com/news/nathaniel-julies-case-postponed-to-august-three-accused-to-plea-again/). At the time of submission of this thesis, in June 2023, no further news or updates have been published about this case.

The impact of being unable to speak up to defend oneself, illustrated by this incident in a community setting in South Africa, is echoed and amplified in the Life Esidimeni tragedy which occurred in institutional settings, also in the province of Gauteng (Makgoba, 2017). South African mental health legislation and policy provides for deinstitutionalisation from restrictive institutional care to least restrictive community-based care where needed (Govender, 2017). This mental health policy directive was misused by policy makers in the Gauteng Province Department of Health in 2015 to justify the cancellation of a contract with a private service provider and, in 2015 and 2016, to rapidly move mental health care users with intellectual and psychosocial disability from this institutional facility, Life Esidimeni. Patients were moved to inadequate non-governmental, community-based centres in the province. Neither the patients nor their families were consulted in this process. This was done primarily as a cost-saving measure despite concerns expressed by disabled people's organisations (DPOs) and service providers about the safety and health status of the patients being moved. The moves resulted in severe trauma and multiple deaths amongst affected service users. The chair of the inquiry into these deaths, retired Deputy Chief Justice Dikgang Moseneke, in his report noted that the move was directly the cause of 144 deaths, 1418 cases of trauma and morbidity and, at the time of the judgment, 44 unaccounted-for patients (Moseneke, 2017). By August 2021, eight people were still reported missing (Seleka, 2021). At least half of those who died in inadequate community care facilities had intellectual disability with complex care needs (Kleintjes et al., 2020). The voices of the affected were represented by their relatives, or professionals working in the field. While these perspectives are essential, it is notable that, to date, no survivor of this situation has been accommodated to speak for themselves or to have their voice heard.

Both of these incidents highlight the vulnerability of people with intellectual disability. These case studies also demonstrate the absence of self-advocates in public dialogue about their situation, their lived experience and needs, and also demonstrates the urgency in finding appropriate ways in which to support people with intellectual disability to speak up for their rights and needs. Conversely, such as in the case of Nathanial Julius, when a person with an intellectual disability did speak up, the consequences of his limited speech resulted in his being killed. This raises the question whether South Africa has put in sufficient supports for people with intellectual disability (Kleintjes et al 2020). These two cases illustrate the still prevalent lack of societal understanding and support of people with intellectual disability in the South African context (Stein et al., 2018). They emphasize the lack of their self-representation and reasonable accommodation to enable self-representation in the narratives about their lives.

What is Self-Advocacy?

Self-advocacy differs from “advocacy”, which refers to representation of the views of another, while self-advocacy refers to speaking on behalf of oneself and motivating for one’s own needs. There are many definitions of the term "self-advocacy”, but Tilley et al. (2020) found that the most common components include “the notion of speaking up for yourself or others, standing up for your rights, making choices, being independent and taking responsibility” (p. 1152). The underlying principle of self-advocacy is that all people have the right to make decisions and choices, to stand up for themselves in order to improve their quality of life (Kwok, 2008).

Self-advocacy emerged as a response to the broader civil rights movements of the 1960s and 1970s. In the 1960s, disability advocates joined the growing civil rights movement and women’s rights movement to promote equal treatment (Kim et al., 2021; Test et al., 2005). Nissen et al. (2021) describe the “unconventional” approach to political participation, where these marginalised groups would use demonstrations as social statements. People with different kinds of disabilities came together to fight for a common cause, around the time that psychiatric institutions were closing and people with psychosocial disability were moving into ordinary communities (Tilley et al., 2020).

Self-advocacy is central to the disability rights movement, and has, since the 1970s, taken off in countries all over the world (Buchanan & Walmsley, 2006; Frawley & Bigby, 2015; Kim et al., 2021; Tilley et al., 2020; Walmsley & The Central England People First History Project Team, 2013). In 1984, “People First” London Boroughs was founded, following the attendance of a small number of people with learning difficulties (or intellectual disability) at the International

Conference held in the United States of America (USA) (Buchannan & Walmsley, 2006). Early self-advocacy was very much the creation of advocates (Buchannan & Walmsley, 2006). Self-advocacy organisations for people with intellectual disability began to emerge in Scandinavia, North America and the United Kingdom (UK) in the 1980s (Buchanan & Walmsley, 2006) as institutions were closing (Tilley et al, 2020).

The discourse shifted from considering people with intellectual disability as patients to recognising the rights of this population as members of society (Anderson & Bigby, 2017; Buchanan & Walmsley, 2006; Walmsley et al., 2013). Promoting the social inclusion of marginalised groups, including people with disabilities, became core to social policy, with a key aim of reforming disability systems to improve the participation of people with disability (Frawley & Bigby, 2015). Similarly, though for the most part, 20th century the views of people with intellectual ability as damaged and requiring institutionalisation in social practice and policies have shifted to reforms which aim to support the integration and improvement of living standards of people with intellectual disability, notable disparities remain in access to societal resources by people with intellectual disability and other citizens (Tideman & Svensson, 2015) Further, while positive shifts have been noted internationally in attitudes towards people with intellectual disability, the label of “intellectual disability” itself continues to be a stigmatising one (Logeswaran et al., 2019). Adults with intellectual disability have increasingly being encouraged to take control of their lives through a range of goal-setting, choice- and decision-making opportunities (Curryer et al., 2015). Self advocacy is important if people with intellectual disability are to communicate their own perspectives on and obtain preferred support in order to achieve their goals, and through their participation shift negative attitudes of other voices currently participating in these processes (UNICEF, 2021).

The United Nations Convention on the Rights of People with Disabilities (UNCRPD) (United Nations, 2006), as well as its additional Optional Protocol were ratified by the South African government in 2007. The introduction of the CRPD was revolutionary as it aims to create a foundation of equality into South African law, particularly for those with disabilities (South Africa Law Reform Commission, 2020). This equality refers to the inclusion of people with intellectual disabilities in self advocacy, where they have a say in the areas that affect their wellbeing and quality of life. The CRPD strives to end discrimination and create an inclusive society, working towards the actualisation of human rights for all. Regardless of a person's capacity to self advocate, society needs to provide opportunities and supports for optimal participation within areas of the person's life where they can self-advocate (Karr, 2011). The ratification of the CRPD in South Africa supports the country's constitutional focus on creating a foundation of equality within South African law, particularly for those with disabilities (South Africa Law Reform Commission, 2020). This equality also refers to the inclusion of people with intellectual disabilities in exercising their right to have a say about issues that affect their and other citizens wellbeing and quality of life.

Article 29 of the UNCRPD (United Nations, 2006) specifically addresses political and public inclusion. This article states that people with disability should be guaranteed equal opportunity in political and public life, including aspects such as voting, free expression, allowing supporters in the process, or providing reasonable accommodations (United Nations, 2006). Despite being a signatory to this convention, in South Africa there are limited opportunities for participation and, in fact, a real lack of available public spaces to support this participation for people with intellectual disability. One example, the South African electoral provisions currently exclude people with intellectual disability from exercising their vote (Kleintjes et al, 2020), with a failed challenge to the electoral commission to change these provisions in time for these citizen's participation in the May 2019 national elections (Kleintjes et al., 2020). Nissen (2021) highlights the inequality in democracy, where exclusion from being able to vote hinders true participation in civic society. The South African Human Rights Commission's (SAHRC) 2019 report on the November 2017 public hearings into the state of mental health services for people with intellectual and psychosocial disability, has recommended that the Department of Justice and Constitutional development review the human rights impact of these provisions of the Electoral Act (SAHRC, 2019). This challenge is similar in several American states, which also do not allow people with intellectual disability to vote (Kopić, 2017). In contrast, the UK, through legal cases, changed their policies by stating that the right to vote is not a privilege, and that in the twenty-first century the standpoint should be inclusion (European Union Agency for Fundamental Rights, 2010).

Self-advocacy can occur on many levels, from personal to political systemic, including political participation (Frawley & Bigby, 2011).

International initiatives have been designed to address the lack of social and political participation for people with intellectual disability, but unfortunately they have had little traction, and in fact have encountered several barriers to self-advocacy (e.g., Anderson & Bigby, 2017). As the availability of services is influenced by policy directives, strategies need to be developed to increase the involvement of people with intellectual disability in the formulation of policies that affect them, by representing their own needs and rights on relevant regulatory bodies.

This study will therefore focus on self-advocacy by people with intellectual disability at the social policy level, specifically it will focus the identification of strategies which can support this level of participation. The inclusion of people with intellectual disability in social policy development and implementation is a relatively new phenomenon as historically this population was excluded from civic and political participation, as noted above (Frawley & Bigby, 2011). This focus on policy level participation is important to contribute to work which can support self-representation of the needs and perspectives of people with intellectual disability within initiatives to reform social policies aimed at improving the lives of all people with disabilities. Nissen (2021) describes participation as meaning involvement and co-operation, and political participation as meaning a focus on activities affecting politics and engagement in development and decision-making.

Smith and Mueller (2022) refer to Mel Baggs, a writer with a disability and one of the founders of the neurodiversity movement, who described self-advocacy as being fundamentally about true equality, respect and power, working to change societal and structural imbalances. Not only is self-advocacy about accommodations, activism, but also about disrupting the status quo through motivating for equality in society and social policy, (Smith & Mueller, 2022).

What is Social Policy?

The term “social policy” is used to refer to the policies which governments create to meet human needs for security, education, work, health and wellbeing (Spicker, 2022). It can be stated that “social policy” is a policy that is developed in an effort to create wellbeing in a social environment, overcoming undesirable social conditions and inequalities (Haque, 2021). In particular, a policy will be considered a social policy if it meets the needs and wants of the people and addresses their problems (Haque, 2021).

Including all state policies which impact on the wellbeing of people with intellectual disability will be beyond the scope of this doctoral study. This study will therefore focus on self-advocacy in social policy, in particular, those of the Department of Health, Education and Social Development.

Study Context

This study was conducted in South Africa, a country situated at the southern-most tip of the African continent. As noted, South Africa has ratified the United Nations Convention on the Rights of Persons with Disabilities as well as the optional protocol (UNCRPD) (United Nations, 2006), committing the country to respect and implement the rights of persons with disability, as documented in the various articles of the convention. Despite its inclusive policy framework, it has been noted by the World Bank that South Africa is still one of the most unequal countries in the world, socially and economically (Sulla & Zikhali, 2018). This is crucial as South Africans with disabilities have been described as the nation's poorest, despite significant levels of economic and social inequality, with limited opportunities for equal access (Sulla & Zikhali, 2018; McKenzie, Ned, Watermeyer & Dada, 2022, Watermeyer, 2006). Within this South African context, disability, poverty, gender, and race are intimately linked (Emmett, 2006). Human rights are underpinned by equality and dignity, but people with disability have historically been discriminated against and marginalised, resulting in an ongoing struggle for their rights, evidenced in the two cases highlighted in the preamble.

This is in more recent times been compounded by the economic, poverty- inducing impact of the climate crisis on human health and development (McKenzie et al 2022; Kleintjes, Abrahams, Tako, Lake & Tomlinson, 2022). For many people with intellectual disability their lived experience is one of survival, trying to live in a world that could even be described as hostile towards them (McKenzie et al 2022).

McKenzie, Ned, Watermeyer and Dada (2022), describe how in South Africa people with disabilities and their families often face ongoing battles for access to health care, education, transport, and other services, as well as stigma, bullying and discrimination, on top of the everyday demands of coping with an impairment. These social determinants have a profound impact on health (Lund, Abrahams, Garman, van der Westhuizen & Sorsdal, 2022). In addition, Simelane, Mokitimi, Nassen and de Vries (2022), highlight how children and adolescents with mental disorders in fact often fall through the cracks and receive little to no support.

This pervasive discrimination and stigma undermine the right of people with intellectual disabilities to 'full and effective participation and inclusion in society' as enshrined in the CRPD. Participation is considered both a basic human right and a critical health outcome for people with intellectual disabilities. It is therefore clear how the rights of people with intellectual disability are not being asserted, as there are limited opportunities for self advocacy in this context, on a personal or a policy level (McKenzie et al 2022).

In addition to restricted civic activities, most South Africans with intellectual disability also do not have adequate access to health services, or other related public services (Daniels, 2018; Mkabile & Swartz, 2020). Mkabile and Swartz (2020) describe how, due to a history of being disadvantaged, there are structural barriers hindering access to participation for people with intellectual disability. Community-based services, where available, are primarily run by nongovernmental organisations (NGOs), which face several barriers to providing services which are observant of the basic human rights of those in their care (McKenzie et al., 2013).

Education for people with intellectual disability continues to be a challenge, where, in South Africa, the majority of children with disability do not attend school (Capri et al., 2018). In fact, it was shown that only two out of 100 children with disability receive schooling in developing countries (Capri et al., 2018).

Adults with intellectual disability often cannot find work, as they are deemed incapable, or the accommodation that would need to be made to support them would be too demanding for the employer (Capri et al., 2018). In addition, Capri et al (2018) highlight the lack of reliable and affordable public transport infrastructure and accommodations for people with intellectual disability. As a result, South Africans with intellectual disability do not have equal access to education and employment, and are restricted from public access when these opportunities may arise.

There are also accounts of financial difficulties due to duty of care, where parents, often single mothers, have to stay at home to care for their minor and adult children with disability – resulting in high levels of stress and mental health difficulties among parents of people with intellectual disability, particularly where the person with intellectual disability has challenging behaviours (Coetzee, 2016).

Capri et al. (2018) highlight how little is known about South African evidence-based strategies on which to build better human rights practices for people with intellectual disability. People with intellectual disability face more difficulties when accessing justice, health, educational, employment and social services (Capri et al., 2018).

This highlights the wide range of human rights violations experienced by people with intellectual disability and the importance of their being empowered to speak up regarding the injustices that they may experience through limited access to the social resources enjoyed by others in society. Bisht (2019) explains that all leaders who value participation and storytelling, and having people describing how they overcome challenges, support the idea of advocacy and self-advocacy. Promoting their engagement and participation in decisions that affect their lives is paramount to social inclusion. The question is, how can people with intellectual disability self-advocate: what strategies can be employed to support participation at this level?

The notion of strategies around self-advocacy for people with intellectual disability has not been studied in a South African context, especially around policy participation. At the date of submission (30 June 2023), when conducting an informal search through Ebscohost, in the following databases (Academic Search Premier, Africa-Wide, CINAHL, MEDLINE, APA PsychInfo, APA PsychArticles, and APA PsychTests) with the following search terms (intellectual disability OR developmental disability, AND self-advocacy OR self advocacy, AND South Africa) the only paper that this search yields is the one generated from this study itself. An additional search was run through Google Scholar, which yielded a recent publication by Kahonde (2023).

In this paper, the author states that Africa, as a continent is lagging in recognising people with intellectual disability as people who are able to self advocate, speak about their own lives, and act as agents in decisions that affect their lives.

Problem Statement

Despite Article 8 (prejudice and stereotyping), and Articles 29 and 30 (political and social community participation respectively) in the UNCRPD, the practical inclusion of people with intellectual disability as members of South African communities, including civic activities, has not yet been achieved (Capri et al., 2018; Mkabile & Swartz, 2020). Mkabile and Swartz (2020) express the significant level of discrimination and stigma that people with intellectual disability face – resulting in strategies around self-advocacy for inclusion not being a priority. This study aims to address this knowledge gap, and find strategies that could be implemented in a local context.

Rationale and Significance

Persons with intellectual disability comprise an estimated 1-2% of the world's population, most of whom live in low- and middle-income countries (LMIC). Adnams (2010) notes that in the South African context, where this study took place, there is a lack of reliable data on the prevalence of intellectual disability due to exclusion in local epidemiological studies, and inadequate inclusion in census and routine data collection for disability in the country. Adnams (2010) estimated that the prevalence rate of intellectual disability in South Africa may be higher than in other LMIC due to high rates of preventable causative conditions, such as nutritional deficiencies, tuberculosis meningitis, foetal alcohol spectrum disorder, violence and trauma.

South Africa is considered an upper middle-income economy, yet is known to be one of the most unequal countries in the world, with significant disparities between a small affluent segment of the population and the large majority of citizens, a significant proportion of whom are unemployed, and living below the poverty line (Sulla & Vikali, 2018). According to Statistics South Africa (StatsSA, 2014), approximately two thirds of the population of South Africa, including people with disability, are reliant on their own meagre resources or state support for their basic health and wellbeing needs. Despite a robust policy foundation for disability, the needs of people with disability, including intellectual disability, for health, social service, education and other supports remain a low public service priority in terms of implementation and resourcing of these policies (Makgoba, 2017; Sulla & Vikali, 2018). Despite being a country with constitutional protection and promotion of its citizens' human rights, not all members of society, particularly those with disability, are seen as equal, and have equal opportunity for political participation (Nissen, 2021).

Families and other supporters within non-governmental organisations are currently the main advocates for the rights and needs of people with intellectual disability (Kleintjes et al, 2020). There is a limited group of NPO's in South Africa who specifically include a focus on advocating for the state to fulfil its constitutional mandate to uphold the basic human rights of children and adults with intellectual disability as enshrined in the South African Constitution, and Bill of Rights, (Republic of South Africa, 1996; Republic of South Africa, 1997; Republic of South Africa, 2013; Republic of South Africa, 2016; Republic of South Africa, 2018), and in the UNCRPD (United Nations, 2006). The most notable of these organisations are the Western Cape Forum for Intellectual Disability (WCFID) and its affiliate organisations, and the South African Federation for Mental Health (SAFMH), with a few other organisations including Intellectual Disability within their broader focus on disability advocacy. These initiatives are in the main still being driven primarily by service providers and families, with as yet limited direct participation by people with intellectual disability themselves in policy-development and implementation within the country. The SAFMH has a specific programme focusing on self-advocacy by people with intellectual disability, and by people with psychosocial disability which have supported some input to policy related processes, but there are no well-developed national initiatives for self-advocacy by people with intellectual disability at the time of writing (Kleintjes et al, 2020, Daniels, 2018, WCFID, 2022).

Pfeifer (2022) describes how the motto "nothing about us, without us", was first invoked by the South African disability rights movement in the 1990s. This became a call from activists for inclusion, to overcome systemic oppression and be a part of the decision making processes that affect their lives.

Therefore, enabling representation of people with intellectual disability themselves in advocacy about issues which impact on their health, wellbeing and social inclusion is in keeping with the expression, “nothing about us, without us” (Rowland, 2004). This empowers people with intellectual disability to have their voices heard about these issues that affect their lives, encouraging inclusion and motivating for active participation.

Policy change over the past two decades has recast people with intellectual disability from dependants to citizens, and their right to participate in the political life of the community alongside other citizens has been asserted (Frawley & Bigby, 2011). While several articles suggest that the guiding structures and frameworks are in place for political participation by people with intellectual disability, these are not always actualised (e.g., Curryer et al., 2015; Iriarte et al., 2014; Petri et al., 2020).

In line with the UNCRP and the rights-based South African constitution, this study posits that people with intellectual disability have a right to self-advocate in the development of public policies and plans which impact on their lives, and to do so in an environment which enables such participation. That is to say, expert opinion in policy processes should include experts-by-experience, such as people with intellectual disability, and their supporters (Petri et al., 2017; Ryan & Griffiths, 2015; The ARC, 2015; UN, 2006). A key reason for policy makers to engage people with intellectual and or psychosocial disability is to have first-hand accounts of their policy priorities and to include their views in drafting comprehensive, relevant, human rights-based policy (Kleintjes et al., 2013). In South Africa, currently, there is very limited direct involvement of people with disability in self-advocacy, and these activities are primarily based within the largest non-profit organisation (NPO) sector, or is primarily service provider driven or directed at families and supporters (Kleintjes et al., 2013).

This study is important because it aims to investigate strategies to improve self-advocacy for people with intellectual disability in a South African context, giving rise to opportunities for change, for their voices to be heard, and for a potential shift in societal thinking with regards to the citizenship and rights of people with intellectual disability.

Aim of the Study

The overall aim of the study is to identify what strategies are best for people with intellectual disability to self-advocate for inclusion of their priorities in social policy development and implementation in South Africa.

Research Question

The research question to address in this study is:

> What strategies are best for people with intellectual disability to self-advocate for inclusion of their priorities in social policy development and implementation which impact on their lives in the South African context?

Research Objectives

Four objectives have been set to address the research question. The first three objectives explore different sources of data on strategies which people with intellectual disability may utilise to advocate for their needs to be reflected in social policy processes. The 4th objective aims to answers the research question in a format accessible to people with intellectual disability and their supporters by triangulating the findings on strategies for self-advocacy identified in Objectives 1 – 3. This accessible format takes the form of a self-advocacy toolkit which provides a practical compilation of strategies for self-advocacy which can improve the self-advocacy knowledge and actions of self-advocates with intellectual disability and their supporters (Tascona, Harman & Price, 2021).

The study objectives, and related method of investigation, are:

1. To conduct a scoping review on strategies for people with intellectual disability to self-advocate for inclusion of their priorities in social policy development and implementation.

2. To document practice-based self-advocacy strategies used in toolkits developed by South African and international NGOs- and DPOs to assist people with intellectual disability to self-advocate.

3. To document local and international self advocates and self advocacy supporters views on potential strategies to improve the inclusion of their priorities in social policy development and implementation.

4. To develop a self-advocacy toolkit with people with intellectual disability to promote their participation in social policy development and implementation processes in South Africa.

Chapters Outline

This thesis is presented in eight chapters.

Chapter One: The chapter initially defines key concepts used, provides an account of origins of the self-advocacy movement and an overview of self-advocacy for people with intellectual disability. It then proposes the reasons for undertaking the current study and the aims and objectives of the study.

Chapter Two: A background to the thesis will be provided. This chapter will situate the study in relevant literature and theory. Theoretical underpinnings and the rationale for the chosen model for the study will be discussed.

Chapter Three: This chapter provides an overview of the overall methodology for the study. In each of the chapters to follow, the methods used to gather data for specific objectives of the study is further explicated.

Chapter Four: This chapter addresses objective one, focusing on a scoping review of the literature on strategies for people with intellectual disability to self-advocate, with a specific focus on their influencing social policy development and implementation.

Chapter Five: This chapter addresses objective two, which is a grey literature review of existing self-advocacy toolkits to identify recent strategies used to improve self-advocacy for people with intellectual disability.

Chapter Six: This chapter addresses objective three, documenting local and international perspectives of key informants with and without intellectual disability, self advocates and self advocacy supporters, with regards to people with intellectual disability participating as self-advocates and potential strategies suggested for self-advocacy.

Chapter Seven: This chapter addresses objective four, documenting the process of development of a toolkit of self-advocacy strategies for people with intellectual disability to promote their participation in social policy development in a South African context.

Chapter Eight: This concluding chapter of this study discusses the main findings of the study as it informs the research question, proposing recommendations for self-advocacy strategies for people with intellectual disability, discusses strengths and limitations of the study, and proposes directions for future research.

Chapter Two

Framing the Study

Introduction

This chapter situates the study in relevant literature, outlines models of disability which inform the focus of this study, provides a brief account of models and frameworks that are available to frame the study, and describes a rationale for the model which was selected to underpin the conduct of the study.

Understanding Disability

In order to understand the diverse perspectives on disability, it is useful to examine the models that have been formulated to understand disability, and the impact of having a disability on the lives of people with disability (Grover, 2014; Retief & Letšosa, 2018). As Olkin stated (2022), the way people think about disability affects how they feel about disability, and can affect how people with disability are treated.

The Moral/Religious Model

The moral/religious model of disability is the oldest model of disability and is found in a number of religious traditions (Retief & Letšosa, 2018). In this model, disability is viewed as a punishment from God for a particular sin or sins that might have been committed by the person with disability (Retief & Letšosa, 2018). It is also sometimes perceived as the fault of the parents or ancestors, due to sins they may have committed (Retief & Letšosa, 2018). This model has a profoundly negative impact on the individual with disability and their family, as due to the nature of the link between disability and sin, entire families are excluded from social participation in their local communities (Retief & Letšosa, 2018, Olkin, 2022).

This moral and/or religious model of disability is less prevalent today, than it was historically, (Retief & Letšosa, 2018) however there may still be communities that perceive disability within this framework of understanding. In these communities and societies, people with disability are often severely marginalised, certainly not supported to advocate for themselves, and, in fact, even face the prospect of abandonment or infanticide (Retief & Letšosa, 2018). This is echoed by Bogart (2021) who provides a contextual case study in Botswana (South Africa's neighbour) where it has been found that the moral / religious model is still prevalent. This is important to consider as a lower and middle income country, where people who are disabled may face additional stigma and exclusion due to religious or moral community beliefs (Bogart, 2021).

The Charity Model

The charity model perceives people with disability as victims of circumstance who should be pitied (Retief & Letšosa, 2018). This perspective considers people with disability as people who are suffering and experiencing tragedy, and advocates that able-bodied people should help them in any way possible (Retief & Letšosa, 2018). Many people in the disability community regard the charity model in a very negative light, as this model depicts people with disability as helpless and dependent on other people for care and protection, contributing to the preservation of harmful stereotypes and misconceptions about people with disability. The charity model advocates aid for people with disability, but does this without enablement or empowerment (Retief & Letšosa, 2018). This perpetuates speaking on behalf of people with disability, rather than creating spaces for self-advocacy.

The Medical Model

From the mid-1800s onwards, the medical model of disability gradually became the dominant model in response to significant advances in the field of medical science (Retief & Letšosa, 2018). The medical model relies heavily on diagnostic labels (Byrne et al., 2016; Grover, 2014), viewing disability as a defect that the health professionals need to fix or "cure" (Grover, 2014). In short, the medical model views disability as a medical problem that resides in the individual, a defect in or failure of a bodily system with the focus on cure or fixing the defect as far as possible (Retief & Letšosa, 2018).

The social model posits that the medical model lacks a holistic understanding of what disability entails for the person with disability, both within their immediate environments and within broader society. Historically, the focus on defects of the mind and body are reflected in terms such as “idiots”, “fools”, “arrested development”, “imbeciles”, “mental deficiency” and “morons” which were used in South African legislation to describe people with intellectual disability (Fisch, 2011; Girimaji & Pradeep, 2018; Reynolds et al., 2018). The medical model does not consider contextual factors, which include the role that barrier-free environmental access can make to the independence and human dignity of persons with disability. Nor does it consider the human, social, political and economic rights of persons with disability, the rights to full inclusion and integration into society, as well as the abilities of people with disability (Byrne et al., 2016; Degener, 2016; Du Plessis, 2013; Republic of South Africa, 2016).

Considering that people with intellectual, mental, physical and other disabilities may never experience - nor seek- a “cure” that eliminates their disability, it is contended by Retief and Letšosa (2018) that medical professionals and other stakeholders who adhere to the medical model may promote the perspective that individuals in this population are failures or embarrassments, thus perpetuating stigma, discrimination and exclusion from various aspects of life enjoyed by able-bodied individuals. The disability movement rejects this perception, both internationally and nationally, and the need was expressed for a shift in thinking purely medically about disability (Retief & Letšosa, 2018).

The Social Model

The social model emerged in the 1960s and 1970s, inspired by the activism of the British Disability Movement (Oliver, 2013; Retief & Letšosa, 2018). In 1975, the British organisation, Union of the Physically Impaired Against Segregation (UPIAS) contended that it is society which disables physically impaired people (Retief & Letšosa, 2018). This view holds that disability is a construct, something imposed on existing impairments, and manifests in how people with disability are isolated and excluded from full participation in society. This became known as the social interpretation, or social definition, of disability (Retief & Letšosa, 2018). Following the UPIAS social definition of disability, in 1983 Mike Oliver, an academic with disability, coined the phrase “social model of disability” in reference to these ideological developments (Retief & Letšosa, 2018).

The social model differentiates between impairment and disability (Degener, 2016). “‘Impairment” relates to a condition of the body or the mind, and from a social model perspective, “disability” is the result of the way the environment and society respond to that impairment (Degener, 2016). This model argues that disability is caused by the way in which society is organised, rather than by a person’s impairment or difference (Levitt, 2017; Oliver, 2013; Retief & Letšosa, 2018). According to the social model, disability is ultimately a socially constructed phenomenon with implications for the socio-political and economic inclusion – or exclusion – of people with disability in mainstream society, which includes the impact of stigma, discrimination, poverty and access to services (Levitt, 2017; Grover, 2014; Retief & Letšosa, 2018; Woods, 2017). This model highlights systemic barriers, negative attitudes, and exclusion by society experienced by people with disability. The social model was developed alongside the self-advocacy movement, which shares the basic tenet of the social model that persons with a disability should be supported in expressing and having their needs met, regardless of their capacity or perceived level of functioning (Carmichael, 2004; Grover, 2014).

While the social model was developed ideologically to advocate for marginalised groups and has facilitated great change in the disability sector, it has been argued that this perspective has significant limitations (Degener, 2016; Du Plessis, 2013). For example, some argue that the model may be used to the extreme whereby personal characteristics are not considered at all (Du Plessis, 2013). In addition, concerns have also been raised that the focus of the social model on self-determination and autonomy does not explicitly account for the reality of human need for interdependence or co-construction in context (Ref?) .

Social model theorists have responded to these critiques by pointing out that they do not deny the impact of illness or the role of health professionals, and the right to equal access to healthcare, but rather distinguish the difference between a person’s illness/impairments and their disability (Retief & Letšosa, 2018). Oliver (2013) addressed the criticisms of the social model by acknowledging two areas of concern. The first of these suggested that there is no place for impairment within the social model of disability. The second alleges that the social model fails to take account of difference and presents people with disability as one unitary group, whereas there are other intersectional issues such as race, gender, sexuality and age which impact in complex ways on people's needs and lives. Oliver (2013) contends that he did not suggest that the individual model should be abandoned, nor did he claim that the social model was an all-encompassing framework within which everything that happens to people with disability could be understood or explained. Rather, the overall contention is that disabling barriers need to be identified and eradicated and accessibility to participation in society improved (Oliver, 2013).

The Identity Model

Similar to the social model of disability – yet with a fundamental difference in emphasis – is the identity model (or affirmation model) of disability (Retief & Letšosa, 2018). This model shares the social model's understanding that the experience of disability is socially constructed, but differs to the extent that this model considers disability as part of a positive identity. This model perceives being a minority group as an asset, a valued defining quality. The identity model has influenced many in the disability community, inspiring people with disability to adopt a positive self-image that celebrates "disability pride" (Retief & Letšosa, 2018).

It contends that people with disabilities have to understand themselves as part of a broader fabric of a community of people with disability, and have a sense of their disabled identity as being a political identity as well (Smith & Mueller, 2022).

The Biopsychosocial Model

Engel (1977) argued that the medical model was insufficient to encapsulate a person's experience of disability, where one needed to also account for the consideration of behavioural, psychological and social dimensions in understanding a person's disability or medical condition (Engel, 1977; Full, 2017). The biopsychosocial model was initially proposed to address this gap, within the field of psychiatry, but it quickly expanded to other fields of medicine. The biopsychosocial approach systematically considers biological, psychological, and social factors and their complex interactions in understanding health, illness, and health care delivery. In a paper by Full (2017), it is noted that the ‘pendulum’ of whether or not to use this model, ‘continues to swing’ – meaning that there are still debates about whether or not to use this model.

The Human Rights Model

With the adoption of the UNCRPD, a new model emerged: The human rights model of disability (Degener, 2016). The UNCRDP's definition of disability, which is underpinned by both the social model and the human rights model, considers disability as more than just a medical condition, instead looking at the whole person in context. This convention defines disability as a long-term physical, mental, intellectual or sensory impairment, with disability conceptualised by “the interaction between persons with impairments and attitudinal and environmental barriers that hinders their full and effective participation in society on an equal basis with others” (United Nations, 2006, Preamble, no. 5). The human rights model has gained prominence, particularly in law and policy contexts, since the adoption of the UNCRPD (Lawson & Beckett, 2021).

According to Article 1, the purpose of the CRPD is “to promote, protect and ensure the full and equal enjoyment of all human rights and fundamental freedoms by all persons with disability, and to promote respect for their inherent dignity” (United Nations, 2006, p. 4). Degener (2016) highlights how the UNCRPD is the first human rights instrument acknowledging that people with disability are rights holders and that impairment may not be used as a justification for denial or restrictions of human rights. From the human rights perspective, all human rights should be regarded as universal, indivisible, interdependent, and interrelated, concepts that must be central to the development and implementation of policies in order to ensure social inclusion for people with disability (UN, 2006).

Human rights are underpinned by equality and dignity, but people with disability have historically been discriminated against and marginalised, resulting in an ongoing struggle for their rights. The human rights model is important as a model of disability policy, as it provides a road map for the development of social policy that has a human-rights focus, and highlights systems and frameworks for monitoring progress (Lawson & Beckett, 2021).

The human rights model of disability gives consideration to different layers of identity, acknowledging the issues of intersectionality (Degener, 2016). This model addresses identity politics, and acknowledges that persons with disability might identify with other minority groups. Article 6 of the UNCRPD, for example, states that "women and girls with disabilities are subject to multiple discrimination" (United Nations, 2006, p. 7), which Degener (2016) notes is the first binding intersectionality clause in a human rights treaty.

Social Model and Human Rights Model in the South African Context

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

The perspective initiated the shift from the medical model to the social and human rights models in policies and legislation (Republic of South Africa, 2016). For instance, the White Paper on the Rights of Persons with Disability applies the social and rights-based model of disability (Republic of South Africa, 2016). This White Paper expands upon the White Paper on an Integrated National Disability Strategy (INDS) which is underpinned by the social model of disability in South Africa (Republic of South Africa, 1997).

The South African Strategic Policy Framework on Disability for the Post-School Education and Training System (Republic of South Africa, 2018) embraces the social model's definition of disability. The objective of the policy framework is to work towards removing disabling barriers to inclusion and creating opportunities for people with disability to take part in the life of the community. These barriers may be due to economic, physical/structural, social, attitudinal and/or cultural factors. These white papers are still policy documents and are therefore not enforceable, hence the emerging call from disability rights activists and other stakeholders for the promulgation of a Disability Act to enforce the implementation of these provisions (Capri et al., 2018; Kleintjes et al., 2020). As stated previously, in 2007, South Africa became a signatory to the United Nations Convention on the Rights of Persons with Disabilities (United Nations, 2006), demonstrating the intent to address human rights for all. South Africa's legal system has yet to systematically and fully assimilate this international convention into domestic legislation as they may pertain to the rights and needs of people with intellectual disability (Capri et al., 2018). In a review by the South African Law Reform Commission in 2020, it was found that these difficulties are still prevalent, where inclusion and goals around equality have not been adequately met (South African Law Reform Commission, 2020).

The UNCRPD (United Nations, 2006) incorporates both social model and human rights tenets, in keeping with current thinking within the disability movement. Clegg and Bigby (2017) found that often many people with mild intellectual disability "prefer the social model position where society should change and not them" (p. 82). The South African disability movement adopted the social model of disability, applying a human rights approach, as a means of advocating for the rights of people with disabilities (Du Plessis, 2013). The tenets of these models suggest that we should be confronting disabling societies, challenging the relationships between service users and service providers, addressing social exclusion and isolation, and valuing the lived experience and expertise of people who live with a disabling condition (Byng & Duchan, 2005). A fundamental aspect of these models concerns equality and equal access. When barriers are removed, people with disabilities can be independent and equal in society, being socially included, with choice and control over their lives (Republic of South Africa, 2013).

Rationale for Selection of Theoretical Frame

Anderson and Bigby (2017) describe how the dominant narratives in the self-advocacy sphere are about speaking out, engaging with ideas about rights and empowerment, as well as providing spaces for personal narratives and developing resilience. Therefore, the principles of the human rights and social models have been used to inform the theoretical framework of this study.

Although some researchers treat the social model and the human rights model as synonymous, Degener (2017) highlights a number of important differences between them. One key difference is that the social model addresses the construct of disability, while the subject matter of the human rights model is disability policy (Lawson & Beckett, 2021). The human rights model is built upon the social model, and complements it (Lawson & Beckett, 2021). Lawson and Beckett (2021) further posit that the relationship between the social model and the human rights model does not need to be perceived as one superseding or improving on the other, and could be used in a complementary way. Further, both models are valuable tools, which scholars, disability activists, or anyone else working to achieve equality, participation, inclusion, quality of life and dignity for people with disability, need in their toolbox (Lawson & Beckett, 2021).

In line with the idea of a complementary approach, Berghs et al. (2019) question whether the social model is still fit for purpose, or whether another model could be used, a more active model that sets out actions and agendas for change. The dialogue amongst people with disabilities who are politically and socially active often surrounds human rights. As such, Berghs et al. (2019) suggest a “social model of human rights”.

The above conceptualisation marries the two constructs, and highlights how both are underpinned by a human rights ethos, focusing on participation, inclusion and having voices heard. This is why, for the purpose of this study, a “Social Model of Human Rights” orientation to exploring the research question will be employed.

The South African disability movement adopted the social model of disability, while also applying a human rights and development approach, a means of advocating for the rights of people with disabilities (Du Plessis, 2013). This is echoed by local researchers in this field, who state that individuals may live with various impairments, but their political and social environments do the disabling (Capri et al., 2018). The impairment alone is not sufficient for disablement to occur (Capri et al., 2018). The issue of societal inclusion and exclusion of people with intellectual disability on psychomedical, socio-political or accessibility grounds touches on core questions of rights claims, justice, citizenship, equality, resources and protections inherent in the social model and human rights model frameworks (Capri et al., 2018).

An interesting perspective is that of Berghs et al. (2019), who argue that irrespective of debating the different merits of models and frameworks, ultimately, the focus should be on uniting to support people with disabilities. The authors argue that irrespective of identity politics, the intention should be to improve the quality of life for people with disabilities. Berghs et al. (2019) assert the need for a new model, a new tool, that can effectively create action.

Conclusion

The rationale behind the choice of these models to underpin this study is that the tenets of both the social and human rights models suggest that we should be confronting disabling societies, challenging the relationships between service users and service providers, addressing social exclusion and isolation, and valuing the lived experience, human rights and expertise of people who live with a disabling condition (Byng & Duchan, 2005).

The evidence highlights how being a self advocate can promote wellbeing and improve the lives of people with intellectual disabilities, and how this empowerment can improve a person's ability to speak out against injustice (Gilmartin & Slevin, 2010). Self advocates experience positive outcomes in their lives, not only in the domain of rights realisation and social inclusion, in line with the social and human rights models but also in other areas such as self-esteem, connections with others and quality of life through their experience of self-advocating (Tilley et al., 2020). Self advocacy raises awareness of issues such as institutionalisation and the nature of disability services (Frawley & Bigby, 2015). This was echoed in an international literature where Kim et al. (2021), in their study conducted in South Korea, found that one of the biggest benefits of being in a self-advocacy group is that of the creation of the opportunity for "hearing their voices", highlighting the positive impact of self advocacy on people with intellectual disability.

However, the brief review of the literature presented thus far also demonstrates how stigma, discrimination and exclusion reflect how the rights of people with intellectual disability are not being upheld, with limited opportunities for self advocacy in this context, on both a personal and a policy level (McKenzie et al 2022). This study therefore aims to research the phenomenon of self advocacy, in particular, strategies to support self-advocacy to actualise reasonably accommodated opportunities for inclusion. Specifically, the study aims to generate new knowledge to inform action in self advocacy which can influence the inclusion of the priorities of people with intellectual disability in the domain of social policy development and implementation in South Africa.

Chapter Three

Methodology

Introduction

This study aims to identify strategies people with intellectual disability can use to self-advocate for inclusion of their priorities in social policy in South Africa. Specifically, it explores the research question “What strategies are best for people with intellectual disability to self-advocate for inclusion of their priorities in social policy development and implementation which impact on their lives in the South African context? This study is conceptualised as formative research, an exploration of the phenomena of study in a context where there is little locally generated evidence to inform contextually appropriate understanding of the phenomena of study and any actions which may follow, in the area of self-advocacy as described in the above chapters.

This chapter describes the philosophical underpinnings of the research, and details and motivates the methodology employed to answer the research question for the study. The research approach, researcher orientation, study setting, sample selection, and methods of data collection and analysis are elaborated. A section on research rigour is provided to highlight how the research process, procedures, and researcher stance were considered in assuring the integrity with which data were generated and interpreted to assure trustworthiness and credibility of the findings and conclusions drawn from the research.

Study design

Generally, research methodology can be either quantitative, qualitative or be a mixed-methods design. Mixed-methods design includes both qualitative and quantitative data collection and analysis (Creswell, 2003). This study is qualitative by design as it aims to expand understanding of the research question through an in-depth exploration of what is already known and in use regarding strategies for policy participation for people with intellectual disability, as well as exploring current perspectives of people who experience or are involved in these self-advocacy initiatives. Qualitative research is conducted from the perspective that multiple realities are represented in participant perspectives and other narrative data sources, and that context is critical in exploring and understanding the phenomenon being investigated (Reiners, 2012; Frechette, Bitzas, Aubry, Kilpatrick, & Lavoie-Tremblay 2020; Beyer, 2022; Creswell, 2003 McMillan, 2016). In qualitative research, it is also understood that researchers, within their context, bring their own unique perspectives on reality to their exploration of the research question, and that the findings of the research will be influenced by these researcher subjectivities. Researchers may be viewed as the key research instrument in qualitative research as all observations and analytic processes unfold through the researcher's worldview, influencing all research decisions and actions.

There are many approaches to qualitative research (Creswell, 2003), and for this study, a phenomenological approach has been employed to inductively explore the research question. Phenomenological enquiry was established by Edmund Husserl in the 20th century. Husserl, considered the "father" of phenomenology, established his philosophy to counter the dominant positivist philosophy of the time that privileged knowledge as "true" only when it was generated from an objective and empirical stance (Horrigan-Kelly et al, 2016). Husserl's *transcendental phenomenology* instead focuses on the relationship between consciousness and objects of knowledge. He argued that the objective world cannot be understood outside of consideration of "intentionality of thought", that is, the content of thought (or consciousness) in relation to an object or phenomenon of study. Within his philosophy, intentionality of thought can include, amongst others, perceptions, memories and judgments of an experience (subjective experience) as well as the experience of one's own conscious stream of thought about and in relation to others' intentionality of thought (inter-subjective experience). Further, in expressing thought about a phenomenon, he postulated that the expression of thought cannot be taken at face value to mean only one thing. Expressive language in itself brings ambiguity to intended meaning, and may be stated in a particular way depending of the speaker's or writer's view of the researcher's capacity to conceive of and beliefs about the essence of the intended communication. Then, in turn, the expression is received and understood within the framework of the researchers own intentionality of thought. Further, expression of experience is historically and culturally situated. In Husserl's phenomenology, therefore, what we know-our "truth" about a phenomena- is not necessarily as they objectively are, but as the experience of the phenomena is understood by us (Marinay, 2020).

Husserl's *transcendental phenomenology* focuses on reflective description of the perceived understanding of objects or phenomenon (Marinay, 2020). Transcendental phenomenologists neither assume a stance of pure description nor do they offer explanations about or interpretations of study phenomena, but rather take a stance of reflection on the phenomena, employing an approach known as transcendental-phenomenological reduction (Marinay, 2020). In applying this approach to research, the researcher is called upon to adopt an attitude and commitment to questioning and being prepared to invalidate – to distance themselves from - their own or commonly held beliefs and knowledge about phenomena, as their research unfolds. This epoche, or placing one's views "in parenthesis" is thought to allow for new understanding to unfold, acknowledging that the researcher must account for the influence of Self (the transcendental ego) on what constitutes truth in the process of enquiry. In other words, the researcher is required to "bracket" their own lived experience and personal perspectives during the research process in order for their previously held knowledge and experience to be held in check to enable a focus on the phenomena as represented anew by data collected during the study (Schmitt, 1959, Reiners, 2012; Frechette et al, 2020; Beyer, 2022).

In contrast, Martin Heideggar, a student of Husserl, rejected the notion of bracketing experience, postulating that it is impossible for a person to negate their experiences in relation to the phenomenon of study as they are embedded in the fabric of that reality (Reiners, 2012; Frechette et al, 2020; Beyer, 2022, Horigan-Kelly et al, 2016). Heidegger conceptualised the concept of "Dasein", a German word meaning " Being there" or Being-in-the world", in relation to oneself as human within context, as well as "being in the world" in relation to others. In contrast to Husserl who argued that consciousness informs conceptualisations or descriptions of reality or experiences, Heidegger's phenomenology focuses on the interpretation of experience of "Being-in the world". Interpretation of experience-past is transformed by understanding and interpretating current experience, which in turn also influences understanding an interpretation of future potentiality related to experience, in an "evolving hermeneutic circle of interpretation" (Horrigan-Kelly et al, 2016). The way a person, or here, a researcher, understands the present enquiry is conceptualised as impacted by past-built and current understanding of a phenomenon, and interpretation of future potentiality in relation to the human experience focused on in the research enquiry.

The approach to this study goes beyond a reflective description of the essence of the phenomena of study as set forth by Husserl, with its focus on bracketing experience. Rather, the orientation of this study is more closely aligned to Heidegger's hermeneutic (interpretative) phenomenology, in that it sees the researcher as a person in the world, not merely bringing her own worldview to the research process, but as being-in-the world of enquiry, being interpreted by and interpreting that context (Reiners, 2012; Frechette et al, 2020; Beyer, 2022, Horigan-Kelly et al, 2016.

Heidegger's *interpretive phenomenology* therefore provided an appropriate lens through which to understand this research as an enquiry that explores historically and culturally embedded past and current perspectives on useful strategies for self-advocacy by people with intellectual disability, as presented in reviewed literature and the various perspectives shared by the study's research participants (Reiners, 2012; Frechette et al, 2020; Beyer, 2022, Horigan-Kelly et al, 2016). Understanding and consequent interpretation of perspectives were also influenced by the researcher's own personal and intersubjective experience.

While there are descriptive elements to the thesis, particularly in the literature reviews, the findings of these reviews and the interview and focus group data are based on the researcher interpretation of those finding to arrive at recommended strategies for self -advocacy, and curation of these into a preliminary self-advocacy toolkit for use by people with intellectual disability and their supporters in the current local policy context.

The toolkit potentially provides an evidence-informed tool, appropriately presented to people with intellectual disability (Tacsona et al 2021), for use in further inclusive research with people with intellectual disability and their supporters[1].

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[1] *The researcher was approached in May 2023 by a local NGO who provides support to services offered to people with intellectual disability, to support the organisation in re-establishing their self-advocacy group within the organization, based on the findings of the results captured in the toolkit. This initiative aims to strengthen their goal of providing an inclusive space for adults with intellectual disability to self-advocate within the organization for issues they feel should be included in the organizational focus, and to use the organization as a platform for their self advocacy initiatives given the current scarcity of organizational support to self-advocacy by people with intellectual disability. The organization also plans to strengthen its focus on inclusive research, and capacity-building for self-advocacy within the organization is also envisioned as key to*

Retrospectively, having conducted the study, the use of this epistemological frame has resonated with my experience of the research process. As the research took place, my understanding of the field of study has evolved toward a point where, in this thesis, the study findings have been presented as understood and interpreted at this point in time, also highlighting the need for further enquiry which can inform the field, beyond the current study, in the ever-evolving circle of interpretation. Below I describe my positionality as a researcher, in an effort to clarify how my experiences may have contributed towards - or limited - the trustworthiness of the research process and its findings.

The Researcher

I am a registered occupational therapist and have been practicing in the field of intellectual disability for five years, at the junction between intellectual and psychosocial disabilities in particular. I work , as a clinician, and a skills development educator for adults with intellectual disability, in the contexts of private practice, public hospital and residential facilities, as well as in the NGO sector in adult education and service delivery. During this research, my professional skill set assisted me in being mindful of, and utilising, strategies to minimise personal risk to the participants and to prepare to manage any discomfort that might have arisen during interviews. In terms of reflexivity, my training and work experience in the occupational and mental health domains assisted me in being conscious of the constant need to reflect on how my own beliefs, judgements and practices might be impacting on the research activities, as well as that of the participants of the study. As a clinician in the field of disability and Neurodiversity, working by using evidence-based practice, often the answers to questions of the "why" therapeutic choices are made are simply, because they have been found to work. A challenge of this study for me has been that contextualized practice in self-advocacy in our context is in its infancy, and that I have needed to challenge this usual way of thinking, of focusing on practice (using what works), in order to assume an explorative orientation to the study, navigating to a focus instead on contributing to the limited body of work on self-advocacy by people with intellectual disability (exploring what could work) to inform local practice in the future. My own worldview is shaped by my family and community history and

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providing skills to enable people with intellectual disability to contribute to shaping the focus of and informing the organization's research. The work to establish the self-advocacy group is currently at the conceptual stage.

culture, and my life experiences as a person living in a racially-constructed, heteronormative, ableist society.

Study Methods

Data analysis processes outlined below vary somewhat for each objective, but are all compatible with the sensibility of an interpretive phenomenological approach of “a constant dialogue between the researcher, the participants, the literature and the data” in order for the meanings related to the phenomena of study “to emerge and evolve”. This analytic approach involves 4 elements, namely developing a sense of the data as a whole (naïve reading), unpacking the data in detail to identify similar and dissimilar themes (structural analysis), synthesising the data, through interpretation, into a comprehensive understanding of the phenomena of study (comprehensive understanding), and finally, evaluating this interpretation as it relates to the research question, already established literature, and the implications drawn from the findings (critical refection).

Below the methods describe the process of naive reading, structural analysis and synthesis of the data, while chapters 4-7 provides the researcher’s understanding of the interpreted data, or results. Finally chapter 8 provides a critical reflection on these findings.

Data collection has focused on bringing to the circle of interpretation data on past and current knowledge (what is already known and currently understood) to inform my understanding and interpretation of the data (recommendations on what might be most useful in future strategies to use in our context).

This section of the chapter details the methods used to address each objective of the study, with results of each reported in separate chapters of the scoping review (Chapter 4), the toolkit review (Chapter 5), the interviews with key informants (Chapter 6) and the development of a self-advocacy toolkit (Chapter 7).

A summary of the data collection methods is contained in Table 3.1 below. As noted above, this included a scoping literature review, a grey literature review of existing toolkits, and semi-structured interviews which were triangulated in identifying strategies for supporting self-advocates with intellectual disability to self-advocate in the policy-making space. These findings were also translated into a toolkit incorporating the strategies, with the dual purpose of firstly, presenting the core findings in an accessible format for supporters of and self-advocates with intellectual disability, and secondly to use that format to engage self-advocates about their views about the accuracy of the findings through experiential exposure to the toolkit and a focus group discussion.

Table 3.1

Summary of Data Collection Methods

	Literature Review	Grey Literature Review	Semi-Structured Interviews	Focus Group
Objective 1: To conduct a scoping review on strategies for people with intellectual disability to self-advocate, with a specific focus on their influencing social policy development and implementation.	X			
Objective 2. To document practice-based self-advocacy strategies used in toolkits developed by South African and international NGOs- and DPOs to assist people with intellectual disability to self-advocate.		X		
Objective 3: To document local and international self advocates and self advocacy supporters views on potential strategies to improve the inclusion of their priorities in social policy development and implementation.			X	
Objective 4: To develop a self-advocacy toolkit with people with intellectual disability to promote their participation in social policy development and implementation processes in South Africa.	X	X	X	X

Objective One: This scoping review of the literature on strategies for people with intellectual disability to self-advocate was conducted to collate *what is already known* about strategies for self-advocacy by people with intellectual disability, with a specific focus on their influencing social policy development and implementation.

Objective Two: This focused grey literature review of recent self-advocacy toolkits was conducted to collate *what is already in use* as strategies to improve self-advocacy by people with intellectual disability.

Objective Three: Interviews with local and international key informants with and without intellectual disability, self advocates and self advocacy supporters, provided *insights on current perspectives* on strategies for self-advocates with intellectual disability to participate in policy level self-advocacy.

Objective Four: documents the process of triangulation of the findings of Objectives 1-3 to develop a toolkit of self-advocacy strategies for people with intellectual disability. That is, member checking with participants on the appropriateness and comprehensiveness of the toolkit took the form of an experiential exercise to expose the self-advocates to the toolkit ahead of obtaining their feedback in a focus group discussion.

It is also hoped, in the spirit of the aim of this thesis, that the toolkit- meant to develop over time – will contribute to promoting their right to self advocate for their social and health related needs in their *future participation* in social policy development in a South African context. Tascona et al (2021) emphasises the importance of meaningful knowledge translation of research findings to communicate to and enable utilisation of research findings by target audiences for the research. Key target audiences of this study are self-advocates with intellectual disability and their supporters. The format of an academic thesis would not be accessible to people with intellectual disabilities and their supporters, given the limitations on language and comprehension skills which accompany intellectual disability, as well as the fact that supporters may lack the skills to translate research findings into a useful format for self-advocacy that is informed by the evidence generated by the study. Objective 4 therefore addresses the need to consider the accessibility of this research for people with intellectual disability and their supporters. It provides opportunity for a key target audience of this study to engage with the identified strategies in a format which is directly accessible to self-advocates and their supporters. The study therefore triangulates the research findings of Objectives 1-3 to develop a practical collection of resources or tools (a self-advocacy toolkit) which can be used to improve the knowledge of self-advocates with intellectual disability about self-advocacy , and support their choice-making regarding strategies to include in their self-advocacy plans.

The following sections outline the methodology selected for each of the objectives outlined above in full detail.

A) Methodology: The Scoping Review – Objective 1

Objective 1: To conduct a scoping review on strategies for people with intellectual disability to self-advocate, with a specific focus on their influencing social policy development and implementation.

Munn, Peters, Stern, Tufanaru, McArthur and Aromataris (2018) highlight some of the key considerations in choosing whether to conduct a scoping review or a systematic review of the literature. Scoping reviews, are similar to systematic reviews in that they follow a structured process, however they are performed for different reasons and have some key methodological differences (Munn et al, 2018). If researchers are enquiring about the feasibility, appropriateness, or effectiveness of a certain treatment or practice, then a systematic review is the most valid approach (Munn et al, 2018). However, should the researcher want to better understand the scope or coverage of a body of literature then a scoping review would be the better choice (Munn et al, 2018).

Arksey and O'Malley (2005) describe how, at a general level, scoping studies might aim to map the key concepts underpinning a research area and the main sources and types of evidence available, and can be undertaken as stand-alone projects in their own right, especially where an area is complex or has not been reviewed comprehensively before. The authors provided four specific reasons why a scoping review may be conducted, which include being able to identify evidence in a given field, to examine how research is conducted on a certain topic, to identify key factors relating to a concept and to identify and analyse knowledge gaps, possibly as a precursor to a systematic review (Arksey & O'Malley, 2005; Munn et al, 2018). A scoping review was the appropriate choice for this thesis, as the review was undertaken to gain insight into evidence in the field of self-advocacy, and to specifically identify key factors relating to strategies to improve the self-advocacy skills of people with intellectual disability in a South African context.

Conducting the Review

The process was conducted using the five steps suggested by Arksey and O'Malley (2005) to ensure that the relevant literature was documented in a rigorous and transparent manner, namely:

1. Stage 1: Identifying the Research Question
2. Stage 2: Identifying Relevant Studies
3. Stage 3: Study Selection
4. Stage 4: Charting the Data
5. Stage 5: Collating, Summarising and Reporting the Results

Stage 1: Identifying the Research Question

This study addressed the following research question, as well as the sub-questions for this review.

Research Question:

- What is known about self-advocacy strategies for people with intellectual disability around social policy development and implementation?

Sub-Questions:

a) What is the current extent of engagement of people with intellectual disability in policy development internationally?
b) What key knowledge and skills are needed for people with intellectual disability to utilise strategies for self-advocacy in policy participation?
c) What tools are available to assess self-advocacy capacity?

Stage 2: Identifying Relevant Studies

In order to be as comprehensive as possible, a thorough process was followed to answer the research question and sub-questions of the review.

Establishing search terms

The first step in this process was to establish suitable search terms. A MeSH term search was conducted with the assistance of the librarian and the research supervisor. There was no record of “self-advocacy”, but the nearest match was “patient advocacy”. This, however, did not comprehensively capture the nature of this study. Within discussions in supervision, as well as discussions with the librarian, it was decided that “patient advocacy” is not a key focus of the study. As mentioned in Chapter One, the lenses of the social and human rights models do not view people with disability as patients, but as citizens with rights (Anderson & Bigby, 2017; Walmsley et al., 2013). The participants on which this study is focussed are not patients but citizens of South Africa with intellectual disability.

Through discussion and multiple iterations of the search terms, the following search terms were employed for the scoping review:

1. “intellectual disability” or “intellectual disabilities” or “mental retardation” or “learning disability” or “learning disabilities” or “developmental disability” or “developmental disabilities”;
2. AND “strategies” or “methods” or “techniques” or “interventions” or “best practices” or “tool” or “toolkit”;
3. AND “self-advocacy” or “self-advocacy capacity”;
4. AND “policy” or “policies” or “law” or “laws” or “legislation”.

Search strategy

In discussion with the librarian, and supervisor, it was decided to use several databases to ensure a thorough review. PUBMED, Scopus and Ebscohost were the three major platforms that were used, with Academic Search Premier, Africa-Wide, CINAHL, MEDLINE, CINAL complete and MEDLINE and APA PsychInfo, APA PsychArticles, and APA PsycTests complete searched in Ebscohost. In addition, ERIC and Web of Science were searched to see if any other relevant articles could be included.

Inclusion and exclusion criteria

Due to time constraints for the conduct of this study, funded for three years, 2020-2022, as well as resource limitations in terms of the number of researchers available to conduct the study (the primary researcher and a research assistant) three limitations were put in place for the review in order to conduct a manageable scoping review. Usually a scoping review will not include any time limits, however for this review a 10 year period was set to source the most recent work on strategies for self-advocacy. This scoping review follows all the usual steps and stages of a traditional scoping review, but certain limits have been placed on the extensiveness of the search within the study context. The overall study was funded by the National Research Foundation of South Africa which provides funding for completion of a doctoral study within a 3 year period, necessitating a streamlining of the review to accommodate the limited time available for completion of the study. In addition, due to the limited available resources, there was no funding for a full research team, and therefore the number of researchers was limited, to myself and a research assistant. The articles sourced were also limited to English publications. Thirdly, the grey literature search was limited to dissertations (a more focused grey literature review on strategies currently been used for self-advocacy has also been conducted, as reported in chapters 3 and 5).

Inclusion criteria for the articles therefore were:

- Peer-reviewed qualitative, quantitative and mixed method studies.
- Studies published in English.
- Studies published in low-, middle- and high-income countries.
- Peer reviewed articles published in academic journals from 2010–2020.
- Studies focused on people with intellectual disability.
- Studies focused on self-advocacy strategies and self-advocacy skills.
- Studies focused on self-advocacy for policy development and implementation.

Exclusion criteria were studies which focused on people without intellectual disability, on children and adolescents with intellectual disability, non-English articles, and articles that did not outline self- strategies or self-advocacy skills . In addition, while there would be inclusive research on self-advocacy which might pertain to people with intellectual disability within mainstream self-advocacy, initiatives by people with disabilities, this study is particularly focused on identifying literature that could assist the researcher to identify self-advocacy initiatives which are most accessible and implementable by people with intellectual disabilities. Therefore inclusive articles on self-advocacy which did not focus on enabling people with intellectual disability to self-advocate were not included in the study.

Stage 3: Study Selection

The search was conducted on two dates, several months apart to ensure a rigorous search, and to include studies up to the last data collection date. The initial search, on the 12th of November 2020, was conducted by the researcher and co-researcher independently, and the second search was on the 3rd of May 2021, repeated using the same search strategy, conducted by the researcher alone.

This second reviewer has a postgraduate degree and experience with conducting research reviews. The reviewer assisted with the screening of abstracts and shortlisted full texts to arrive at the final papers for inclusion in the review. Agreement was also reached on the inclusion or exclusion of papers sourced from the references of the included full texts, and the finalisation of the data recorded in the extraction form.

The search was conducted on EbscoHost, Scopus and on PubMed. Sourced articles were reviewed by title and abstract, then by full text using inclusion and exclusion criteria to derive the final list for inclusion:

- 32 articles were sourced in the EbscoHost review.
- 11 articles were sourced in the PubMed review, of which three were duplicates of articles already retrieved in the EbscoHost search.

After full text reading, comparison and joint agreement on which papers met the inclusion criteria, seven articles were included that met all the inclusion criteria. The reference lists of these included articles were also reviewed for other relevant articles that met inclusion criteria.

No additional articles were sourced that met all the inclusion criteria. See Figure 1, above, for a diagrammatic representation of the scoping review process with regards to study selection.

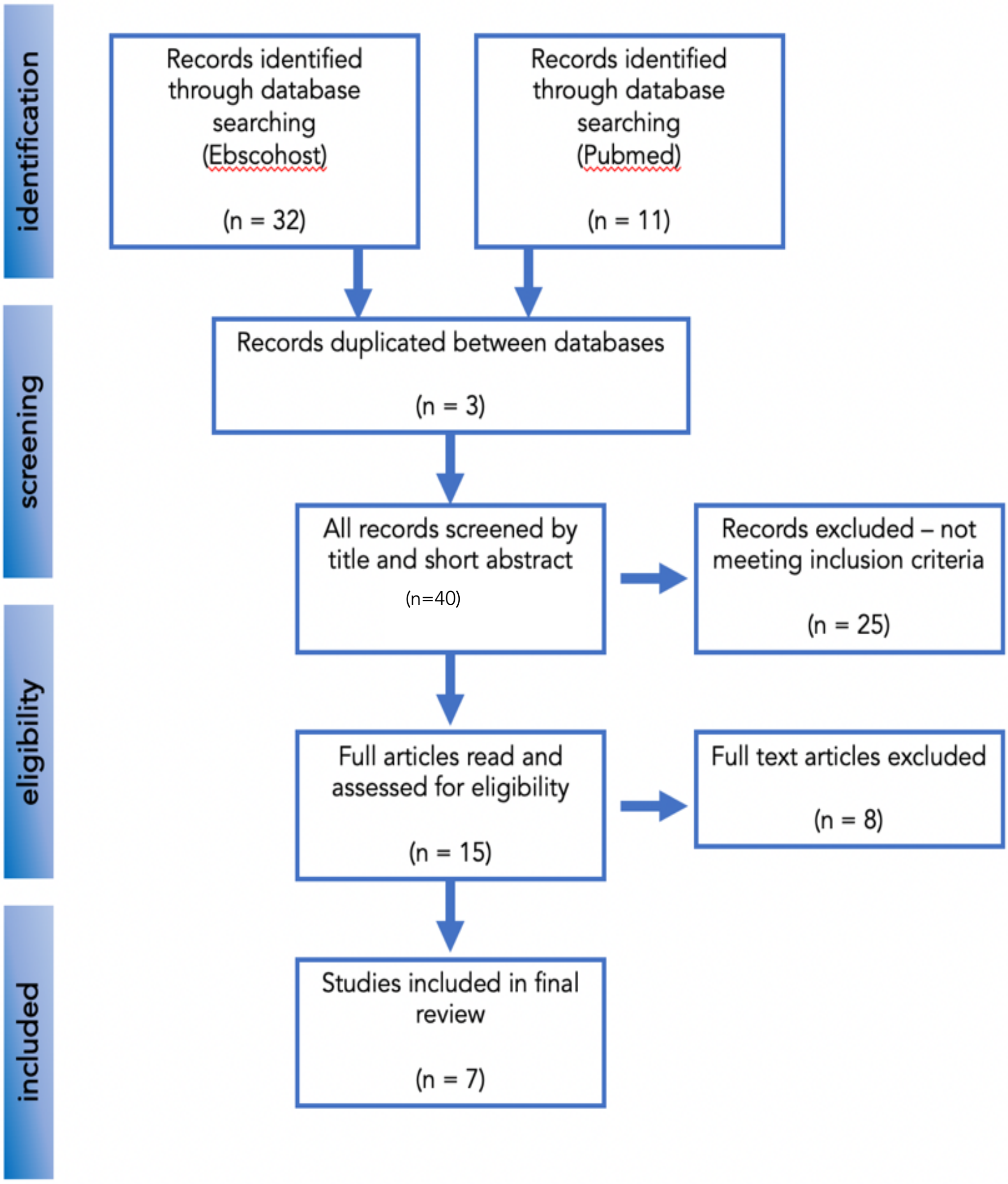


Figure 1
Diagrammatic Representation of The Scoping Review Process

Each included article was read several times by the researcher and research assistant, extracting the findings and entering these on the standard data extraction form. Content analysis was used in the extraction of data from the articles. Content analysis is a process of systematically coding and categorizing large amounts of text in order to find trends and patterns, their frequency, and discourses (Vaismoradi et al., 2013). This method was selected as an initial approach, as the first analysis was guided by the four tenets of self advocacy as suggested by the conceptual framework by Test et al (2005). This was used to form a preliminary coding frame for content analysis of the included documents.

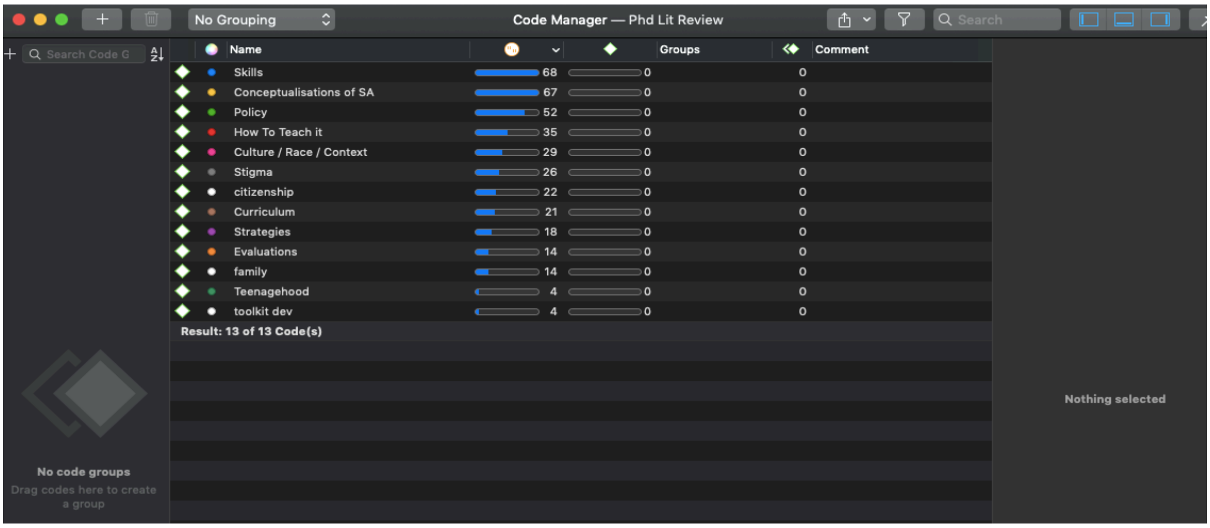
For rigour, an initial hand coding was conducted by the researcher and research assistant which took place in order for both researchers to become immersed in the data and to observe trends. The researcher and research assistant discussed the separate coding of data for the initial three interviews and confirmed consistency in the extraction process.

Following this, the researcher then coded the remaining articles by using qualitative data analysis software, Atlas TI (version 9). No critical appraisal was conducted as it is not deemed necessary for a scoping review (Arksey & O'Malley, 2005; Munn et al., 2018). At this stage, the inductive approach was used where the researcher added emerging themes as they arose. Once the articles had been added to Atlas TI, the initial codes were created, where the analysis began thematically. Relevant chunks of data were placed under each theme. When other emerging categories and themes emerged, using open axial coding, and therefore new codes were initiated for this. Braun and Clarke (2006) provide a six-phase guide on conducting a thematic analysis, which was used in this study. These steps include: familiarise with data, generate initial codes, and search for themes, review themes and codes, and write up.

Articles were excluded that did not focus on intellectual disability, were had an inclusive research design but had no link to self-advocacy or did not meet any of the other inclusion criteria.

Stage 4: Charting the Data

A data extraction form was developed to capture relevant data for the review, including: Authors' name(s), date and setting of study, purpose of study, sample and methods used, findings related to research question and sub-questions specifically, engagement in policy development, strategies for self-advocacy, skills needed to enhance self-advocacy, and availability of tools to assess self-advocacy skills development.



Name		◆	Groups		Comment
Skills	68	0		0	
Conceptualisations of SA	67	0		0	
Policy	52	0		0	
How To Teach it	35	0		0	
Culture / Race / Context	29	0		0	
Stigma	26	0		0	
citizenship	22	0		0	
Curriculum	21	0		0	
Strategies	18	0		0	
Evaluations	14	0		0	
family	14	0		0	
Teenagehood	4	0		0	
toolkit dev	4	0		0	

Result: 13 of 13 Code(s)

An example of an initial coding framework is presented in Figure 2, below:

Figure 2

Coding Frame for Scoping Review

Data Analysis

Each included article was read several times by the researcher and research assistant, extracting the findings and entering these on the standard data extraction form. Content analysis was used in the extraction of data from the articles. Content analysis is a process of systematically coding and categorizing large amounts of text in order to find trends and patterns, their frequency, and discourses (Vaismoradi et al., 2013). This method was selected as an initial approach, as the first analysis was guided by the four tenets of self advocacy as suggested by the conceptual framework by Test et al (2005). This was used to form a preliminary coding frame for content analysis of the included documents.

An initial hand coding was conducted independently by the researcher and research assistant which took place in order for both researchers to become immersed in the data and to observe trends. The researcher and research assistant discussed the separate coding of data for the initial three articles and confirmed consistency in the extraction process.

Following this, the researcher then coded the remaining articles by using qualitative data analysis software, Atlas TI (version 9). At this stage, the researcher inductively added emerging themes as they arose. Once the articles had been added to Atlas TI, the initial codes were created, where the analysis began thematically. Relevant chunks of data were placed under each theme. When other emerging categories and themes emerged, using open axial coding, and therefore new codes were initiated for this. Braun and Clarke (2006) provide a six-phase guide on conducting a thematic analysis, which was used in this study. These steps include: familiarise with data, generate initial codes, and search for themes, review themes and codes, and write up.

Stage 5: Results

The results of this scoping review are reported in chapter four.

B) Methodology: Review of Toolkits – Objective 2

Objective 2: To document local and international self advocates and self advocacy supporters views on potential strategies to improve the inclusion of their priorities in social policy development and implementation.

Introduction

Self advocacy toolkits are compilations of resources which can be personalised to provide self-advocates with the self-assurance, based on knowledge, skills and practice, to confidently advocate for their rights and needs (http://advocacyfocus.org.uk/self-advocacy-toolkit/).

The intention of this review was specifically to identify recently developed self-advocacy toolkits which have been developed by organisations supporting people with intellectual disability who want to self-advocate for their needs. The purpose of this review is to identify examples of strategies currently in use to improve self-advocacy by people with intellectual disability within these toolkits. A secondary aim was to identify supporters who developed these toolkits who could possibly be interviewed at a later stage of the study.

Method

Grey literature is an important source of information, however, there are many characteristics of grey literature that make a systematic search difficult. Accessing online grey literature can be challenging for a researcher, given the vast amount of information, lack of standard indexing and controlled vocabulary, and lack of archiving (Godin et al., 2015).

Godin et al. (2015) recommend that researchers develop a detailed search plan which outlines the resources, search terms, websites and limits to be used, prior to conducting the search.

While no “gold standard” for a methods to conduct a stand-alone grey literature search was found, scoping review frameworks, already include guidelines for the inclusion of grey literature searches. Accordingly, the steps outlined by Arksey and O’Malley (2005), which were also used to conduct the scoping review for this study in Chapter Four, were adapted to derive a search plan for this stand-alone online grey literature review. These steps are as follows:

Stage 1: Identifying the Research Question
Stage 2: Identifying Relevant Documents
Stage 3: Document Selection
Stage 4: Charting the Data
Stage 5: Collating, Summarising and Reporting the Results

Stage 1: Identifying the Research Question

Research question

What strategies are documented in toolkits to improve self-advocacy by people with intellectual disability?

This review also addressed the following sub-question:

a. Which skill components were identified to develop self-advocacy capacity?

Stage 2: Identifying Relevant Documents

Establishing search terms

Through multiple iterations of the search terms, trying out different variations of the following terms, the below search terms were employed for the search:

- “self-advocacy” AND
- “toolkit” AND
- “intellectual disability”

Inclusion and exclusion criteria:

Inclusion criteria

Inclusion criteria for the documents were that they should be:

- a toolkit or tool.

- for people with intellectual disability.
- descriptive of strategies for self-advocacy.

By the very nature of toolkits, skills development is implied, so not specifically noted as an inclusion criteria. Further, as the scoping review confirmed that self-advocacy for policy participation is a still-scarce focus for self-advocacy efforts of people with intellectual disability, the grey literature included was not restricted to toolkits which focused on self-advocacy strategies at policy level, so as to ensure that a broader range of strategies, which might also apply at policy level, were identified.

Exclusion criteria

Exclusion criteria for the documents were:

- about people without intellectual disability, i.e., only physical disabilities.
- not a toolkit, e.g., is a website or a page that links to other pages.
- toolkits not focused on self-advocacy strategies.

Stage 3: Document Selection

The search was conducted on Google on two dates, several months apart to ensure a rigorous search, and to include popular documents up to the last data collection date. The same search strategy was employed on both occasions. This particular objective aimed to identify what occurs at grassroots level in in terms of self-advocacy , and to do so for the most recent literature, given that these toolkits evolve over time, which would not be reflected in the peer reviewed literature, and certain grey literature (case studies, dissertations, government documentation and others).

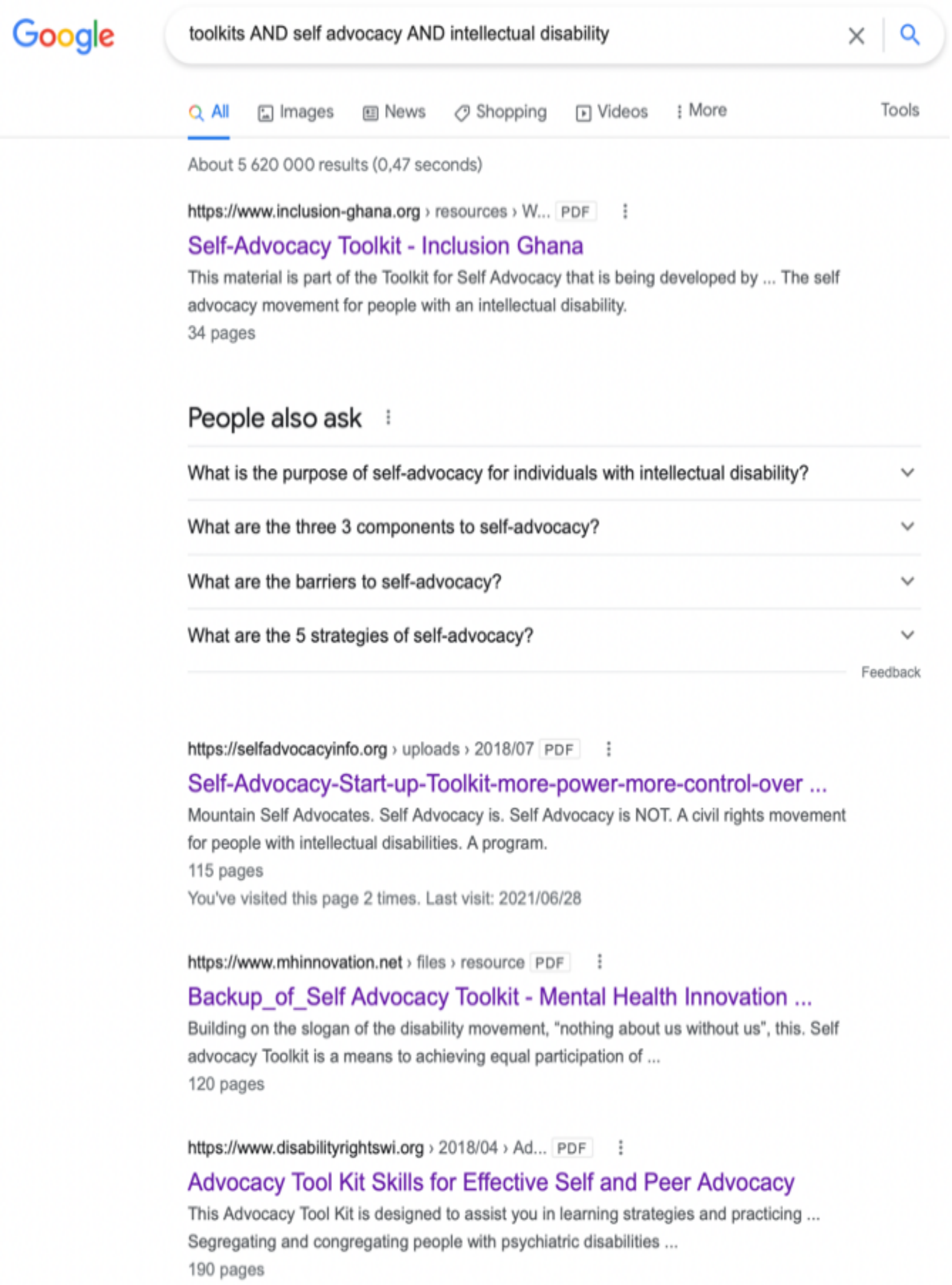
The initial search was conducted on 8 December 2020 and was repeated on 16 June 2021 with the timeframe for the inclusion of documents set as 1 December 2020–30 June 2021.

Links generated were reviewed to ascertain whether content would meet the inclusion criteria. Several of the pages were merely websites and not toolkits and were therefore excluded. This process was conducted systematically, with each webpage being opened and screened before moving onto the next. See **Appendix B** for included links.

There were very few links that were specific to intellectual disability. Often the term "disabilities" was used and only accounted for physical disabilities. The links often accessed specific areas of self-advocacy, rather than learning about self-advocacy itself. For example, toolkits excluded were about "Taking Charge of my Healthcare" or a toolkit aimed at children, "Show them how smart you are".

As Godin et al. (2015) explain, abstracts are often unavailable when searching grey literature, and in this case an executive summary or table of contents was screened. Where screening indicated that the document might be suitable for inclusion, the entire document was then downloaded and an initial full text reading conducted in order to more clearly determine relevance for inclusion. The documents meeting the inclusion criteria were retained. When data saturation was reached, that is, where similar themes and content were emerging across all the toolkits, no further toolkits were downloaded. This process yielded 19 toolkits, of which one, on further review, was found to be a duplicate.

More detailed full text reading of the remaining 18 documents, with inclusion criteria in mind, further refined the documents to be included for the review. Nine toolkits were excluded as they did not fully meet the inclusion criteria. This resulted in nine included toolkits for review.



About 5 620 000 results (0,47 seconds)

https://www.inclusion-ghana.org › resources › W... PDF

Self-Advocacy Toolkit - Inclusion Ghana

This material is part of the Toolkit for Self Advocacy that is being developed by ... The self advocacy movement for people with an intellectual disability.

34 pages

People also ask

What is the purpose of self-advocacy for individuals with intellectual disability?

What are the three 3 components to self-advocacy?

What are the barriers to self-advocacy?

What are the 5 strategies of self-advocacy?

https://selfadvocacyinfo.org › uploads › 2018/07 PDF

Self-Advocacy-Start-up-Toolkit-more-power-more-control-over ...

Mountain Self Advocates. Self Advocacy is. Self Advocacy is NOT. A civil rights movement for people with intellectual disabilities. A program.

115 pages

You've visited this page 2 times. Last visit: 2021/06/28

https://www.mhinnovation.net › files › resource PDF

Backup_of_Self Advocacy Toolkit - Mental Health Innovation ...

Building on the slogan of the disability movement, "nothing about us without us", this. Self advocacy Toolkit is a means to achieving equal participation of ...

120 pages

https://www.disabilityrightswi.org › 2018/04 › Ad... PDF

Advocacy Tool Kit Skills for Effective Self and Peer Advocacy

This Advocacy Tool Kit is designed to assist you in learning strategies and practicing ... Segregating and congregating people with psychiatric disabilities ...

190 pages

Figure 3

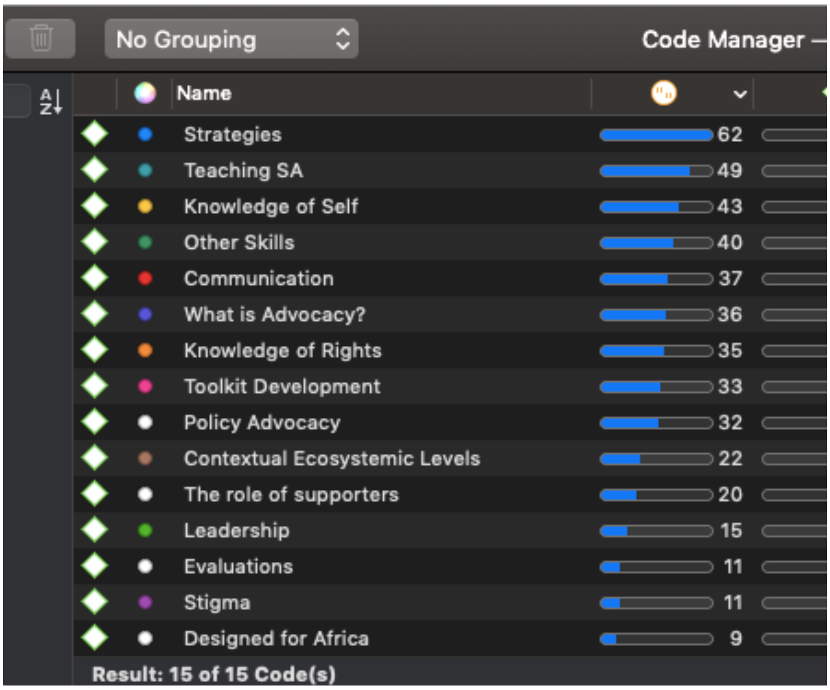
Screenshot of the Toolkit Review Search

Developing a Coding Frame

Much like the analysis used in the scoping review, a dual analysis approach was used in the review of toolkits. For content analysis, the conceptual framework on self-advocacy designed by Test et al. (2005), was used to form a preliminary coding frame for content analysis of the included documents.

While this formed the foundational frame, emerging themes were also noted throughout the process. Each toolkit was hand coded with a highlighter in order for the researcher to become familiar with the content. Vaismoradi et al. (2013) explain that one needs to become immersed in the data, to obtain a sense of the "whole", after which one then spends time opening codes and creating categories of data. Both a deductive, top-down approach and an inductive, bottom-up approach were used in the analysis. The deductive approach was applied by using a prior conceptual framework – the headings provided by Test et al. (2005) as a guideline for coding. In addition, the inductive approach was used where the researcher added emerging themes as they arose. This is evident in the coding analysis above, where the several categories encompass both approaches.

Following this, the researcher then coded the remaining toolkits by using qualitative data analysis software, Atlas TI (version 9). At this stage, the inductive approach was used where the researcher added emerging themes as they arose. Once the toolkits had been added to Atlas TI, the initial codes were created, where the analysis began thematically. Relevant chunks of data were placed under each theme. When other emerging categories and themes emerged, using open axial coding, and therefore new codes were initiated for this. Braun and Clarke (2006) provide a six-phase guide on conducting a thematic analysis, which was used in this study. These steps include: familiarise with data, generate initial codes, and search for themes, review themes and codes, and write up. The final stage, with the data examined and organised, has been described as the charting or reporting stage, where one can see the results as a summary.



Name	
Strategies	62
Teaching SA	49
Knowledge of Self	43
Other Skills	40
Communication	37
What is Advocacy?	36
Knowledge of Rights	35
Toolkit Development	33
Policy Advocacy	32
Contextual Ecosystemic Levels	22
The role of supporters	20
Leadership	15
Evaluations	11
Stigma	11
Designed for Africa	9

Result: 15 of 15 Code(s)

Figure 4:
Coding Frame for The Review of Toolkits

Analysing the Data

Once the coding frame was developed and the initial codes were formed, the toolkits were loaded to the qualitative coding software, Atlas TI. Using the coding frame, and being immersed in the data, allowed for a thorough analysis. Once the toolkits had been added to Atlas TI, the initial codes were created, where the analysis began thematically. Relevant chunks of data were placed under each theme. When other emerging categories and themes emerged, new codes were initiated for this. When other emerging categories and themes emerged, using open axial coding, and therefore new codes were initiated for this. The inductive approach was used where the researcher added emerging themes as they arose. Braun and Clarke (2006) provide a six-phase guide on conducting a thematic analysis, which was used in this study. These steps include: familiarise with data, generate initial codes, and search for themes, review themes and codes, and write up. The final stage, with the data examined and organised, has been described as the charting or reporting stage, where one can see the results as a summary.

The attached diagram is a visual representation of the steps taken in the review of the toolkits.

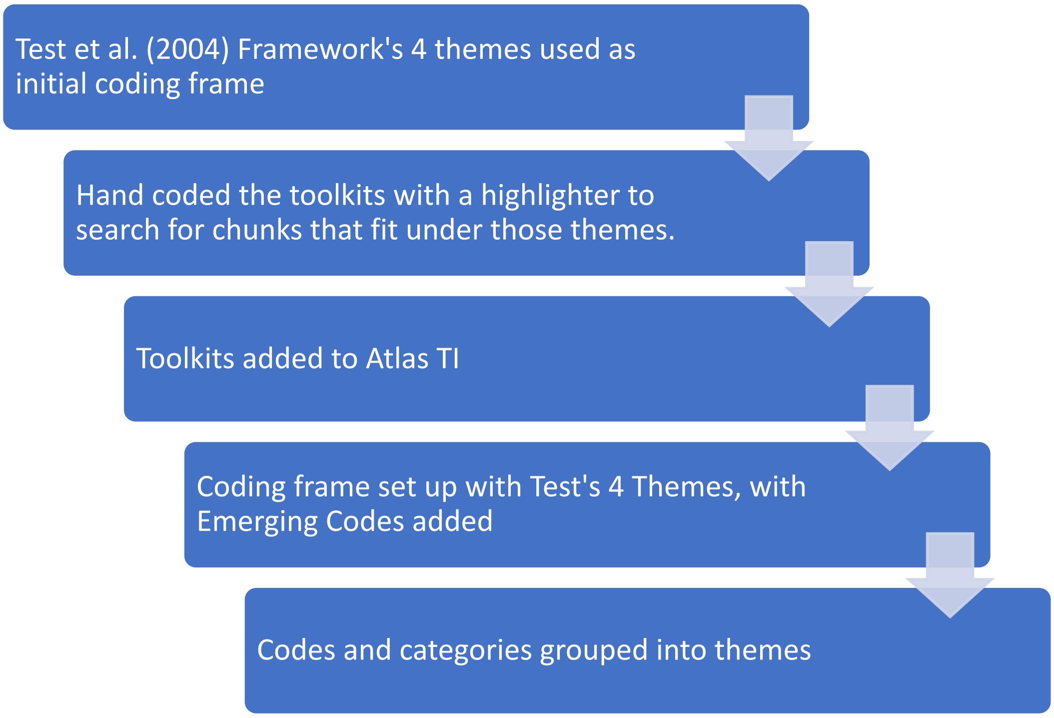


Figure 5:
Stages of Analysis for the Review of Toolkits

Stage 4: Charting the data

A data extraction sheet, below, was developed to extract relevant information from the analysed toolkit data, summarising the key elements of self-advocacy strategies recommended and utilised in the sourced toolkits, as well as the skills which the toolkits aimed to develop in self-advocates.

Data Analysis

Vaismoradi et al. (2013) explain that one needs to become immersed in the data, to obtain a sense of the "whole", after which one then spends time opening codes and creating categories of data. Both a deductive, top-down approach and an inductive, bottom-up approach were therefore used in the analysis. The conceptual framework on self-advocacy designed by Test et al. (2005), was used to form a preliminary coding frame for content analysis of the included documents. The 4 elements of Test et al's (2005) conceptual model are: knowledge of rights, knowledge of self, communication and leadership.

This coding framework was loaded to a qualitative data analysis software programme, Atlas TI (version 9). As a first step, each toolkit was hand coded with a highlighter in order for the researcher to become familiar with the content as a whole. Data content was then deductively coded to this a prior coding framework. During the process of coding, where additional content were found which did not fit with this initial coding framework based on this conceptual model, these additional themes were inductively added by the researcher, working through all the toolkits till all 9 were analysed in this way.

Once the toolkits had been added to Atlas TI, after the initial codes were created, the analysis began thematically. Relevant chunks of data were placed under each theme. When other emerging categories and themes emerged, using open axial coding, new codes were initiated for this. Braun and Clarke (2006) provide a six-phase guide on conducting a thematic analysis, which was used in this study. These steps include: familiarise with data, generate initial codes, and search for themes, review themes and codes, and write up.

Stage 5: Results

The final stage, with the data examined and organised, has been described as the charting or reporting stage. This can be found in Chapter Five.

C) Methodology: Interviews – Objective 3

Objective 3: To document local and international perspectives of key informants with and without intellectual disability, self advocates and self advocacy supporters, with regards to people with intellectual disability participating as self-advocates and potential strategies suggested for self-advocacy.

Research Design for the Interviews

This style of research was conducted from the perspective that multiple realities are represented in participant perspectives, and that context is critical in exploring and understanding the phenomenon being investigated, taking a deep dive into the lived experience of the people who experience the phenomenon (Reiners, 2012; Frechette, Bitzas, Aubry, Kilpatrick, & Lavoie-Tremblay 2020; Beyer, 2022; Creswell, 2003 McMillan, 2016). Qualitative analysis provides an appropriate means of deriving meaningful interpretations of the text collected during these interviews (Creswell, 2003).

Context is critical in exploring and understanding the phenomenon being investigated (McMillan, 2016). Qualitative analysis provides an appropriate means of deriving meaningful interpretations of the text collected during these interviews (Creswell, 2003). This type of research guided by a phenomenological lens, like other qualitative research, can apply many methods including interviews, observations, action research, discussions, focus group meetings and analysis of the text (Beyer, 2022). As per the nature of phenomenology and the enquiry into the phenomenon of being a self advocate, it is clear why interviews with key stakeholders has provided a more in-depth understanding of this phenomenon (Reiners, 2012, Beyer, 2022). These interviews provide insight into the lived experience around self advocacy.

Study Population and Sampling

Key informants with and without intellectual disability were sought from various organisations and various locations locally and internationally. Commonly in qualitative research, an emphasis is placed on data saturation, so while a range of six to eight participants was estimated for inclusion, it was planned to interview until no new information was gleaned (Palinkas et al., 2015).

Inclusion and Exclusion Criteria

Key informants identified for inclusion were:

a) Self-advocates with intellectual disability (i.e., at any stage of participation in advocacy), who were:
    - 18 years and older, or the age of majority of their country (perhaps 21 years old).
    - Able to understand the research study aims and their participation in the study (see informed consent procedures).
    - Able to communicate verbally in English, Afrikaans or IsiXhosa.
    - Willing and able to participate in individual interviews.
    - Not experiencing an episode of mental and emotional distress at the time of the interview.
    - A self-advocate or have done some work speaking and writing about issues of public service provision for people with intellectual disability.

b) Professionals or trainers or supporters (personal or professional) or organisational workers involved in self-advocacy training of people with intellectual disability who were:
    - 18 years and older, or the age of majority of their country (perhaps 21 years old).
    - able to communicate verbally in English.
    - involved in the training of self-advocacy for people with disability, including intellectual disability.

Recruitment

Purposive, criterion sampling was used, as each participant needed to fulfil certain criteria, outlined in the inclusion criteria section, above (McMillan, 2016). Site visits for field work to local organisations were planned as part of the recruitment strategy, but in light of the international and national restrictions on travel due to the Covid-19 pandemic, this made recruitment more challenging. There were protocols planned for these site visits, but this was not possible at the interview stage of this study. It was also hopeful that, during the course of the interviews, it would be possible to visit one or two of the national sites or an international site, but unfortunately this was not possible due to lockdown conditions. The aim of this would have been to observe the self-advocacy activities (as a participant observer) that these organisations may be using in action to identify practical strategies, and to develop insights which would guide the development of the toolkit for this research.

The original recruitment strategy also included using snowballing to identify subsequent key informants who could be approached, but it proved exceptionally difficult to access participants through this strategy because of the national lockdown. All of the toolkit creators from Chapter 5 were contacted to invite for the interviews, one replied. This was the first interview conducted. Then due to the lack of response from other toolkit creators, another strategy was needed, and the researcher needed to adapt in line with the constraints imposed by the global pandemic.

The researcher joined a number of Facebook groups, which catered to Self-Advocates with Intellectual Disability. The researcher then posted about the nature and aim of the study, inviting interested community members to contact the researcher, by commenting on the post, or sending private messages, for more information, or to note that they wanted to participate in the study. Several interested international participants stepped forward and initiated contact. In addition, local professionals shared the post with their organisations and more people offered to take part.

Interested individuals were then contacted individually to confirm interest, assess eligibility for inclusion and to obtain consent for their participation in the study. Consent form and information sheets attached as **Appendix C and D**. As such, two interviews occurred in person, and five were done online via Zoom or Skype. Nine key informants were recruited and interviewed for the study in seven interviews. Two interviews had more than one participant.

The participants who are self-advocates were selected for interviews if they had personal experience of self advocacy, and were able to communicate this experience themselves (as indicated in inclusion criteria on page 55). These participants were invited to have a personal supporter join them for the interviews to assist them where needed. Only one supporter in the interview process required his supporter, his mother, to attend, to assist him with the setup of the technology used for our online conversation, as well as to clarify points made by the participant whose speech was unclear to the researcher at times. Her primary role, was that of supporting her son to share his own views, and hence there was no analysis of their data as separate. All interviews were conducted in English.

Data Collection Tools

Semi-structured interviewing was used, as interviewing allows for a detailed exploration of participants views and experiences. In addition, a phenomenological interview is structured in a way which aims to understand a person's perspective, and for this study, the importance of narratives and storytelling was paramount, giving people with intellectual disability the space to discuss their lives and contribute to research (Corby et al., 2020).

Data Management

All information for the study has been backed up onto a secure hard drive in a password protected folder, as per the data management plan (**Appendix A**).

Interview Schedule

The interview questions were developed by the researcher based on the findings of both the scoping literature review and the grey literature review of toolkits. The interviews aimed to explore the key perspectives which impact self-advocacy for people with intellectual disability.

In similar studies with similar populations, the researchers started with what was known and concrete, and moved to more abstract concepts (e.g., Cartwright et al., 2015; Moyson & Roeyers, 2011), a method of enquiry particularly suited to people with intellectual disability. It is common to use open-ended questions in these interview schedules to facilitate storytelling and a greater understanding of the nuances of perspective and experience of participants (McMillan, 2016). Questions were therefore structured in such a way as to elicit the participants' experience of self-advocacy through open-ended questions. See **Appendix E** for the interview questions.

Informed Consent Procedures

Information sheets and consent sheets were used throughout the interview process. Each participant was briefed about the purpose of the study and how the data could be used in the future, such as for presentations and publications. Informed consent was obtained from the participants themselves, those with and those without an intellectual disability, as they are over 18 years old. The informed consent document (**Appendix C**) included a statement that the participants could refuse to participate in the study or withdraw at any time. Before they consented, the participants were briefed on the fact that a transcriber would potentially hear their interviews.

As the researcher planned to do the audio transcriptions herself, in order to familiarise herself with the content and potential themes within the interviews, but as a provision, due to limited time for the conduct of the study, a clause was added to the informed consent sheet. This clause was included so that a transcriber could assist should this become necessary. In the conduct of the study, the researcher was able to transcribe six of the interviews, and then the transcriber was recruited for the final three interviews.

The informed consent form was read out loud to each potential participant with intellectual disability if required, and a series of questions was asked to assess participants' understanding of the research and their potential participation, and whether they were able to freely exercise their right to participate, or to decline participation (Horner-Johnson & Bailey, 2013):

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

7. What do you think I will be doing with the information I get from you?

Pilot Interviews

Two pilot interviews were conducted with key informants to assess time taken for the interview, whether the interview schedule was appropriate and understood, and whether the questions adequately elicited data which informed the research questions. This informed any changes, additions or amendment of the draft questionnaire, the length of the interview, the researcher stance and the context within which the interviews took place in the interests of improving the depth of data collected from the participants. The first pilot interview was with two professionals who had created a similar toolkit, and the second pilot interview was with a self-advocate and self-advocate supporter.

The question schedule seemed to adequately facilitate an interview which addressed the research questions. The time taken was appropriate, and therefore, no changes were made to the interview schedule, and the pilot interviews were included in the dataset.

Data Collection

All international interviews were conducted with people whose first language is English. The local interviews with key informants in South Africa were also conducted in English, and although several participants' first language was not English, they were all fluent in English. Interviews were recorded with respondents' permission. Interviews took place between March 2021 and June 2021.

After the interviews the researcher took notes of key themes which had emerged during the interviews. This was to add rigour when considering the theme-building stage of the analysis of the transcribed interviews. The researcher also wrote up impressions of the quality of the data from each interview at the conclusion of the interview for audit purposes.

The researcher transcribed the interviews verbatim. Six of the interviews were transcribed by the researcher. The final three interviews were transcribed by an external transcriber, who signed a confidentiality agreement (**Appendix G**). This information has been backed up onto a secure hard drive in a password protected folder, as per the data management plan (**Appendix A**).

The service provider and NGO community in South Africa, which were involved in this study, is relatively small, and organisations and individuals may be identifiable if care was not taken to anonymise their participation (however this has been noted in the informed consent sheet – **Appendix C**). Procedures were taken to ensure that participants felt comfortable that their views would be kept confidential, and their identities protected. Participants in the interviews were allocated a number-identity before being sent for transcription, with a list of personal details of participants kept under separate storage by the principal investigator. Care will be taken to anonymise the participants in papers and other outputs using quotations.

Data Analysis

Braun and Clarke (2006) provide a six-phase guide on conducting a thematic analysis, which was used in this study. These steps include: familiarise with data, generate initial codes, and search for themes, review themes and codes, and write up.

Once the pilot interviews were conducted and transcribed, the researcher, along with a research assistant, independently coded two of the interviews. Open axial coding was conducted, and common ideas and themes arose. The researchers then met to discuss the findings, and compare and contrast codes, categories and initial impressions of themes. Upon discussion, common codes and general categories were identified. Once a general coding frame was developed, the researcher continued to do the coding of the remaining nine interviews. Both preliminary hand coding and a thorough coding analysis were conducted using Atlas TI, a qualitative coding analysis software.

An inductive thematic analysis of the transcribed interviews was conducted. The goal of an inductive thematic analysis is to identify themes that emerge and patterns that present from the data, so as to identify data related to answering the research question or a particular issue, as may be relevant to the focus of the study’s research question(s) (Maguire & Delahunt, 2017).

The thematic analysis found codes, categories and themes that emerged. Transcriptions were read through several times by the researcher to obtain an overall view of what themes might be emerging from the data.

D) Methodology: Toolkit Review – Objective 4

Objective 4: To develop a self-advocacy toolkit with people with intellectual disability to promote their participation in social policy development and implementation processes in South Africa.

Introduction

Toolkits with activities and discussions are an excellent method for creating a space to learn. A toolkit can be designed to assist a person in learning strategies and practicing certain skills so that they feel comfortable and confident as self-advocates (Disability Rights Wisconsin, 2007).

Method

Toolkits with activities and discussions are an excellent method for creating a space to learn. A toolkit can be designed to assist a person in learning strategies and practicing certain skills so that they feel comfortable and confident as self-advocates (Disability Rights Wisconsin, 2007).

Developing the Toolkit

The scoping literature review did not identify a “gold standard” to inform the development of a toolkit, nor did it identify any standardised assessment tools that could be applied to evaluate the utility of a toolkit of this nature.

As no guidance for a development process was identified through the scoping literature review and the grey literature review, several Google Scholar searches were conducted to identify a process which could be used to guide the toolkit development process, using search terms as “toolkit” AND “development” , “toolkit development” AND “intellectual disability”, “toolkit development”, “toolkit guidelines”, “toolkit creation” and “how to develop a toolkit”. Only one website was identified through this process which provided a clear step-by-step guide to developing a toolkit which seemed compatible with the aims and objectives of this study. This website had developed a toolkit for youth who are part of the LGBTQIA+ community who are experiencing homelessness (retrieved Feb 2021 from http://lgbtq2stoolkit.learningcommunity.ca/guide-to-creating-toolkits/). This work was also based on research with a vulnerable and marginalised population, with the process resonating well with aims, ethos and processes planned for the production of a similar tool for this study. The toolkit development process outlined includes the following five steps:

1. **Conduct an environmental scan**: What other toolkits exist?
2. **Include your key stakeholders in the process**: Engage people who have insight into the issues related to the programme being developed, as well as people who will participate in the programme and other key external stakeholders.
3. **Curate programme materials**: Determine what content is most relevant and clearest to depict a key topic in your toolkit and analyse potential accessible resources and tools to include in the toolkit.
4. **Use clear and concise language**: Text should be the minimum required to make our point. Key terms should be defined, and if possible, jargon and acronyms should be avoided.
5. **Consider appropriate design and layout:** Text should be divided into meaningful sections with headings. Images and audio-visual material can be used to break up long sections of text. Key term tags can be used to make your toolkit easy to search and scan specific aspects of the toolkit.

Table 3.2 below summarises the process followed to develop the current toolkit using the five steps.

Table 3.2

Five Step Process to Developing the Toolkit

Steps	Actions Taken
Environmental Scan to identify the current trends in strategies for self-advocacy for people with intellectual disability	• Conducted Scoping Literature Review to identify strategies for self-advocacy. • Conducted Grey Literature Review of available toolkits to identify strategies for self-advocacy to include in the toolkit, and methods to develop toolkits.
Include your key stakeholders in the process	• Conducted Interviews with key stakeholders included in that step above – barriers to participation identified, tools for change identified, as well as potential avenues and strategies for change.
Curate programme materials	This chapter: • Triangulates the three sources of information and finds key categories and themes. • Decides what themes and related ideas, content and activities would be important to retain, and which could be excluded. • Collate the prioritised materials into a first draft of the toolkit. • Once materials were curated, organise them into sections with important headings.
Clear and concise language	• Key ideas were refined and important terms defined. • The principles of using short and simple sentences accessible to people with intellectual disability were applied in choosing and refining copy for the toolkit. • This was confirmed through member checking by sending the draft to the interview participants. • A verification of the suitability and accessibility of the toolkit content was also conducted with a group of young people with intellectual disability.
Design and layout	• The materials were then designed, using headers, images and videos to break up long text. • The final version of the document was then transferred to an online platform called Canva. • This was also discussed by the experiential review participants in both the interviews as well as the focus group in terms of changes to be made to make it more accessible

	• A verification of the suitability and accessibility of the toolkit content was also conducted with a group of young people with intellectual disability.

Triangulation of Study Findings and Content Inclusion Process

The process of triangulation for the topics to be included occurred by looking at the findings of each chapter, and comparing and contrasting the results. The three sources of information were triangulated and tabulated. This was initially hand coded to search for categories and themes, after which a table of topics, was developed. Several iterations of the process of comparing and contrasting and documenting the findings in the table were used to finalise the table. This process was an ongoing journey of revisions and additions. The research assistant assisted with the sourcing and curation of the materials to be included in the initial drafting of the toolkit. All subsequent activities in finalizing the toolkit (seeking input from participants on the toolkit, conducting and interpreting responses to the experiential review of the toolkit) was done by the researcher.

Tidey et al. (2022) suggest several principles for the practical implementation of a toolkit for people with intellectual disability. The principles and recommendations put forward by the authors are around active involvement of people with intellectual disability (co-creation and co-facilitation), the use of multimodal education materials, a practical, hands on, implementation strategy (tools such as role play, art, drama or painting), gaining insights from the service users themselves, flexible lesson plans to accommodate for emerging themes, awareness of the needs of the participants (bathroom breaks, snacks, plain language, etc.), and considering the evolving nature of a programme like this, to meet universal design trends and change over time (Tidey et al., 2022). These principles are helpful to consider when in the toolkit review process.

The content of this first toolkit focuses on the most commonly identified skills in the research. More specific content has not been included for the more complex individual skills. An example is money management, or learning to read, as in order to learn about money, or literacy, a whole separate toolkit will be needed. As seen in the table below, a number of topics identified were found in only one of the study chapters. These specific skills may need separate, specialist toolkit development for those who want to, or need to, learn specific skills.

Member Checking

The draft toolkit was then reviewed in order to see if it adequately reflected the viewpoints raised in the interviews and encapsulated the data from the scoping literature review and review of toolkits. Member checking took place through two processes, firstly the review by the key informants who were interviewed in Chapter Six, and secondly, the toolkit was reviewed by a new group of young people with intellectual disability, the recruitment of whom will be described below under *participant reviewers*.

Feedback from Interview Participants

Once the toolkit materials were compiled, the researcher sent the first draft to the participants (key stakeholders) from the interviews (Chapter 6) for member checking, review and feedback. The draft was send via email and WhatsApp to the participants for review, along with the questions below, as they had previously given consent to give feedback to the toolkit. Using Whatsapp as a medium was selected as the participants had expressed that many of them come from home with lower incomes, and therefore do not have access to emails and have limited data. Commonly in this context, Whatsapp is used as a main communication platform.

Responses were via email or WhatsApp, and are documented in **Appendix F**. Elements that were positive were recorded, and items that needed consideration were also recorded in the table. Changes and adaptations that were suggested were made prior to the toolkit review process.

Toolkit Review Process by People with Intellectual Disability

As no formal evaluation tools were found in the scoping literature review, the review of existing toolkits, or the interviews, it was necessary to consider how best the process would be assessed. Godin et al. (2015) noted that at best, most evaluations of toolkits are conducted via qualitative questionnaires or enquiry. Cox et al. (2021), in their study to support the delivery of good maternity care for parents with intellectual disability, conducted a two tier consultation to elicit feedback about best practice. The authors consulted key stakeholders (professionals, and people with intellectual disability and their supporters) in an interview process to understand their views of best practice. Following that, the healthcare professionals engaged with the resources and received feedback through an online survey or discussion group.

A similar method was used in this study, in that a two tiered approach was selected, interviews before and after the exposure, as well as a focus group.

Short interviews were conducted before and after a process with a new group of participants who were engaged in an experiential exposure to the toolkit. This aimed to look at knowledge and understanding before and after they experienced the toolkit. In addition, a focus group session was held at the end of the experiential period, which aimed to obtain participants' views about the activities selected, the duration of sessions, the accessibility of the toolkit, from language to font use and colour choices. The focus group sessions were structured around the toolkit, and the group went through each toolkit activity and gave feedback on each session. This feedback was critical, as gaining the perspectives of people with intellectual disability who had hands-on experience of the toolkit was paramount to finalising the current toolkit as a baseline offering. This may need future revisions to activities and delivery to be responsive to specific self-advocacy focal points for training of self-advocates with intellectual disability. The methodology utilised at these points in the study will now be explicated. The following points will describe the methodology of the toolkit review process and the data collection:

Setting

The experiential toolkit review took place in a community-based setting in the Western Cape, South Africa. The NGO, situated in Maitland, a suburb on the outskirts of Cape Town, is a non-profit organisation that provides a programme for young adults with intellectual disability regardless of race, gender and religious background (NGO name and website URL are not provided to maintain anonymity). The organisation aims to encourage, enhance and support the development of adults with intellectual disability, helping them attain a high quality of life.

There are training centres in both Johannesburg and Cape Town. The minimum group size for the training is six participants, although the average group size is 10 trainees. Trainees need to be between the ages of 18 and 35 years old. In the Johannesburg branch, which opened in 2000, there are two different courses, a short-term and long-term course.

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

- The candidate is between 18 and 35 years old.
- The candidate can understand basic English.
- The candidate's intellectual disability is classified as mild.
- The candidate is required to obtain a score of 13 or above on the Montreal Cognitive Assessment (MOCA) and have basic life skills.
- The candidate has potential to thrive in the open labour market.
- The candidate must be able to understand and agree to the terms and rules of the NGO, and sign a participation document when he or she begins the course.

Management of the NGO gave permission for the researcher to use their context to host the toolkit review process. The physical space used was a classroom-style space, with desks, a projector, as well as a canteen area with communal spaces for teatime breaks.

Participant reviewers

Participants for the toolkit review process were students of the above programme at a local NGO. There were 10 students enrolled in the programme at the NGO at the start of the toolkit review process, but due to Covid-19 restrictions, and absenteeism, only seven of the participants attended all the sessions of the toolkit review. This resulted in seven people who agreed to be consulted and who completed all of the toolkit review sessions.

Informed consent

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

Informed consent was obtained from the participants themselves, as they are over 18 years old. The informed consent document included a statement that the participants could refuse to participate in the study or withdraw at any time. The participants were briefed on the fact that a transcriber could potentially hear their interviews before they consented. It was noted after reading the informed consent form that all participants clearly understood what was required of them and what the process would entail.

Interviews before and after the toolkit experience

The individual intake interviews that were conducted before the experience of the toolkit aimed to gain an understanding of the participants' current level of understanding of self-advocacy. The participants were invited into a separate room where the questions were asked, and their open-ended answers were recorded. The same set of questions were asked in a similar setting after the six-session experiential exposure to the toolkit.

The questions that were asked were:

- What do you think self-advocacy is?
- Can you think of a strength, and weaknesses of yours when dealing with other people?
- What do you know about "human rights"?
- Can you think of anything unfair in South Africa?
- If you wanted to spread a message, what strategies could you use? How would you do it?
- Why is communication important?
- If you could share one message with the president, what would it be?

These questions aimed to elucidate their understanding within the components of self-advocacy addressed in the previous chapters.

Experiencing the toolkit

Six sessions were held for the toolkit review process. These sessions were run for a period of four hours per session, with regular breaks between activities. Sessions started at 8.30am and finished at 12.30pm. The toolkit activities were run, using mixed modalities of information giving, video watching, group discussions and individual tasks. One of the tasks for the toolkit was for the group to decide on an issue of justice that they would like to self advocate for. The strategies that emerged in the toolkit review were voted on, one being selected as the strategy of choice. In this case the participants decided to make a video about the issues that face people with intellectual disability in South Africa. More information is under Chapter Seven.

Focus group

After the toolkit experience was complete, a focus group was conducted. The focus group consisted of all the participants sitting together in the communal lounge and going over the toolkit. The following questions aimed to elucidate the perceptions of the participants, by using simple language, and prompts to facilitate general discussion.

Examples of open-ended questions were posed, such as:

- Which parts did you like?
- Which parts were difficult?
- Did you have a favourite activity?
- Was the text easy to read, or could it be different colours or sizes?

Despite having prompting questions, a general discussion was held about the process, led by the participants themselves. After this general discussion, where the researcher took notes, one participant suggested that in order to do a thorough review, it would be ideal if the group went over the toolkit page by page and commented on each activity. This idea was supported by the group. Therefore, an in-depth review was conducted, and detailed notes were taken, as feedback was given to the researcher.

Researcher observations

The researcher journaled her impressions after each toolkit session. Emerging themes and categories were noted, as well as whether the activities elicited the desired outcomes, how the participants were responding and their perspectives on the tools. The analysis and findings are detailed below. There were moments when, as the researcher, my clinical reasoning and judgment required me to adapt to the emerging needs of the group. Examples of this is when the group seemed to be losing focus, or were not understanding the activity as intended. One adaptive strategy suggested by participants to address issues of focus was to use more videos instead of information giving, to allow for more discussions, to shift the order of activities, and to allow for more time for recap sessions.

Data Analysis

Analysis of Interviews

The initial interview questions were asked, and the answers were written down. The answers provided by the participants to the interview questions that were asked were tabulated. The discussion points and answers before and after were noted and compared qualitatively. A comparison was noted between the two. Notes were taken as to trends and themes that emerged in this process.

Analysis of Focus Group

The focus group information not only provided an opportunity for validation of the researcher's analysis and observations of the data, but also provided additional insights on the activities to include or exclude from participants' perspectives. Notes were taken during this session, with permission of the participants, which were analysed for inclusion in the dataset, in order to make revisions to the existing toolkit.

Overall Study Ethical Considerations

The study, at all times, adhered to the guidelines of ethical considerations outlined in the Declaration of Helsinki (World Medical Association, 2013). Ethical approval for the study was granted from the University of Cape Town, Faculty of Health Science, Human Research Ethics Committee, Ref 850-2020.

Potential risks for participants in the course the study

This study involved no physical risk, and no significant emotional risk was envisaged or encountered.

Distress Protocol

In the unlikely event that questions and discussions would have evoked any discomfort, in either the interviews or the pilot study, the researcher planned to address these concerns in a non-judgmental manner and evoke the plan from the distress protocol **(Appendix K)**. While the researcher is also a mental health clinician, as is the study supervisor, a proposed plan of action was developed.

Should any issues of distress be identified in the research, it was ensured that there were mental health professionals available for debriefing and further referrals who was on standby for the duration of the study. These are experienced Telehealth professionals who could assist local or international participants. The aims of these debriefing or support sessions would be for containment and to support the participant in assisting them to think through who they could approach in their community for further support if needed.

The steps identified were in line with what is commonly done in qualitative research (Draucker, Martsolf and Poole, 2009; Haigh & Witham, 2015). The steps identified should there be any distress were: 1) identify distress 2) stage 1 response: stop the interview and offer immediate support 3) review if participant is willing / able to continue. If not then move to number 4. 4) stage 2 response: set up a debriefing space for the participant with one of the mental health professionals on standby, where discussions will be held to support them in accessing local services for ongoing support where needed. 5) follow up with the participant.

The project was supported by clinician-researcher supervisors with experience in working with people with intellectual disability, and the research team as a whole was supported by an advisory committee of experienced clinicians and researchers, which included self-advocates with intellectual disability to provide oversight to the ethical conduct of the study.

Confidentiality

The lead researcher ensured that all data collected were securely stored. The names of the participants have been removed from the data set, ensuring that no private information is shared. All audio recordings were kept in a safe place and only the researchers, transcribers and research supervisors had access to these recordings. All notes were filed in secure folders on password protected devices.

Informed consent procedures

The informed consent forms and information sheets were emailed to key informants for the interviews. They were asked to sign digitally where the interviews were conducted online. For the pilot study, the consent forms were filled out manually. For both components, each participant was briefed and told why they were being asked to participate in the study, and were given an information sheet explaining the purpose of the study and how the data could be used in the future, such as for presentation and publication. Informed consent was obtained from the participants themselves, as only adults were included as participants. Both key informants with and without intellectual disability were asked to sign for their participation independently, as the nature of this study is about self-advocacy. This study did not include people with diminished capacity to the extent where they would need supported signing. More information can be found in each section in the thesis.

Considerations of Rigour in the study

Poggenpoel and Myburgh (2003) highlight the importance of reducing researcher threat to trustworthiness by spending time adequately preparing, ensuring reflexivity, staying humble, and working with other team members, such as co-researchers supervisors and peers, for triangulation, checking in and feedback. A reflective stance does not remove the potential of my own sensibility in the world to impact on my understanding and interpretation of the study data, necessitating active explication of measures that have been used in the research to assist me to understand and interpret participants' lived experience in a trustworthy manner. Several strategies have been engaged to assist me to ensure that the findings and interpretations of the findings are as accurate a representation of the views of participants and others with whom have engaged in the process of understanding my work in this study.

In keeping with the interpretative phenomenological stance to the research, the considerations of rigour for this study have been accounted for through the frameworks designed by De Witt, & Ploeg (2006), Sandelowski, (2006), Anney (2014) and Baillie (2015), who put together guide on ensuring the quality of the findings of qualitative research, by looking at trustworthiness criteria (De Witt, & Ploeg, 2006; Sandelowski, 2006).

Confirmability

This refers to the degree to which the results of the analysis process would be similar if conducted by other researchers. Pilots of data extraction processes were conducted (construction of coding frames and analysis of transcriptions) using two researchers to improve consistency of data analysis (Anney, 2014). A research assistant was recruited who did the coding of the first two interviews as well as reviewing the articles for inclusion in the scoping review. This research assistant has completed her Master's degree in inclusive education, with a special interest in inclusion, disability and teaching. This was approved as part of the ethics approval.

Credibility

Credibility relates to the confidence that can be assumed regarding whether the research findings represent a realistic interpretation of the original data, and whether there is confidence in whether the findings are truthful and accurate (Anney, 2014; Lincoln & Guba, 1985). This was addressed as follows:

- Prolonged Engagement in Field or Research Site: The researcher has five years' experience working at the adult education site at which the experiential assessment of the completed toolkit took place, which has assisted in gaining insight into the context, participants, and culture, and minimizing the risk of distorting information.
- Reflexivity: A journaling diary was maintained by the researcher, with regular entries to ensure that there was an audit trail of decisions taken during the study. These field journals were maintained in order to reflect on the process, as well as on issues that might have arisen and might have influenced the researcher's perspective on respondents and their responses, and impacted on her interpretation of the data (Anney, 2014).
- Expert Advisory Team: An advisory team for the project was established to provide technical support and expertise to promote rigour for this study by reviewing various aspects of the conduct of the study, including regular advisory committee meetings to ask questions and get advice on parts of the study.

- Triangulation: Triangulation of the findings of the scoping literature review, the review of existing toolkits, as well as the interviews provided evidence informed strategies for inclusion in the toolkit.
- Member Checking: This strategy allows participants to provide feedback on whether the research findings accurately reflected their intended input. Specifically, participants provided emailed comments and in-person feedback in a focus group discussion on whether they agreed with the findings represented in the toolkit and on what needed to be changed. This was achieved through emailing the toolkit to participants for feedback, as well as having a focus group discussion.

Dependability

Dependability involves an assessment of the quality of the processes for integrating data to ensure consistency in the processes (Baillie, 2015). The researcher recorded an audit trail of research decisions and activities (Anney, 2014), and these were reviewed in supervision and at expert advisory group meetings.

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 to provide a detailed view of the research context, settings, timeframe, participants and procedures provided information to assess whether the current study could inform studies in other contexts.

Data Management

The University's data management policy (University of Cape Town (UCT), 2018) informed the study's data management plan, as follows (see **Appendix A**):

All data were stored on a secure laptop that is password protected. All information was backed up onto a secure hard drive in a password protected folder. Data were collected through: the scoping review, the review of existing toolkits, the interviews and focus group. Participant interview recordings were allocated a numbered identity before being transcribed, with a list of personal details of participants kept under separate storage by the principal investigator.

All data has been stored within a secure data repository within the Department of Psychiatry and Mental Health, UCT. The project will retain data for the exclusive use of the project for a period of no longer than two years following completion of the project to complete publications and other products which may be possible. The data will be stored for a period of five years after the conclusion of the study.

Chapter Four

Results of the Scoping Literature Review

Introduction

This chapter details the results of the scoping review, Objective 1, which aimed to identify strategies for people with intellectual disability to self-advocate, with a specific focus on their influencing social policy development and implementation.

As Arksey and O'Malley's (2005) Stages 1-4 were outlined in the Chapter 3 Methodology section, and therefore this chapter will focus on the results of the scoping literature review (Stage 5). This chapter will start by showing the table which collates the findings and then will move on to the results found. Then the chapter will continue with the discussion of the findings.

Characteristics of the Included Studies

In Table 4.1, the characteristics and findings of included studies are presented.

Author	Year	Title	Journal	Aim	Methods	Findings			
						Engagement in policy development and implementation	Strategies for self-advocacy identified	Skills identified	Evaluation tools
Petri, Beadle-Brown, & Bradshaw	2020	Redefining Self-Advocacy: A Practice Theory-Based Approach	Journal of Policy and Practice in Intellectual Disabilities	To look at the ways self-advocates with intellectual disability participate in the broader social movement of people with disability.	Data collected from 43 advocates and self-advocates with intellectual disability. 8 of the participants had an intellectual disability. Interviews and focus groups were held.	Several self-advocates with intellectual disability have had experience engaging with politicians about policy issues. This could co-occur with parent advocates and professional advocacy. Collaboration noted between different forms of interdependent advocacy; professionals, parents and self-advocates had similar practices and had to learn similar skill sets.	Going to tribunals Myth busting Doing NHS complaints Going to conferences Telling politicians what they want Using a website Writing up (articles, letters, blogs, leaflets, fliers) Interviews Using Media (press, TV, social media) Organising meetings (support meetings, rallies)	Learning how to introduce at hospital Learning how to manage money Becoming independent Learning about self Learning about rights Writing letters Learning new skills Conflict Resolution Being informed Communicating effectively	No measurement or evaluation tools noted.
Feldman, Owen, Andrews, Hamelin, Barber, & Griffiths	2012	Health self-advocacy training for persons with intellectual disabilities	Journal of Intellectual Disability Research	The purpose of this study was to provide an evaluation of the health rights training portion of the 3Rs health self-advocacy curriculum.	A randomised control design was used with pre-, post- and follow-up testing with participants who had intellectual disability. They participated in the programme.	Evidence of a lack of inclusion in social and health-related policy, people not included. Study contends that people with ID can participate in self-advocacy around health policies.	None identified	This study was specific to Health Self-Advocacy. The two skill components were noted as: (1) health knowledge, and (2) health rights, respect and responsibility.	Questions around knowledge were assessed after the intervention to measure learning.
Curryer, Stancliffe, & Dew	2015	Self-determination: Adults with intellectual disability and their family	Journal of Intellectual & Developmental Disability	Article highlighting the current levels of self-determination for people with intellectual disability	Journal Article Opinion Piece	Despite the aspiration for choice and control within the UNCRPD and Australian disability policies, the reality for many adults with intellectual disability is different – where several barriers to self-advocacy and self-determination have been noted. Examples of these barriers include: parental control, having to prove capacity, skill levels, family dynamics, etc.	None identified	Decision-making Understanding of consequences	No measurement or evaluation tools noted.

Iriarte, O'Brien, McConkey, Wolfe, & O'Doherty	2014	Identifying the key concerns of Irish persons with intellectual disability	Journal of Applied Research in Intellectual Disabilities	This paper aims to define the key concerns of adults with an intellectual disability in relation to their participation in society using an inclusive research strategy for both data gathering and data analysis.	Twenty-three focus groups involving 168 people with intellectual disability were held in 10 locations in a 3-month period. A thematic content analysis conducted, and 19 themes were identified.	One main concern identified was citizenship, where issues were addressed such as choice, control and the experience of feeling included or excluded from society. While participants were keen to have their voices heard, more of the participants experienced barriers to self-advocating generally.	Having Self-Advocacy groups Dissemination of information via media	Values a sense of belonging. Communication skills. Understanding rights to make choices. Social skills and connections. Peer relationships.	No measurement or evaluation tools noted.
Frawley & Bigby	2015	Reflections on being a first generation self-advocate: Belonging, social connections, and doing things that matter	Journal of Intellectual & Developmental Disability	This paper investigated what involvement in self-advocacy has meant to long-term members of a self-advocacy group in Victoria, Australia.	An exploratory qualitative approach using open-ended in-depth interviews, with self-advocates and supporters.	Despite the policy emphasis on participation in mainstream places and spaces, some evidence suggests that stigma and discriminatory practices create significant obstacles to inclusion for people with intellectual disability. Despite the challenges, several of the participants in this self-advocacy group did have experience self-advocating in the policy arena.	Social Awareness: activities such as concerts Organising and participating in Conferences Media: Making and educational videos	Leadership skills. Identity development. Relationships and social connections.	No measurement or evaluation tools noted.
Frawley, & 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	This study investigated the political orientations of advisory body members with intellectual disability, their participatory experiences, and the types of support they received.	Qualitative methods Case study and Ethnographic methods: - in-depth interviews - observation - document analysis 9 people with intellectual disability who were members of disability advisory bodies were interviewed, together with 12 other members of these bodies.	The inclusion of people with intellectual disability in participatory forums is relatively new, as until recently they were excluded from concepts of citizenship and its associated civic and political participation. There are currently 9 Self-Advocates with Intellectual Disability who are involved in Disability advisory bodies engaging with policy makers.	• Participatory forums • Disability advisory bodies	Access to information, knowledge development, engaging in processes, forming relationships with stakeholders, and skill development.	No measurement or evaluation tools noted.

Grenwelge & Zhang	2012	The effects of the Texas Youth Leadership Forum Summer Training on the self-advocacy abilities of high school students with disability	Journal of Disability Policy Studies	This study evaluated the effects of the youth leadership summer training on the self-advocacy abilities of high school students with disabilities.	A nonequivalent group design was used. The sample included 68 high school juniors and seniors aged 16 to 22, with 34 in the experimental group and 34 in the control group.	The participants had not experienced self-advocacy on a political level. This study emphasises the value for policy makers to include self-advocates in social policy development.	Not applicable	Used Tests Framework: Knowledge of Rights, Knowledge of Self, Communication and Leadership. The TXYLF curriculum addressed skills in the following areas: (a) disability history, (b) team-building & leadership (c) self-advocacy, (d) legislative advocacy, (e) postsecondary education, (f) employment, and (g) volunteerism.	A Pre/Post Questionnaire was used which aimed to measure the participants' self-advocacy abilities before and after intervention.

Table 4.1

Characteristics and Findings of Included Studies

Stage 5: Results

Characteristics of the studies

This scoping literature review found seven relevant articles that met the inclusion criteria. All of the included articles in this review were published in higher income countries. Four were from Australia, one from the UK, one from Canada, one from the US and one article that spans across several countries (including Ireland, Australia, UK).

In terms of methodology, two articles were quantitative studies, both testing whether their respective methodologies would improve the capacity of persons with an intellectual disability to self-advocate (Grenwelge & Zhang, 2012; Petri et al., 2020). Four were qualitative studies which aimed to gain the perspectives of people with intellectual disability (Feldman et al., 2012; Frawley & Bigby, 2011, 2015; Iriarte et al., 2014). The final article was an opinion piece (Curryer et al., 2015).

The articles were published in several journals. These included two from the *Journal of Applied Research in Intellectual Disabilities*, three from *Journal of Intellectual & Developmental Disability*, one from *Journal of Disability Policy Studies*, one from the *Journal of Policy and Practice in Intellectual Disabilities* and one from *Journal of Intellectual Disability Research*.

Findings related to the review sub-questions

Details of the findings for individual articles regarding engagement in self-advocacy has been summarised in Table 4.1 above. Below section focuses on analysis of cross cutting issues which have arisen from the articles in relation to each sub-question.

Sub Question A: Engagement of People with Intellectual Disability in Policy Development

Figure 3 below summarises interpretation of the cross-cutting issues which these articles have raised regarding engagement in self-advocacy historically and currently.

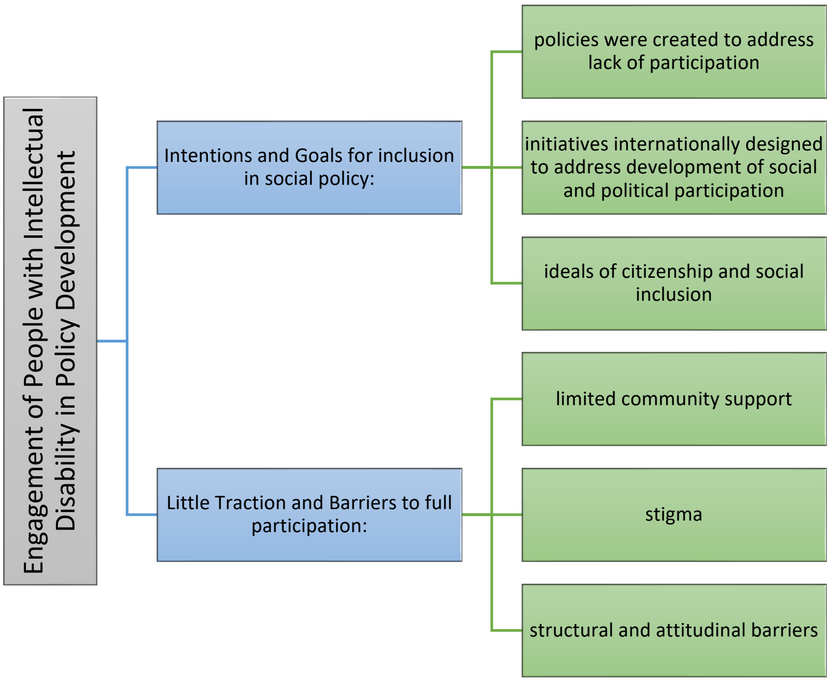


Figure 6: *Thematic Analysis of the Engagement of People with Intellectual Disability in Policy*

Intentions and Goals for inclusion in social policy:

Frawley and Bigby (2011) note that, historically, people with intellectual disability were excluded from the activities of citizenship and its associated civic and political participation, meaning that they were side-lined from these social policy-related activities. All seven of the articles reviewed share the sentiment that political inclusion and citizenship for people with intellectual disability is a key goal of self-advocacy. (e.g., Curryer et al., 2015; Feldman et al., 2012; Frawley & Bigby, 2011, 2015; Grenwelge & Zhang, 2012; Iriarte et al., 2014; Petri et al., 2020). Frawley and Bigby (2011) more than a decade ago highlighted that citizenship and social inclusion for people with intellectual disability is a journey that is only just getting started, a journey that is still true today, according to these articles.

Little Traction and Barriers to full participation:

Several articles note that while guiding structures and frameworks are in place for political participation by people with intellectual disability, these have not been fully actualised (e.g., Curryer et al., 2015; Iriarte et al., 2014; Petri et al., 2020). Policy change over the past two decades has recast people with intellectual disability from dependants to citizens, and their right to participate in the political life of the community alongside other citizens has been asserted (Frawley & Bigby, 2011). These policies were created to address lack of participation, but have had limited success (Anderson & Bigby, 2017).

Review articles reported on internationally designed initiatives to address the lack of social and political participation for people with intellectual disability, but that unfortunately these initiatives have had limited traction, with several barriers to self-advocacy reported, including structural and attitudinal barriers, stigma and limited community support (e.g., Anderson & Bigby, 2017; Curryer et al., 2015; Iriarte et al., 2014; Petri et al., 2020).

Sub Question B: The Strategies for Self-Advocacy

Four of the seven articles identified and named specific strategies that can be employed for self-advocacy (Frawley & Bigby, 2011, 2015; Iriarte et al., 2014; Petri et al., 2020). Thematic analysis identified three themes common to these papers. These were: a) strategies for self-advocacy in public spaces, b) strategies for self-advocacy that use social and digital media, and c) strategies for self-advocacy that use the written word in more formal contexts such as print media or emails or letters.

Figure 4 below summarises the categories and themes for self-advocacy that were found in the reviewed papers.

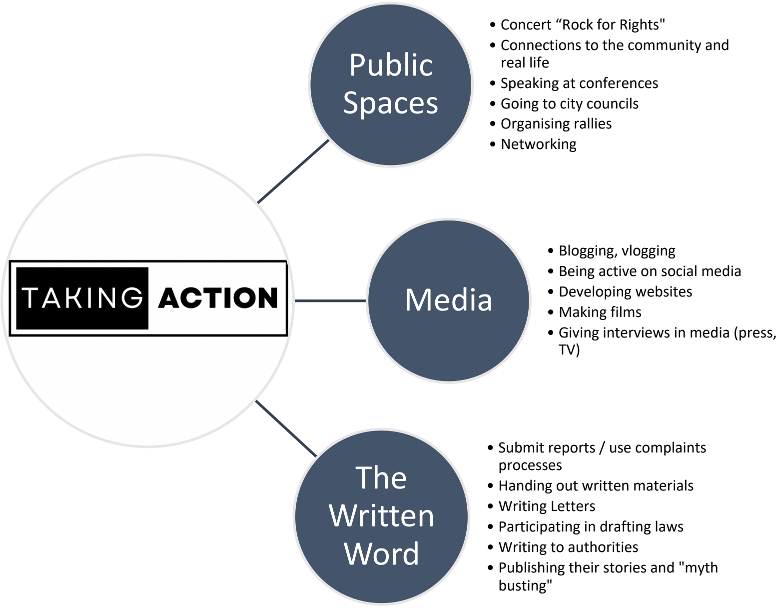


Figure 7: *Thematic Analysis of Strategies for Self-Advocacy*

With regard to public spaces, Petri et al. (2020) described strategies such as organising rallies to advocate for a specific cause. Frawley and Bigby (2015) spoke about hosting a concert to raise awareness, titled “Rock for Rights”. Strategies identified include being able to participate in political campaigns, relevant conferences and awareness raising activities (Anderson & Bigby, 2017; Frawley & Bigby, 2015; Petri et al., 2020). Petri et al. (2020) further describe how awareness raising can take many forms, such as direct teaching or giving speeches. There are self-advocacy initiatives that could inform social policy development and implementation more directly, such as holding public hearings on disability issues where individuals with disability can make suggestions and engage in legislative advocacy (Grenwelge & Zhang, 2012). To combat the above, in an effort to include people with intellectual disability in social policy, there have been efforts to create disability advisory bodies which are mandated to include all the diverse subgroups that fall under the rubric of ‘‘people with disabilities” (Frawley & Bigby, 2011). Participants involved in these groups have identified priorities around citizenship and political engagement. Australian governments have used disability advisory bodies as a key strategy to elicit the views of people with disability and involve them in the processes of policy making (Frawley & Bigby, 2011).

Several types of media were suggested as strategies to self-advocate in the four articles that included this (e.g., Frawley & Bigby, 2011, 2015; Iriarte et al., 2014; Petri et al., 2020). Strategies for self-advocacy mentioned were giving interviews on radio or television, making films and videos, social media (online communication platforms), and blogging (self-published writing, photography and other media to share knowledge about issues of interest) and vlogging (blogging which primarily uses video format).

In terms of the written word, papers suggest that people with intellectual disability can participate in drafting laws and policies, or go to ministries and city councils to deliver letters, (Feldman et al., 2012; Frawley & Bigby, 2011, 2015; Petri et al, 2020).

Creating awareness of issues was key to self-advocacy with awareness-raising a common sub-theme across public spaces, online media and in offline written pieces. Personal participation by people with intellectual disability can create the kind of visibility in the community that can counteract myths and stigmatising views about people with intellectual disability people as lacking capacity for accommodation, as well as directly bringing their perspectives to consultation spaces (Anderson & Bigby, 2017; Frawley & Bigby, 2015; Petri et al., 2020. Having an online presence (Frawley & Bigby, 2015; Iriarte et al., 2014; Petri et al., 2020) or even a simple strategy such as handing out written materials (Petri et al., 2020) can all create awareness.

Self-Advocacy Skills Development

Building self-advocates' capacity for self-advocacy is an important strategy for enabling and improving their self-advocacy initiatives. Figure 8, below provides a diagrammatic representation of the themes that emerged across the papers about knowledge and skills that would be needed for self-advocacy.

Figure 8

Thematic Analysis of Knowledge and Skills for Self-Advocacy

All seven articles identified knowledge components and skills that are needed for a person with intellectual disability to self-advocate (Curryer et al., 2015; Feldman et al., 2012; Frawley & Bigby, 2011, 2015; Grenwelge & Zhang, 2012; Iriarte et al., 2014, Petri et al., 2020).

One of the articles specifically mentioned the conceptual framework for self-advocacy by Test et al. (2005) to frame their intervention (Grenwelge & Zhang, 2012). This was also a framework identified in the initial overview of the literature for this study, which has been used as an a priority framework for this scoping review (see methodology). This model identifies 4 important areas which are key to developing capacity for self-advocacy, namely knowledge of self and knowledge of rights, communication and leadership. Elements of these components were found in several of the articles, despite only Grenwelge and Zhang (2012) using Test et al's (2005) model as a conceptual framework. The following are descriptions of the components found in the review:

a) Knowledge of self includes self-awareness, referring to understanding of one's personal preferences and priorities, of one's strengths and weaknesses, and one's identity as a person with a disability (Grenwelge & Zhang, 2012).

b) Knowledge of rights was mentioned in all seven articles. This included ideas about rights related to citizenship, knowledge about rights and responsibilities, and an understanding of the relevant laws and policies that are currently in place (Curryer et al., 2015; Feldman et al., 2012; Frawley & Bigby, 2011, 2015; Grenwelge & Zhang, 2012; Iriarte et al., 2014, Petri et al., 2020).

c) Challenges to communication were identified in relation to advocating for what one needs, whether verbally or in written form (Iriarte et al., 2014; Grenwelge & Zhang, 2012). Curryer et al. (2015) describe how despite having possible decision-making difficulties, people with intellectual disability can still make choices and advocate for their priorities in their own lives.

d) Leadership is broadly defined in Test et al.'s (2005) conceptual framework and encompasses many sub-components, which can include confidence to speak up for oneself and others, confidence to challenge the status quo and speak out, team building and group work skills. Several of these components were spoken about in the articles found (eg. Frawley & Bigby, 2011; Grenwelge & Zhang, 2012).

Sub-Question C: Tools to Assess Self-Advocacy Strategies or Capacities

This sub-question was included in the review as it was felt that having an assessment tool for self-advocacy skills development would be crucial in any self-advocacy intervention or skills training, to assess whether the intervention is working. No standardised self-advocacy checklists or assessment tools were found in this review, and there was little mention of evaluation processes for self-advocacy interventions. Grenwelge and Zhang (2012) noted that most evaluation tools in the arena of self-advocacy are qualitative in nature. There were two studies that had evaluation tools, namely, Grenweldge & Zhang, (2012) and Feldman et al (2012).

In terms of the interventions and measurement tools, Grenwelge and Zhang (2012) used the Texas Youth Leadership Forum's pre- and post-questionnaire based upon the four components of Test et al.'s (2005) framework to evaluate their efforts. Self-advocacy checklists and assessment tools were also sought to provide a guidance in the selection of suitable questions to consider for the focus group guide post the experiential toolkit exposure session. However, the assessed elements of these studies applicable for use in this study, as they measure elements not relevant to the research questions asked in this study.

Feldman et al. (2012) were looking at the post-intervention effects and knowledge that was sustained after their randomised control trial, and administered a questionnaire after the intervention to measure their results. These questions or evaluation strategies were not elaborated on in the paper, and none of the other articles listed their questions in these papers.

Discussion

Through speaking and standing up for themselves and others with intellectual disability and their rights, self-advocacy by people with intellectual disability aims to redress inequalities and discrimination as well as to develop confidence, skills and leadership capacity for self-advocacy. In addition, self-advocacy with other self-advocates can assist in creating a collective identity as an essential foundation for grassroots activism (Fenn & Scior, 2019; Tilley et al., 2020). This has further been described as a “social movement” (Fenn & Scior, 2019, p. 1349) of self-advocacy “by” and “for” people with intellectual disability which challenges “exclusionary” models of culture which privileges oppressive understandings of disability (Anderson & Bigby, 2020).

Self-advocacy initiatives can provide opportunities to engage with ideas about rights and empowerment, to share and celebrate self-advocates’ personal resilience, and to provide a sense of belonging, social connection and occupation (Anderson & Bigby 2017). Frawley and Bigby (2015) explain that inclusion should refer to engagement in education, employment, family, other social relationships and civic society. Examples of included components found in the literature are: learning about oneself, learning new skills, learning about the law, and rights, money management, conflict resolution, using social media, communicating effectively, etc.

Self-advocacy in legislation and policy is key to the concept of citizenship. Citizenship was identified as one of the components of full and effective participation and inclusion in the community, set out by the UNCRPD (United Nations, 2006). Frawley and Bigby (2011) further state that a large part of political inclusion in society is conceptualised as citizenship in terms of the relationship between people and the state, and that “a key responsibility of citizens is engagement in civic and political life of the state” (p. 27).

Concern is often expressed about the capacity of people with intellectual disability to participate, and also about their credentials as people with an intellectual disability (Frawley & Bigby, 2011). It was noted that few self-advocates have severe and profound learning disability, with no evidence as to whether membership of a self-advocacy group supports the wellbeing of such individuals being found; in fact this population is largely absent in the literature on self-advocacy (Tilley et al., 2020). This is echoed in the notion of capacity, and the performance components required from a person in order to participate in self-advocacy activities (Wilby, 2007). For people with mild to moderate intellectual disability, those who can perform self-advocacy activities, a significant obstacle is feeling that they are not respected, which effectively undermines their confidence (Frawley & Bigby, 2011).

Gelfgren et al. (2022) describe how the internet, as well as technical developments and devices such as computers, smartphones and tablets, permeates almost every aspect of life. The authors contend that this has changed the ways in which people with (or without) disability access information, communicate with each other and build communities. Digital media has many positives and is seen as a means for communication, participation, inclusion, and giving voice to the unheard voices, and here the advocacy organisations are expected to aid the people they represent in being heard and acknowledged. Social media can be a challenging topic, where advocates and self-advocates have the opportunity to engage with whomever they decide (Gelfgren et al., 2022).

In the article published by Gelfgren et al. (2022), the authors highlight the complexities of negotiating advocacy online. Their study addressed only advocates, though they do acknowledge the importance of finding out the perceptions of service users with disability themselves. Social media has the capacity to make people with and without intellectual disability feel less alone, provide those with minimal community contact a way to connect with others, self-advocate, and strengthen relationships (Bassey et al., 2021). Pearson and Trevisan

(2015) describe how popular social media platforms such as Facebook and Twitter have proved important tools for challenging government policy. While there are certainly positives to this strategy, the reality of the digital divide, particularly in the South African context , can be far more complex. The digital divide relates to those who have access and resources to social media (or any type of media in this regard) and those who do not, in terms of digital competence, economic status, age, cognitive capabilities, technical equipment and digital connection (Gelfgren et al., 2022). In South Africa, one of the most unequal countries in the world, socially and economically the majority of people have limited access to digital resources (Sulla & Zikhali, 2018), with South Africans with disability, described as the nation's poorest (Sulla & Zikhali, 2018; McKenzie, Ned, Watermeyer & Dada, 2022, Watermeyer, 2006), being the most marginalised from digital communication opportunities. This makes accessing platforms in the new era of disability activism rather challenging (Pearson & Trevisan, 2015).

In line with the CRPD, often people with intellectual disability form part of other minority groups and have complex intersectional identities (United Nations, 2006). It is well known that multiple personal and environmental variables, including disability, gender, race/ethnicity, or sexual orientation define a person's cultural identity, and system factors interact with cultural factors to shape access to opportunities available in communities (e.g., Raley et al., 2020). And yet, it was noted that there was remarkable similarity in the experiences of the self-advocate participants despite differences in the location, size and resources of the groups of which they were members (Anderson & Bigby, 2017). However, in this review it was noted that the majority of articles do not consider a person as a holistic being, taking into account the elements of their intersectionality. Roberts et al. (2014), who conducted a review on self-advocacy for students, noted that seven studies did not report ethnicity and eight did not report on community setting information — and no study investigated the relationship between ethnicity and self-advocacy. Tilley et al. (2020) address how their study was limited to people with Caucasian backgrounds. Walker and Test (2011) further highlight the need for research designed to identify strategies that can lead to improved self-advocacy skills for people from culturally diverse backgrounds. Dorozenko et al. (2015) highlight the paucity of research on the intersectional identities of people with intellectual disability, neglecting other elements of identity such as gender, ethnicity or cultural contexts.

Considering that none of the papers in this scoping literature review came from South Africa, understanding the contextual factors that shape access to these self-advocacy strategies is key, and a focal point for this study. In fact, this scoping review highlights the significant gap in the research, where in a ten-year period, only seven articles could be sourced, and in addition, only articles from higher income countries were found. This finding was echoed by Petri et al. (2020) who describe how disability advocacy, including intellectual disability self-advocacy, has been largely under-researched. This highlights the need for greater attention to this important issue, in the form, amongst others, of research.

While the goal is equal access for all, and having people with intellectual disability realise their rights, and become strong self-advocates, it is clear that there are structural and systemic barriers that may be hindering access.

Limitations of the Scoping Review

Limitations of this scoping review include the possibility that more findings could have been found if non-English papers were also indexed, no time limits had been set and a wider range of grey literature had been included, but was not possible due to time constraints and human resources available for the review. The review might also have missed some studies due to selection of terms or searching other additional databases.

Strengths of the Scoping Review

This scoping review has identified practical strategies for people with intellectual disability to self advocate, within several domains of their lives, including social policy participation. The review has also highlighted the significant gap in the peer reviewed literature from lower to middle income countries, and in turn, the lack of evidence informed opportunities for self advocacy.

Conclusion

Self-advocacy by people with intellectual disability has the potential to address systemic barriers to inclusion. By including the voices of people with intellectual disability in legislation and policies that affect their lives is key to the concept of citizenship which is fundamental to full participation in society outlined by the UNCRPD (United Nations, 2006). There are strategies such as being present in public spaces with marches and demonstrations, speaking to public officials, as well as digital and print media, such as printing in magazines or writing letters, and also using social media as a platform to self advocate. While the aim is full participation in society for people with intellectual disability, there are a number of factors hindering this participation, including stigma, particularly around the credentials of a person with an intellectual disability to speak for themselves. Another significant factor in the South African context limiting participation is the limited access and resources available. This scoping review identified strategies for self advocacy, as well as enablers and barriers to inclusion for people with intellectual disability in social policy.

Chapter Five

Results of the Toolkit Review

Introduction

This chapter details the results of the toolkit review, Objective 2, which aimed to identify strategies for people with intellectual disability to self-advocate, with a specific focus on their influencing social policy development and implementation.

As Arksey and O'Malley's (2005) Stages 1-4 were outlined in the Chapter 3 Methodology section, and therefore this chapter will focus on the results of the toolkit review (Stage 5). This chapter will start by showing the table which collates the findings and then will move on to the results found. Then the chapter will continue with the discussion of the findings.

This review of toolkits will document South African and international NGO- and DPO-based strategies that are in existing toolkits to assist people with intellectual disability to self-advocate.

Table 5.1, below, highlights the content and themes that emerged from the grey literature review of toolkits

Table 5.1

Characteristics and Findings of Included Toolkits

Name of Toolkit	*Developed by*	*Country of Origin*	*Strategies suggested for self-advocacy at all levels including social policy*	*Skills that are developed*	
The Self-Advocacy Toolkit - For mental health service users	*Christina Angela Ntulo (Basic Needs) (2015)*	*Uganda*	*Write a mission statement* *Build community and local political support* *Engage social media* *Broader media advocacy* *Communicating with policy makers*	*Knowledge of disability* *Knowledge of rights* *Speak up for yourself* *Conflict resolution* *Deciding what to advocate for*	*Active listening* *Effective speaking* *Negotiating* *Build up frustration tolerance*
Guide to Autism Advocacy: Toolkit	*Autism Speaks (2013)*	*USA*	*None noted*	*Goal setting* *Communication* *Decision making* *Understanding perspectives of others* *Negotiation skills* *Knowledge of rights*	*Being able to identify a goal* *Be able to devise the plan* *Communication skills* *Consider the perspective of the other party* *Body language* *Studying non-verbal cues* *Body language*
Advocacy Toolkit Skills and Strategies for Effective Self and Peer Advocacy	*Disability Rights Wisconsin (2007)*	*USA*	*Using the phone for phone calls* *Hold an informal meeting* *Write a letter of complaint* *File a formal complaint* *Advocacy in person* *Court proceedings* *The internet as a means of sharing messages*	*Taking notes* *Organisation* *Being assertive* *Talking to the right person* *Communication skills*	*Properly document and keep records* *Self-awareness* *Be able to break down a problem* *Identify your rights* *Develop a goal and strategy* *Compromise*
Self-advocacy toolkit	*Inclusion Ireland (2022)*	*Ireland*	*None expressed*	*Expressing feelings* *Expressing preferences* *Knowing rights and policy*	*Saying what you want* *Speaking up*
Advocacy toolkit for self-advocates	*National down syndrome congress (n.d.)*	*USA*	*Phone calls* *Put it in writing*	*Knowledge of process for legislation* *Relationship building skills* *Reaching out for help* *Choice making*	*Learning how to access information* *Knowing your rights and responsibilities* *Problem solving* *Listening and learning*
Self advocacy start-up toolkit	*Self Advocacy Resource and Technical Assistance Center (SARTAC) (2018)*	*USA*	*Letter writing campaigns* *Meeting with public officials* *Rallies and demonstrations* *Non-violent civil disobedience* *Posting on social media / sending info* *Holding public forums / workshops*	*Knowledge of self-advocacy* *Knowledge of self* *Knowing of how to speak up*	*Developing partnerships* *Knowledge of rights*

The essential self advocacy toolkit	*Advocacy Focus (2022)*	*UK*	*Meetings* *Phone calls* *Emails* *Letters*	*Knowledge of rights* *Knowledge of accessing information* *Knowledge of self, strengths and weaknesses* *Preparing for a meeting / call / email* *Following up*	*Conflict resolution* *Taking the knocks* *Communication* *Listening* *Negotiation* *Assertiveness* *Emotional control*
They work for us: A self-advocate's guide to getting through to your elected officials	*Autistic Self Advocacy Network (ASAN) & SARTAC (2022)*	*USA*	*Meetings* *Phone calls* *Emails* *Letters* *Social media*	*Understanding government* *Understanding laws and rights* *Conversational skills*	*Phone call etiquette* *Knowing how to speak up* *Delivering a speech*
What makes a good self advocacy project: A toolkit	*Disability Research on Independent Living and Learning (DRILL) (2020)*	*UK*	*Social media* *Article for paper, radio, tv and magazines* *Speak to policy makers*	*Planning skills* *Gathering information* *Deciding how to measure success*	*Money management* *Accessing information* *Reflection skills* *Using simple, plain English*

Stage 5: Results

Characteristics of the toolkits:

Eight of the nine toolkits were developed in two high-income countries, namely the United States of America (US) and the United Kingdom (UK). Only one toolkit was developed in a lower to middle-income country (Uganda). It was noted that no toolkit development process was described or identified in the review, nor were there any suggestions as to the methodology for developing a new toolkit.

All the toolkits had content on intellectual disability, but several toolkits were written from different perspectives with a focus on particular phenomena. For example, while the *Advocacy Toolkit* speaks to all kinds of neurodiversity, including people with intellectual disability, the toolkit has specific focus on individuals with autism (Autism Speaks, 2013). The *Self Advocacy Toolkit for Mental Health Service Users* (Ntulo, 2015) encompasses a range of mental health service users, which does include people with intellectual disability, as well as people with psychosocial disability and those with co-occurring intellectual and psychosocial disability.

Three of the toolkits were designed in an easy-to-read format, aiming to be accessible to people with intellectual disability (Self Advocacy Resource and Technical Assistance Center [SARTAC], 2018; National Down Syndrome Congress [NDSC], n.d.; Autism Self Advocacy Network [ASAN] & SARTAC, 2022). This too was considered in the development of the toolkit for this study.

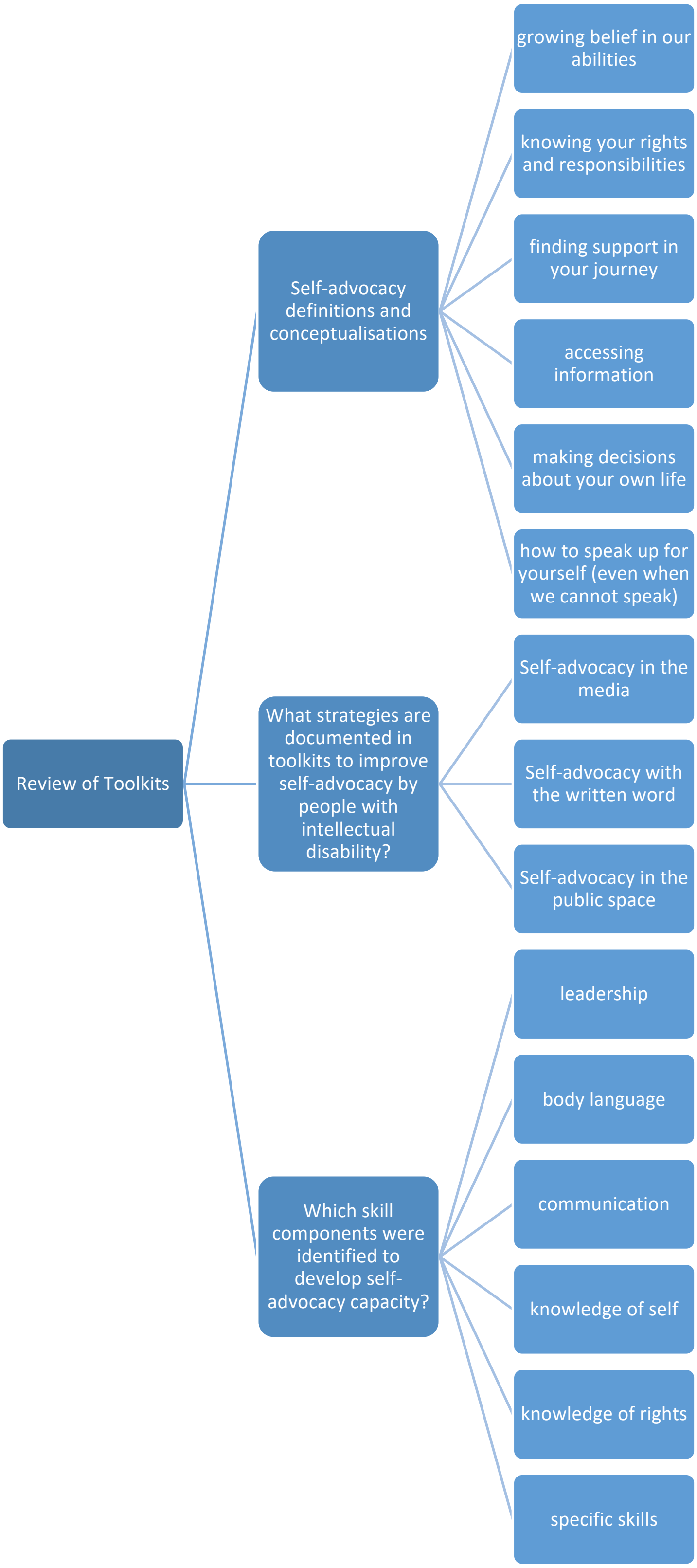


Figure 9 :

Thematic analysis of findings of the review of toolkits

Self-advocacy definitions and conceptualisations

All toolkits had various definitions and formulations of the concept of self-advocacy. In summary, self-advocacy was conceptualised as learning how to speak up for oneself (even when we cannot speak), making decisions about one's own life, learning to access information so that one can understand things that are of interest , finding out who will be supportive in one's journey, knowing one's rights and responsibilities, problem solving, listening and learning, reaching out to others when help and friendship are needed, and learning about self-determination (Inclusion Ireland, 2022; NDSC, n.d.; Ntulo, 2015). Self-advocacy was also described as being about growing confidence and belief in one's abilities, and about knowing one's right, including being included in all aspects of the community, as are people without disability (Inclusion Ireland, 2022). Several toolkits described the history of the self-advocacy movement (e.g. Ntulo, 2015; SARTAC, 2018).

Only one toolkit outlined their theoretical framework. Inclusion Ireland's (2022) work is underpinned by the social model values of dignity, inclusion, social justice, democracy and autonomy. They describe how they created the toolkit with the United Nations Convention on the Rights of Persons with Disabilities (UNCRPD) to guide their work (Inclusion Ireland, 2022). The toolkit promotes the UNCRPD goal of bringing the realisation of all human rights for persons with disabilities more urgently to the fore and provides a framework for advocacy and participation in society (Inclusion Ireland, 2022).

Of the nine toolkits, eight addressed social policy (ASAN & SARTAC, 2022; Autism Speaks, 2013; Disability Research on Independent Living and Learning (DRILL), 2020; Disability Rights Wisconsin, 2007; Inclusion Ireland, 2022; NDSC, n.d.; Ntulo, 2015; SARTAC, 2018).

One guide spoke within the social policy frame, and suggested that the toolkit can "provide tools and advice to self-advocates who are interested in becoming more involved in legislative advocacy to work on policies and laws (NDSC, n.d.), where another (SARTAC, 2018) included a quote from a self-advocate who said, "You could become a political force. You could become a future leader in your local group, or your state, or the national organization. That's what happened to me!" (p. 20). In summary, most of the reviewed toolkits report that self-advocates have experience and personal stories of their experiences to bring to self-advocating at a social policy level (ASAN & SARTAC, 2022; Autism Speaks, 2013; Disability Rights Wisconsin, 2007; DRILL, 2020; Inclusion Ireland, 2022; NDSC, n.d.; Ntulo, 2015; SARTAC, 2018).

None of the toolkits reported on assessment tools, or provided evidence about how and whether they have been implemented . All toolkit creators were contacted for interviews to clarify issues such as this, but only one organisation replied, with the toolkit developed by two colleagues. They have been interviewed, and their feedback is included in Chapter Six. As highlighted in Chapter Four, without assessment tools or measurements, it would be challenging to observe and note changes in self-advocacy skills or knowledge that has been gained.

Disability Rights Wisconsin (2007) split the types of strategies that were included in their toolkit into two categories, namely: Informal and formal advocacy strategies. In their toolkit, they state that informal strategies are strategies that do not involve bringing in an outside decision maker. Formal Advocacy Strategies, on the other hand, typically involve an outside decision maker, such as policy makers (Disability Rights Wisconsin, 2007). They also provide examples of formal advocacy processes such as court hearings, grievance procedures or complaint processes.

Strategies Identified

Strategies were defined in one toolkit as “plans for an approach to address an issue or solve a problem” (Disability Rights Wisconsin, 2007, p. 1).

Two of the documents did not suggest explicit strategies for self-advocacy, e.g., Speaking Up, Speaking Out (Inclusion Ireland, 2022) and Guide to Autism (Autism Speaks, 2013) and focused more on the development of self-advocacy skills and how one would apply these. The other toolkits identified specific strategies for self-advocacy as well as skills necessary to conduct these self-advocacy activities.

There were a number of strategies that were identified in the process of reviewing the toolkits, and again, these fitted well into other categories of public spaces, using the written word in print and digital media and making use of connecting on social media.

Self-advocacy in the public space

With the category of public spaces, several toolkits had suggestions around ways to increase visibility in the community. Strategies included hosting rallies and demonstrations or non-violent protests (SARTAC, 2018), having meetings with relevant stakeholders, as well as speaking to public officials (Advocacy Focus, 2022; ASAN & SARTAC, 2022; Disability Rights Wisconsin, 2007; NDSC, n.d.; SARTAC, 2018). Other strategies mentioned in the SARTAC toolkit included having a workshop where people can learn and sending information , out, (SARTAC, 2018).

Self-advocacy using the written word

Using the written word was a significant theme throughout the toolkits, which referred to writing letters, policy documents, letters of complaint, or position pieces. In fact, the writing of a letter of complaint was a strong recommendation across several of the toolkits (Disability Wisconsin, 2007; NDSC, n.d.; Ntulo, 2015; SARTAC, 2018). ASAN and SARTAC (2022), recommended using emails and making phone calls as a way to connect. DRILL (2020) suggest writing articles for newspapers, creating content for radio and TV, or even writing to professional magazines.

Self-advocacy in social media

This links to the idea of using media as a strategy to convey a message of self-advocacy. The internet was raised, with a specific focus on social media (Advocacy Focus, 2022; ASAN & SARTAC, 2022; Disability Rights Wisconsin, 2007; DRILL, 2020; NDSC, n.d.; Ntulo, 2015; SARTAC, 2018). Specific options were mentioned, such as Facebook and Twitter (SARTAC, 2018).

Skills Identified

Skills are techniques, or performance components, for becoming competent in an area (Disability Rights Wisconsin, 2007; Wilby, 2007). A number of skills were suggested in the toolkit review process. In line with the conceptual framework by Test et al. (2005), all of the documents addressed at least one of the components (knowledge of self, knowledge of rights, communication and leadership), with leadership addressed by three of the toolkits.

There were also other areas of skill that presented themselves during the review. The importance of having negotiation skills was raised, with learning to negotiate successfully reported as the centrepiece of self-advocacy (Advocacy Focus, 2022; Autism Speaks, 2013; Disability Rights Wisconsin, 2007), as well as being assertive (Advocacy Focus, 2022; Disability Rights Wisconsin, 2007).

Advocacy Focus (2022) emphasize the idea of active listening. This was also echoed in the Ntulo's toolkit (Ntulo, 2015) where it was stated that “Listening is one of the most important skills you can have” (p. 62). It was suggested that by becoming a better listener, one can learn to persuade and negotiate, and in turn avoid conflict and misunderstandings, all necessary for the success of your advocacy campaign (Ntulo, 2015). Linked to this was the importance of understanding the perceptions of others (Autism Speaks, 2013)

Another important skill that emerged in the review was about understanding and using appropriate body language (e.g., Disability Rights Wisconsin, 2007). Disability Rights Wisconsin (2007) further explain how one should use positive body language to convey confidence and assertiveness; including dressing and grooming appropriately; shaking hands firmly; trying to maintain eye contact; maintaining good posture; and trying not to fidget.

All of the above-mentioned issues, as well as conflict resolution, compromise and non-verbal skills were noted – but essentially could be grouped under the theme “communication” (Advocacy Focus, 2022, Autism Speaks, 2013; Disability Rights Wisconsin, 2007). Several toolkits identified other specific skills which would support a person in their capacity to self-advocate, such as money management, public speaking, phone etiquette, note-taking and frustration tolerance (e.g., Advocacy Focus, 2022; Autism Speaks, 2013; Disability Rights Wisconsin, 2007).

Nissen (2021) describes the difference between electoral and non-electoral political participation, where, non-electoral participation could be seen by introducing dimensions of legal political protest and civil disobedience.

A pictorial representation has been developed as a summary of the self advocacy strategies found and is titled Figure 10: Summary of Strategies Suggested for Self Advocacy found in the Review of Toolkits

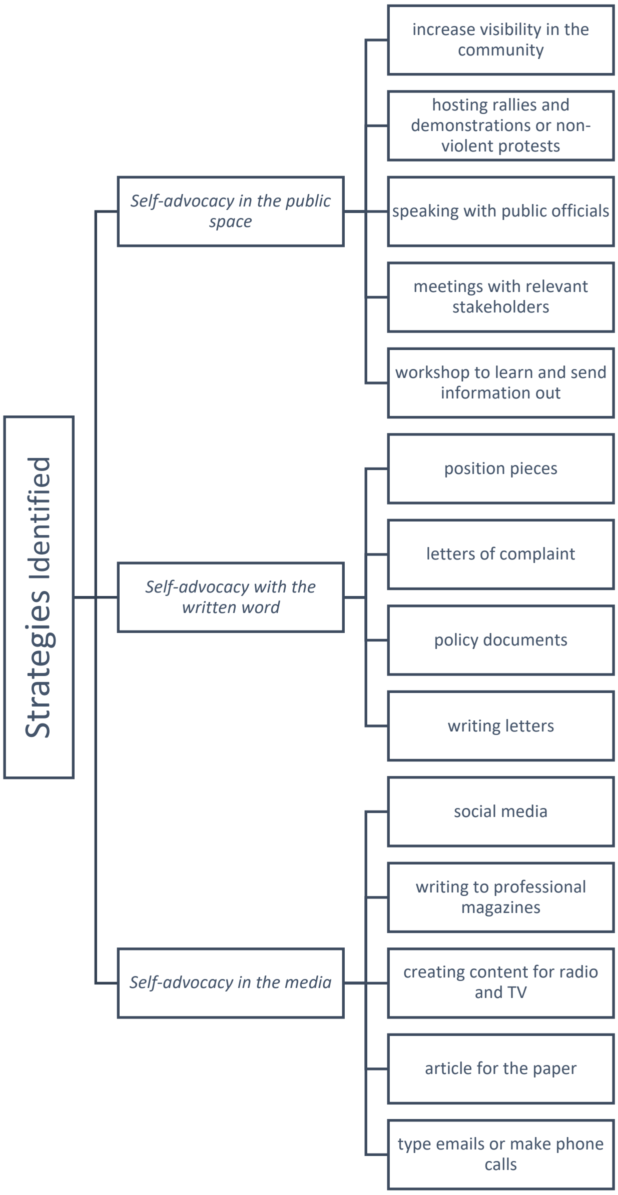


Figure 10:

Summary of Strategies Suggested for Self Advocacy found in the Review of Toolkits

Discussion

The review of existing toolkits was useful in answering the question: What strategies are used in toolkits to improve self-advocacy by people with intellectual disability? By conducting this analysis, the toolkit review identified both strategies and skills needed in the development of self-advocacy capacity for people with intellectual disability.

This review also reflects the lack of focus in this area, as there are limited models and frameworks in which to conceptualise this work. Only one of the toolkits described their conceptual framework, using a social model lens, supportive of the merits of the choice of this model to underpin this study. In addition, since all the toolkits emphasized the role of understanding your rights, this also speaks to the human rights model. This reinforces the notion that the social and human rights models are useful frameworks to underpin self-advocacy work, in that a fundamental aspect of these models concerns equality and aims to explore ways of removing barriers that restrict life choices for people with disability (e.g., Anderson & Bigby, 2017).

The review highlights the need for the voices of people with intellectual disability to be included in literature, in all forms of writing, and to use the written word as a strategy to self-advocate for all priority needs, including priorities around social policy.

Using media for representation, thus the internet, emerged as a prominent theme. For most people, especially the young, the internet is part of everyday life. There are indications that social media use is more widespread among young people with intellectual disability than the general population of people with intellectual disability (Borgström et al., 2019). While there is evidence of the harmful aspects of the internet, Borgström et al. (2019) highlight the opportunities that are presented with internet access. One might say that connecting over the internet is the tool of the younger generations.

Different factors affect the potential for access (Borgström et al., 2019), such as the digital divide, functional impairments, education, training, political, economic and attitudinal climates. This is in line with the slow pace of access for people with intellectual disability to all services. In the toolkit authored by Ntulo (2015), it is emphasized how the self-advocacy movement for people with intellectual disability lags far behind many other civil rights efforts, such as those related to women's rights or children's rights, or physical disability.

Considering the barriers to access in South Africa for people with disability, limited access to services, including skills development and opportunities for self-advocacy, creates a context where people with intellectual disability are likely to be unable to actualise their potential (Mkabile & Swartz, 2020). This isolation from civic and societal participation further disadvantages people with intellectual disability (McKenzie et al., 2013).

Further to this is the cost that may be associated with any of the self-advocacy strategies suggested, particularly in a country where people, especially those with intellectual disability, often have extremely limited resources, as well as limited access to health, education, work and other basic human rights.

As Stein et al. (2018) explain, it is less expensive for the country to put good health and support systems in place than not to do so, and they stress the need to remember a focus on human rights for people with intellectual disability. In fact, a recent news publication from UCT (Martin, 2022) described the disparities in access to education, health and other social and human rights between those with and without disabilities as significant. Martin (2022) discusses the view of Emeritus Professor, Colleen Adnams, who outlined the perpetual cycle of disability leading to exclusion, poverty and limited resources. With these limited resources, and so many people with intellectual disability trapped in these cycles, there is unlikely to be sufficient finances to attend conferences, print flyers, buy data to use online social media, buy poster boards and stationery or money to pay for transport.

With limited structural and social opportunities for self-advocacy strategies, this becomes a real challenge to inclusion (Borgström et al., 2019). It is clear that there needs to be environmental and structural support provided to people with intellectual disability to facilitate their self-advocacy strategies, plans and initiatives. Applying a social model of human rights framework can support the amplifying of the voices of people with intellectual disability, enabling them to realise their rights, and adjusting the social contexts to foster participation and citizenship.

Limitations of the Toolkit Review:

This review of existing toolkits has several limitations. This review was conducted by the researcher alone, due to resource limitations for this aspect of the study. The availability of an additional research assistant would, as with other aspects of the study, has brought additional perspectives-and rigour- to the process of data collection and analysis. A decision was made to only search Google, as the focus of the study was to identify "living", evolving recently developed practical toolkits, as examples of work currently being used, less likely to be found using traditional search engines. It may be that utilising other grey literature sources could have yielded more results. In hindsight, expanding the narrow timeframe selected for the search, to identify recent toolkits, may have been better, to be able to secure a wider range of professionals who had already implemented their toolkits to provide information on lessons learnt about implementation of the toolkits and how, if at all, these toolkits may evolve over time.

Strengths of the Toolkit Review:

The review adds to the body of knowledge on the tenets of self advocacy, as well as the key knowledge and skills a person with an intellectual disability may need in order to self advocate. In addition this review identified several as practical strategies that could be utilized as a person with an intellectual disability to self advocate.

Conclusion:

There were several practical suggestions put forward as self-advocacy strategies in public spaces. These strategies speak strongly to the right to social inclusion, for people with intellectual disability (in fact, all people) to have a presence in the community, to have their ideas interwoven into the fabric of mainstream thinking and action, including in the domain of social policy. This point motivates the importance of providing opportunities to use appropriate strategies to support these self advocacy initiatives to influence social engagement which can challenge the negative stereotypes about people with intellectual disability in society and promote their rights to equal space in society.

Chapter Six

The Results of the Interviews

Introduction

This chapter details the results of the interviews, Objective 3, which aimed to document local and international perspectives of key informants with and without intellectual disability, self advocates and self advocacy supporters, with regards to people with intellectual disability participating as self-advocates and potential strategies suggested for self-advocacy.

This chapter will start by presenting a table which describes the interview participants, and then will describe the results found. The chapter will continue with the discussion of the findings.

Description of Participants

Table 6.1, below, describes the participants that were interviewed for the study.

Table 6.1

Interview Participants

No.	Pseudonym	Brief Description
1	Meredith & Mark	Meredith and Mark are community health workers in an organisation in Europe, with outreach internationally. They have founded a self-advocacy programme and have extensive experience in self-advocacy work with people with intellectual disabilityy. They had recently developed and piloted a self-advocacy toolkit to support their work at the time of the interview and were eager to train people to run the programme internationally. They were contacted via email and replied that they were interested in being interviewed.
2	Lexi	Lexi is a self-advocate with cerebral palsy and an intellectual disability who replied to the Facebook advert. She was eager to be a part of this project and have her voice and opinion heard as a disability service user. She has experience as a radio show host and self-advocating in the public sector in America.
3	Zola	Zola is a community health worker and therapist at a local South African non-governmental organisation. She has experience working with people with intellectual disability and experience working with self-advocacy groups for people with intellectual and psychosocial disability.
4	Ben	Ben is a young man with an intellectual disability who is living and working in the community in South Africa. He has recently completed a learnership programme which included self-advocacy training. He opted to participate to discuss his self-advocacy efforts during a recent hospital admission and his experience at his local police station.
5	Richard	Richard is a manager of a South African NGO which offers training programmes and learnerships for people with intellectual disabilityy. These programmes are registered with the local education department, so this ensures that learners obtain a qualification. As part of their curriculum, the organisation tackles issues of advocacy and self-advocacy. Richard has co-facilitated advocacy events for people with intellectual disability.
6	Alex	Alex is a young man with an intellectual disability who is living and working in South Africa. He has recently completed a learnership programme which included self-advocacy training. He opted to participate to discuss his self-advocacy efforts and his experiences as a person with a disability in his community context.
7	Ellis George	George is a young man with Down's Syndrome and an intellectual disability, from America, who has become an international self-advocate on social media. He has become an

		internet sensation and posts regularly. His mother, Ellis, was present as a supporter during the session.
8	Derek	Derek was reached through snowball sampling, as a person that one of the other participants had worked with previously. He has an intellectual disability and is currently working at a local organisation in South Africa and acts as the self-advocacy representative for his organisation.
9	Izzy	Izzy was also reached through snowball sampling, as a person with whom one of the other participants had worked. She has an intellectual disability and is currently working at a local organisation in South Africa. She is an active self-advocate.

As identified in the table above there were nine interviews, and there were 11 participants. Six participants were individuals with intellectual disability, where only one required their supporter be present in the interview (Interview 7 above). This was a personal supporter. The participants in interview 7 were internationally based, whereas the others were from the local South African context. Four participants were professionals in the self advocacy sector. Two participants (Interview 1) were international representatives, whereas the other two were local professionals. This resulted in four professional supporters of self advocacy interviewed in this chapter. In summary participants with intellectual disability (n=6), family supporter (n=1), and professional supporters (n=4).

Results

The following diagram is a visual representation of the themes that emerged in the data analysis, with theme names drawn from the dialogues of various participants.

Quotations are used to illustrate participants' first-hand experiences of the issues they raised. In terms of the analysis of these interviews, it is noted that while there were stakeholders from a variety of backgrounds, locations, and included both self-advocates and professional supporters of these self-advocates, the findings across stakeholders tended to be very similar despite an active stance of engaging with the data both to identify similarities and differences of opinion across the informants.

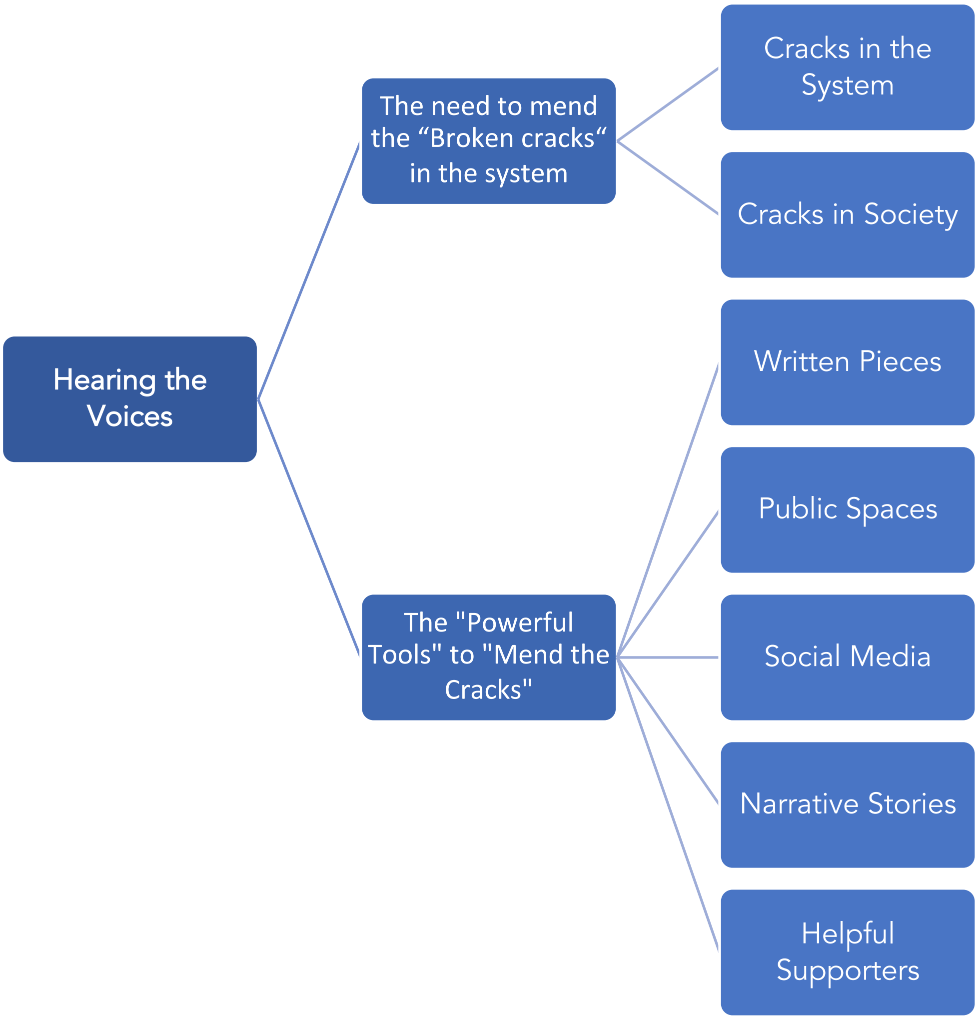


Figure 11

Visual Representation of Interview Themes

Overall Theme and Sub-themes

The overall theme entitled "Hearing the Voices" encapsulates the desire of participants that there be greater attention to hearing the voices of people with intellectual disability.

The first sub-theme, entitled *"The need to mend the "Broken cracks" in the system"* addresses the limitations that are placed on participants being able to self-advocate, and is split into "Cracks in the System" and "Cracks in Society".

The second sub-theme, entitled *“The ‘Powerful Tools’ to ‘Mend the Cracks’"*, details participants’ strategies associated with self-advocacy being actualised. This sub-theme was built upon the following categories: “Written Pieces”, “Public Spaces”, “Social Media”, “Narrative Stories”, “Helpful Supporters”.

Overarching Theme: Hearing the Voices

The overarching theme that was evident across all the interviews was the idea of hearing the voices of people with intellectual disability. All nine interviews highlighted the importance of listening and hearing the voices of people with intellectual disability. The notion of active listening was acknowledged by several participants. There was a dominant discourse of exclusion of the voices of people with intellectual disability across the interviews.

Richard spoke about his experience in the NGO sector, and how the default scenario is that the voices of people with disability are not included in conversations that involve them.

> Interviewer: *Why do you think that is so much systemic stigmatising of people with disabilities and how do you think we can challenge those stigmas ?*
>
> Richard: *The problem is … is that we have also excluded people with intellectual disability from the conversation … you know it starts off with the understanding that people with intellectual disabilities have a voice…. why would we exclude people with intellectual disabilities from the conversation? (Richard)*

Izzy echoed this view and emphasized the importance of hearing the voices of people with intellectual disability, as well as disputing the notion that people with intellectual disability cannot be self-advocates:

> *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. (Izzy)*

Alex also spoke about the fact that, even when people with intellectual disability are given a chance to speak, those listening do not engage actively with the messages that are being shared:

> Interviewer: *And so, how do you think we can make change like with the government? If you know, we wanna say that we want better healthcare for people with disabilities, how do we do that?*
>
> Alex: *The best way to fix everything in human communication is to listen. And, uhm, hear, but not actively listen … you listen with your mouth closed, listen with intent you know … listen with your ears open, really focus on what the person is saying, and you take in what the person is saying, you know? … But it is important for me to stand up for myself and like … believe in what I want, and like, you know, stand up for what I believe in and uhm … fight for what I want. (Alex)*

This was expanded upon by Lexi who emphasized the importance of people with intellectual disability also having opportunities to listen to the voices of others with intellectual disability, placing value on listening to the voices of other marginalised peers, the "other", and how storytelling can be a means of raising awareness. She highlights that while people with intellectual disability have their own stories, and their views may be different as they are not a homogenous group, self-advocacy initiatives can weave these stories to convey shared narratives for change:

> *That doesn't mean our journeys are the same that doesn't mean our outlets are going to be the same it's all gonna be different … but if we just take the powerful tool of our ears and our voices and listen maybe we could combine those stories and make a difference.… OK this is how I think we can reconnect the world. By using what we're using now … our voices!* (Lexi)

Sub-Theme 1: The need to mend the "Broken cracks" in the system

This first subtheme addresses the limitations that are placed on participants being able to self-advocate, and the difficulties that they have faced. Two sub-themes were conceptualised, namely, Cracks in the System, and Cracks in Society. These important sub themes highlight the disempowering effect that a context within which self advocacy takes place.

e) Cracks in the System

Lexi spoke about how the political system in an international first world country has let people with disabilities down:

> *There are lots of broken cracks with the (political system). Although it (the law) was passed thirty years ago there's still a lot of broken cracks.* (Lexi)

Zola described this in the local South African context, sharing her perspective that disability is not a priority in South Africa :

> *But in our country we are constantly making excuses about the high employment and how people with disabilities at the bottom of the food chain.* (Zola)

In the interview with Mark and Meredith, they both identified that even in a higher income country, such as their own, their experience was that there was slow progress in positive change through self advocacy efforts by people with intellectual disability and that there is a lack of impact of advocacy and self-advocacy in terms of corresponding increases in the effort within their political agenda to reform barriers to , for example, quality services:

> Mark: *There's very little out there at the moment and certainly when we were just starting this work, you know.*
>
> Meredith: *Well I suppose you were still coming out of that whole era and it's it's it's there is progress but it under it but it is, change is slow and of course when you look at mental health services or disability services they're not top of the priority in terms of the political agenda.*

Richard echoed this sentiment, and highlighted the lack of integration of people with intellectual disability in society despite the ideals of transformation, meaning that people with intellectual disability are often present in the communities but are not participating in society. He spoke about how the legislation is present, but is not being actualised:

> *I've said this before on various occasions we've reached transformation but we haven't reached integration so transformation means we've got the legislation that says certain things with regards to discrimination, specifically discrimination in the workplace and those sort of things which is which is what we deal with [at the NGO] but we haven't*

> *been able to reach integration as yet so we still struggling with the part where we go we have this legislation which is the transformative part of it but we haven't integrated that into our mainstream society.* (Richard)

f) Cracks in Society

It was observed that professionals interviewed tended to speak from a broader perspective on stigma and the limited opportunities, including limitations on self-advocacy, which people with intellectual disability encounter in society, based on their experience of observing the challenges experienced by self-advocates with whom they work. On the other hand, the perceptions of the self-advocates with intellectual disability were expressed in more practical terms, with their experiences relayed more closely attuned to their lived experience. Self-advocates expressed their views of how other's perceptions of them and their capabilities can serve to further nullify their voices and the impact of their voices, as well as impacting negatively on their perceptions of themselves.

Ben spoke about stigma and how this impacts his identity as a person with an intellectual disability and how people with intellectual disability are often infantilised and are perceived as *less than* other people:

> Ben: *It's views that are given by other people, that make people think like that … that intellectual disability is not right and stuff like that.… You are baby. You are a baby … you act like a baby and stuff like that.*
> Interviewer: *Not as grown up as the other people?*
> Ben: *Not as grown up as the other people.*

Lexi expressed similar frustrations with the experience of society towards her having a disability, and the barriers this poses for speaking up for her own and other's needs:

> *It's just so many misconceptions and it's inaccurate! It's very inaccurate and I'm frustrated with that. Even the way they like portrayed the condition to look like on, like, drawings. They make it seem like we're aliens and we have these misconfiguring bodies and it's like really disheartening when I have to do my research on cerebral palsy. You know ? … and I just want people to realise that there is more to our stories than just a diagnosis and you know one of the biggest problems I have is that doctors aren't willing*

> *to see past the diagnosis. They tell you "OK take this pill". A pill is not gonna help me! Awareness is gonna help me! Your understanding is gonna help me!* (Lexi)

Alex similarly spoke about how having to challenge the misconceptions that others have about his disability can be draining. He felt that this constant having to explain oneself- or be misrepresented in the minds of others- can have a negative effect on self-esteem:

> Alex: But, uhm, the other side of that ,ne, I have seen that people are very ignorant about me being different and stuff, you see what I'm saying?
>
> Interviewer: *Hmm …*
>
> Alex: *Like they barely notice it and stuff. And, that's actually a (inaudible) because I'm always (inaudible) and I always have to say the same thing, 'I'm autistic, this and that', 'do you know this and that?' or 'this is going to happen' and like that.… It's not a real fun thing to have to go anywhere and explain yourself you know?*
>
> Interviewer: *One hundred percent.*
>
> Alex: *It's just really tiring.*

Sub-Theme 2: The Powerful Tools to Mend the Cracks

The Powerful Tools outline strategies for the voices of people with intellectual disability to be heard, in a variety of ways.

a) Written Pieces

Writing strategies were highlighted as a viable strategy by several of the participants. These writing strategies were broken into different sub-sections, but all participants wrote about the nature of the written word, and the value that it has.

Lexi spoke about her experience as an author and radio show personality. She writes articles, and position pieces on her experience of being a person with a disability. Elaborating on her journey into writing and publishing, Lexi noted that her cerebral palsy has been more of a personal priority to self-advocate for, than her intellectual disability:

> *I am a published author … I lost my best friend with cerebral palsy. He passed away and then I published a book in his memory, called (X). He also had cancer as well. And then after I wrote that book … I realised it was an outlet for me to write about my experiences about grief and so forth. But then I started to focus on writing about cerebral palsy because I realised it was a lot of misconceptions with that, and then I got published on a site and my journalism journey has installed my advocacy journey.* (Lexi)

Ben spoke about the following suggestions in terms of writing to the government:

> Interviewer: *How do you think we can do that?*
>
> Ben: *You must make groups of people … you can make groups of people they can join a march or do research on what do you want to do … or do letters … write a letter to the government.*

b) Public Spaces

All participants spoke about using public forums to share their messages and create platforms to hear their voice. In the quote above, Ben highlighted the opportunities to access public spaces and be present in the communities. Lexi described being present on various panels and being present and visible in several interviews. Richard described an example where his institution had experience in arranging a placard demonstration on gender-based violence initiated by young adults with intellectual disability and how valuable it is to be seen.

Meredith echoed this point and described the value of being present in the community, and how this can lead to normalisation and representation of people in the community. She described a participant in her group who felt purposeful:

> *And you know he would just love having the job of going out and I think there was something more than being located in a public space was really important. And for some and for him to just, even you know, maybe I misinterpret, but I think for him just even just seeing the visibility of being in the public space and sometimes I would purposely not get enough milk, so he could just enjoy that experience of walking through a public cafe and feeling a sense of purpose in a regular public space.* (Meredith)

Izzy described the importance of being seen and respected in a crowd of people:

> *Now for me, when it was when I actually had to do a presentation or speech or talk for myself, then I at first, my first time I was nervous. Because I'm standing in front of, how can I say, a hundred people then I have to give my life story. But then later on again I got used to it because yeah, because its people that I know will be in the audience and they now want to talk to me.* (Izzy)

c) Social Media

One of the participants, George, who has become an overnight internet sensation, spoke about the value of social media to connect all over the world. In the interview, supported by his mother, they described how he became famous over the weekend. His video proceeded to have over 10 million views:

> Mom: *Somehow during or after dinner we were hunting Easter eggs, and someone said … his video has a lot of views and so then we kind of started watching it, and within the first day it had over one million views. And, he had an article from Newsweek about it at one million views, and we started getting phone calls from people all over wanting to interview him, and wanting to know about him and it was just truly an overnight sensation, I guess.*
> Interviewer: *An overnight celebrity.*
> Mom: *Yes, fifteen seconds of fame.*
> George: *Yes, that's right ... fame!*

Several of the participants referred to using social media as a platform to spread awareness. Lexi, George and his mother named specific social media sites that have been utilised to share their perspectives and hear their voices. Lexi spoke about how she uses social media platforms such as Facebook, Instagram for advocacy efforts:

> *I mean there's a lot of negatives with the pandemic but there's a lot of good with it too … so I'm so happy we were able to connect. I just send you my Instagram and so forth and I hope to hear from you soon!!! And radio show personality, ah, right now because of the pandemic I'm doing all my advocacy things through Zoom and through social media as well.* (Lexi)

d) Narrative Stories

Ben reflected on the South African context, the oppression that he faces as a person with an intellectual disability, and suggested that storytelling could be a strategy for raising awareness:

> *We need to work on the treatment of people with disabilities. Like the president said so. Yes we do and maybe as you say to tell those stories so that we can highlight the injustice and the oppression, injustice, ya … and prejudice. With the stereotypes and stuff like that.* (Ben)

Lexi alluded to the same point, and addressed lack of emphasis on disabled voices throughout history, and how these voices are often silenced. She provided a concrete suggestion to promote inclusion, and calls for mainstreaming of disabled voices in society:

> *Disability rights histories in school you know you have all these things about the civil rights movement and what Martin Luther King did but you have nothing about disability advocates like Jim Bracken, Judy Heumann and Katie Komen, there there's so many advocates out there that deserve to be taught in schools and maybe if we start teaching that in schools … maybe it'll lead one step closer to exclusion and understanding.* (Lexi)

She provided advice for future self-advocates and highlighted the importance of advocating for oneself and how, in turn, the action of standing up can be an example for others. This displays the value of peer-to-peer support in the advocacy world:

> *Kind of advice that I would have for future activists is regardless of what people may think keep telling your story because one day you're gonna be the survival guide for somebody else so don't give up and just don't advocate for yourself but advocate for the next generation.* (Lexi)

e) Helpful Supporters

As echoed in the point above, the idea of supporters is so important to the success of self-advocacy initiatives.

Derek spoke about the role of using supporters and how they may be necessary in scaffolding the process and helping the person with intellectual disability achieve their goals:

> Interviewer: *Is it only people with disabilities at the committees or is it a whole bunch of different people?*
>
> Derek: *Uh, a few of them has disabilities and its (inaudible) like normal people. They helped him up, and (inaudible) in the meetings and so on.*
>
> Interviewer: *Okay, and the other people who are part of the advocacy group, who are they?*
>
> Derek: *They are also, a few of them is our staff members. Like the job coaches are staff members and some of them is the trainees from each workshop and the job coach leads the meeting and we have one of our general managers to sit in the meeting also.*
>
> Interviewer: *So, it's almost like they're your supporters. They help you in those situations.*
>
> Derek: *Yeah supporters, yeah.*
>
> Interviewer: *Okay.… And, do you think it's important to have these supporters in these in these spaces?*
>
> Derek: *Uh, from my side, I think they need support because some of them is … don't, don't, know how to read and write, so they need someone to help them out.*

Izzy echoed this point, and described her first-hand experience of having a supporter who assisted her with self-advocacy initiatives:

> Interviewer: *And tell me, tell me a little bit about the, the, idea of the supporters. Who was your supporter? What did they do for you?*
>
> Izzy: *Now, you see, I actually paid the supporter. Now, yes, so the supporter that would now help me with getting my reports ready, that time she was the general manager.*
>
> Interviewer: *Okay …*
>
> Izzy: *Oh yeah, so whatever she did was she, compile my reports with me, but in a professional way on her laptop. Yeah, and then she will now sit with me and ask me, now what do I want to say? And then, (name) was my other supporter, she was actually technically in the board meeting, so she was my supporter and she was my chauffeur.*

Ben spoke about how, ultimately, we are all human beings, and we need to connect on a human level. He emphasised the role of supporters, whether they are family, colleagues, peers, friends, or professionals, but ultimately the importance of human connection as a powerful tool to having voices heard:

> *We talk to one another as human beings. We do a … humble with each other and uhh we do Ubuntu.… we need people to support us so that our voices will get heard.* (Ben)

The following figure is a pictorial summary of the strategies identified in this chapter.

Figure 12

Summary of Self Advocacy Strategies Identified by Participants

Discussion

This interview series has indicated a clear desire amongst participants that there should no longer be a silencing of disabled voices, and equally, there should be the provision of influential spaces for peoples' voices to be heard.

The overall theme "Hearing the Voices" encapsulates the desire of participants that there be greater attention to hearing the voices of people with intellectual disability. Two subthemes were found, one that addressed the barriers to self advocacy, and one that addressed the enablers or supports to self advocacy. The first sub-theme, entitled *"The need to mend the "Broken cracks" in the system"* addresses the limitations that are placed on participants being able to self-advocate, and is split into "Cracks in the System" and "Cracks in Society". The second sub-theme, entitled *"The "Powerful Tools" to "Mend the Cracks"*, details participants' strategies associated with self-advocacy being actualised. This sub-theme was built upon the following categories: "Written Pieces", "Public Spaces", "Social Media", "Narrative Stories", "Helpful Supporters".

In terms of the analysis of these interviews, it is noted that while there were stakeholders from a variety of backgrounds, with different levels of functioning, the findings are similar. This may be due to the fact that all participants recruited already supported and were involved in self-advocacy in some way, a wider range of participants might have introduced more diverse voices, but the purpose of these interviews, greater clarity on the experience of and strategies for, was met.

There were several barriers that emerged in the interviews, limiting the participation of people with intellectual disability, and having their perceptions discussed in social policy. The results detail participants' views that there are limitations that are placed on people with intellectual disability being able to self-advocate. Consistent with the findings above, a study by Abbott and McConkey (2006) demonstrated that individuals with intellectual disability were able to identify the barriers to social inclusion they had experienced, and they could articulate ways of reducing or removing them. This highlights how important it is to listen to the perspectives of those with lived experience as they are the experts in the issues they face. Often the perspectives default to the people around the person with an intellectual disability, where often there are factors such as overprotection by authority figures and fostered dependence on others (Test et al., 2005) limiting participation. These identity issues lie at the heart of self-advocacy, in that if one perceives oneself as less than, or as a potential source of trouble, and the recipient of others' judgements, this limits the possibility of self-advocating for their priorities (Williams & Porter, 2017). Participants also pointed out the change in attitudes that was needed from other people in the community (Abbott & McConkey, 2006). Often the perspectives of people with intellectual disability are simply dismissed. The participants of the interviews in this study challenged the perceptions of others who thought them incapable of speaking up for themselves.

There are limited spaces for people with intellectual disability to engage in discussions about their rights, social policy and decisions about their lives, often caused by issues of stigma and discrimination. As found in the South African Health Review (Kathard et al., 2020), editors and authors Kathard, Padarath, Galvaan, and Lorenzo note that there are systemic inequities that perpetuate hierarchy, patriarchy, racism, and ableism. These inequalities perpetuate the identity of a person with an intellectual disability as *less than*.

Test et al.'s (2005) article highlights how individuals with disability who are strong self-advocates often challenge the perceptions of others about the credentials of a person with intellectual disability to self-advocate. This echoes this theme in the current study, that society often sees this population as incapable of making decisions about their own lives (Test et al., 2005). This was also found in the paper by Berghs et al. (2019), where people with disability felt that they were not being treated as human by society. Capri et al. (2018) further this idea by highlighting how the public infantilisation, abuse and taunting of people with intellectual disability can further isolate them from attempting community and socio-political activities.

A societal shift is needed where these voices become prioritised, in order to support people with intellectual disability to actualise their human rights. This is reflected in the social and human rights models, or social model of human rights, where it is evident that when barriers are removed, people with disability can be independent or interdependent and equal in society, being socially included, with more choice and control over their own lives (Republic of

South Africa, 2013). Rights protection and destigmatisation through public awareness and education is vital in changing the attitudes and practices of the general public, civil leaders, policy makers and service providers (Kleintjes et al., 2013).

O'Brien et al. (2022) describe how, in their collective experience conducting inclusive research with people with intellectual disability, allowing self-advocates into the social policy space allows for their personal experiences to influence the policies that affect their lives. The self-advocates felt valued and that their opinions were catalysts for change (O'Brien et al., 2022).

Participants in this study identified several "Powerful Tools" and strategies through which self-advocacy can be promoted, either from practical experience as supporters, or from the lived experience of participants. For people with intellectual disability, an important way that rights are lifted off paper and brought to life is through advocacy efforts (Brolan et al., 2012). Brolan et al. (2012) state, "CRPD rights, like all human rights, are mere words on paper unless there is energy and momentum to facilitate their respect, promotion and fulfilment (p. 1088)". Environments that foster self-advocating behaviours are critical to promoting self-advocacy (Test et al., 2005). Furthermore, with greater emphasis placed on inclusion in the community, independent living, and meaningful occupations for people with intellectual disability, it is clear that self-advocacy training may be a powerful way to change perceptions about their capability for independence, or supported independence, in order to have movement on actioning this (Schmidt et al., 2020).

Being connected to others in the community, and being socially included, is key to self advocacy. The concept of interdependence, phrased in our local context as *Ubuntu*, is echoed in literature internationally. Williams and Porter (2017) highlight the concept of interdependence. In their study they highlighted how the theme of 'other people' had great importance where self-advocates tended to talk about "we" rather than "I" (Williams & Porter, 2017). Described in the interviews above as being the survival guide for others, the importance of peer support was also an interesting phenomenon found in several other studies. According to Williams and Porter (2017), the definition of a "peer" is someone who identifies with the label of intellectual disability, particularly members of self-advocacy groups, who supply confidence and support, contributing and helping others.

Having a team of people around a person with an intellectual disability can assist them with self-advocacy strategies and interventions. Several practical strategies emerged from the interviews above, that of public spaces, written word and social media, which were consistent with the findings in the scoping review in Chapter Four, and the review of toolkits in grey literature, found in Chapter Five. The practical strategies that emerged in the interviews, in addition to the above, are similar to the findings of Schmidt et al. (2020) who found that strategies could include interactive multimedia education, peer led group interventions, writing interventions, and specific health condition-related programmes. In conclusion, a range of strategies are needed to actualise self-advocacy initiatives by people with intellectual disability, with their central involvement in the implementation of these strategies being absolutely crucial for engagement in social policy, and general inclusion for people with intellectual disability (Abbott & McConkey, 2006). Politicians, or those in positions of power, should align with the people who the policies will apply to, those who stand to gain the most from the policy development, in this case, the people with intellectual disability, to ensure that the decisions taken create positive outcomes for the quality of life for this population (O'Brien, 2022).

Limitations of the Interviews

A wider geographic scope could have supported the inclusion of several more HIC settings and possibly identified LMIC setting to compare and contrast data on the self advocacy movement, as would the inclusion of non-English papers. This could have shed more light on the current strategies that are being used in a wider range of countries. Another limitation of this phase of the interviews was the recruitment options, as these interviews were conducted during the Covid 19 pandemic.

Strengths

This research added to the body of knowledge about the perceptions of people with intellectual disability and their supporters about the experience, but of self-advocacy and ways to improve participation in self-advocacy. By understanding the lived experience of these participants around the phenomenon of self advocacy, research informed practice can support this community in active societal participation.

Conclusion

Self advocates and self advocacy supporters shared their views on self advocacy, the barriers and enablers to participation, and identified several strategies for self advocacy. Identified barriers included having limited spaces for people with intellectual disability to engage in discussions about their rights, social policy and decisions about their lives, often caused by issues of stigma and discrimination, and societal perceptions of people with intellectual disability as incapable of making decisions for themselves. Yet these interviews highlighted that in fact individuals with intellectual disability are able to identify the barriers to social inclusion they had experienced, and they could articulate ways of reducing or removing them. Suggestions for enablers and strategies for self advocacy included being present in public and community spaces, using digital and print media, telling narrative stories, using social media, and having helpful supporters. This chapter highlights how important it is to listen to the perspectives of people with intellectual disability as they are the ones with lived experience and are experts in the issues they face.

Chapter Seven

Results of the Development of a Self-Advocacy Toolkit

Introduction

This chapter details the results of the development of a self advocacy toolkit, Objective 4, which aimed to develop a toolkit with people with intellectual disability to promote their participation in social policy development and implementation processes in South Africa.

This chapter will start by presenting the triangulation of study findings, of the objectives 1, 2 and 3. Following this, this chapter will highlight the self advocacy topics identified in the study chapters, and will describe the learning objectives designed for the toolkit, well as the activities that were proposed, and where the activities were drawn from. Researcher observations will be discussed, leading up to the presentation of the results of the experiential toolkit review and all the elements involved (individual interviews, toolkit engagement and participation, focus group, and video production). Finally, this chapter will present a discussion of the findings.

Triangulation of Study Findings and Content Inclusion Process

The process of triangulation for the topics to be included occurred by looking at the findings of each chapter, and comparing and contrasting the results. The three sources of information were triangulated and tabulated. The following image was developed to depict the overarching themes across the chapters of the research:

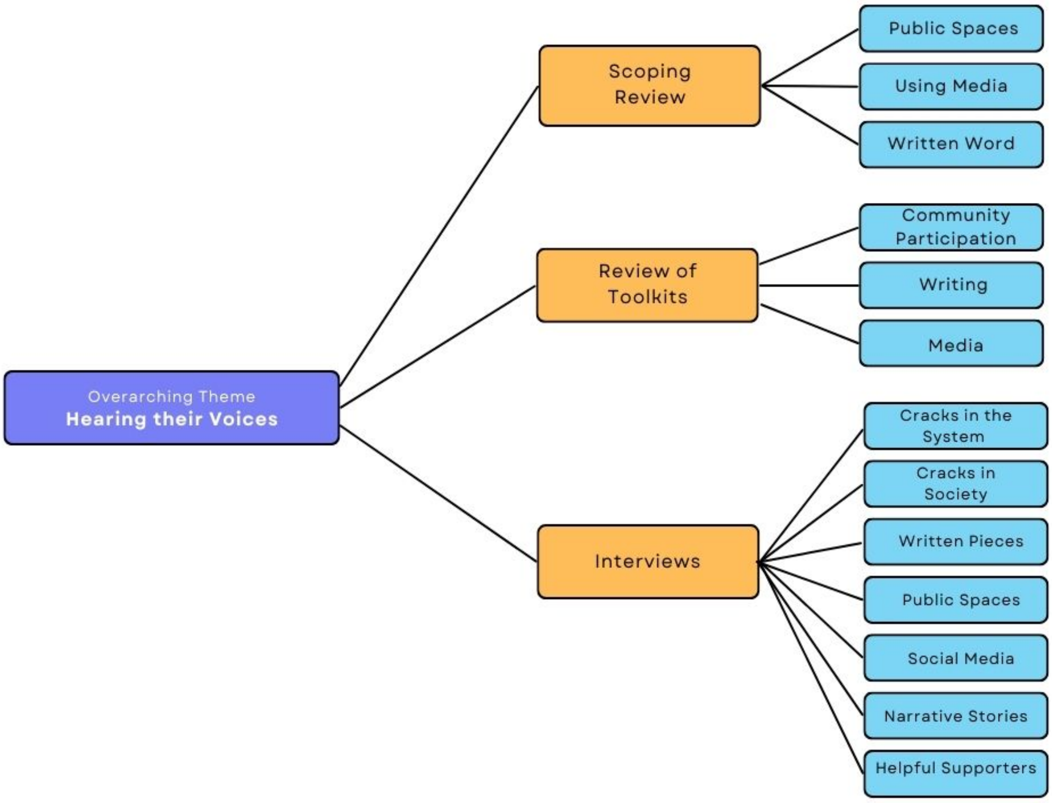


Figure 13

Triangulation of Themes across Study Methods

The findings from the previous chapters informed the development of Table 7.1. Several iterations of the process of comparing and contrasting and documenting the findings in the table were used to finalise the table. This process was an ongoing journey of revisions and additions.

The content of this first toolkit focuses on the most commonly identified skills in the research. More specific content has not been included for the more complex individual skills. Including examples of more specific content such as money management, or learning to read, learning about money, or literacy, would mean that a whole separate toolkit will be needed. As seen in the table below, a number of topics identified were found in only one of the study chapters. These specific skills may need separate, specialist toolkit development (or extensions to existing toolkits) for those who want to, or need to, learn specific skills.

Table 7.1

Self-Advocacy Topics Identified in Study Chapters

Topics Identified	Scoping Review	Grey Literature Review of Toolkits	Interviews
Knowledge of self-advocacy	X	X	X
Knowledge of self	X	X	X
Rights awareness	X	X	X
Knowledge of injustice / stigma	X	X	X
Identification of rights violations	X	X	X
Strategies for self-advocacy	X	X	X
Understanding of communication	X	X	X
Technology skills	X	X	X
Literacy	X	X	
Public speaking	X	X	
Identify priorities for self-advocacy			X
History of people with Intellectual Disability			X
Knowledge of government and policy	X	X	
Managing money	X	X	
Writing letters	X	X	
Leadership skills	X	X	
Identity development	X	X	
Awareness raising	X	X	X
Public speaking	X	X	X
Group skills	X	X	
Conflict resolution		X	
Active listening		X	
Frustration tolerance		X	
Negotiation skills		X	
Body language		X	
Non-verbal cues		X	

Assertiveness		X	
Record keeping		X	
Expressing feelings		X	
Phone call etiquette		X	
Reflection skills		X	
Note taking		X	

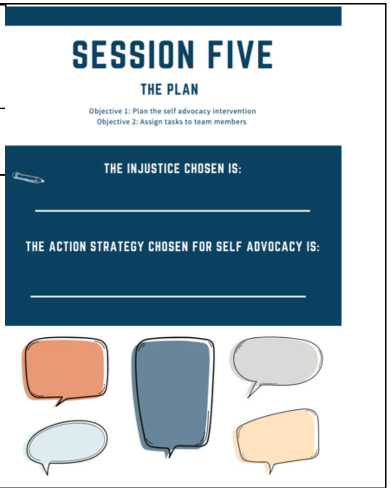
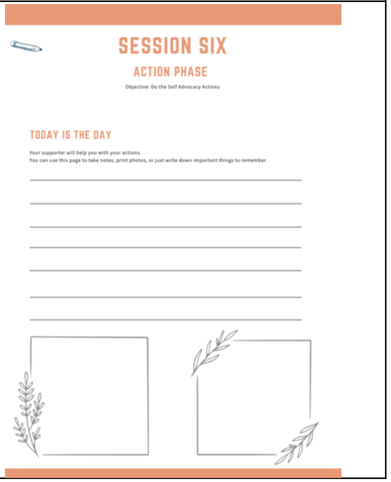
The following table (Table 7.2) highlights the learning objectives outlined for each session, as well as the activities that were proposed, and where the activities were drawn from. Table 7.3 also includes a pictorial snapshot of the toolkit programme.

Table 7.2

Learning Objectives for the Toolkit

Session:	Title:	Areas to focus on:	Specific Tasks and Where they were sourced		Image from the toolkit
1	What is self-advocacy	*Initial interviews conducted* Objective 1: Understand What is Self-Advocacy Objective 2: Learn about famous self-advocates Objective 3: Understand Strengths and Weaknesses in terms of self-advocacy	Information giving about self-advocacy	Scoping Review Grey Literature Review Interviews	 SESSION ONE WHAT IS SELF ADVOCACY? *Initial assessment conducted* Objective 1: Understand What is Self Advocacy Objective 2: Learn about famous self advocates Objective 3: Understand Strengths and Weaknesses in terms of self advocacy SELF ADVOCACY IS: Speaking up for yourself Asking for what you need or want Making your own choices and decisions about things that affect you Telling people about your thoughts and your feelings Asking for help and support NOTES FOR SUPPORTER: Self-advocacy is the ability to speak-up for yourself and the things that are important to you. This includes: • Understanding specific needs. (This is part of self-awareness) • Knowing what help or support will address those needs, like tutoring or classroom accommodations. • Communicating those needs to teachers and others. Self-advocacy means you are able to ask for what you need and want and tell people about your thoughts and feelings. Self-advocacy means you know your rights and responsibilities, you speak-up for your rights, and you are able to make choices and decisions that affect your life. This means that you are making the choices and you have to be responsible for the choices you make. LINK TO VIDEO The Power of Self-Advocacy https://youtu.be/cEhfcOBPVMU NOTHING ABOUT US WITHOUT US
			Video on Self-Advocacy	Developed with co-researcher based on sourced documents	
			Stories of Self-advocacy warriors	Interviews	
			Advocacy characteristic activity	Developed with co-researcher based on sourced documents	
			Role model activity	Interviews	
			Who am I?	Scoping Review Grey Literature Review Interviews	
			Understanding the self	Scoping Review Grey Literature Review Interviews	
			Group Discussion	Developed with co-researcher based on sourced documents	
			The power of yet	Developed with co-researcher based on sourced documents	

2	Rights and Justice	Objective 1: Discuss Human Rights and Responsibilities Objective 2: Learn about Justice and Equity Objective 3: Discuss inequalities in our context	Information giving Rights	Scoping Review Grey Literature Review Interviews	 SESSION TWO RIGHTS AND JUSTICE Objective 1: Understand Human Rights and Responsibilities Objective 2: Learn about Justice and Equity Objective 3: Discuss inequalities in our context WHAT ARE HUMAN RIGHTS Human rights are rights we have simply because we exist as human beings - they are not granted by any state. These universal rights are inherent to us all, regardless of nationality, sex, national or ethnic origin, colour, religion, language, or any other status. They range from the most fundamental - the right to life - to those that make life worth living, such as the rights to food, education, work, health, and liberty. WHERE CAN WE FIND THEM? South Africa has our human rights in our own Bill of Rights, Chapter 2 of the Constitution of the Republic of South Africa, 1996. The Bill of Rights protects the rights of every South African, and it's important that all South Africans know their most basic rights afforded to them. Below are some of the most crucial rights you should know. RIGHTS VS RESPONSIBILITIES Rights are the rules that help make everyone equal, but you also have some responsibilities. This means that you care about other people's rights. Here are some examples: • The right to a clean environment and the responsibility to take care of their environment by cleaning the space they live in. • A right to food and the responsibility not to be wasteful. • A right to good quality education and the responsibility to learn and respect their teachers and peers. • A right to quality medical care and the responsibility to take care of themselves and protect themselves from irresponsible exposure to diseases such as HIV/Aids. • A right to protection from exploitation and neglect and the responsibility to report abuse and exploitation. All human beings have rights We can find these rights in the Bill of Rights These rights are to keep us safe and healthy We need to respect everyone's human rights
			Role model activity	Developed with co-researcher based on sourced documents	
			Important terminology	Scoping Review Grey Literature Review Interviews	
			Activity: I am but I'm not	Developed with co-researcher based on sourced documents	
			Supporters and environments	Scoping Review Grey Literature Review Interviews	
3	Strategies for Change	Objective 1: Explore strategies available to effect change Objective 2: Reflect on the advantages and disadvantages of the action strategies Objective 3: Select the strategy that will be used for this self-advocacy initiative	Video on human rights and Judy Heumann	Interviews	 SESSION THREE STRATEGIES FOR CHANGE Objective 1: Explore strategies available to effect change Objective 2: Create a pro and con list of these action strategies Objective 3: Select the strategy that will be used for this self advocacy initiative RAISING AWARENESS AND FIGHTING INJUSTICE Raising awareness for injustices is very important because it is how stereotypes get broken. Often people believe certain things because they have never received proper information. By raising awareness of certain issues, you can teach people the truth and help break stereotypes. This can make you a kinder, more caring human being. ACTIVITY: CASE STUDY ON RAISING AWARENESS FOR DISABILITIES Click the link to watch a video about Judy Heuman. https://youtu.be/NfBRPbvvur8 Use information from the video and discuss Judy Heumann and the impact that she had on people with disabilities: Remember: • Judy Heumann is an interesting and incredible woman, your writing about her needs to reflect this. • Think about why she did this kind of advocacy • Look at the impact that Judy had on the future of people with disabilities all over the world. She didn't only spread the message for herself - she wanted to cause change for all people like her, all over the world. EQUALITY EQUALITY EQUALITY
			Types of injustices	Grey Literature Review Developed with co-researcher based on sourced documents	
			Select an injustice that matters most to you	Grey Literature Review	
			Activity: making a poster	Developed with co-researcher based on sourced documents	
			Understanding action strategies	Scoping Review Grey Literature Review Interviews	
			Select a strategy that will work best for you	Developed with co-researcher based on sourced documents	

4	Skills Needed	Objective 1: Address personal skills for self-advocacy Objective 2: Practice these skills in a practical way Objective 3: Reflect on own capacity and areas for development	Concept: Garden of self-advocacy skills	Scoping Review Review of Toolkits Interviews	 SESSION FIVE THE PLAN Objective 1: Plan the self advocacy intervention Objective 2: Assign tasks to team members THE INJUSTICE CHOSEN IS: THE ACTION STRATEGY CHOSEN FOR SELF ADVOCACY IS:
			Role Play	Interviews	
5	Developing the Action Plan	Objective 1: Plan the self-advocacy intervention Objective 2: Assign tasks to team members	Break down the plan to use the strategy to self-advocate for the injustice identified	Scoping Review Grey Literature Review Interviews	 SESSION SIX ACTION PHASE Objective: Do the Self Advocacy Actions TODAY IS THE DAY Your supporter will help you with your actions. You can use this page to take notes, print photos, or just write down important things to remember.
			Make a timeline	Scoping Review Grey Literature Review Interviews	

6	Action Phase	Objective 1: Execute a self-advocacy intervention	Execution of chosen intervention	Scoping Review Grey Literature Review Interviews	 SESSION SEVEN REVIEW AND REFLECT *Post Assessment conducted* Objective 1: Reflect on Strengths and Areas to Improve Objective 2: Reflect on entire process Objective 3: Discuss any next steps What did I do well? What can I do better next time? What was the best part? What was the hardest part? What did I learn? How was working in a team?
7	Evaluation	*Post Interviews conducted* Objective 1: Reflect on Strengths and Areas to Improve Objective 2: Reflect on entire process Objective 3: Discuss any next steps	Individual interview Grey Literature Review		 SELF ADVOCACY EXIT INTERVIEW NOTES FOR SUPPORTER Participants may not be able to read / write. If they are able to, they may proceed and answer the questions independently. In the case where literacy skills are a challenge, it is recommended that the facilitator read the questions to the participant independently and write their answers down on their behalf. Use discretion and grade appropriately. QUESTIONS What do you know about "self advocacy"? Name 2 of your strengths, and 2 of your weaknesses when dealing with other people? What do you know about "human rights"? What is injustice? Can you think of anything unfair in South Africa? If you wanted to tell the governemnt to listen, what strategies could you use? Why is communication important in advocacy? What skills would you need to spread the message? If you could share one message with the president, what would it be?

8	Reflection	Focus Group	Group discussion	 FINAL COMMENTS AND FEEDBACK What did you think of this toolkit? Are there any things that you think are missing? Is the language used easy to understand? Do you think the activities will help somebody learn to become a self advocate? What tips would you have for the supporters? Do you think the content is easy to understand? Is there anything that needs to be changed?

Researcher observations

The researcher journaled her impressions after each toolkit session. Emerging themes and categories were noted, as well as whether the activities elicited the desired outcomes, how the participants were responding and their perspectives on the tools. The analysis and findings are detailed below. There were moments when, as the researcher, my clinical reasoning and judgment required me to adapt to the emerging needs of the group. Examples of this is when the group seemed to be losing focus, or were not understanding the activity as intended. One adaptive strategy suggested by participants to address issues of focus was to use more videos instead of information giving, to allow for more discussions, to shift the order of activities, and to allow for more time for recap sessions. This highlights the usefulness of platforms where vlogging is possible, such as social media, where as described in Chapter 6, one participant's video has garnered millions of views.

The following are excerpts from the researcher's journal:

> *The 'not yet' list went better than expected, the participants really enjoyed this activity and expressed that they are all still learning in different areas.*
>
> *In some of these discussions, more facilitation is required. I have had to change the methods for this session and include more videos and group discussions.*

The following is a link to the first draft of the toolkit:

https://www.dropbox.com/s/g4adfi7emqghraw/Toolkit%20draft.pdf?dl=0

Findings and Results

Feedback from Interview Participants

The feedback from participants was largely positive, with some constructive feedback and suggestions put forward. The toolkit was felt to be accessibly developed, based on the criteria elucidated in the questions below. The lack of guidance on how to develop such materials was also noted by trainers from Inclusion Ireland (2022) in their training manual sourced during the grey literature review. When discussing toolkit revisions in the interview stage of this study, in Chapter Six, one organisation noted, "When planning and undertaking this work we found it difficult to get training materials suitable for working with people with intellectual disability. Being experienced trainers, we adapted exercises to suit the specific needs of the group. Mindful of this gap in materials we decided to document our work and learning over the period, recording what exercises worked well. We are still learning; hence this manual is a living document" (Inclusion Ireland, 2022 [page number omitted to ensure participant anonymity]).

In terms of the visual components, all participants who responded remarked on the visually appealing nature of the toolkit:

> *Overall the design of the manual looks great, visually it's very attractive – the way it is presented with the graphics, the text is well spaced out and a lot of great material on so many subject areas. We really like some of the exercises and activities like 'who am I' and 'the power of yet'.* (Meredith, Participant 1)
>
> *I like the layout, easy to follow, nice flow to read, not too much unnecessary words, simple language, yet professional, well done.* (Zola, Participant 3)
>
> *It has easy language I love how it's illustrated and created. I think it would give future advocates a better understanding.* (Lexi, Participant 4)

Lexi added the importance of mainstreaming the voices of self-advocates and sharing their quotes, as a way for future advocates to look up to them, as role models:

> *I absolutely love it for the most part my only advice would be to include quotes from advocates that will help the future advocates understand what it means to advocate.* (Lexi, Participant 4)

Ellis spoke to the contextual aspects of the toolkit and suggested a more global approach:

> *Those with intellectual disabilities may have a more difficult time with some of these activities. But, I think you have reached a great middle ground with the information, training, and approach. know this is specifically designed for use in South Africa. But, if you take out "South Africa" broaden a few of the references I think it could be applicable (and useful!) just about anywhere in the world! The issues you are addressing are global in nature.* (Ellis, Participant 7)

Findings and Feedback from the Experiential Toolkit Review

i) Individual Interviews

There were participants who had no knowledge or experience of self-advocacy prior to the toolkit review. Only one participant had a definition that was clear before experiencing the toolkit activities:

> *Self-advocacy means when you do things yourself and are able doing things on your own.*

After the toolkit review process, all participants were able to provide a concrete definition of self-advocacy in the interviews. Two participants who were unable to generate an answer in the initial interview were able to provide strong answers after their experience with the toolkit.

> *Participant A: (before the experiential review)*
>
> > *What is self advocacy?*
> >
> > *Not sure what it is.*
>
> *Participant A: (before the experiential review)*
>
> > *What is self advocacy?*
> >
> > *It is when you can stand up for yourself.*
>
> *Participant B: (before the experiential review)*

What is self advocacy?

I don’t know.

Participant B: (before the experiential review)

What is self advocacy?

How to talk for yourself. How to defend yourself. How to stand up for yourself.

Ahead of the experiential learning process, there were limited responses around the notion of rights in terms of education, the right to vote, the right to speak up as a right. Afterwards, all participants showed a development of awareness of rights. The participant who previously said, *“I’m not sure”*, in the post interview said, *“we all have the right to talk for ourselves”*.

These practical examples highlighted by people with intellectual disability describe practical examples of their lived experience and their feelings around their lack of access. This is indicative of the interpretive phenomenological approach in action. With each stage of the research, the understanding of the phenomenon of self advocacy is deepened.

In terms of rights violations and injustice, one participant identified unfair practical experiences such as lack of houses or water in the initial interview, but in the second interview identified broader, more overarching underpinnings of the experience: *“Other people don’t see us with disabilities. They don’t treat us like equals”.*

In both sets of interviews, several strategies for self-advocacy were mentioned. There was a shift from more narrow suggestions in the initial interviews such as: go see them in person, maybe an email or a letter, talk face to face, and two mentions of media – towards a wider range of strategies such as: make a video, use social media platforms such as WhatsApp, Telegram, Facebook, Instagram, or even making a poster, in the second round of interviews.

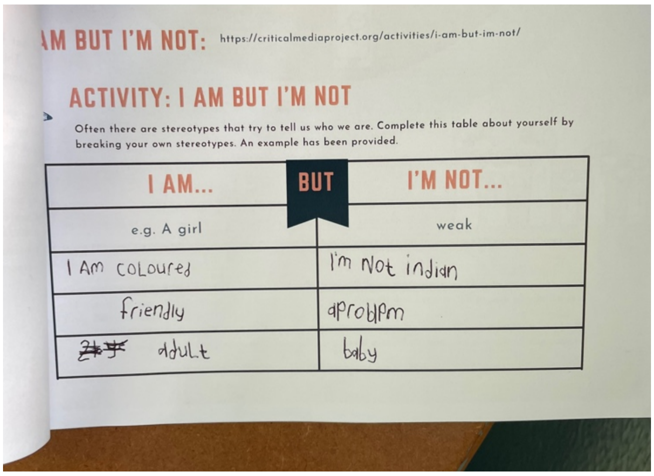
ii) Toolkit Engagement and Participation

The participants, for the most part, found the toolkit was engaging; in particular, the visuals, videos and activity-based tasks received the most positive feedback. Based on researcher observations, feedback from participants and notes taken, it was clear that revisions to the initial draft were needed as the participants were a mixed group in terms of capacity and knowledge. There were several more abstract activities which were more difficult for some of the participants to complete – for example, thinking about own strengths and weaknesses.

Findings during the experiential review of the toolkit developed in this study indicate that given the chance to speak up, when the participants opened the conversation, having a discussion on their priorities, these young people with intellectual disability express typical needs to assure their future, such as the need to be recognised on an equal footing with other citizens, the need for equal access to education and skills development, opportunities for employment, and equal access to services which can support a better, inclusive life.

Figure 14

Participant Completing "Who am I" Activity



AM BUT I'M NOT: https://criticalmediaproject.org/activities/i-am-but-im-not/

ACTIVITY: I AM BUT I'M NOT

Often there are stereotypes that try to tell us who we are. Complete this table about yourself by breaking your own stereotypes. An example has been provided.

I AM...	BUT	I'M NOT...
e.g. A girl		weak
I Am coloured		I'm Not indian
friendly		aproblem
adult		baby

Figure 15

Participant Responses to the "I am, but, I'm not" Activity

As part of the toolkit experience, the participants were able to produce their own self-advocacy intervention. Several of the participants voiced having experiences where their perspectives were disregarded due to their intellectual disability, which they deemed was an injustice experienced by all participants and they therefore decided to use this issue as the focus of their self-advocacy intervention.

The participants brainstormed their idea, and decided to make a video. Through discussions, some chose to be in the video, some preferred to be behind the scenes, and others gave input to the song choices, the script and general direction. The self-advocacy intervention that the participants selected highlighted their skills and capacities, where they created a video, and produced it themselves, where the researcher acted as a helpful supporter in case the participants needed help. The researcher acted as a supporter in helping the participants download specific songs and supported the editing of the video together with the participants. The video that was created was developed solely by the participants of the group. When they chose a strategy to share their message about injustices that they face, the option of social media was the one that they selected. In the video they call for people to "stop bullying, judging, discriminating and having hatred for people with disabilities". This video was pitched at a social policy level where it was stated: "In South Africa people with learning challenges gets treated badly because of their disability. It is the government's responsibility to take a stand and improve the support for people with learning challenges".

The audio selected by the participants was a song written by Eminem, titled: "not afraid". They explained that they chose these lyrics as they wanted to share that they were not afraid to stand up for themselves and for their rights. The lyrics are as follows:

> *I'm not afraid (I'm not afraid)*
> *To take a stand (to take a stand)*
> *Everybody (everybody)*
> *Come take my hand come (come take my hand)*
> *We'll walk this road together, through the storm*
> *Whatever weather, cold or warm*
> *Just lettin' you know that you're not alone*
> *Holla if you feel like you've been down the same road*

After watching the video they had created, several of the participants chose to share the video on social media. This was supported by all of the participants, and shared with their networks, as they showed pride in the product that they had created.

iii) Focus Group

A focus group was held with the participants after their experiential sessions with the toolkit. The group aimed to discuss general feedback, and went through the handout. One example of an activity that had positive reception was the Role Play activity. In the discussion around experiencing self-advocacy, in the role play of the medical scenario where the participants were asked to role play having to stand up for themselves and share their own voices to a doctor, one participant stated:

> *This happened to me before, no matter how many times I said I could speak for myself, the doctor just kept talking to my mommy, even though they know I'm almost twenty-three.*

In terms of the discussion around labels and the words used to describe themselves, one participant stated:

> *There's almost two kinds of ways of looking at disability right, there's the learning challenge, and then there's full on disabilities like wheelchairs. We all have challenges, so a learning challenge is better.*

As a part of this discussion, another participant stated:

> *With the right support we can all help our challenges.*

Another participant echoed this statement and said that, in terms of terminology:

> *"Disabilities" feels too harsh.*

iv) Video Production

Figure 16
Photograph of supporters taken by Film Crew

After the toolkit review process was complete, an opportunity arose for these young adults to have a similar video created, filmed by a professional film crew. This was in collaboration with the Western Cape Forum for Intellectual Disability. This video was aimed at creating awareness regarding service users' perceptions of having an intellectual disability, and how they want to be treated. This video was conceptualised as a visual policy brief for stakeholders in social policy spaces.

The opportunity was discussed with the participants, and several raised their hands to be involved in the video. The process was described, and it was explained that the video would be used for awareness raising purposes, and those who wanted to be involved came in on a specific day allocated for filming.

On the day of filming, participants arrived and were briefed on the events of the day. They signed a consent form, developed in conjunction with the Western Cape Forum, which gave their permission for the video to be shared publicly (**Appendix I**).

The following hyperlink accesses the video that was produced by the participants of the toolkit review:

Click the link to view the video; the password is "advocacy".

Link: https://vimeo.com/764882856
Password: **advocacy**

Discussion

The toolkit was found to be a useful way to teach adults with intellectual disability about self-advocacy strategies. Much like the toolkit produced by Inclusion Ireland (2022), found in the review of toolkits in Chapter Five, it is noted this this toolkit may also follow the same trajectory and lend itself to multiple iterations and revisions over time. Thoele et al. (2020) had a similar finding, where one needs to consider toolkits as evolving and dynamic – where new ideas and strategies further develop and improve upon the implementation process over time.

Toolkits can be used to facilitate the integration of evidence into practice. Thoele et al. (2020) highlight how a toolkit is a useful approach, designed by professionals (or people with experience), to align with strategies that support implementation. The authors describe how toolkits may be created as an amalgamation of educational material, assessment tools, etc. (Thoele et al., 2020). In a study conducted by Turnpenny et al. (2018), the authors highlight how most research underpinning engagement in social policy for people with intellectual disability tends to favour those who can understand and access information easily and those who can communicate their thoughts effectively. The authors further echo the findings of this study, where in previous chapters it is stated that the perspectives of people with intellectual disability are often ignored or not taken into account (Turnpenny et al., 2018).

This was confirmed by the participants in the toolkit review, but also in the filmed video. Young adults with intellectual disability continue to feel excluded, infantilised and not taken seriously (Capri & Swartz, 2018). It seems our society generally dismisses and ignores the perceptions of people with disability (Kopić, 2017).

One participant who shared his lived experience as a person with an intellectual disability in South Africa, tells the story of his doctor who does not ask him any questions, rather deferring to his mother. “I can speak for myself”, he says, as he notes significant distress around being othered. In fact, several of the participants voiced having experiences where their perspectives were disregarded due to their intellectual disability. Capri and Swartz (2018) describe how, in countries like South Africa, issues of infantilisation are likely to be very prevalent as there is less general awareness of disability rights issues. In fact, the authors further validate the lived experience of people with intellectual disability – precisely what the participant was describing about healthcare – saying that people with intellectual disability are often not deemed capable of commenting on their health or healthcare. Their voices are silenced. Kim et al. (2021) found this in their study as well, where society sees people with intellectual disability as dependents who cannot make decisions for themselves.

Adopting strategies which enable the inclusion of the voices of people with intellectual disability in civic (or any) activities holds potential for diversifying perspectives brought to public participation in policy development and implementation, which is currently primarily the domain of citizens without disability. One strategy that the participants chose was that of media, in this case, creating a video.

Saunders et al. (2018) describe how media has influence to inform and shape societal issues around disability. While their paper focussed on people with traumatic brain injuries, the authors make significant points about representation of people with disability in media overall (Saunders et al., 2018). The media has power to influence the public's knowledge and perspectives and is often the main source of information for the broader society (Saunders et al., 2018). The media might have significant power to shift narratives around social policy and the nature of social justice, being in a strong position to mould or sway public knowledge and opinion (Saunders et al., 2018). Nissen (2021) describes this strategy as "E-participation".

It has been noted that despite earlier chapters emphasising the importance of the written word, the participants in this study call for more visual and interactive methodologies for engagement. This brings back the notion of capacity, as the written word strategies require a person with an intellectual disability to be literate, whereas a video, in which their perspectives are recorded, does not require reading ability at all. This also highlights the role of supporters in the self-advocacy process, whether to scribe, to write or to help with digital editing, helpful supporters can be vital to a self-advocacy plan.

The self-advocacy strategy selected, that of the video, brings to the fore the concept of narrative stories, to appeal to the viewer. According to the United Nations (United Nations, 2022), images and stories in the media can deeply influence public opinion and establish societal norms. People with disability are seldom found in the media, and when they are featured, they are often negatively stereotyped and not fairly represented (United Nations, 2022). The media can be a tool to fight stigma, and challenge the misconceptions of society. In fact, the media has a role in reinforcing, maintaining or changing the perceptions of the public – therefore taking back the power and controlling the narrative is key. The idea of global citizenship, where human beings are members of a global community, focussing on human rights and social justice is key (Nissen, 2021).

Limitations of the Experiential Toolkit Review

A significant limitations for this experiential review is the requirement for participation, as only people with mild intellectual disability, those who were already candidates at The Living Link were included. This resulted in a toolkit that is geared for mild intellectual disability, not catering for the more moderate, severe and profound populations. This is a limitation that would need to be considered in future research, as the toolkit adapts and changes over time.

Strengths of the Experiential Toolkit Review

This experiential toolkit review has created an evidence informed tool that can be used to support self advocacy for people with intellectual disability. Strengths of this review include having a rigorous experiential process, with several sub elements, all of which highlighted the voices of people with intellectual disability. This experiential review has shown skills development and increased capacity for the participants involved in the domain of self advocacy, and has the potential to support the learning of many populations in the future to actualise their human rights and engage in social policy development and implementation, having a say about issues that affect their lives. In addition, this work has created a visual policy brief that can be (and has been) shared in a variety of contexts to raise awareness.

Conclusion

Self-representation by self-advocates not only asserts their right to participation, a foundational aspect of the social model of human rights, but can also challenge negative stereotypes about people with intellectual disability, contributing to changing societal perceptions about the passivity and incapacity of people with intellectual disability (Anderson & Bigby, 2017). This was well reflected in by the participants in this toolkit review , who highlighted the need for self advocacy and having their voices heard in their video.

Chapter Eight

Discussion

Introduction

This study set out to investigate the question: What strategies are best for people with intellectual disability to engage in self-advocacy initiatives to influence social policy development and implementation which impact on their lives in the South African context? This study is posits that effecting those strategies and creating change would require supports to enable people with intellectual disability to act on their interests, their priorities, and also their human rights in self-advocating at a social policy level.

This study was undertaken based on the fact that people with intellectual disability not only have a right to participate in social policy development and implementation, but also, upon reflection of these study findings, that they also have an interest in doing so. The findings of this study indicate a clear desire amongst people with intellectual disability – and their supporters – for the voices of people with intellectual disability to be heard. While the study has identified several strategies for participation, as well as work that can be done to prepare self-advocates with intellectual disability to participate, their inclusion in civic and political life will only be achieved if those who are willing to participate are accepted into the policy-making arena (Frawley & Bigby, 2011). Self-advocacy is both an end in itself for these rights-holders, but also an essential means through which to positively influence this inclusion.

Stigma, Exclusion and the Issue of Terminology

Kopić (2017) discussed how people with intellectual disability are considered "less than", and live largely in segregation, being side-lined from mainstream society. All participants in this study, across the interviews, and experiential toolkit review brought their personal experience to agreement with Kopic's view, as they repeatedly noted that they are not accepted by society; and continue to feel excluded from decision-making which impacts on their lives. They, and other people with intellectual disability, live in societies in which prejudice and stigma continue to impact on their exclusion, including the exclusion of their self-identified priorities for public social policy directions (Kleintjes et al., 2013, Capri et al., 2018; McKenzie et al., 2013). While this was certainly identified as a key issue in the South African context, this was also echoed by the international study participants.

There were also an internalised sense of being made to feel different and feelings of being othered noted when talking about the terminology used to describe – and view people with intellectual disability. Some participants in this study found the term "disability" to be too harsh, which is noted in the literature by Fisch's (2011) who proposal that, in the future, the term "disabled" may be as offensive as "retard". This was found similarly in the video, where the participants chose to use the term "learning disability". Clegg and Bigby (2017) concur, finding that, in fact, many people with mild intellectual disability often reject the label of intellectual disability, rejecting, at core, the stigmas – and associated negative experiences – that are associated with the label of being disabled. Dorozenko et al. (2015) speak to how some people with intellectual disability lack of awareness of their intellectual disability due to cognitive capacity, while others, those who are aware of this deeply devalued social category, actively resist the label "intellectual disability". They feel the stigma and barriers inherent in this term, as well as the feelings of not having their perspectives considered as a result of them being regarded as too disabled to share their opinions. The authors further explain how the view that people with intellectual disability are inherently different is imposed on people with the label, a social construction by the labellers which is inherently self-fulfilling as society relates to these individuals in ways in which supports their being -in the world as stigmatised, lesser beings (Dorozenko et al., 2015). This highlights how those in the othered group may be silenced by those in the position of power, not able to self-advocate, as the stigmatising dialogue is constructed around them, about them (Dorozenko et al., 2015; Smith & Mueller, 2022).

The White Paper on The Rights of Persons with Disabilities (Republic of South Africa, 2016) notes that language reflects the social context in which it is being used. This plays an important role in perpetuating discrimination and segregation, emphasising that the use of language needs to be considered as a powerful tool to facilitate – or impede – change (Republic of South Africa, 2016). This is a conversation that needs to be ongoing, not only to dispel stigma, but to listen to the voices of people with intellectual disability about how they would like to be addressed, fostering a space where people can self-advocate for the terms used to describe themselves (Smith & Mueller, 2022), as these terms frame all considerations of rights within society, relative to others.

Underestimating the pervasive ableism – and related stigmatisation and isolation – in South Africa, only serves to further perpetuate the barriers to people with intellectual disability achieving true inclusion and realising their rights, at all levels of society, including those related to political participation (Capri et al., 2018; McKenzie et al., 2013). Several articles suggest that with political inclusion and citizenship for people with intellectual disability as the goal, guiding structures, frameworks and policies have been put in place to promote political participation by people with intellectual disability, however, these have not been sufficiently actualised (Clegg & Bigby, 2017; Curryer et al., 2015; Iriarte et al., 2041; Petri et al., 2020) due to both these attitudinal and practical impediments to their participation.

Identity Politics and Othering

Attitudinal barriers and stigma result in concerns about people with intellectual disability and their ability to participate in self-advocacy activities, resulting in a lack of consultation or minimal influence of their views on public policy engagement directions (Anderson & Bigby, 2017; Frawley & Bigby, 2011). Capri et al. (2018) elucidate how people with intellectual disability are considered to be a politically "unfit" homogenous group, and therefore, are excluded from participation in activities associated with citizenship. This negatively impacts the degree to which implementation of social policies reflect the diversity of their needs within society, making it essential for policy development teams to include self-advocates with intellectual disability in policy-related processes (Grenwelge & Zhang, 2012).

An essential way in which to promote the inclusion of their voices is to improve opportunities for people with intellectual disability to self-advocate for their priorities (Raley et al., 2020). However, lack of exposure to appropriate mechanisms for engagement in policy-making environments also make it difficult for people with intellectual disability to participate where opportunities arise for providing input into these processes. In the toolkit authored by Ntulo (2015), she makes the point that the self-advocacy movement for people with intellectual disability in Africa lags behind many other civil rights efforts, such as those related to women's rights or children's rights, or the rights of people with physical disabilities, these groups in themselves vulnerable to discrimination and harm, drawing attention to the issue of layered discrimination at the intersections of these personal characteristics and identities.

Excluding people from societal opportunities based on their disability touches core issues of rights, justice, citizenship, equality, resources and protections (Capri et al., 2018). A social model of human rights is key to ensuring participation of people with intellectual disability in activities of citizenship, realising their rights and having their say in the social policies that affect their lives. Society should be confronting disabling societies, challenging the relationships between service users and service providers, addressing social exclusion and isolation, and valuing the lived experience, human rights and expertise of people who live with a disabling condition (Byng & Duchan, 2005). A fundamental aspect of citizenship concerns equality and consideration of the perspectives of people with intellectual disability (e.g., United Nations, 2006; Anderson & Bigby, 2017). Self advocacy can promote wellbeing and can improve a person's ability to speak out against injustice (Gilmartin & Slevin, 2010).

Capacity Complexity

While equality, justice and equal opportunities are vital, one cannot ignore, and must take into account, a person's capacity to perform self-advocacy tasks. While a supportive environment is essential for participation, it must be acknowledged that some people with intellectual disability's the range of their personal capacities may preclude self-advocating at the level of policy participation. It must be emphasised that people with intellectual and developmental disabilities can and should be supported to self-advocate in all possible domains of their lives including their choices and preferences in their daily routine, their preferred leisure activities, and the way in which they are supported by others who provide for their daily care and social inclusion (Inclusion Europe, 2003). While tools for improving skills of people with intellectual disability to self-advocate were found in this study, few were found which focus on skills development to build capacity for participation at the level of policy making processes by people with intellectual disability, and none specifically addressed strategies for inclusion of people with greater degrees of disability. Despite this point, which essentially highlights that not all people with an intellectual disability have the capacity to directly self-advocate at a political level, considering all people with intellectual disability as impaired or unfit, and not able to participate in social policy, would be a great injustice (Capri et al., 2018). Advocacy for the rights of people with intellectual disability who cannot themselves advocate for their rights within certain settings, is currently taken up by their families, other informal and formal supporters and professionals, however, they are also important stakeholders for self-advocates with intellectual disability to include in their self-advocacy initiatives, by being present, and participating in whichever way may be possible within the social policy spaces. (Inclusion Europe, 2003). There is incredible power that can be associated with presence, just being seen can lead to changes and shifts in attitudes, regardless of one's capacity to speak.[2]

Benefits of Self-Advocacy

There is no doubt that self-advocates experience positive outcomes in their lives, not only in the domain of rights realisation and social inclusion, but also in other areas such as self-esteem, connections with others and quality of life, through their experience of self-advocating (Tilley et al., 2020). As one's belief in one's own abilities can increase, a range of new and more positive social identities can be formed, providing new and novel ways of engagement and doing, developing new capacities to focus upon and celebrate their strengths (Anderson & Bigby, 2017; Tilley et al., 2020). In some instances, self-advocates have come to have a more positive relationship with the label and experience of intellectual disability (Tilley et al., 2020). This can be achieved in, for example, self-advocacy groups which have been highlighted as important places for people with intellectual disability to share their life experiences and in turn raise awareness of issues such as institutionalisation and the nature of disability services (Frawley & Bigby, 2015).

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[2] *The researcher was made aware that at a recent public mental health policy meeting with top officials, with whom many meetings had taken place to advocate for certain service provisions for a facility for people with intellectual disability. At this particular meeting, for the first time, residents of the facility were asked to welcome and share a message with the government officials. These self-advocates chose to bring along fellow residents many of whom could not express themselves verbally but offered a small gift of a product they had made with an accompanying smile of welcome. Officials were deeply moved; some having met for the first-time people with intellectual disability whom they are entrusted to make policy decisions about. One high-ranking official noted that he felt "that this meeting was different. I somehow for the first time have a good understanding of the issues you have been presenting at our meetings".*

Kim et al. (2021), in their study conducted in South Korea, similarly found that one of the biggest benefits of being in a self-advocacy group is that of the creation of the opportunity for "hearing their voices", highlighting how effective self-advocacy can be in empowering people with intellectual disability to actualise their rights and become members of society with civic participation.

Strategies Identified for Self-Advocacy

The overall aim of the study was to investigate what strategies are best for people with intellectual disability to self-advocate for inclusion of their priorities in social policy development and implementation in South Africa. This study has identified several strategies for people with intellectual disability to engage in self-advocacy initiatives to influence social policy development and implementation which impact on their lives in the South African context.

The scoping review, a review of existing toolkits in grey literature, as well as documenting local and international perspectives of key participants with intellectual disability and their supporters identified several strategies which can be used to equip and support people with intellectual disability to self-advocate for their needs in the policy space (and in general). Strategies suggested by this study for self-advocacy, namely the use of Public Spaces, Social Media, Written Pieces, Narrative Stories and Useful Supporters. Have informed the development of a self-advocacy toolkit with people with intellectual disability to promote their participation in social policy development and implementation processes in South Africa.

With regard to public spaces, the scoping review identified several strategies, including being able to participate in campaigns, conferences and awareness-raising activities, organising rallies, using concerts or events to raise awareness (Anderson & Bigby, 2017; Frawley & Bigby, 2015; Petri et al., 2020). These findings were consistent across the scoping review and the review of toolkits, as well as the interviews.

In all articles in the scoping review, several types of media were suggested as a strategy to self-advocate (e.g., Frawley & Bigby, 2015; Iriarte et al., 2014; Petri et al., 2020). In contrast, specific suggestions for media applications were also included in strategies emerging from the review of toolkits. Using media for representation and the internet emerged as a prominent theme. For many urbanised people, especially the young, the internet is part of everyday life (Pearson & Trevisan, 2015; Gelfgren et al., 2022. Several participants in the study spoke about the influence of social media on their lives and their self-advocacy experience, emphasising how widespread access to online platforms is for young people, including those with intellectual disability (Borgström et al., 2019). While there is evidence regarding the harmful aspects of the internet, which we need to carefully consider for a vulnerable population such as people with intellectual disability, Borgström et al. (2019) highlight the opportunities that are present with internet access. One might say that connecting over the internet is the tool of the younger generations (Ref) As noted in previous chapters, there is a recurrent and important issue called the "digital divide", which emphasises a disparity in internet access between people with disability and people without disability to varying degrees all over the world.

Written self-advocacy input was a third focus that emerged across all stages of the study. The scoping review included ideas for people with intellectual disability participating in drafting laws and policies, written submissions on draft document to ministries and city councils, distributing or displaying in public protest action written materials to the community or wider public, and writing letters to various stakeholders to have their voices heard.

Kopić (2017) describes how society does not consider people with intellectual disability in connection with creative pursuits, like writing and storytelling. However, the findings of the participants emphasise the significance of storytelling in promoting the views of the storytellers. At the first ever Design for Humanity Summit (2021), Babita Bisht, Chief of Resource Mobilisation & Communication (2019), discussed the importance that storytelling and communication plays in humanitarianism. She described how good communication and storytelling can change attitudes, beliefs and practices. A good story can capture people's attention, bringing issues to life, engaging with people and creating a sense of connection. This is reflected in our South African context where storytelling is important in African culture, echoed in the notion of *Ubuntu*, mentioned in the interviews. This strategy appears to allow people to connect through stories, and experience, and the nature and needs which come with being human. In this study, it was also found that self-advocates with intellectual disability provided their input in many instances with reference to personal experience, the telling of their own story to provide input on, or illustrate the points they wanted to make. By sharing their lived experience, self-advocates have the opportunity to influence the social policies that affect their lives, should the supports and structures be put in place for people to listen (O'Brien et al., 2022).

The findings support the notion that having a network of helpful supports is critical in empowering people with intellectual disability to have their voices heard. These supporters can hold a pivotal role in that they can be present to aid people with intellectual disability to self-represent, rather than representing on their behalf (Kim et al., 2021). Policy makers need to make space for both, in a physical sense but also fostering an environment that promotes this kind of engagement. One needs to be conscious of challenging factors such as overprotection by authority figures and fostered dependence on others (Test et al., 2005).

As evidenced in the literature and supported by the participants in this study, having supporters who can help with the advocacy initiatives of people with intellectual disability is paramount to successful self-advocacy initiatives. In this study, participants spoke about their connections with others, their supporters, and essentially, how everything that any person does, irrespective of disability, is co-constructed and interdependent. Community, identity development and self-advocacy are central to a person with an intellectual disability (Smith & Mueller, 2022). Many people with intellectual disability can, with skills training, exposure and support, participate in these processes with reasonable accommodations. This can lead to true and meaningful participation of people with intellectual disability in the policy space.

Self-advocacy to enhance policy participation for people with intellectual disability can promote the inclusion of their voices and perspectives in influencing social policy decisions which impact on their lives. This study has shown that there are a number of strategies, or tools, a person can have in their toolbox to self-advocate, each with their own strengths and weaknesses. Adopting strategies which enable the inclusion of the voices of people with intellectual disability in civic activities can hold potential for diverse perspectives to be brought forward into mainstream society. A concerted effort is needed to strengthen opportunities for the actualisation of these strategies for self-advocacy, increasing participation in society to assist people with intellectual disability in their move into their rightful place, as equals in society.

Recommendations emanating from the study

Acknowledging the rights of people with intellectual disability, and listening, really hearing their voices, is key to positive change; and true societal inclusion. Allow the people with lived experience the space to tell their stories and make recommendations, so changes can be made in social policy, to really make a difference. Where people with intellectual disability have potential for, and interest in, participating in policy processes, self-advocacy skills training and support in choosing a self-advocacy strategy are key to enhancing policy participation to promote the inclusion of their voices.

The findings of this study therefore highlight the following practical recommendations:

1. Raise awareness about intellectual disability and the issues that this population faces
2. Create spaces for people with intellectual disability (and other disabilities) to be involved in the policy development of policies that affect their lives. This would need to include accommodation which would include supporters joining these individuals in preparing and delivering their input to policy discussions.
3. Prioritize involvement on a community level for people with intellectual disabilities. This includes removing barriers to access and encouraging participation.
4. Consider using easy to read information in public spaces to improve access and understanding for people with intellectual disability. An easy-to-read version of the toolkit could be a future endeavour which would be beneficial to those accessing the toolkit. Further investigation into the strengths and weaknesses of each strategy should be conducted, further conceptualised and unpacked, in order to streamline the options available to self-advocate.
5. Ensure that there is better diversity on screen and in media. Limited representation reinforces stigma, and therefore there needs to be voices of people with intellectual disability represented in all types of media, and in medica reports including citizen inputs, to bring the their own stories to public discussions .

6. Prioritize the upskilling of people with intellectual disability, particularly the skills that can support their capacity to self advocate and make their own choices, striving for self determination.
7. Strive for collaboration and connection with other NGOs, or individuals who are having similar lived experiences to learn from one another. Social media is one strategy where this is currently happening.
8. Working with the social policy stakeholders to reconsider the current policies and frameworks which disadvantage people with intellectual disability. One such example is that hospitals could provide information about waiting times, or have a number based queue so that people with intellectual disability can set their expectations and better understand how long they have to wait. This is a valuable point to consider, as these are the social policy issues that are affecting people with intellectual disability which they wanting to speak up about.
9. There is a need for greater support to organising people for self-advocacy. Current provider led supportive initiatives need funding to expand their endeavours, and over time, to in our context, also examine how international models of organising for self advocacy (Tilley et al., 2020) may be initiated in the South African context.

Considerations for Future Research

Future research could broaden on this work, addressing the feasibility and acceptability of the toolkit, measuring quantitative and qualitative outcomes, and adapting the toolkit where needed. Specific focus could be paid to the specific skills not included in this toolkit, such as workshops for social media and writing skills. It is advised that future researchers continue working alongside people with intellectual disability to have their voices heard and gain their insights into what they need, creating spaces for self-advocacy. It is also advised that further research be done into the performance components, capacities or skills that a person needs to have in order to be a self-advocate. This study consulted people with intellectual disability, but the experiences of engaging people with intellectual disability needs to be broadened in future studies to move from consultation to greater direct involvement of people with intellectual disabilities in the conceptualisation and implementation of such studies. Another important consideration for future research is developing a toolkit that is geared the more moderate, severe and profound populations of people with intellectual disability. Further work is also needed to develop a better understanding of the types of strategies for inclusion of people with more severe disability in self-advocacy initiatives at all levels of their engagement in society, as well as, if not directly, but as co-supporters of self-advocacy initiatives by people with intellectual disability who are able to develop skills for policy-level participation.

Limitations of the Study

This research has several limitations across the different areas of investigation. Limitations of the scoping review included limitations set on the inclusion criteria, specifically, the review included limitations set on the timeframe, with a focus on a ten year review, limitations to peer reviewed journal articles and theses, and limitation of articles to those published in English, to accommodate the limited time and people - the researcher and a research assistant -available for completion of the study. The review might have missed some studies due to selection of terms or searching additional databases. The inclusion of a wider range of grey literature might have yielded more results.

In terms of the review of toolkits, this analysis has several limitations. This review was conducted by the researcher alone, where, should additional research assistants have been used, could add to the rigour of the study. There was a limit placed on the search engine selection for this part of the research. Namely, only Google was used, whereas utilising other grey literature sources could have yielded more results.

When interviewing key informants with intellectual disability and their supporters, limitations include the limited number of countries that were sourced in this study. A wider geographic scope could have brought other HIC and some LMIC to compare and contrast the strategies used in different setting to progress the work of the global self advocacy movement.. Another limitation of this phase of the study was the recruitment options, as these interviews were conducted during the Covid 19 pandemic.

The final limitation or consideration to note is that of my own biases as a clinician in the field, and my own lived experience working in this space. Balancing the elements of myself as a clinician and a researcher is a challenging task and required that I reflect on my dual roles. This research has made me consider how much autonomy people with intellectual disability truly are fighting for, not only on a social policy level, but in their lives, and this research has shown me how challenging this can be, as told in the narratives of those with lived experience. I would recommend that society follow the advice of the key informants of this study, and listen to the stories, because we may learn more than we realise.

Strengths of the Study

While there were a number of identified limitations, this study also has a number of strengths.

The scoping review showed a snapshot of the most recent developments in this field that has been published in peer reviewed literature. This review highlights the current engagement and participation of people with intellectual disability in social policy. Despite the limited research in this area, this review has succeeded in finding a number of self-advocacy strategies, which have the potential to reach a wider audience in order to amplify the voices of people with intellectual disability.

The toolkit review in grey literature highlighted the key knowledge and skills a person with an intellectual disability may need in order to self advocate. In addition this review identified several practical strategies that could be utilized as a person with an intellectual disability to self advocate.

The interviews with key informants has added to the body of knowledge about the perceptions of people with intellectual disability and their supporters about self advocacy from a “being-in the world” perspective.. The research can contribute, by sharing the understanding and the lived experience of these participants about the phenomenon of self advocacy, to research-informed practice which can more appropriately support this community in active societal participation.

In addition, the development of the toolkit has created a locally produced evidence -informed and potentially evolving resource that can inform practice in the conduct of and support to self advocacy by people with intellectual disability in the South African context. Strengths of this review include having a rigorous experiential process, with several sub elements, all of which highlighted the voices of people with intellectual disability. This experiential review has shown skills development and increased capacity for the participants involved in the domain of self advocacy, and has added to the growing body of knowledge about strategies to support people with intellectual disability to actualise their human rights and engage in social policy development and implementation, having a say about issues that affect their lives.

Contributions of the Study

Findings of this study have been presented at two international conferences and one local conference to date. In addition, some of the findings have been published in one peer reviewed article to date(add ref). A second article is underway at the time of this thesis submission. The first draft of the toolkit is available, with further development opportunities available for use by NGOs and DPOs working with enhancing self-advocacy initiatives in our local context.

Conclusion

The theme of mainstreaming the voices of people with intellectual disability is central to the findings of this study. This phenomenological study contributes to the body of knowledge about the perceptions and lived experiences of people with intellectual disability and their supporters, which could inform their self-advocacy work to promote better care and quality of life for this population.

Having a presence in policy development and implementation is key for people with intellectual disability – as this space is currently primarily the domain of citizens without disability. This highlights the need for a societal shift as well as practical interventions to support the inclusion of diverse voices, including those of people with intellectual disability. A specific focus is needed, one that shifts the narrative towards people with intellectual disability as active participants, as citizens in society. Adopting a social model of human rights lens, it is clear that we need to be confronting disabling views and practices in societies, challenging the status quo, addressing social exclusion and isolation and valuing the lived experience and expertise of people with intellectual disability. This study has successfully identified strategies for people with intellectual disability to engage in self-advocacy initiatives to influence social policy development and implementation which impact on their lives in the South African context.

It is crucial that the voices of people most affected must be central to this narrative, and that spaces and supports for self-advocacy need to be prioritised, as this study calls for the public to listen, and hear the voices of people with intellectual disability, creating opportunities for self advocacy.

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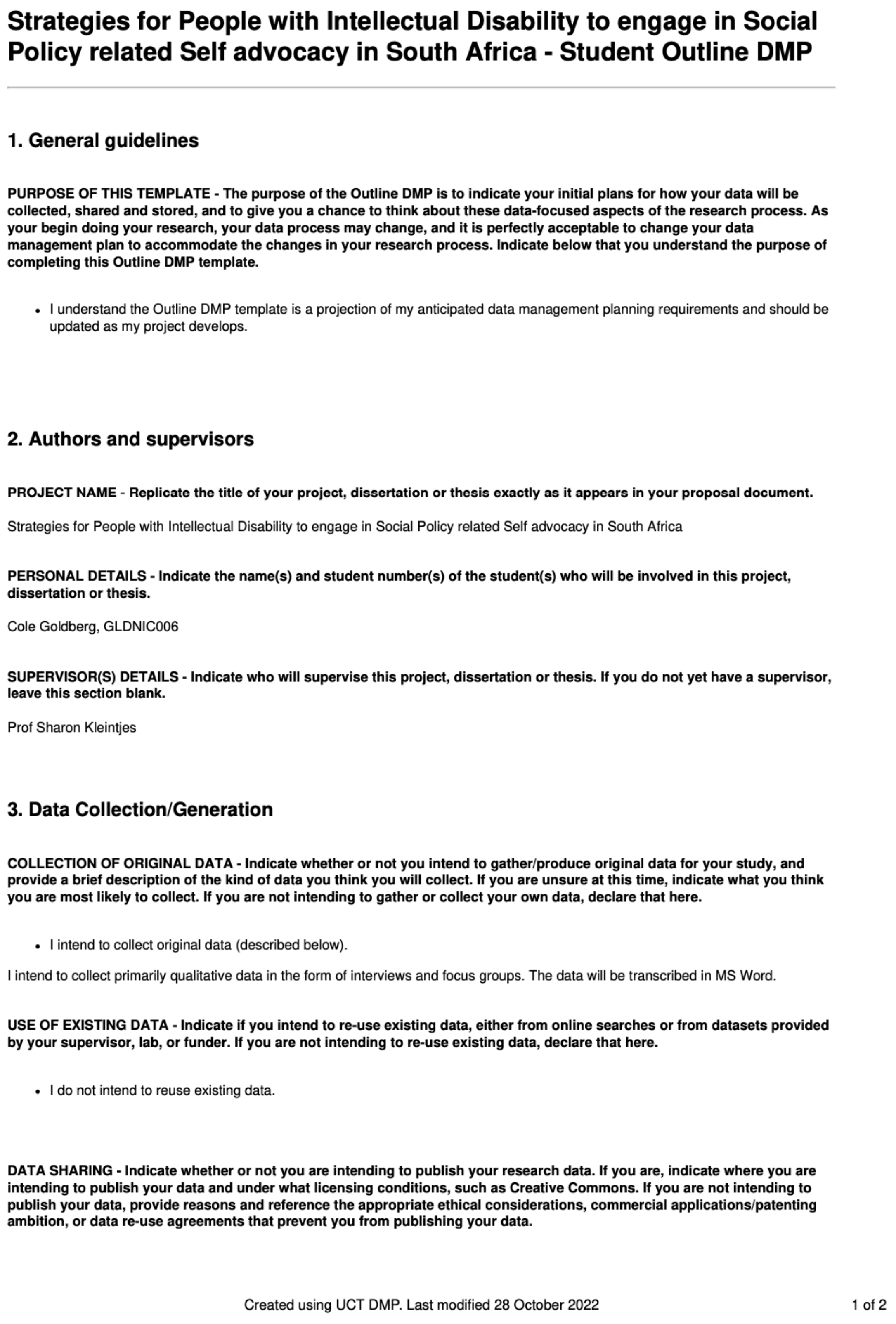
Appendices

Appendix A: Data Management Plan



Strategies for People with Intellectual Disability to engage in Social Policy related Self advocacy in South Africa - Student Outline DMP

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1. General guidelines

PURPOSE OF THIS TEMPLATE - The purpose of the Outline DMP is to indicate your initial plans for how your data will be collected, shared and stored, and to give you a chance to think about these data-focused aspects of the research process. As your begin doing your research, your data process may change, and it is perfectly acceptable to change your data management plan to accommodate the changes in your research process. Indicate below that you understand the purpose of completing this Outline DMP template.

- I understand the Outline DMP template is a projection of my anticipated data management planning requirements and should be updated as my project develops.

2. Authors and supervisors

PROJECT NAME - Replicate the title of your project, dissertation or thesis exactly as it appears in your proposal document.

Strategies for People with Intellectual Disability to engage in Social Policy related Self advocacy in South Africa

PERSONAL DETAILS - Indicate the name(s) and student number(s) of the student(s) who will be involved in this project, dissertation or thesis.

Cole Goldberg, GLDNIC006

SUPERVISOR(S) DETAILS - Indicate who will supervise this project, dissertation or thesis. If you do not yet have a supervisor, leave this section blank.

Prof Sharon Kleintjes

3. Data Collection/Generation

COLLECTION OF ORIGINAL DATA - Indicate whether or not you intend to gather/produce original data for your study, and provide a brief description of the kind of data you think you will collect. If you are unsure at this time, indicate what you think you are most likely to collect. If you are not intending to gather or collect your own data, declare that here.

- I intend to collect original data (described below).

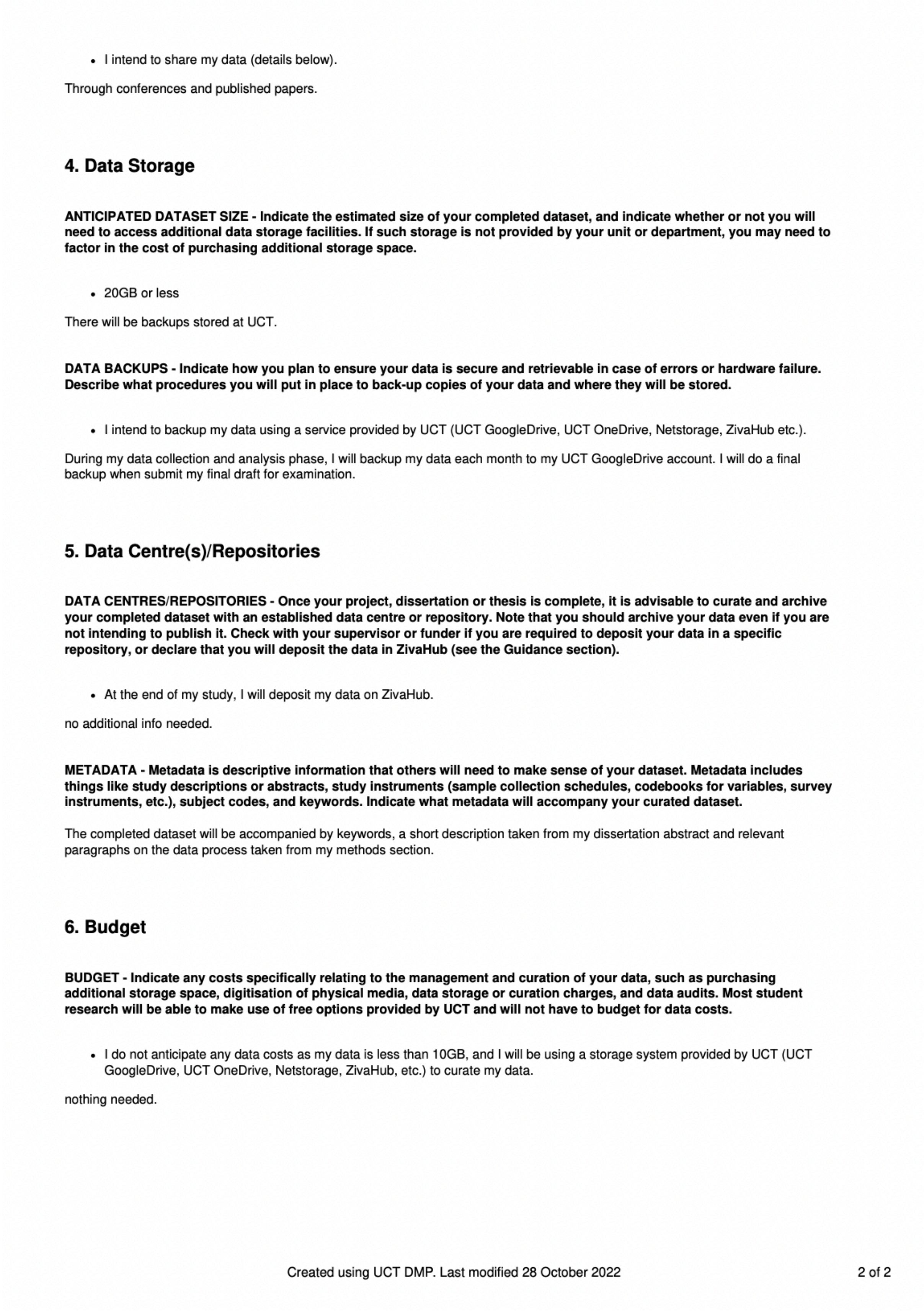
I intend to collect primarily qualitative data in the form of interviews and focus groups. The data will be transcribed in MS Word.

USE OF EXISTING DATA - Indicate if you intend to re-use existing data, either from online searches or from datasets provided by your supervisor, lab, or funder. If you are not intending to re-use existing data, declare that here.

- I do not intend to reuse existing data.

DATA SHARING - Indicate whether or not you are intending to publish your research data. If you are, indicate where you are intending to publish your data and under what licensing conditions, such as Creative Commons. If you are not intending to publish your data, provide reasons and reference the appropriate ethical considerations, commercial applications/patenting ambition, or data re-use agreements that prevent you from publishing your data.

Created using UCT DMP. Last modified 28 October 2022 1 of 2



- I intend to share my data (details below).

Through conferences and published papers.

4. Data Storage

ANTICIPATED DATASET SIZE - Indicate the estimated size of your completed dataset, and indicate whether or not you will need to access additional data storage facilities. If such storage is not provided by your unit or department, you may need to factor in the cost of purchasing additional storage space.

- 20GB or less

There will be backups stored at UCT.

DATA BACKUPS - Indicate how you plan to ensure your data is secure and retrievable in case of errors or hardware failure. Describe what procedures you will put in place to back-up copies of your data and where they will be stored.

- I intend to backup my data using a service provided by UCT (UCT GoogleDrive, UCT OneDrive, Netstorage, ZivaHub etc.).

During my data collection and analysis phase, I will backup my data each month to my UCT GoogleDrive account. I will do a final backup when submit my final draft for examination.

5. Data Centre(s)/Repositories

DATA CENTRES/REPOSITORIES - Once your project, dissertation or thesis is complete, it is advisable to curate and archive your completed dataset with an established data centre or repository. Note that you should archive your data even if you are not intending to publish it. Check with your supervisor or funder if you are required to deposit your data in a specific repository, or declare that you will deposit the data in ZivaHub (see the Guidance section).

- At the end of my study, I will deposit my data on ZivaHub.

no additional info needed.

METADATA - Metadata is descriptive information that others will need to make sense of your dataset. Metadata includes things like study descriptions or abstracts, study instruments (sample collection schedules, codebooks for variables, survey instruments, etc.), subject codes, and keywords. Indicate what metadata will accompany your curated dataset.

The completed dataset will be accompanied by keywords, a short description taken from my dissertation abstract and relevant paragraphs on the data process taken from my methods section.

6. Budget

BUDGET - Indicate any costs specifically relating to the management and curation of your data, such as purchasing additional storage space, digitisation of physical media, data storage or curation charges, and data audits. Most student research will be able to make use of free options provided by UCT and will not have to budget for data costs.

- I do not anticipate any data costs as my data is less than 10GB, and I will be using a storage system provided by UCT (UCT GoogleDrive, UCT OneDrive, Netstorage, ZivaHub, etc.) to curate my data.

nothing needed.

Appendix B: Final List of Toolkits Reviewed for the Grey Literature Review

1. Disability Rights Wisconsin. (2007). *Advocacy toolkit skills and strategies for effective self and peer advocacy*. https://www.brainline.org/sites/default/files/Advocacy%20Tool%20Kit_2007.pdf

2. Advocacy Focus. (2022). *The essential self advocacy toolkit.* https://advocacyfocus.org.uk/self-advocacy-toolkit/

3. National Down Syndrome Congress (NDSC). (n.d.). *Advocacy toolkit for self-advocates*. https://www.ndsccenter.org/wp-content/uploads/PA-NDSC-Advocacy-Toolkit-for-SA.pdf

4. Ntulo, C. A. (2015). *The self advocacy tool kit - For mental health services users.* Basic Needs. https://www.cbm.org/article/downloads/54741/The_Self_Advocacy_Toolkit_-_For_Mental_Health_Service_Users.pdf

5. Inclusion Ireland. (2022). *The self-advocacy toolkit.* https://inclusionireland.ie/the-self-advocacy-toolkit/

6. Self Advocacy Resource and Technical Assistance Center (SARTAC). (2018). *Self advocacy start-up toolkit.* https://selfadvocacyinfo.org/wp-content/uploads/2018/07/Self-Advocacy-Start-up-Toolkit-more-power-more-control-over-our-lives-2018.pdf

7. Disability Research on Independent Living and Learning (DRILL). (2020). *What makes a good self advocacy project: A toolkit.* https://www.drilluk.org.uk/wp-content/uploads/2020/09/Toolkit-A4-final-for-web.pdf

8. Autistic Self Advocacy Network (ASAN) & Self Advocacy Resource and Technical Assistance Center (SARTAC) (ASAN & SARTAC). (2022). *They work for us: A self-advocate's guide to getting through to your officials.* https://autisticadvocacy.org/wp-content/uploads/2017/02/They-Work-For-Us-A-Self-Advocates-Guide-to-Getting-Through-to-your-Elected-Officials.pdf

9. Autism Speaks. (2013). *Guide to Autism Advocacy.* https://www.autismspeaks.org/sites/default/files/2018-08/Advocacy%20Tool%20Kit.pdf

Appendix C: Informed Consent for Interviews

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 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. This research project is for degree purposes, so that we can better understand your perspectives on self-advocacy.

How will you take part in the research?

The steps we will take in the research are:

1. I will ask you to have a discussion around making decisions and standing up for what you believe in
2. I will write down and record your ideas.
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 send you a draft of the toolkit to find out what you think of the findings and to get some feedback from you. 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 about what skills you might need if you want to be involved in self-advocacy as well as 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 stored on my laptop and a safe hard drive with a secret password. I plan to take every step to protect your privacy, but it is important to note that the community of people who work with people with intellectual disabilities is quite small, so there may be a small risk of being identified. That said, I will not use any direct quotations that could make people know who you are.

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. We also plan to write up these findings into an article to be published, and to present the findings at research meetings or conferences. We 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?

Nothing bad will happen if you agree to participate.

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.

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

Taking part in this research study is done is only if you want to. You do not have to. If you do agree to take part but decide 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:

Cole Goldberg	Gldnic006@myuct.ac.za	0844928255

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.
UCT Faculty of Health Sciences Human Research Ethics Committee has given permission for this study to take place. If you have any concerns about the way this research is conducted please contact Prof. Mark Blockman, Chairperson: Research Ethics Committee, Faculty of Health Sciences, University of Cape Town, 7700, Tel. + 27 21 – 406 6338 or 0214066492
Email: hrec-enquiries@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 D: Information Sheet for Interview Participants

		
My name is Cole Goldberg	I am a research student at UCT	My research is about self-advocacy (speaking up for yourself)

Research about Self-Advocacy by People with Intellectual Disability

Information for Participants

What is Self-Advocacy? Self-advocacy is about speaking up for yourself to people who make decisions that affect you to include your needs in their actions and plans so you can live a quality life in your community. This can include government plans that affect your life.

What is research? Research involves collecting and sharing information that can help us better understand an issue that concerns us. This research will look at what will help people with intellectual disability self-advocate (speak up for themselves) to government for services and supports they need to live a quality life.

What information do I want to collect? I would like to speak to you about how you are involved in self-advocacy activities and what you think people should know about self-advocacy.

How will we collect the information? We will meet once or twice for an hour to discuss and I will record and write down your ideas. I will also ask you to look over the toolkit I make and let me know what you think about it. I will send you a copy of it so that you can let me know what you like and what you would change.

How will this affect you? I will not pay you for your time, but will give you copies of your ideas to remember our chat or to share your ideas with others. I will also write up your ideas in my research report to the university and other reading material. Your name will not be written in my reports so your taking part in the research will remain private (confidential).

	If you or a person who supports you when you make decisions would like more information to decide if you would like to take part in this research, please contact me on 0844928255 or my research supervisor Prof. Sharon Kleintjes (+27 21404 2166) or (sr.kleintjes@uct.ac.za). If you have any concerns around the ethical clearance for this study, please contact the UCT Faculty of Health Sciences Human Research Ethics Committee (hrec-enquiries@uct.ac.za)

Appendix E: Question Schedule for Interviews

- Tell me about yourself?
- How did you come to do self-advocacy work?
- What was the process which you took to where you are now?
- What supports have you needed to do the actual self-advocacy work?
- Do you have any tips or ways of making the content easier to access?
- Have you found material that has been helpful in this endeavour?
- What challenges have you experienced in this area of self-advocacy?
- Do you have strategies to improve the capacity to self-advocate?
- How would you suggest developing a toolkit based on your experience with self-advocacy?
- What do you think can be done about stigmatising (or bad) attitudes around self-advocacy for people with intellectual disability?

Appendix F: Feedback from Participants

	Feedback	Pieces that work	Considerations
Interview 1	Thanks so much for forwarding us on your manual and apologies again for delay in responding, I know what it's like when you're waiting for feedback on a document! Before X went off on holidays, we had a discussion which involved some comments and questions: Overall, the design of the manual looks great, visually it's very attractive - the way it is presented with the graphics, the text is well spaced out and a lot of great material on so many subject areas. We really like some of the exercises and activities like 'who am I' and 'the power of yet'. When looking at the Manual we were keeping in mind the group of self-advocates we work with. However, most would not have literacy skills, would need a lot of support to fill out the forms, understand some of the language and various concepts; most of the participants we work with attend disability day services and are not in paid work and so much of the material would be too advanced. We were wondering what level the Manual is aimed at – who is your audience? Perhaps more information on this at the beginning would be helpful. The scope and subjects covered are very big issues and wondered over how many weeks would the training run and is there any follow-up support for participants to implement the plans or the changes they wish to make in their lives? A suggestion would be to test the programme, run it as a pilot first and then get feedback. Well done again and hope these comments are helpful.	Design visually it's very attractive. graphics text exercises and activities like 'who am I' and 'the power of yet'	Consider literacy skills of self-advocates. Assistance in filling out forms. understand some of the language and various concepts. some material would be too advanced
Interview 2	OMG!!! This is absolutely amazing. You have really done a great job. This will work well for self-advocates and advocates/supporters as well. Just always remember patience with the diversity and disability of your audience in facilitating your concepts (especially with those who may have issues with direct eye contact for long periods of time). Be engaging and encouraging. GOOD VIBES!!! GOOD VIBES!!! This is very eye catching & attention grabbing... Making one want to start and finish the course. I would not change one darn thing. I LOVE IT!!!	Eye catching Design	Eye contact / facilitation styles
Participant 3	I absolutely love it for the most part. My only advice would be to include quotes from advocates that will help the future advocates understand what it means to advocate. It has easy language. I love how it's illustrated and created. I think it would give future advocates a better understanding and I do believe that there's a strong balance.	Illustration Design	Include quotes from self-advocates
Participant 4	What are your thoughts on the toolkit? I like the layout, easy to follow, nice flow to read, not too much unnecessary words, simple language, yet professional, well done! Are there any things that you think are missing? You can add more pictures, this will include persons that are not able to read. Look at ETR easy to read documents. I can check with Z if she can show u a document like this... Ok! Is the language used easy to understand? I think so... I like the simplicity, easy to follow... Not boring at all... well done! Do you think the activities will help somebody learn to become a self-advocate? Yes, it's important that the self-advocate is included in this process, and the activities are straightforward and easy to follow also gives s/advocate a better understanding of starting a s/advocate group. What advice would you have for the facilitators who will be running the programme? It's always important to get the self-advocate to participate as much as possible, this is their process... facilitator is only there to facilitate.. Nothing about us without us... Is the slogan... So let's encourage the self-advocate to take a lead role but with support... Facilitators are playing the role of encouragement, with support the s/advocate can achieve, and although they have challenges. They have the right to inclusion. What tips would you have for the supporters? The supporter is there... To help explain and give clarity to the s/advocate... supporters take a back seat really to decision making.. Because it's more to help the s/advocate.. Supporters are always assisting behind the scenes with preparing s/advocate so that they can	Layout Flow Language Activity choices	Add more images. Encourage the facilitator to let the participants lead.

	speak out for themselves in a confidential way and also in the best way they can express themselves.. Regardless if these s/advocate can/cannot read and write.. A supporter role can vary.. Depending on the task the s/advocate needs.. I can explain a little more about this in detail if u need.. Ok! Do you think the language is pitched too high? Not at all. Do you think the content is easy to understand? Yes it is. What, if anything, needs to be changed here? I think maybe more pictures.. Again the ETR easy to read.. Needs to be included (Chat to me about cartoons at some time OK.. I have an idea.. It's about putting together a series of cartoons explaining self-advocacy). In terms of the activities, do you feel that there is a good balance? This is fine. Or is there too much writing to be done? No it's fine. When you test this document on a participant.. I would like to see the outcome.. ok.. But in your action reflect.. You can pick up on more things that needs changing..		
Participant 5	No feedback received.		
Participant 6	Just some of my thoughts. Little things but hopefully it will assist. · The language and the way it is set out is fine. We know however that some will understand, others may find some of the concepts challenging. The facilitators would therefore play a big role in ensuring that everyone understands. · This one is just really my own. The examples that are used (Self-advocacy warriors and Case Study) are great international examples but is there any way to get a greater local context? Local examples may help the individuals understand how this can be done in their own communities when they hear local names and circumstances. They may realise that change starts with the smaller steps to get to the bigger stages of the world. · Regarding becoming a self-advocate. I definitely think that this will help someone to understand what is self-advocacy. Once again I think context is going to be important.. I can be a self-advocate in my community or.. I can take it further and challenge societal structures by getting involved in Government legislation. · I wouldn't say that it is too much writing but my experience has been that less writing is always better.. So any way to minimise it would be great. My two cents…….		
Participant 7	It looks very nice and is easy to understand.	Visuals	
Participant 8 (parent and son)	We have more closely reviewed your toolkit and think that it is brilliant! This training has the potential for really helping a lot of people. I have a few small comments that you can take or leave. 1) I know this is specifically designed for use in South Africa. But, if you take out "South Africa", broaden a few of the references, I think it could be applicable (and useful!) just about anywhere in the world! The issues you are addressing are global in nature. 2) There are a few references to videos that will be used in the training. If possible you can give a short description of the video in your text. That way the training can still be relevant and useful anywhere, even if there's no access to the videos (internet issues, timing, etc.). The videos obviously add to the training, but it could stand alone in case there are issues. I think you have done an amazing job with this!! It's difficult to address the many different levels of disabilities. Those with intellectual disabilities may have a more difficult time with some of these activities. But, I think you have reached a great middle ground with the information, training, and approach. Thank you for letting us be a part of your process. It could indeed be world changing!	Well balanced information and activities	Global applications Add video links and search terms – with a short description Complexity of activities

Participant 9	No feedback received.		
Participant 10	Positive feedback.		

Appendix G: Transcriber Agreement

Name of study: Strategies to Promote Self-Advocacy for People with Intellectual Disability in South Africa

Dissertation Research

I ……………………………………………………………………………

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

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

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

Signature ……………………………………….

Date ………………………………………………

Appendix H: Informed Consent for Toolkit Review Participants

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 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. This research project is for degree purposes, so that we can better understand how to teach self-advocacy skills.

How will you take part in the research?

You will be a part of a group of people who will try out the toolkit, and share your ideas of what you think of it.

Why have you been asked to take part?

You have been asked to participate in this research because you are involved in a training programme for people with intellectual / learning disabilities and I would like to see if you think the toolkit can be a useful tool to develop your ability to stand up for yourself.

Will your participation in the research study be kept confidential?

Yes, your name will not be used. When we use the recordings, all information that can help others 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 stored on my laptop and a safe hard drive with a secret password. I will not use any direct quotations that could make people know who you are.

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. We also plan to write up these findings in an article to be published, and to present the findings at research meetings or conferences. We 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?
Learning new skills, learning about yourself, and learning about self-advocacy.

What are the possible disadvantages of taking part?
Nothing bad will happen if you agree to participate.

Are there any risks in taking part in the research study?
I do not think there will be any risks.

What if I decide not to take part in the research study?
Taking part in this research study is done only if you want to. You do not have to. If you do agree to take part but decide later that you do not want to anymore, that is also okay.

What if I have questions?
If you have any questions, you can contact me at a later stage:

Cole Goldberg	Gldnic006@myuct.ac.za	0844928255

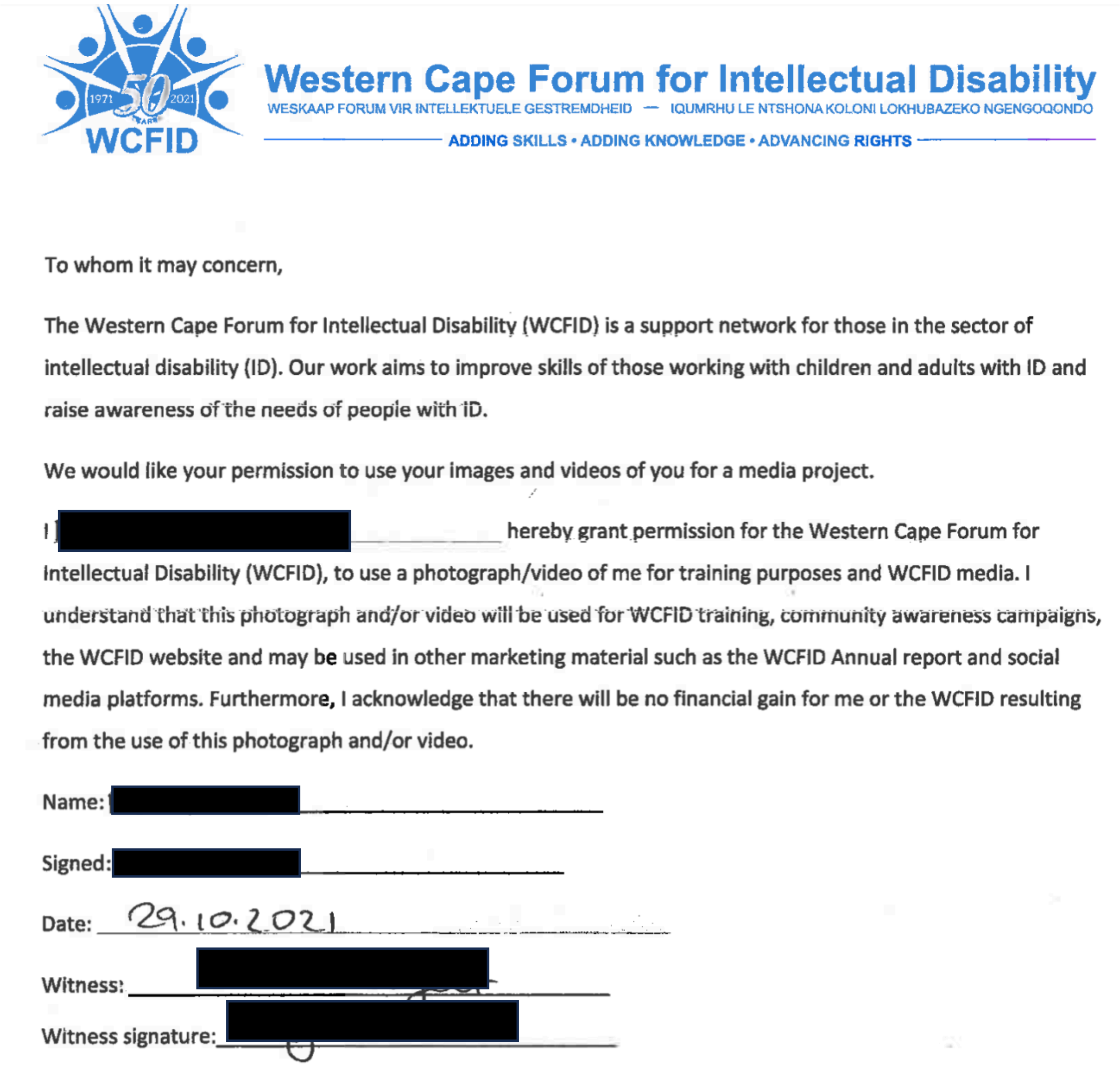
or my supervisor, Prof. Sharon Kleintjes (+27 21404 2166) (sr.kleintjes@uct.ac.za), Department of Psychiatry and Mental Health, University of Cape Town, Private Bag Rondebosch, 7700.
UCT Faculty of Health Sciences Human Research Ethics Committee has given permission for this study to take place. If you have any concerns about the way this research is conducted please contact Prof. Mark Blockman, Chairperson: Research Ethics Committee, Faculty of Health Sciences, University of Cape Town, 7700, Tel. + 27 21 – 406 6338 or 0214066492
Email: hrec-enquiries@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 I: Informed Consent for Sharing of Self-Advocacy Video



1971 50 YEARS 2021 WCFID

Western Cape Forum for Intellectual Disability

WESKAAP FORUM VIR INTELLEKTUELE GESTREMDHEID — IQUMRHU LE NTSHONA KOLONI LOKHUBAZEKO NGENGQONDO

ADDING SKILLS • ADDING KNOWLEDGE • ADVANCING RIGHTS

To whom it may concern,

The Western Cape Forum for Intellectual Disability (WCFID) is a support network for those in the sector of intellectual disability (ID). Our work aims to improve skills of those working with children and adults with ID and raise awareness of the needs of people with ID.

We would like your permission to use your images and videos of you for a media project.

I [redacted] hereby grant permission for the Western Cape Forum for Intellectual Disability (WCFID), to use a photograph/video of me for training purposes and WCFID media. I understand that this photograph and/or video will be used for WCFID training, community awareness campaigns, the WCFID website and may be used in other marketing material such as the WCFID Annual report and social media platforms. Furthermore, I acknowledge that there will be no financial gain for me or the WCFID resulting from the use of this photograph and/or video.

Name: [redacted]

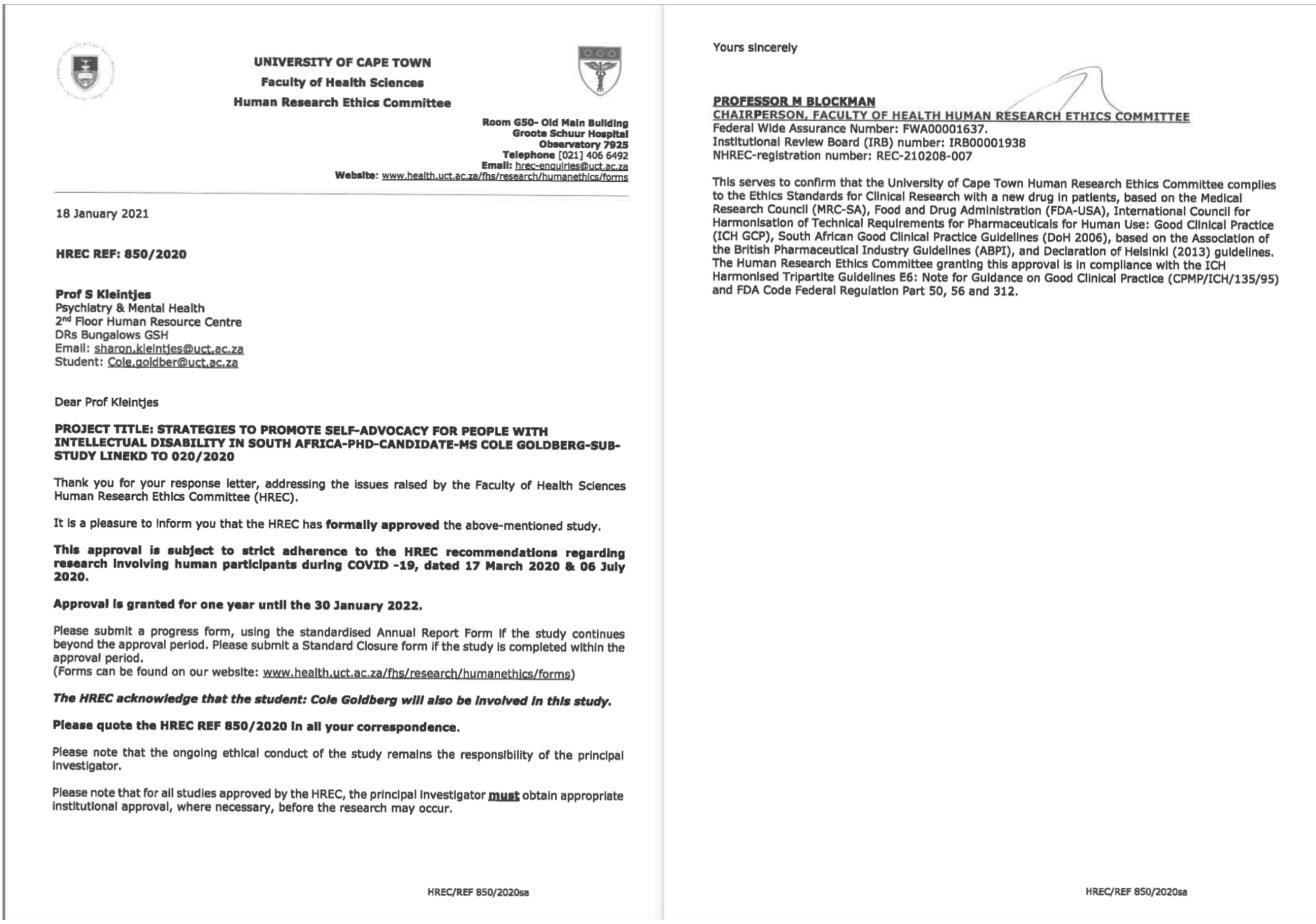
Signed: [redacted]

Date: 29.10.2021

Witness: [redacted]

Witness signature: [redacted]

Appendix J: Ethical Approval



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-enquiries@uct.ac.za
Website: www.health.uct.ac.za/fhs/research/humanethics/forms

18 January 2021

HREC REF: 850/2020

Prof S Kleintjes
Psychiatry & Mental Health
2nd Floor Human Resource Centre
DRs Bungalows GSH
Email: sharon.kleintjes@uct.ac.za
Student: Cole.goldber@uct.ac.za

Dear Prof Kleintjes

PROJECT TITLE: STRATEGIES TO PROMOTE SELF-ADVOCACY FOR PEOPLE WITH INTELLECTUAL DISABILITY IN SOUTH AFRICA-PHD-CANDIDATE-MS COLE GOLDBERG-SUB-STUDY LINEKD TO 020/2020

Thank you for your response letter, addressing the issues raised by the Faculty of Health Sciences Human Research Ethics Committee (HREC).

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 January 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: Cole Goldberg will also be involved in this study.

Please quote the HREC REF 850/2020 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

PROFESSOR M BLOCKMAN
CHAIRPERSON, FACULTY OF HEALTH HUMAN RESEARCH ETHICS COMMITTEE
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.

Appendix K: Distress Protocol