Dissertation: Exploring the perceptions of service providers regarding the need for and availability of services that affect the well-being of LGBTQIA+ individuals living with intellectual and developmental disability in Cape Town, South Africa.

Nathi Poswa (PSWNAT002)

University of Cape Town, Faculty of Health Sciences

Department of Psychiatry and Mental Health

PRY7023W: Master of Philosophy in Intellectual Disability

Supervisor: Professor Sharon Kleintjes

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Name: Nathi Poswa

Student number: PSWNAT002

Signature: Signed by candidate

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[1] IsiXhosa word meaning, "Thank you".
[2] IsiXhosa phrase meaning, "Don't worry sibling".

I have experienced so much growth over the past three years. I appreciate that my commitment to lifelong learning and improving the lives of minority communities has granted me the titles ‘researcher’ and ‘changemaker’.

Abstract

Background: Limited studies have focused on the service providers' perspective regarding the need for and availability of services for people with intellectual and developmental disability (IDD) who identify as lesbian, gay, bisexual, transgender, queer, questioning, intersex, and asexual (LGBTQIA+) (Stoffelen, Kok, Hospers, et al., 2013). The purpose for the study was to promote a better understanding of what service-providing organisations, policymakers, researchers, advocacy groups, and the government should focus on to advocate for and meet the needs of LGBTQIA+ people with IDD. **Method:** The study design was qualitative. A scoping review of the literature was undertaken, and semi-structured interviews were conducted with 13 service providers who work with people who have IDD, people from the LGBTQIA+ community, and individuals with both identities. **Results:** The results indicated that, for people with IDD who are LGBTQIA+, service availability and access is dependent, in part, on service providers' core beliefs rather than policy guidance. The results indicate that there is a need for sexuality education that focuses on different sexual orientations for people with IDD and their service providers. **Study implications:** More research is needed to explore the perceptions of transgender individuals with IDD regarding the availability of and access to gender affirming healthcare, as well as research to inform the development or adaptation of LGBTQIA+ inclusive educational programmes for service providers, users and their caregivers. Future research should include LGBTQIA+ service users' primary accounts, to inform decision-making for service developments and educational resource developments regarding all aspects of their sexual health and well-being.

Key words: Intellectual and developmental disability, LGBTQIA+, service needs, service providers, quality of life, well-being

Definitions

Intellectual Developmental Disorder (IDD): The International Classification of Diseases (ICD-11) classifies Intellectual Developmental disorder (IDD) as a neurodevelopmental disorder (World Health Organization, 2018). Disorders of intellectual development are noted to have onset in the developmental period, presenting with significant impairment in cognitive functions, and in adaptive functioning in the conceptual, practical and social domains (World Health Organisation, 2018). This is an equivalent term to "Intellectual Disability (Intellectual and Developmental Disorder") used in the Diagnostic and Statistical Manual of Mental Disorders-5th edition (DSM5) (American Psychiatric Association, 2013, p. 33).

Lesbian, Gay, Bisexual, Transgender, Queer, Questioning, Intersex, and Asexual plus (LGBTQIA+) (Psychological Society of South Africa, 2013): This term encompasses all other sexual identities that do not fit into heteronormative and cisgendered notions of gender or sexuality (Rethink Mental Illness, 2021). This definition is used throughout the thesis to indicate the researcher's use of the term, however, other terms, such as "LGB", "LGBT", and "LGBTI", are used to indicate the original terms used in papers included in the thesis, where those papers are quoted and referenced. This has been done to maintain the integrity of those papers.

Service Users: In this dissertation, LGBTQIA+ individuals living with IDD who use in-patient, residential and walk-in IDD and LGBTQIA+ organisations' services are referred to as service users.

Service Providers: Staff, carers, working professionals and policy makers responsible for providing for the service needs of LGBTQIA+ people, people with IDD, individuals who identify with both identities, along with external non-governmental organisations (NGOs) that offer walk-in services to the LGBTQIA+ community and people who have IDD and identify as LGBTQIA+, are referred to as service providers in this dissertation.

Sexual Orientation, Gender Identity, Gender Expression and Sex Characteristics (SOGIESC): This is an overarching, umbrella term to describe people whose sexual orientation, gender identities, gender expression and/or sex characteristics places them outside culturally mainstream categories (International Organization for Migration (IOM), 2020).

List of Acronyms

AIDS: Acquired Immunodeficiency Syndrome

APA: American Psychological Association

CBM: Christoffel-Blinden Mission

CGE: Commission for Gender Equality

DoJ&CD: Department of Justice and Constitutional Development

HIC: High-income Countries

HIV: Human Immunodeficiency Viruses

HREC: Human Research Ethics Committee

IDD: Intellectual and Developmental Disability

LGBTI: Lesbian, Gay, Bisexual, Transgender, and Intersex

LGBTQIA+: Lesbian, Gay, Bisexual, Transgender, Queer, Questioning, Intersex, and Asexual plus

MeSH: Medical Subject Headings

NTT: National Task Team

NGO: Non-governmental Organisation

PRISMA-ScR: Preferred Reporting Items for Systematic Review and Meta-Analysis for Scoping Reviews

QoL: Quality of Life

SAHRC: South African Human Rights Commission

SAMRC: South African Medical Research Council

SASH: South African Stress and Health

ScR: Scoping Review

SDGs: Sustainable Development Goals

SES: Socio-economic Status

SL&RR: Sexual Lives & Respectful Relationships

SOGIESC: Sexual Orientation, Gender Identity, Gender Expression and Sex Characteristics

SPIDER: Sample, Phenomenon of Interest, Design, Evaluation, Research type

SSI: Semi-structured interview

STD: Sexually Transmitted Disease

TEDI: Teacher Empowerment for Disability Inclusion

UCT: University of Cape Town

UN: United Nations

UNCRPD: United Nations Convention on the Rights of Persons with Disabilities

WCFID: Western Cape Forum for Intellectual Disability

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Chapter One: Introduction

This chapter provides an overview of research on the service needs, availability of services, and access to services for people from the LGBTQIA+ (lesbian, gay, bisexual, transgender, queer, questioning, intersex, and asexual) community who have intellectual and developmental disability (IDD). The chapter also outlines the theoretical and conceptual frameworks that informed how the study was conducted. Finally, the chapter outlines the research question, aims, and objectives of this study.

1.1 Background

Although the South African Bill of Rights condemns discrimination of any kind and allows freedom of expression in South Africa (Msipu Phiri, 2017; Republic of South Africa, 1996a), it is unclear how many individuals with IDD identify as LGBTQIA+ in the country, because this group has received little attention in the past (Stoffelen et al., 2013). Another reason is that, in different societies, sexuality can raise ethical and cultural concerns (Matin et al., 2021) that lead to non-disclosure by individuals with IDD.

How challenges in political, social, and economic status impact access to social and health-related resources, and how services impact the quality of life and well-being of people living with a disability and those not living with disability, has been the focus of many studies (Kavanagh & Krnjacki, 2012). Research focused on exploring the effects of prejudice on the well-being of marginalised sub-groups within lesbian, gay, bisexual, transgender, and intersex (LGBTI) groups is more recent (Leonard & Mann, 2018), but the intersection of the marginalised identities of disability and LGBTQIA+ has received even less attention (Ikhile et l., 2024).

1.2 Overview of The Literature

1.2.1 Service Users

LGBTQIA+ individuals are viewed as going against societal norms in terms of sexual orientation (Nyeck & Shepherd, 2019); while people with IDD are also viewed as functioning outside of expected societal norms (Thompson et al., 2001). Compared to the rest of the population, people with IDD rarely identify as LGBTQIA+ (Burns & Davies, 2011). This may be due to the scarcity of role models or that individuals may try not to express their diverse sexual orientation, gender identity, gender expression and sex characteristics (SOGIESC) to fit in with societal norms (English et al., 2019). Rodríguez-Roldán (2020) also maintains that vulnerability to violence, discrimination, and abuse in most facets of life (for example, policing, work, housing, and intimate partner violence) is where the IDD community and LGBTQIA+ community intersect. That people with IDD are also at increased risk for physical and economic abuse is illustrated by the recent Life Esidimeni tragedy in South Africa, when the lives of 144 people (Gwala & Zali, 2021) were lost due to a government decision to move them from a highly-funded care facility to under-resourced, and in some cases unregistered, community-based centres run by carers without the necessary skills to support these individuals (Capri et al., 2018b).

People with IDD who identify as LGBTQIA+ (either cumulatively or individually) are likely to experience discrimination (Rodríguez-Roldán, 2020), violence (Tallantire et al., 2016), hate crimes (Hate Crimes Working Group, n.d.) and corrective rape (DoJ&CD, n.d.) in a global and South African context, again mitigating against revealing this aspect of their identity for fear of retaliation. As invisible are these service users in society, so too is the provision of appropriate services to LGBTQIA+ service users with IDD an underserved focus within the relevant service sectors.

1.2.2 Healthcare Access of Service Users

Spira et al. (2015) note that, in South Africa, 90% of transgender individuals do not have access to prevention materials for human immunodeficiency viruses (HIV) and acquired immunodeficiency syndrome (AIDS). Additionally, the National LGBT Health Education Centre (2016) shows higher health disparities for LGBT populations, as they reflect higher rates of HIV and sexually transmitted diseases (STDs), higher levels of substance abuse (Müller, 2016) and smoking, and lower rates of mammography and pap smear screening, among others. The physical well-being of the LGBTQIA+ community can be said to be poor, as this group has inadequate healthcare or lacks access to healthcare (Spira et al., 2015) to look after their physical health.

More than the general population, individuals with IDD are prone to other physical and mental health issues, which means that they tend to visit hospital and social institutions more often than the general population (Ervin et al., 2014). Murphy & Bantry-White (2020) recall an incident where individuals with IDD in a health facility in Ireland experienced harsh treatment from service providers in 2014. A similar occurrence was reported in the United Kingdom where adults with IDD in a residential hospital were mistreated, (Flynn & Citarella, 2012). Gobrial (2012) also mentions that the needs of children with IDD are not a priority in Egypt as the country only spends 7.1% of its total expenditure on healthcare, which is lower than the average 9.1% value across other African countries. In South Africa, local health institutions and NGOs (Capri et al., 2018a) are underfunded while tertiary mental health institutions are well-resourced (Kleintjes et al., 2020). This speaks to the significant lack of attention by healthcare decision-makers and service implementers when it comes to the well-being of marginalised groups such as the people with IDD.

1.2.3 Socio-Economic Status of Service Users

In broader society, people with IDD and LGBTQIA+ individuals are also marginalised in terms of access to socio-economic resources. LGBTQIA+ individuals experience

discrimination in the workplace, which results in socio-economic status (SES) differences (American Psychological Association (APA), 2022). The financial and employment status of LGBTQIA+ individuals in South Africa might be particularly affected in a country such as South Africa, where the World Bank (2022) notes that the unemployment rate in South Africa was 33.6% as at 2021. . Spira et al. (2015) note that these statistics translate directly into the LGBTQIA+ community, with the Human Rights Watch (2011) also positing that, for those who are economically disadvantaged, there is often no hope for better living conditions. More specifically, Spira et al. (2015) note that 57% of transgender individuals in South Africa are unemployed.

In terms of the South African context, scoping reviews (ScRs) done by McKenzie et al. (2013) and Capri et al. (2018b) report that people with IDD mostly reside at home with caregivers. A small group of people occupy psychiatric, correctional or group home services or facilities on a long-term basis (McKenzie et al., 2013; Capri et al., 2018b). This includes people who were admitted to hospitals historically with multiple disabilities and require 100% care; and those with mental health-related difficulties or behavioural challenges, where there is currently no community-based support. This small group also includes people who have been in conflict with the law or declared state patients under the Mental Health Care Act (No. 17 of 2002) (Republic of South Africa, 2002) or the Criminal Procedures Act No. 51 of 1977 (Republic of South Africa, 2015). Additionally, the vast majority of families in South Africa are living in poverty, so most individuals with IDD in South Africa rely on a care dependency or disability grants to cover monthly expenses. While each of these groups, people who are LGBTQIA+, and people with IDD, may be negatively impacted socio-economically, people with these intersecting identities, that is, people with IDD who are LGBTQIA+ individuals, may well experience greater exclusion from access to broader societal resources needed to improve their quality of life and well-being.

1.2.4 Policies in South Africa

Service providers interact with the people they support daily, while disability organisations follow nationally established, and establish their own, policies and protocols that set the scope and boundaries within which employees offer services. Service users have access to services and support where these policies and protocols are followed, which means they have a direct impact on their lives (English et al., 2019). As such, service users with IDD can be included or excluded from "full and fair access" by disability services and their employees, because of these policies and practices (Bates & Davis, 2004, p. 196).

The Mental Health Act (No. 17 of 2002) (Republic of South Africa, 2002) emphasises the human rights of patients with mental health conditions in South Africa (Stein et al., 2018). However, challenges with the implementation of this act are still prevalent, with the South African Human Rights Commission (SAHRC) (SAHRC, 2017) report on the status of mental health services in South Africa stating that many South Africans who may benefit from accessing services do not obtain treatment, despite mental health conditions being highly prevalent in the country. Only 25% of South Africans with a mental health condition receive services, according to a South African Stress and Health (SASH) study (Seedat et al., 2008). Given the prevalence rates, South Africa and the rest of the globe have extremely low budgets for mental health services (SAHRC, 2017).

The Integrated National Disability Strategy (INDS) was created in 1997 as a response to the "abled-disabled dichotomy" (Kruger, 2015, p. 756). The INDS's aim was to shift the negative perspectives of society and to eliminate social barriers that hinder the pleasure of a wholesome life by individuals with IDD. Its other aim was to address issues that are peculiar to the population of people with IDD in a person-centred approach.

A brief review of the policies aimed at improving the lives of LGBTQIA+ individuals in South Africa showed that the National Task Team (NTT) on Gender and Sexual Orientation-

Based Violence, led by the Department of Justice and Correctional Development (DoJ&CD), specialises in issues related to the LGBTI community (DoJ&CD, n.d.). The NTT is made up of government agencies and organisations involved in criminal interventions, including the Commission for Gender Equality (CGE), the SAHRC, and other civil society organisations (DoJ&CD, n.d.).

The Prevention and combating of Hate Crimes and Hate speech, Act 2023 (Republic of South Africa, 2024) is a LGBTQIA+-friendly policy in South Africa that, at the time when the study was being finalised, had yet to be proclaimed. The Act intends to advocate for the rights of, among other minorities, LGBTQIA+ individuals. This is especially important and will be helpful as the country currently lacks a legal framework that addresses hate crimes against the LGBTQIA+ community.

The Promotion of Equality and Prevention of Unfair Discrimination Act 4 of 2000 (PEPUDA) is the country's anti-discriminatory law and came into force in 2003 (PEPUDA, 2000). Chapter 1 of the PEPUDA states that discrimination based on disability or sexual orientation is prohibited. However, previous sections have highlighted the poor state of the human rights of LGBTQIA+ individuals and those with IDD in South Africa. From an IDD researcher perspective, Kleintjes et al. (2020) attribute this as partially due to gaps in legal frameworks and funding opportunities, contributing to policy implementation challenges.

1.3 Theoretical and Conceptual Frameworks

Many possible perspectives can inform the lens through which research is conducted, and it is important that the researcher makes explicit the framework that guides conceptualising, conducting and interpreting the research findings (Reeves et al., 2008). During the literature overview, no frameworks were found that specifically address the issue of LGBTQIA+ community members with IDD. In this study, Jones and McEwen's (2000) model of intersectional theory and Schalock's (2010) Quality of Life (QoL) model of intellectual

disability was used. Both these perspectives were applied, together with evidence cited in the initial literature review provided in the study proposal, to create a conceptual framework to inform my understanding of the service needs, availability of services, and access to services for people with IDD from the LGBTQIA+ community.

1.3.1 Intersectional Theory

Intersectionality, a term that was coined by Kimberlé Crenshaw in 1989, refers to the notion that discrimination can be rooted in more than one identity dimension (Crenshaw, 1989). Crenshaw (1989, p. 149) illustrates this as she highlights that black women often experience "double-discrimination" which is a combined manifestation of discrimination based on two identity dimensions: race and gender.

Crenshaw (1991) asserts that human beings have many layered identities that are shaped by social interactions, history, and the functioning of power structures. As the current study focuses on two minority identities; IDD and LGBTQIA+, intersectionality is an applicable and crucial framework. This is also because it gives us the perspective and vocabulary needed to analyse the relationships and interdependence among social systems and identities that were previously viewed as isolated and individual (Crenshaw, 1991; Atewologun, 2018).

To extend the perspective on how layered identities influence one's life, Jones and McEwen (2000) conducted interviews in the United States with 10 undergraduate women with different racial identities. Jones and McEwen's (2000) findings corroborate the notion that identity is intersectional, as the study participants also understood their identity in relation to other dimensions (i.e. gender, sexual orientation, class, religion, culture, and race).

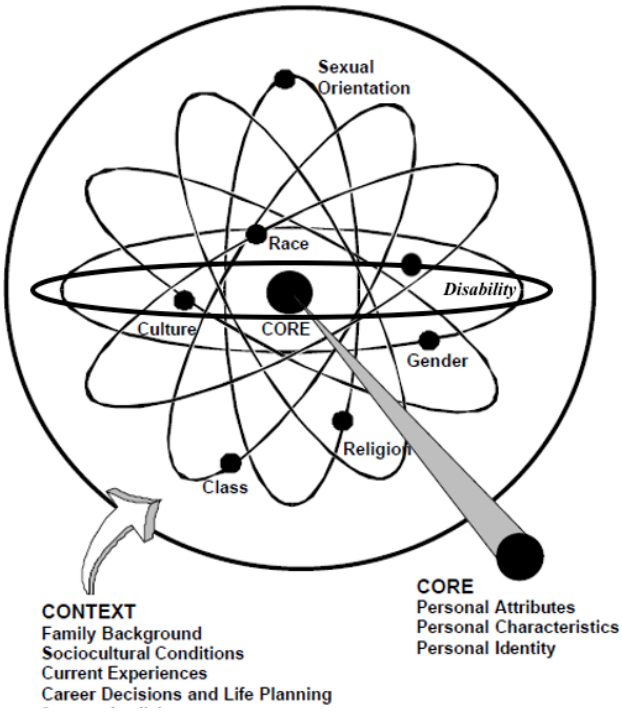
Figure 1 illustrates Jones and McEwen's (2000) model of multiple dimensions of identity. The figure shows that each dimension has its own circle, but all dimensions intersect at some point, as also suggested by Crenshaw (1989; 1991). At the centre is the individual's core

sense of self, which comprises personal attributes, personal characteristics, and personal identity. The bigger circle encompasses both the core and intersecting identity dimensions and symbolises the contexts in which individuals experience various aspects of their identity, such as family background, socio-cultural conditions, current experiences, career decisions and life planning (Jones & McEwen, 2000).

This model demonstrates that an individual's core identity is also influenced by issues outside of themselves, which may become part of their identity. Although research demonstrates that disability is an important and complex aspect of one's identity (Forber-Pratt et al., 2017), Jones and McEwen's (2000) model lack an intersectional dimension related to ability/disability as a dimension of identity. This is possibly because Jones and McEwen's (2000) participant pool were neurotypically and physically normatively developed individuals. Given that the current study focuses on IDD, a dimension of disability was incorporated into the model.

Figure 1

Model of Multiple Dimensions of Identity (Jones & McEwen, 2000)



Note: Adapted from Jones and McEwen (2000), p. 409. Copyright 2000.

Intersectional analysis enables us to recognise the interconnectedness of aspects of policies, programmes, services, and laws that have an impact on numerous areas of our lives. The complex view which this approach provides permits a broader view of the potential wide-reaching impact these issues can have on service opportunities and access which supports basic human rights (Association for Women's Rights in Development, 2004; Institute of Medicine, 2011). Jones and McEwen's (2000) model of multiple dimensions of identity, rooted in Crenshaw's (1989; 1991) framework of intersectionality, provides a useful lens through which to try to understand the factors that contribute to laws, policies and programmes aimed at ensuring availability of services and access to services that are sensitive to the intersecting aspects of identities of LGBTQIA+ people with IDD.

1.3.2 QoL Model of Intellectual Disability

Schalock (2010) notes that the QoL concept, as it relates to IDD, emerged in the 1980s to sensitise individuals to the important aspects in people's lives and as a tool to lead the development of policies and practices for people with IDD. Schalock's (2010) QoL model of Intellectual Disability was used for three purposes: to frame service delivery; to provide evidence-based practices; to ensure quality improvement. Because it has explanatory power and serves as a solid foundation for both service delivery practices and evidence-based practices, the QoL conceptual model potentially offers a method for understanding the service needs of people with IDD from a subjective perspective.

According to Schalock (2010, p. 5), the model focuses on three factors, with eight domains for a QoL, namely: personal development; self-determination; interpersonal relations; social inclusion; rights; emotional well-being; physical well-being; material well-being. Schalock (2010) identified relevant indicators that inform us of the existence of a specific domain in an individual's life. Based on a global examination of QoL literature in the fields of school, special education, mental/behavioural health, and aging, the factors indicated in Table 1 are the most prevalent indicators for each of the eight domains (Schalock & Verdugo, 2002).

Table 1

A conceptual framework of the service needs and availability of services that affect the well-being of people with IDD from the LGBTQIA+ community (Schalock, 2010).

Factor	Domains	Exemplary indicators
Independence	Personal development	Education status, personal skills, adaptive behaviour (Activities of daily living/instrumental activities of daily living)
	Self-determination	Choices/decisions, autonomy, personal control, personal goals
	Interpersonal relations	Social networks, friendships, social activities, interactions, relationships
Social participation	Social inclusion	Community integration/participation, community roles, supports
	Rights	Human (respect, dignity, equality) Legal (legal access, due process)
Well-being	Emotional well-being	Safety and security, positive experiences, contentment, self-concept, lack of stress
	Physical well-being	Health and nutrition status, recreation, leisure
	Material well-being	Financial status, employment status, housing status, possessions

1.4 Problem Statement

In the same way that there is a paucity of services directed at improving the quality of life and wellbeing of people with IDD who are LGBTQIA+ individuals, there is also a paucity of research focused on engaging this under-researched topic globally, and in South Africa. As part of this under researched area there are limited studies which have focused on service providers' perspectives regarding the need for and availability of services for people with intellectual and developmental disability (IDD) who identify as LGBTQIA+ (Stoffelen et al., 2013).

As a first exploratory investigation into this area of study of a vulnerable and marginalised group in a South African context, this study engaged with service providers as key informants to explore their perceptions of the need for, availability of, and access to appropriate services to promote the well-being of this group of individuals.

1.5 Rationale for the Study

Very little is known about the availability and appropriateness of services offered to people with IDD in the health and social services sector (Stoffelen et al., 2013), including in South Africa. The current study looked at the experiences of service providers with experience of working with people from the LGBTQIA + community, in particularly people who have IDD and who are LGBTQIA+ individuals. The study aimed to explore their experience of barriers and facilitators to their services contributing to improving these individual's quality of life and wellbeing which they encountered in the service provision space. Service providers were prompted to reflect on and consider issues in service provision which have arisen in their work when offering services to people from the LGBTQIA+ community, in particular those with disabilities/IDD. These service providers' experiences are thought to offer an insider perspective on what service providers within the health and

social services sector might find inhibitive or supportive of service provision for people with IDD from the LGBTQIA+ community. The study aimed to infer from these insider perspectives or experiences, key issues which may need to be addressed to improve health and social services available and accessible to people with IDD.

1.5.1 The Importance of Conducting Research with People with IDD Themselves

In our problem statement we have noted that service provider views are only part of the perspectives which need to be addressed in research in this area. A crucial focus of research involving people with disability is the inclusion of first-person accounts of their experiences, which are central to understanding what might best serve their needs. Goldberg and Kleintjes (2022, p. 593) note the importance of directly "hearing the voices" of people with intellectual disability in all aspects of decision-making which impact on the quality of their lives. The current study focused on service providers, whose views may not reflect the same priorities people with IDD who are LGBTQIA+ individuals may raise in research where they are participants.

We chose to start with service provider perspectives as preparatory review of the literature and discussions with local NGOs raised the issue of the safety of potential participants, calling into question ethical issues related to starting with their first-hand accounts when our research team were uncertain about safety issues in recruiting these individuals for a study. Given the intersection of the vulnerabilities experienced by LGBTQIA+ individuals with IDD globally and in the South African context, it was considered premature and potentially too risky to conduct this initial research with local people with IDD who identify as LGBTQIA+. This was more especially because of the dearth of research with these

individuals in the local context, with data from South Africa that supports safe work in this area not as yet being available.

Therefore, it was decided to defer research conducted by the division within which this study took place, with LGBTQIA+ people who have IDD, until greater clarity was obtained on the safe conduct of such research in local context. It was hoped that some insights on this issue might be gained from the current research focusing on service provider experiences in working with people with IDD who identify as LGBTQIA+ , which could inform studies undertaken directly with people with IDD who are LGBTQIA+ in our context. Preliminary suggestions for this generated by the current study are included in the recommendations of the study on page 102-103.

1.6 Research Question

What are the perceptions of service providers regarding the service needs and the availability of services that affect the quality of life and well-being of LGBTQIA+ people living with IDD?

1.7 Aim of the Study

The main purpose of this study was to explore the need for and availability of services that affect the quality of life and well-being of LGBTQIA+ people living with IDD in the Western Cape from a service provider perspective.

1.7.1 Objectives of the Study

- To conduct a scoping review to document the perspectives of service providers regarding the need for and availability of services that promote the quality of life and well-being of LGBTQIA+ individuals living with IDD internationally, in Africa and in South Africa.

- To document the perceptions of service providers regarding the need for and provision of services that promote the quality of life and well-being of LGBTQIA+ individuals with IDD in the Western Cape.

1.8 Layout of the Dissertation

Chapter One of this dissertation provides an overview of the area of focus and rationale for the study. It also focuses on the conceptual and theoretical frameworks that underpin the study, and outlines the study aims and objectives.

Chapter Two outlines the methods used to conduct the study. This chapter describes how the scoping review and semi-structured interviews (SSIs) with service providers for people with IDD and people who are LGBTQIA+ were conducted. Chapter Two also focuses on the data analysis methods used for the study, as well as the issues of rigour and ethical considerations.

Chapter Three details the findings of the scoping review.

Chapter Four provides the findings of the SSIs and focus groups.

Chapter Five concludes the thesis with a discussion of the implications of the study, its limitations, potential value and some recommendations for future research.

Chapter Two: Methodology

2.1 Introduction

This chapter begins with a description of the research design and outlines the researcher's positionality. Thereafter, the methods used in the scoping review and semi-structured interviews are explained, with the focus being data collection and thematic analysis tools. This chapter also details the ways in which rigour was ensured in the study as well as ethical considerations.

2.2 Research Design

Qualitative research is concerned with understanding concepts, experiences, and the opinions of individuals (Bhandari, 2020). Since this study was aimed at understanding the perceptions of service providers who have worked with LGBTQIA+ individuals with IDD, a qualitative enquiry was considered appropriate.

Phenomenology is a qualitative research approach defined by Edmund Husserl in the 20th century to challenge an objective, empirical and positivist philosophy (Sloan & Bowe, 2013). Husserl asserted: "subjective and objective knowledge are intimately intertwined" (Neubauer et al., 2019, p. 94). He ideated phenomenology to be a philosophical method aimed at explaining phenomena as experienced and understood by individuals (Sloan & Bowe, 2013). Husserl's phenomenology is transcendental (descriptive) and asserts that the researcher assumes the position of a "tabula rasa" (Neubauer et al., 2019, p. 93) or blank slate, from which they use participants' experiences to form an understanding of the significance of a phenomenon. Husserl also asserts that a researcher can remove themselves from the "participants' descriptions of facts of the lived experience" and not allow their subjectivity to influence the descriptions offered by the participants, thus "bracketing" their experiences and identity (epoche) (Neubauer et al., 2019, p. 93).

A second strand of phenomenology - known as hermeneutic (interpretive) phenomenology - was developed by Martin Heidegger, whose work initially aligned with Husserl's ideas, but then evolved to challenge them. Heidegger assumed an ontological perspective and focused on the concept of "being in the world rather than knowing the world" (Reiners, 2012, p. 119). This perspective assumes that individuals cannot bracket their experiences and identity, but rather that they can use their preconceived or expert knowledge to guide the research and enhance its meaningfulness (Lopez & Willis, 2004). Hermeneutic phenomenology transcends the significance of an experience and seeks meanings that are infused in everyday events - a concept Heidegger referred to as "lifeworld" (Lopez & Willis, 2004, p. 729).

For this study, hermeneutic (interpretative) phenomenology approach was selected, because it transcends the simple description of the significance of a phenomenon and does not bracket the researcher's experiences and identities (contrary to Husserl's transcendental phenomenology approach).

The current research aimed to inquire about the perspectives of service providers based on their first-hand experiences of working in organisations offering services to LGBTQIA+ individuals, persons with IDD, and individuals with IDD who are also LGBTQIA+ individuals. Heidegger's hermeneutic (interpretative) phenomenology approach was, therefore, an appropriate lens through which to conduct the research (Reiners, 2012; Lopez & Willis, 2004), given the focus on first-hand experiences and insights from those experiences which service providers brought to answering the research question of the study.

2.3 Positionality and Reflective Statement

The Heidegger's hermeneutic (interpretative) phenomenology approach recognises the researcher as being in-the-world of research, and interpreting and being interpreted by the context (Reiners, 2012). That is, the researcher's subjective experiences and identities also influence the understanding and interpretation of perspectives, as hermeneutic

phenomenology ideates (Neubauer et al., 2019). It is therefore important to locate the positionality of the researcher within the study to understand how their own inner world, belief system, values and experiences might have impacted on the research.

I am a member of the LGBTQIA+ community and believe that all human beings should have access to basic services that promote their well-being in society. The value of this positionality is that as a member of the LGBTQIA+ community I have had both positive and negative experiences being in the world and accessing services. Regardless of my being in the world as a LGBTQIA+ person, I acknowledge the diversity within the community and the fact that my identities do not equate to full knowledge of the entire community's experiences, and welcome critique from fellow LGBTQIA+ researchers.

I am also aware that my insider perspective as a LGBTQIA+ person is premised on my own experiences as a neurotypical person who has, to date, had very little contact with people with IDD, and none with these individuals who may identify as LGBTQIA+. Therefore, care must be taken to be mindful that my personal experiences and beliefs could restrict my perspectives and interpretations of the data collected for the study. To this end, I kept a reflexive journal throughout my journey with the project and reflected on these issues in the research supervision. Furthermore, the involvement of a research assistant aided in providing a balance to my understanding of the data generated during the ScR, and in analysing the data from the SSIs and focus groups.

2.4 Scoping Review Method

A Scoping Review is conducted to systematically map out the research that exists on a current topic, and to identify gaps in knowledge (Munn et al., 2018). The main purpose of the ScR done for this study was to document the literature on the perspectives of service providers regarding the need for, availability of, and access to quality of life and well-being

services for LGBTQIA+ individuals with IDD internationally, in Africa, and in South Africa. Specifically, the review aimed to ascertain the views of health, social service and education service providers on (a) service needs, (b) service availability and access, and (c) the impact of these services on the quality of life and well-being of LGBTQIA+ people with IDD.

The guidelines from the Preferred Reporting Items for Systematic Review and Meta-Analysis for Scoping Reviews (PRISMA-ScR) were used to inform the ScR (Tricco et al., 2018). The PRISMA-ScR checklist is included as Appendix 1.

2.4.1 Reviewers

The review process is usually conducted by at least two individuals to ensure trustworthiness and credibility of the data through constant comparison and consensus during the review (Anney, 2014). The ScR was therefore conducted by the researcher (NP) and a research assistant from the University of Cape Town's Division of Intellectual Disability, Department of Psychiatry and Mental Health (BT). NP has an honour's degree in Psychology and is presently employed as a Learning Designer. This requires her to utilise research skills to develop new course material and update old course material. BT is a social worker by training, who has worked in the field of IDD, who recently completed a doctoral degree in the field and who is familiar with the process of conducting ScRs.

2.4.2 Identifying Relevant Studies

Eligibility Criteria. Table 2 provides a summary of the inclusion and exclusion criteria used to determine what articles were to be included in the review. ScRs generally do not put a limit on the number of sources or the time period (Munn et al. 2018), but where limits are introduced motivation for these limits must be clearly stated (Helbach et al., 2022). For this time-limited and resource-limited master's study, grey literature was limited to unpublished academic theses. A time limit of 1994 was set, as this was the first year in which post-Apartheid democratic elections were held in South Africa, which ushered in an inclusive

constitution and policies protecting the rights of all citizens, including individuals with diverse SOGIESC and people with a disability (Seekings, 1997).

Table 2

Inclusion and exclusion criteria

Inclusion criteria	Exclusion criteria
Addresses the perceptions of service providers regarding the service needs, service availability, and service access for LGBTQIA+ people living with IDD.	Does not address the perceptions of service providers regarding the service needs, service availability, and service access for LGBTQIA+ people living with IDD.
Focuses on the views of service providers.	Studies on LGBTQIA+ people living with disability which do not include disaggregated data on people with IDD.
Qualitative, quantitative, and mixed methods studies.	Studies focusing on sexuality instead of sexual orientation.
Published in English.	Studies where the views of service providers are not disaggregated.
Published between 1 January 1994 and 10 March 2023.	Studies not published in English.
Studies in low-, middle- and high-income countries, with no restriction by country.	Studies not within specified timeframe.
Available in full text.	Studies not available in full text.
Grey literature limited to unpublished academic theses.	Grey literature other than academic theses.
Studies on service provider experiences with adult clients who have needs related to a LGBTQIA+ identity.	

Information sources. The University of Cape Town Health Sciences Librarian was consulted to identify relevant Medical Subject Headings (MeSH) search terms, to search for relevant papers from the following databases: Africa-Wide information; CINAHL; Health Source: Nursing/Academic Edition; Humanities International Complete; MedLine; SocINDEX; Scopus; PubMed; PsycINFO; Web of Science. Limiters were used where applicable, and the Boolean operators AND and OR were applied. The search was conducted on 10 March 2023. An example of the search strategy and the results obtained from one database are provided in Table 3.

Table 3

CINAHL search strategy and results (literature search performed: 10 March 2023)

TOPIC: intellectual disability OR mental retardation OR learning disability OR developmental disability OR learning disability	***AND TOPIC:*** lgbtqia+ OR gay OR lesbian OR transgender OR trans OR lgbt OR bisexual OR queer	***AND TOPIC:*** quality of life OR well being OR well-being OR health-related quality of life
Limited to:		
Also search within the full text of the articles		
Apply equivalent subjects		
English language		
All adults		
1 January 1994 – 10 March 2023		
Results: 6		

2.4.3 Selection of Studies

An Excel data sheet was developed to aid study selection. The following headings were included: author names; year of study; study title; study journal; abstract; inclusion criteria (Arksey & O'Malley, 2005) - see Table 4.

Table 4

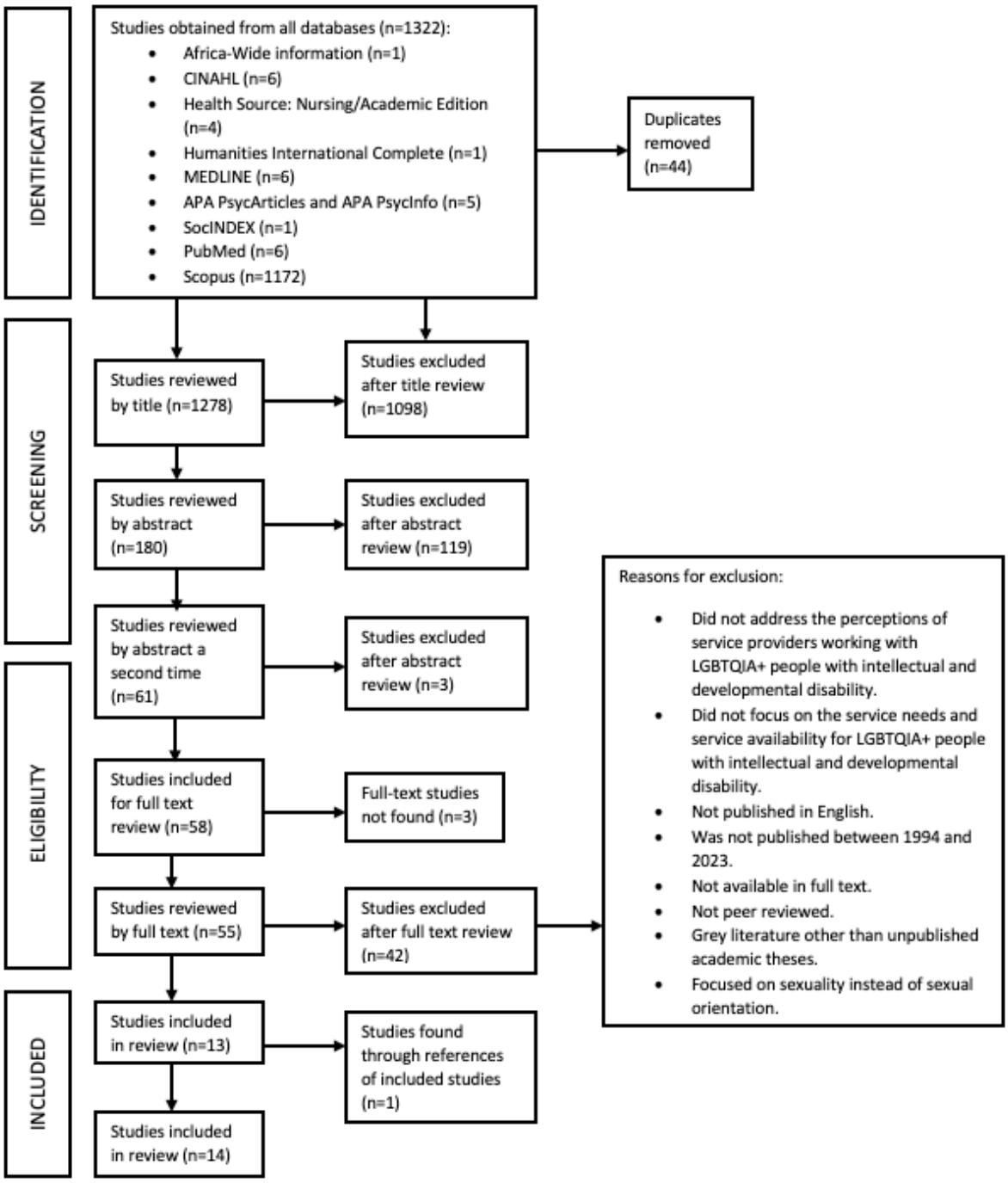
Criteria application sheet

Author, Year & Study title	Journal	Abstract	Criteria 1: Focuses on LGBTQIA+ people with IDD – Y/N	Criteria 2: Focuses on service provider perspectives – Y/N (If Y, specify professional field)	Criteria 3: Focuses on service needs/availability – Y/N (If Y, specify)	Criteria 3a: Addresses barriers to service access – Y/N	Criteria 3b: Addresses opportunities for service access – Y/N	Criteria 4: Focuses on QoL/well-being – Y/N (If Y, specify QoL/well-being)	Criteria 5: Mentions intersectional aspects – Y/N (If Y, specify)	Include in literature review – Y/N

Figure 2 below provides a flowchart that reflects the search strategy process (Tricco et al., 2018).

Figure 2

Flowchart illustrating the search strategy used



The initial search yielded 1322 studies. After duplicates were removed (n=44), the remaining articles (n=1278) were independently reviewed by NP and BT for relevance by title. Consensus was then reached on 180 studies to be included in the abstract review. The abstracts in these studies were reviewed in two stages to ensure rigour (Munn et al., 2018; Tricco et al., 2018). A discussion followed the first round of independent abstract review, with agreement being reached on excluding 119 studies, and including 61 studies for full text review. This joint deliberation crystalised the nuances of inclusion and exclusion, so that a second round of abstract review was done on the 61 studies. Three more articles were then excluded, which left 58 papers for full text review.

Three articles could not be retrieved from the library, via inter-library loan or requests sent to the authors via an online platform (ResearchGate) in March 2023. NP and BT independently read and assessed the remaining 55 full texts for inclusion and exclusion, and a process of comparison and consensus then resulted in a further 42 articles being excluded. NP and BT independently reviewed the reference lists of the papers that were included (n=13) and agreed to include one additional paper.

Quality evaluation is not a prerequisite for a ScR (Tricco et al., 2018), and given the small number of included papers, all 14 papers were included without a quality examination.

2.4.4 Data Charting and Synthesis

Ritchie and Spencer's Framework Analysis approach to qualitative data analysis was used to analyse and synthesise the data (Ritchie & Spencer, 2002; Gale et al., 2013; Hackett & Strickland, 2018). This framework analysis approach was developed in the 1980s to inform social policy research in the United Kingdom. It provides a 5-step process for analysing, synthesising and interpreting qualitative data by sifting, charting and sorting material according to key issues and themes related to the focus of the study.

This method does not ascribe to any particular epistemological framework, nor does it limit itself to either a deductive or inductive approach to data analysis (Gale et al., 2013). The Framework method of analysis used in this study can consecutively incorporate both deductive and inductive qualitative analysis (Gale et al., 2013). As described below, a preliminary coding frame was developed to analyse the data deductively, while leaving room for new ideas to be added to the analysed data inductively (Gale et al., 2013).

Framework analysis provides a structured approach to assist researchers to focus on the core elements of knowledge generation, in order to inform social policy recommendations related to the focus of the research. This framework analysis approach also allows the flexibility to account for new or unexpected knowledge about the focus of the study discernible in the data collected (Gale et al., 2013; Hackett & Strickland, 2018). In this study, the aim was to inform service development and implementation for LGBTQIA+ people with IDD through an interpretative phenomenological approach to qualitative data analysis; therefore, a framework analysis was an appropriate analytical tool for analysis of the data (Hackett & Strickland, 2018). The process followed for this study was adapted from Gale et al. (2013) and Hackett & Strickland (2018), and is described below.

Stage 1: Familiarisation. Following retrieval of relevant articles for the review, NP and BT each read the articles (n=14) independently multiple times to familiarise themselves with the data. Notes were made on each article, and points of interest and significance identified (Hackett & Strickland, 2018; Gale et al., 2013).

Stage 2: Data Coding. NP coded the data for the first two articles, with data elements extracted from the articles using a set of preliminary codes set to reflect the key themes and sub-themes related to the ScR question and the information gleaned from familiarisation with the dataset at stage 1 (Gale et al., 2013). BT conducted quality assurance by recharting and

recoding these articles, then comparing her charting and coding to that done by NP to ensure that the data was similarly and comprehensively charted and coded (Mak & Thomas, 2022).

Stage 3: Developing a Working Analytical Framework. NP and BT then met to discuss the process of charting and coding the two papers and to come to final consensus on their understanding of the elements to be charted in relation to the conceptual framework and research question (Gale et al., 2013; Hackett & Strickland, 2018). This process resulted in the preliminary codes and sub-codes being refined, as indicated in Table 5 (Gale et al., 2013).

Table 5

Preliminary codes and sub-codes

Code	Sub-code
Need for services	Need for inclusive policies
Availability of services	N/A
Barriers to availability of services	Barriers
	Challenges experienced by service providers
	Lack of service provider guidance and support
Access to services	Positive service provider attitudes
Barriers to access of services	Stigma & reluctance
	Limiting views
	Negative attitudes
	Impact of service providers' religious views
	Service provider negative attitudes towards LGBTQIA+ people with IDD
	Lack of knowledge/ignorance
	Fear of negative feedback
	Service provider lack of initiative
Improvement opportunities to access	Recommendation to improve services
Improvement opportunities to availability	Strategies to address barriers
	Opportunities
Intersectional aspects	Identity-related barriers
Impact on QoL	Social inclusion
	Emotional well-being
Total = 9	Total = 19

Stage 4: Applying the Analytic Framework. NP and BT continued to use a process of line-by-line coding of data elements with the remaining articles, to code relevant data using the codes and sub-codes of the coding frame. Again, this was done by NP coding while BT

continued to conduct quality assurance of the charted studies, as described earlier (Mak & Thomas, 2022).

Stage 5: Charting the Data into the Framework Matrix. A data extraction sheet (Appendix 2) was developed by the researcher and reviewer to capture a set of characteristics of the studies. As all the studies were qualitative, the Sample, Phenomenon of Interest, Design, Evaluation, Research type (SPIDER) tool was used (Cooke et al., 2012). Pollock et al. (2022) note that only data items relevant to the ScR questions should be extracted, therefore the SPIDER tool was adapted to include: author(s), year of publication, title of study, country of publication, aims, sample and sample size, study design and methods. The coded data from stage 4 was then charted into the extraction matrix. A series of spreadsheets were used to iteratively summarise the coded data of each transcript, with effort made to retain original meanings while reducing the data to a meaningful summary of the main findings of the review (Gale et al., 2013). The final spreadsheet is provided in Appendix 3.

Trustworthiness of the study was assured by ensuring that the names assigned to the themes and sub-themes reflected the ideas communicated in the relevant studies, and that the themes echoed service providers' perceptions regarding the quality of life and well-being service needs, the availability of services, and access to services that influence the QoL of LGBTQIA+ people with IDD (Hackett & Strickland, 2018). The series of spreadsheets used to chart the themes provides an audit trail of the reviewers' iterative interpretation of the data coded from the articles (Hackett & Strickland, 2018). Although an overwhelming process involving a lot of information, this stage allowed the researcher to remain immersed in the data.

2.5 Interview Method

2.5.1 Study Setting

Participants for the study were recruited in the Western Cape Province, as the researcher's resource limitations precluded a wider recruitment base for this master's study.

2.5.2 Study Population and Sampling

Networking and recommendation are essential to snowball sampling, which is one of the most common qualitative research sampling methods. Typically, the researcher begins with a small pool of contacts who meet the research criteria and who are invited to participate in the study. The willing informants are then asked to propose further contacts who meet the inclusion criteria and who might be willing to participate in the study. They subsequently refer more possible participants, and so on (Parker et al., 2019). The researcher aimed to establish the perceptions of a relatively small community who are not easily identifiable, therefore, the identified key informants were relied on for referral to other informants. Additionally, the researcher also perused online resources for organisations that possibly had contact with other qualifying informants.

After consultation with NGOs and national departments (i.e. social services, health, and justice) that provide services to individuals with IDD and to people who identify as LGBTQIA+ in the Western Cape, the researcher was able to identify six organisations, one official from a national department that offers social protection services, and one independent service provider and researcher in the field of IDD, who were willing to participate in the study. Of the six organisations, three were LGBTQIA+ NGOs, and three were IDD NGOs.

It was not possible to include participants from some of the national departments the researcher had planned to include in the study. This was because permission requests to recruit potential participants from these national departments were not processed by the relevant national departments within the timeframe set for recruitment (January – July 2023),

despite regular follow up. The characteristics of the participants are detailed in the chapter on findings of the interviews.

2.5.4 Informed Consent

For the SSIs, key informants were contacted and confirmation was obtained that they were interested in participating, based on the information on the information sheet (Appendix 4). The participants were then briefed about the overall project, its goal, and how the data gathered would be used going forward. After discussing and answering any queries they had, an informed consent form (Appendix 5) was provided for them to sign ahead of the interview. The consent form contained information regarding the purpose of the study, the benefits, and any potential harm that could be caused. Each SSI session lasted approximately 60 minutes. All study informants understood and spoke English; therefore, the consent form was made available in English. Because the key points of this study are sensitive, participants were informed of their right to withdraw at any time, should the need to do so arise.

2.5.5 Data Collection for Semi-structured Interviews

Semi-structured interviews elicit subjective comments from people about a situation or event that they have experienced (McIntosh & Morse, 2015). A preliminary interview schedule (Appendix 6) (informed by the QoL model of Intellectual Disability and intersectional theory) was developed and used to guide the interviews. The interviews occurred virtually and in-person to accommodate the needs of the participants. With the 13 participants, 12 interviews were conducted in English, and one was done in both English and isiXhosa, as these are the researcher's first languages, and the participant was comfortable using both.

Before the interviews, the researcher shared an information sheet with potential participants (Appendix 4). During this stage, the researcher introduced herself and informed the participants regarding what the study was about and encouraged the participants to ask

questions if they required clarity on certain aspects of the study or interview process. Following this, the researcher inquired of the participants what their understanding of the terms IDD and LGBTQIA+ was, to ensure that participants understood what was meant by IDD and LGBTQIA+. This was important because it was noted during preliminary discussions with NGOs and services that people were not always sure what these terms meant, for example, thinking that IDD referred to autism spectrum disorder (ASD). All included participants had a clear understanding of what these terms mean in modern society and their understanding was compatible with the definitions of these terms as used in this study. Where participants indicated that they would like to participate in the study, they were then asked to sign an informed consent form ahead of their interview. For the rest of the interviews, the researcher read questions from the interview schedule and allowed the conversation to flow while guiding it with prompts from the interview schedule.

At the conclusion of each interview the researcher completed a Post Interview Form (Appendix 7), and a Researcher interview notes form (Appendix 8). The administrative form provided space for demographic details of the participant, and the researcher interview notes provided an opportunity to briefly summarise her recollection of the key issues which arose in the interview, whether she felt that the interview offered substantive information relative to the research topic, whether it introduced issues which needed further follow up with subsequent participants, and whether there were any subjective issues which arose between her and the research participant which might have impacted on the interview. This offered a valuable summary of the interviewing process across the interviews and provided reminders of key issues which arose when the researcher engaged in data analysis

2.6 Data Management

The audio recordings of the interviews were transferred to the researcher's personal computer, which is password protected, and stored in a secure folder. A transcriber, who had signed a confidentiality agreement (Appendix 9), transcribed the audio recordings, then deleted the files from her personal computer, and all tangible copies of written notes were destroyed. Transcripts of the audio recordings are saved in a secure location at the Department of Psychiatry and Mental Health at the Neuroscience Centre, Groote Schuur Hospital. To maintain the participants' anonymity, their names were deleted, and pseudonyms were assigned for identification. The researcher, supervisor, transcriber, and research assistant were the only individuals who had access to the data. No confidential information was disclosed to any party besides those listed above.

2.7 Data Analysis

Thematic analysis is a qualitative descriptive method that is typically used to describe a group of texts (for example, an interview transcript). The researcher studies the data carefully to identify, analyse, and uncover recurring themes — subjects, ideas, and patterns of meaning (Labra et al., 2020). Thematic analysis of the data collected for this study followed a six-step process (Braun & Clarke, 2006) to identify themes from the data. Braun and Clarke (2006) note that both deductive and inductive analysis can be used for the analysis of qualitative data, and the qualitative interview data for this study was analysed both deductively and inductively as detailed below.

2.7.1 Stages of Thematic Analysis

Phase 1: Familiarisation of the Data. Although transcription can be time-consuming and tedious, the researcher achieved familiarity through translation of one interview that was in both English and isiXhosa and transcription of most of the interview transcripts (n=10). The other three transcripts were transcribed by a transcriber, which the researcher then read and

compared against the audio files to ensure accuracy. The researcher also spent time familiarising herself with the data by reading the transcripts and doing initial coding (Braun & Clarke, 2006) and reading the transcripts and extracting codes that were considered relevant to the study (informed by the literature review and theoretical framework), thus employing an initial deductive approach (Braun and Clarke, 2006).

Phase 2: Generating Initial Codes. The research assistant , BT was again introduced at this stage of the process, introducing a second "subjectivity" to the data analysis process, providing the researcher with some insight into whether her independent coding of the data was similar to original meanings within the text.

In terms of relevance of data coded, in line with the phenomenological approach used in this study, care was taken to focus on coding experience-near data, that is data which reflected the participants lived experience of working with LGBTQIA+ individuals, and people with IDD who were LGBTQIA+ individuals, rather than experience-distant data, such as participants' opinions of what might have or does occur (Ajjawi et al, 2023).

For purposes of reflexivity, the researcher also took notes and made comments during the process, as differences and similarities between the interviews, and between the interviews and the literature review were identified.

Both NP and BT coded three transcripts independently. The data was grouped according to differences and similarities, and NP and BT came together to discuss and compare these, in order to arrive at an agreed upon initial coding framework. The researcher captured this on NVivo®, version 12, a qualitative data analysis software programme that is widely used for qualitative data analysis. The codes and sub-codes from the initial coding framework were named and described to provide the researcher with a guide to coding the remainder of the transcripts (n=10) alone.

Phase 3: Searching for Themes. The researcher continued to code the rest of the interview data into the coding frame. None of the codes were abandoned at this stage (Braun & Clarke, 2006).

Phase 4: Reviewing Themes. The researcher continued to refine the themes identified in the previous stage. This meant inductive merging of some themes, breaking others down, and eliminating others to avoid internal homogeneity and external heterogeneity (Braun & Clarke, 2006). To ensure that the themes were coherent, the researcher read the grouped excerpts for each theme. For accuracy, the researcher read the data set again and this helped identify any inconsistencies or data which may have been missed before. As the researcher immersed herself in the data and her understanding of the data deepened, new themes that had not been captured in the initial framework emerged and were captured.

Phase 5: Defining and Naming Themes. The names of the themes were revised iteratively to reflect the data as accurately as possible (Labra et al., 2020). The themes were defined and refined by analysing the data within them and identifying what was interesting about them and the reasons for this, relative to the focus of the study (Braun & Clarke, 2006). Following this, the researcher determined whether a theme had any sub-themes. By the end of this stage, the researcher was able to identify more accurately what the themes were and what they were not (Braun & Clarke, 2006).

Member-checking. Focus groups are a qualitative technique for gathering data about a chosen subject through an organised and targeted discussion among a small number of people (Gundumogula, 2020). Focus groups can also be used as a research strategy for member checking (Klinger, 2005). Focus groups were conducted as a member checking technique to ascertain how well the interviewees' life experiences of working in organisations serving people with IDD with LGBTQIA+ identities had been captured and understood in the analysis of the SSIs. Two focus groups were conducted via Microsoft Teams with eight of the

original participants, with four key informants present in each 90-minute session. The interview guide for the focus groups (Appendix 10) was developed based on the findings of the SSIs. The participants were again asked to sign an informed consent form (Appendix 11) after a briefing about the study purpose, harms and benefits, and use of the data. The two focus groups were conducted in English.

For each QoL domain, the researcher briefly reflected on the findings from the SSIs by verbally communicating her understanding of the data. Questions were then asked using the focus group guide, to which the participants responded verbally or used the chat function in Microsoft Teams. Participants who did not spontaneously share their views on a particular issue were prompted by the researcher to ensure full participation.

To ensure that the participants' views from the focus groups were also included in the final analysis and write-up of the dissertation, the focus groups were also transcribed and coded by the researcher. This was done using the initial coding framework generated during phase 2 to answer the research question. The data produced information that in general supported the researcher's analysis of participants' views, in a few instances elaborating and deepening the interpretation, and in a couple of instances, refined the researcher's interpretation of the findings. These new insights were integrated into the data set and themes.

Phase 6: Reporting. Chapter Four provides the report on the final analysis of the findings, and attempts to be "concise, coherent, logical, non-repetitive, and interesting" (Braun & Clarke, 2006, p. 23). Demonstrative quotations from the data set that highlight the themes and help illustrate the story being told about the data have been provided. Quotations from the interviews are provided, and where relevant, quotations supporting, elaborating or refining the findings have been added from the focus groups for member checking. An argument relative to the study's research questions has been presented (Braun & Clarke, 2006), and the

theoretical concepts used to inform the study have been applied throughout to ensure that the interpretation of the data is consistent with the theoretical and conceptual frameworks.

2.8 Ensuring Rigour in Qualitative Research

2.8.1 Credibility

According to Macnee and McCabe (2008), credibility is the degree to which the research findings are considered accurate. Credibility was ensured by using triangulation by researcher and by method, a reflexive journal and an audit trail, as suggested by Anney (2014).

Triangulation. Three data collection methods were used: a ScR, SSIs, and for member checking, focus groups. Two perspectives were brought into the research, as the researcher was assisted by a research assistant during analysis of the data from the ScR and SSIs. Data obtained from the ScR and SSIs were also triangulated to provide the researcher with greater depth of understanding and interpretation of the findings to inform the research topic of the study.

Reflexive Journaling: Researcher Journal, Post Interview Form and Researcher Notes Form. The researcher kept a reflexive journal for the duration of the study to document any researcher-related issues that arose and had the potential to impact her understanding and interpretation of the data. The researcher also completed a post-interview reflection using a Post Interview Form and a researcher interview notes form, as detailed on page 44 to note her views on the quality of the interview, as well as her potential impact on the interview process.

Audit Trail. An audit trail is a useful tool for ensuring the quality of qualitative investigations (Akkerman et al., 2006). The researcher kept track of all research activities, documenting the research decisions and actions taken throughout the study by taking notes and ensuring version control of documents, which then provided valuable information during the analytical stages and triangulation stages of the research process.

Member Checking. Member checking was achieved by inviting the participants to focus groups to allow feedback and reflection on the findings (Anney, 2014). During the focus groups, the researcher shared a summary of the SSI findings with the participants and allowed them to reflect and comment on the findings. This is detailed in page 47-48.

2.8.2 Dependability

Dependability is "the stability of findings over time" (Bitsch, 2005, p. 86). A researcher assesses the study findings, interpretation, and suggestions to ensure that they are supported by the information gathered from the study informants (Tobin & Begley, 2004). For this study, dependability was ensured by an audit trail.

Audit Trail. As noted above, the researcher kept track of all choices and actions related to the research (Anney, 2014) and retained all notes, audio recordings of interviews, transcripts, and other data gathered from the research field.

2.8.3 Transferability

Transferability is a measure of how well qualitative research findings may be applied to other contexts with different respondents (Tobin & Begley, 2004). According to Bitsch (2005, p. 85), by using "thick description", the researcher helps a potential user establish a “transferability judgement”. In writing the dissertation, the researcher has presented a clear and detailed description of the research context, including setting, timing, participants, and methodology from data collection to data analysis. Although the environment and study were diverse in nature, a thorough explanation gives information on how the study was carried out and allows other researchers to undertake similar studies in other contexts using the same approach (Anney, 2014).

2.8.4 Confirmability

The extent to which a study’s findings can be “confirmed or corroborated by other researchers” is referred to as confirmability (Anney, 2014, p. 279). In this study,

confirmability was informed by an audit trail, as suggested by Anney (2014). The audit trail assisted in keeping track of the decision-making processes that occurred during the study. The raw data, interview and observation notes, documents and any other records collected from the field were stored, as part of this audit trail (Anney, 2014).

2.9 Ethical Considerations

The ScR portion of the study did not require ethical clearance, however ethical clearance for the full study was obtained from the University of Cape Town's Human Research Ethics Committee (HREC) (HREC no.04/2023). This is attached as Appendix 12. Furthermore, the study abided by the Declaration of Helsinki guidelines for ethical considerations (World Medical Association, 2013).

2.9.1 Permissions

Some of the study informants work for institutions that required permission to be sought prior to the SSIs being conducted. A permissions letter was sent to the research committees of the relevant organisations and departments, to obtain permission to conduct an interview with the informant who is their employee (Appendix 11). The permissions letter outlined the factors indicated in the information sheet, and provided the contact details for the researcher, research supervisor, and HREC.

The potential participants were contacted ahead of the SSIs and provided with the information sheet, which outlined the purpose of the study, its harms and benefits, the participants' role and why they were invited to engage in the study, information about confidentiality, how the interviews were to be recorded, stored, and protected, and how the information obtained was going to be used. When the individuals agreed to participate in the study, a date, time, and a place was set for the SSIs.

2.9.2 Potential Risks

This study did not have foreseeable potential for physical harm and emotional risk to the service providers who were interviewed. However, if any of the questions posed or discussions engaged in did cause uneasiness, the researcher addressed these concerns with empathy and without judgement. The participants were informed of their right to withdraw from the study should they feel the need to do so. To negate the risk of informants being targeted because of their opinions regarding the LGBTQIA+ and IDD communities, the informants and their organisations where they are employed were not named during the data analysis phase or in the final dissertation. Instead, pseudonyms were assigned to the key informants and employment organisations, and no information (such as exact location, demographic, appearance, etc.) that could reveal the identity of the individuals, or their organisations has been used.

2.10. Triangulation of Scoping Review and Interviews Findings

Deep immersion in the data provided the researcher with a good understanding of the concordance of themes within the ScR and interview themes. This was enhanced by the researcher notes which were made throughout the study, which included researcher notes on themes the researcher noted across the two data sets. The summary table for the ScR (Table 6) provided an overview of the themes from the ScR as interview data was being analysed, assisting the researcher to compose memo on concordant information between the two data sets in NVivo®, version 12. There were no discordant themes found between the ScR themes and those of the interviews. These researcher notes, table 6 and the interview memos therefore informed the researcher's triangulation of the data.

Chapter Three: Results of the Scoping Review

3.1 Introduction

This chapter reports on the findings of the Scoping Review which aimed to synthesise existing literature and identify key themes on the perspectives of service providers regarding the availability of and access to services that affect the quality of life and well-being of LGBTQIA+ individuals with intellectual and developmental disability globally and in South Africa. This review highlights the characteristics of the studies included in the review, as well as the key themes identified from them.

3.2 Characteristics of Studies Included

The review included 14 studies, all of which were peer reviewed journal articles published between 2003 and 2022. All the studies used a qualitative research design. Thirteen studies were conducted in high-income countries, and one was done in South Africa (Kramers-Olen, 2016).

The findings from these studies (n=14) are summarised in Table 6. Besides the perceptions of service providers (n=14), some studies also included the perceptions of family members (n=5) and service users (n=6). The studies made use of various disability terminology, i.e. intellectual (n=11), cognitive (n=1), and learning (n=2) in referring to IDD. The key findings of the review are reported below.

Table 6

Summary of key findings from the studies included in the research

First Author & Date	Study Location	Title of Paper	Study Design	Phenomenon of Interest	Type of Participant
Abbott, D. (2007)	United Kingdom	Still off-limits? Staff views on supporting gay, lesbian and bisexual people with intellectual disabilities to develop sexual and intimate relationships?	Qualitative (Semi-structured interviews)	Explored views of service providers working with LGB people who have intellectual disabilities, regarding these clients' sexuality, sexual expression and relationships with people who have intellectual and developmental disability at residential facilities.	71 staff from 20 intellectual disability service organizations.
Abbott, D. (2015)	United Kingdom	Love in a Cold Climate: changes in the fortunes of LGBT men and women with learning disabilities?	Qualitative (Semi-structured interviews and photovoice)	Study aimed to see how people with learning disabilities who identified as LGBT had been supported by services and professionals; and to identify ideas and produce resources, for training and policy development.	71 staff in 20 learning disability services and 20 women and men with learning disabilities who were in or wanted to be in a same sex relationship.
De Wit, W. (2022)	The Netherlands	Sexuality, Education and Support for People with Intellectual Disabilities: A Systematic Review of the Attitudes of Support Staff and Relatives	Qualitative (Systematic Review)	Overview of research focused on the attitudes of support staff and relatives concerning the sexuality of both LGBTQIA+ and cisgender people with intellectual disabilities,	31 studies.

				considering both supportive and restrictive attitudes.	
Dudek, S. (2006)	United States of America and Germany	Institutionalized Queers: Homosexuality in Residential Facilities for People with Cognitive Disabilities	Qualitative (Semi-focused interviews and focus groups)	This study aimed to, 1) analyse qualitative data from a pilot study that observed staff and residents with intellectual and developmental disabilities in 2 cooperating residential facilities where people with mild, moderate and severe intellectual disability live; and 2) to develop a programme for service providers based on the results of the research.	10 experts and 25 care workers and program managers.
Kramers-Olen, A. (2016)	South Africa	Sexuality, intellectual disability, and human rights legislation	Qualitative (Systematic Review)	Review of existing literature on sexuality and the factors that act as barriers to sexual expression for individuals with intellectual disabilities.	Included studies focused on people with intellectual disabilities, family members, and residential support workers.
Lofgren-Martenson, L. (2009)	Sweden	The Invisibility of Young Homosexual Women and Men with Intellectual Disabilities	Qualitative (Interviews)	Aimed to identify the experiences and attitudes of service providers and parents regarding the gay, lesbian, and bisexual identities of people with intellectual disabilities.	13 youths and young adults (16–27-year-old people with intellectual and developmental disability), 13 staff members (working within recreational environments,

					group homes, student homes and short-term homes) and 11 parents.
Marks, G. (2020)	Australia	Where's the human dignity in that?': LGBTQIA+ people with intellectual disability exploring sexual lives and respectful relationships	Qualitative (Interviews and focus group)	Aimed to report on a revision of the Sexual Lives & Respectful Relationships (SL&RR) program by Frawley & O'Shea (2017) which was originally developed for cisgender people with intellectual disability, and specifically adapted to support sexually and gender diverse (SGD) people with intellectual disabilities.	9 LGBTQIA+ people with intellectual disability taking a pilot LGBTQIA+ program. 3 program presenters (Peer Educator with intellectual disability who identified as LGBTQIA+; Program Partner with experience in sexual assault and domestic violence; and National SL&RR coordinator.)
Newman, W. (2018)	United States of America	A Transgender Woman with Intellectual Disability and Borderline Personality Disorder	Qualitative (Case study)	Psychiatrists' clinical reflections on the receptivity of service providers and systems available to assist a 23-year-old transgender woman who has intellectual disability,	Service providers at care facilities.

				foetal alcohol syndrome, and borderline personality disorder.	
Smith, E. (2022)	Australia	Social inclusion of LGBTQ and gender diverse adults with intellectual disability in disability services: A systematic review of the literature Published for the British Institute of Learning Disabilities	Qualitative (Systematic Review)	Aimed to explore experiences of social inclusion and exclusion for people with intellectual disability who identify as LGBTQ in disability services and how social inclusion for this population is promoted in these services.	9 articles: LGB people with intellectual disability (n = 57) Transgender people with intellectual disability (n = 2) Parents (n = 2) and residential support workers (n = 2) Cisgender people with intellectual disability (n = 22).
Sommaro, S. (2020)	Sweden	A deviation too many? Healthcare professionals' knowledge and attitudes concerning patients with intellectual disability disrupting norms regarding sexual orientation and/or gender identity	Qualitative (Focus groups)	Aim was 1) to establish knowledge levels of healthcare professionals in habilitation centres regarding LGBTQ identities of residents with intellectual and developmental disability, 2) to explore the perceptions concerning the sexuality and gender identities of people with intellectual disabilities, and 3) the way service providers create	19 healthcare professionals working with children (n=12) and adults (n=7).

				LGBTQ-affirmative practices at habilitation centres.	
Stoffelen, J.M.T. (2017)	The Netherlands	Sexuality and individual support plans for people with intellectual disabilities	Qualitative (Content analysis)	Content analysis of Individual Support Planning (ISP) documents with aim to identify 1) extent to which sexual health and sexual rights are mentioned, 2) what subjects or issues are covered in the instance that these issues are mentioned, and 3) how support related to sexual health is provided to people with intellectual disabilities.	187 ISP documents of people with intellectual disability from 7 service providers.
Wilkinson, V.J. (2015)	United Kingdom	"As Normal as Possible": Sexual Identity Development in People with Intellectual Disabilities Transitioning to Adulthood	Qualitative (Semi-structured interviews)	Attitudes of adolescents with intellectual disability as well as their carers (parents and residential support workers) were explored to provide a triangulated and enriched perspective as well as highlight the role of the patient-carer relationship and how it affects the development of sexual identity.	4 people with intellectual disability who had verbal competence and their carers (2 parents and 2 residential support workers)
Winges-Yanez, N. (2013)	United States of America	Why All the Talk About Sex? An Autoethnography Identifying the Troubling Discourse of Sexuality and Intellectual Disability	Qualitative (Autoethnography)	Author set out to highlight the limitations that people with intellectual disability experience with focus on diverse SOGIESC client.	Researcher who is a service provider with experience in intellectual disability field and

					a relative with intellectual disability.
Yool, L. (2003)	United Kingdom	The Attitudes of Medium-Secure Unit Staff Toward the Sexuality of Adults with Learning Disabilities	Qualitative (Semi-structured interviews)	To explore the attitudes of service providers regarding the sexuality of people with learning disabilities.	4 service providers (i.e., consultant psychiatrist (male), senior care-worker (female), advocacy worker (female), and a domestic staff member (male))

3.3 Inclusiveness of, and Access to, Available Services

3.3.1 Inclusiveness of Available Services

The literature review highlighted LGBTQIA+-inclusive treatment, gender affirming treatment, and LGBTQIA+-friendly sexuality education programmes as the services needed to ensure a positive QoL for LGBTQIA+ people with IDD.

3.3.1.1 LGBTQIA+ Inclusion and Intersectionality. Newman et al. (2018) reported that there are no known resources that address the intersection between an individual's gender, intellectual, and mental health needs at once, as services are usually aimed at assisting with one of these issues at a time. In Sommarö et al.'s (2020, p. 1202) study, service providers referred to service users with IDD, and an LGBTQIA+ identity as an "invisible group", explaining that these identities may individually and jointly act as barriers to providing and accessing certain services. Where there is belief that people with IDD can have an LGBTQIA+ sexual orientation, there may still be the view that their IDD affects their capacity to understand themselves. This affects the freedom to explore diverse SOGIESC (Löfgren-Mårtenson, 2009; De Wit et al., 2022; Wilkinson et al., 2015) and makes it challenging for service providers to support them (Abbott & Howarth, 2007; Yool et al., 2003). Additionally, an individual's family background may also act as a barrier, if parents deny access to LGBTQIA+ friendly services (Winges-Yanez, 2013).

This lack of appropriate support for individuals with IDD in same-sex relationships (Dudek et al., 2006), and the absence of opportunities to promote exploration can lead to limitations in service users showing and developing an LGBTQIA+ identity (Löfgren-Mårtenson, 2009). Service providers can support the emotional well-being of LGBTQIA+ service users by fostering interpersonal relations (Abbott & Howarth, 2007). For example, Marks et al. (2020) indicate how the adaptation and implementation of the Sexual Lives & Respectful Relationships (SL&RR) programme for LGBTQIA+ people with IDD resulted in

the participating service users being satisfied. Newman et al. (2018) also mention one case when police brought a transgender individual with intellectual disability to an inclusive residential home for care after a suicide attempt, and the person was subsequently cared for and supported to access in-patient hospitalisation.

Inclusive Language. Support and treatment should use appropriate language in addressing LGBTQIA+ service users, with service providers indicating openness to diverse sexualities by, for example, using gender-neutral speech, and allowing the introduction of gender-neutral signs for bathrooms (Dudek et al., 2006; Sommarö et al., 2020). The use of correct pronouns can positively affect service users' emotional well-being, as having an LGBTQIA+-friendly service environment provides service users with a sense of safety (Abbott & Howarth, 2007; Marks et al., 2020), fosters a positive self-concept, and can be lifesaving.

Gender Segregation. Dudek et al. (2006, p.7) refer to a phenomenon they call "compulsory homosexuality". This is the notion that service users in unisex residential facilities engage in same-sex physical intimacy because of a need for sexual contact in environments that only have one gender to choose from, and as an expression of friendship (Löfgren-Mårtenson, 2009) rather than because of sexual identity (Abbott & Howarth, 2007; Dudek et al., 2006; De Wit et al., 2022; Winges-Yanez, 2013). This leads to service providers questioning if relationships are exploitative or abusive (Abbot & Howarth, 2007; Löfgren-Mårtenson, 2009), and heightens rejection of same-sex relationships that may be authentic.

Services for Transgender Service Users. Although services may be available, they are still limited in scope, as misidentification of transgender individuals is rarely addressed, and service providers use incorrect pronouns due to uncertainty and hostility (Newman et al., 2018). Similarly, transgender service users do not get support in residential facilities because of gender segregation, a lack of services that provide hormone and surgical treatment to help with transition, and only a few opportunities for peer support or few dedicated resources

(Newman et al., 2018). Failure to provide inclusive and accessible services can jeopardise service users' emotional and physical well-being (Abbott, 2015).

Ultimately, service users should be informed of and given the opportunity to choose their sexual identity and should be allowed to express themselves sexually in relationships if they want to (Abbott & Howarth, 2007; De Wit et al., 2022; Yool et al., 2003), as this informs self-determination. Healthcare professionals also contend that, in order to support a transgender service user's mental health, proper and correct gender treatment is needed (Newman et al., 2018). This means that healthcare institutions need to provide services that cater to the intersectional identities of service users. Additionally, instead of not receiving support or being supported differently, service users should also be assisted with the same respect and dignity afforded neurotypical heterosexual service users (Dudek et al., 2006; Abbott & Howarth, 2007; De Wit et al., 2022).

3.3.1.2 Sexuality and Relationships Education. Several studies have noted that service providers consider that sex education that also focuses on different sexual orientations is important for people who have IDD in various environments (De Wit et al., 2022; Löfgren-Mårtenson, 2009; Marks et al., 2020; Dudek et al., 2006). This is in order to challenge heterosexist attitudes (Kramers-Olen, 2016) and improve understanding that LGBTQ identities are possible in people with IDD (Smith et al., 2022). Similarly, education that focuses on LGBTQ issues is also important to enable healthcare professionals to improve LGBTQIA+-related services in healthcare institutions (Sommarö et al., 2020).

A few studies have indicated that service providers are proactive in educational discussions about relationships, sexuality and sexual orientation (Abbott & Howarth, 2007; Sommarö et al., 2020; Abbott, 2015), regardless of institutions being exclusionary by failing to include diverse sexual orientations in their material (Abbott & Howarth, 2007; Löfgren-Mårtenson, 2009; Wilkinson et al., 2015). This can support availability of inclusive sexuality

education (Dudek et al., 2006), and foster positive emotional and physical well-being (Newman et al., 2018). In one study, female service providers were compared to male service providers, and were found to more likely be proactive in discussions about empowerment (Abbott, 2015) that highlights service providers' identity/sex as possible intersectional factors that contribute to the availability of services.

Noted hindrances to the availability of sexuality and relationships education for individuals with IDD and LGBTQIA+ identities are: a provider's belief that there are no sexuality issues for people with IDD; a belief that not addressing the issue will prevent unwanted pregnancies and sexual abuse; dependence on service users to raise the topic in the belief that initiation by service providers is inappropriate; service users' difficulties in raising the topic due to disability; and anxieties about family disapproval (Abbott & Howarth, 2007; Sommarö et al., 2020; De Wit et al., 2022, Kramers-Olen, 2016). As a result, service providers are often hesitant to proactively help (Abbott & Howarth, 2007; Abbott, 2015; Sommarö et al., 2020), which contributes to poor services, social exclusion and negative emotional well-being.

These intersectional hindrances also contribute to spending cuts, which have resulted in the cessation of existing support groups for service users in the United Kingdom (Abbott, 2015). Abbott and Howarth (2007) note that relying on service users to initiate discussions is a challenge, as they are not always aware that they can seek this type of support. They (Abbott & Howarth, 2007) further noted that there is no right balance in how the provision of sexuality education should be approached, since addressing LGBTQIA+ issues without having introduced basic sexuality concepts is problematic, while only focusing on other sexuality concepts marginalises those who may have an LGBTQIA+ identity.

3.3.2 Service Provider-Focused Barriers to Accessing Services

3.3.2.1 Incompetent Service Providers. A key barrier to service access is service provider incompetence and the resultant fear about working with diverse SOGIESC due to lack of training, policies, confidence, experience, or willingness (Abbott & Howarth, 2007; Abbot, 2015; Sommarö et al., 2020; De Wit et al., 2022) and LGBTQIA+ cultural illiteracy (Smith et al., 2022; Abbott & Howarth, 2007; Sommarö et al., 2020). This may support an unconscious bias toward addressing service users from a heteronormative perspective and a lack of focus on service users' concerns about sexuality (Abbott & Howarth, 2007; Sommarö et al., 2020; Smith et al., 2022; De Wit et al., 2022). This means that even when service providers accept sexuality education as being part of their role, the majority encourage individuals to develop a heterosexual identity (Abbott & Howarth, 2007; Smith et al., 2022), thus asserting heterosexuality as being more "normal" (Löfgren-Mårtenson, 2009, p. 24). Service providers also feel ill-equipped to assist with sexuality and sexual expression issues (Smith et al., 2022), as seen in educators' lack of knowledge regarding what the teaching curriculum should cover (Löfgren-Mårtenson, 2009). In addition, they contend that they have little time to assist clients with gender or sexuality-related issues (Smith et al., 2022), which makes it easy to ignore service users' diverse SOGIESC (Newman et al., 2018).

The findings also indicated limited guidance from a manager or organisation about acceptable and appropriate activities to discuss in relation to sex and sexuality (Smith et al., 2022). This leads to low confidence in addressing sexuality-related issues, as illustrated in service providers experiencing challenges responding to same-sex behaviours such as men having sex with men (Abbott & Howarth, 2007; Smith et al., 2022).

Echoing the above, to make the available service providers competent in supporting service users and capable of making decisions related to sexuality issues, there needs to be training, policy development, and sex education that allows them to respond to discrimination, encourage sexuality development, and challenge heteronormative attitudes

towards sexuality (Abbott & Howarth, 2007; Dudek et al., 2006; Kramers-Olen, 2016; Newman et al., 2018). Abbott and Howarth (2007) and Smith et al. (2022) also suggest that service providers should accept their professional responsibility to assist with service users' sex and sexuality needs, as well as the self-determination to pursue diverse SOGIESC. Dudek et al. (2006) suggested that service providers who fail to do this be moved to a different section of the service organisation.

3.3.2.2 Biased Views. Another barrier to service access is service providers' generally biased views about service users being LGBTQIA+ (Abbot, 2015; De Wit et al., 2022; Dudek et al., 2006). This can be seen in their difficulty recognising the sexual feelings of individuals with IDD (De Wit et al., 2022) and the belief that service users are asexual (Abbott & Howarth, 2007). This is also seen in how they do not consider a bisexual or lesbian identity in women who have sex with women, and how equal treatment, regardless of sexual orientation, often means being treated as heterosexual or asexual (Abbott & Howarth, 2007; Löfgren-Mårtenson, 2009).

The review also showed reserved and stigmatising attitudes regarding sexuality, (Dudek et al., 2006; Smith et al., 2022; Abbott & Howarth, 2007). Same-sex relationships are viewed as taboo, an inferior form of sexuality, or a stage of exploration (Dudek et al., 2006; Löfgren-Mårtenson, 2009; De Wit et al., 2022). Such heteronormative attitudes also limit the service provider's capacity to understand that people with IDD may not always be heterosexual (Kramers-Olen, 2016; Abbott & Howarth, 2007) and leads to service providers reprimanding the exploration and expression of affection in same-sex couples (Löfgren-Mårtenson, 2009; Kramers-Olen, 2016).

Service providers may also think that service users are "confused" about their sexuality (Abbott & Howarth, 2007). Providers that are unsure about the sexuality of people with IDD may cite concerns about sexual abuse risks (De Wit et al., 2022; Smith et al., 2022; Abbott &

Howarth, 2007) and frame non-conforming sexual behaviour as sexual abuse (such as men having sex with men) (Löfgren-Mårtenson, 2009).

3.3.3 Systemic Barriers to Available Services: Policies and Training

Service providers mentioned the absence of policies and lack of awareness of relevant policies as a barrier to working with LGBTQIA+ people who have IDD (Abbott & Howarth, 2007; Abbot, 2015; Sommarö et al., 2020; Yool et al., 2003). Furthermore, when policy and Individual Support Planning (ISP) documents are available, they fail to include actionable guidance on work related to sex and sexuality; instead, they focus on negative and problematic aspects of sexuality (Abbott & Howarth, 2007; Stoffelen et al., 2017). Where they are available, implementing the documents becomes more challenging when service providers have incompatible moral beliefs that they are not able to set aside (Abbott & Howarth, 2007).

Some explanations offered for the lack of actionable guidance in documents include: that LGBTQIA+ identities are often omitted from literature, or the ideas presented are outdated (Abbott, 2015; Dudek et al., 2006; Kramers-Olen, 2016); service users' perspectives regarding their SOGIESC and relationships are excluded when developing ISP documents (Stoffelen et al., 2017) and during the decision-making processes (Yool et al., 2003). Additionally, unless service providers who take the quality of life and well-being of service users seriously are present, organisations do not prioritise research on their quality of life and well-being (Abbott, 2015). Service providers also maintain that updating policies to only include LGBTQIA+ identities may have a negative impact on other minority groups, who may remain marginalised (Sommarö et al., 2020).

Contrarily, Abbott and Howarth (2007) mentioned that inclusive policies are helpful, offer legitimacy, allow service providers to be assertive with parents, and promote same-sex relationships with consent and understanding (Abbott & Howarth, 2007). It would, therefore,

be useful to improve available services through the development of care that is more LGBTQIA+ sensitive, and particularly transgender-sensitive, by reviewing existing policies (Newman et al., 2018). Policies and legislation that support diverse SOGIESC are needed to facilitate the expression and exploration of diverse SOGIESC (Kramers-Olen, 2016; Smith et al., 2022), while guiding work on sex and sexuality, as it has been shown that service providers with policies on LGBTQIA+ issues are confident service providers (Abbott & Howarth, 2007; De Wit et al., 2022). Abbott and Howarth (2007) elaborate on this by saying that policymakers should recognise that service users' emotional and sexual needs are as important as their material and health needs. People with IDD who are LGBTQIA+ should be included in policy documents, as addressing LGBTQIA+ issues would be easy if work documents explain how LGBTQIA+ issues should be addressed (Smith et al., 2022; Sommarö et al., 2020). Service providers also suggest that service users be acquainted with policies, which alludes to the need to create accessible documents (Abbott & Howarth, 2007). Policies are also needed to guide the decision-making of service providers after receiving training on sexuality issues (Abbott & Howarth, 2007).

To further improve services, it will be useful to publish research on the LGBTQIA+ identities of service users, as Abbott (2015) indicates that researchers who publish their findings on the quality of life and well-being of LGB individuals with IDD may also be invited as experts to advise service users. It is also clear that research encourages self-advocacy organisations to create informative and accessible resources for and pertaining to the needs of service users (Abbott, 2015).

As a barrier to service availability, some service providers mentioned not being aware of the existence of LGBTQ training courses at their rehabilitation centres, with new employees reporting not having been introduced to any training of this kind (Sommarö et al., 2020). Two studies (Abbott & Howarth, 2007; Abbot, 2015) suggested that lack of prioritisation of

training could lead to service provider anxieties and lack of confidence when working with sex, sexuality and relationships. On the other hand, even when training is offered, some service providers expressed disinterest and non-willingness to engage (Abbott, 2015).

Service providers suggested that, in order to improve existing services, training should focus on diverse SOGIESC (Dudek et al., 2006; Abbott & Howarth, 2007; De Wit et al., 2022), extend beyond masturbation (Yool et al., 2003), and sensitise providers to transgender issues (Newman et al., 2018) by exploring personal attitudes that have been noted to be mostly negative (Dudek et al., 2006; Smith et al., 2022; Abbott & Howarth, 2007; Abbott, 2015). This is important, as those who attended LGBTQIA+ sensitive training programmes found them helpful, were positive about them (Abbott & Howarth, 2007; Marks et al., 2020), and sought to make services inclusive by reviewing waiting room literature and existing policies (Sommarö et al., 2020; Newman et al., 2018).

Another key reason for having LGBTQIA+ sensitive training for service providers is to raise awareness of two matters: individuals with IDD can have an LGBTQIA+ identity (Smith et al., 2022); where and how to obtain support and information when a service user reveals that they are in a same-sex relationship (Dudek et al., 2006) or are bullied because of their gay identity (Abbott, 2015). Smith et al. (2022) also mentioned the importance of training to enable providers to support service users' self-determination regarding their sexuality. Supervisors should also be trained to provide regular and supportive supervision to subordinates who provide sexuality education and support in service institutions (Dudek et al., 2006; Sommarö et al., 2020; De Wit et al., 2022). For example, Abbott and Howarth (2007) reported that service providers who have managerial support and experience working with LGBTQIA+ service users feel confident and have a positive attitude. Appropriate training resources are considered important in developing service providers' competency in this area of their work.

3.3.4 Promoters for Accessing Services

A service provider's belief that service users also have sexual rights and the same sexual feelings as everyone else (De Wit et al., 2022), and the assertion that they will be treated equally and without coercion, regardless of sexual orientation (Dudek et al., 2006), indicate a positive attitude and contributes to positive experiences when service users access services. Sommarö et al. (2020) similarly note that the nature of services afforded to service users should not be influenced by the service user's LGBTQIA+ identity, nor should service providers overtly express a negative attitude towards same-sex relationships (Löfgren-Mårtenson, 2009). For example: 41% of service providers in the Abbott and Howarth (2007) study indicated that they would support the development of same-sex relationships in people with IDD; while Dudek et al. (2006) mentioned that there should be no assumptions about an individual's sexual orientation.

After speaking to healthcare services, Newman et al. (2018) indicated that service providers actively assisted in changing the identification documents of a transgender individual to prevent misidentification, which indicates social inclusion and access to rights. This evidence alludes to service providers being liberal in their approach to service provision, regardless of an individual's non-conforming identity, and this also fosters an inclusive context and positive emotional well-being. These positive attitudes can be said to be due to level of experience, as service providers who are experienced in working with individuals with IDD from the LGBTQIA+ community feel confident and consider equality and diversity issues (Abbott & Howarth, 2007), which is evidence of social inclusion.

Some of the studies that were reviewed also indicated that having a service provider with a similar identity to that of the service user is beneficial and acts as a positive factor in ensuring the service user's emotional well-being (Dudek et al., 2006; Winges-Yanez, 2013; Smith et al., 2022). Consequently, service providers should be encouraged to recruit staff with experience working with IDD, and sexuality-related issues, to assist service users who

experience challenges regarding their SOGIESC (Abbott, 2015; Winges-Yanez, 2013). Sommarö et al. (2020) also mentioned the appointment of an LGBTQ representative, after a process of reviewing policies, to provide friendly services. On the other hand, although the Peer Educator in the Marks et al. (2020) study is bisexual, they mentioned that they did not connect with service users because of their sexual orientation; rather, they connected on a mental level and based on mutual understanding. This supports the notion offered by De Wit et al. (2022) that perhaps LGBT service providers are not necessarily best suited to support service users.

3.4 Conclusion

The aim of this scoping review was to explore the perceptions of service providers regarding the need for, availability of, and access to services for LGBTQIA+ people with IDD in a global, African, and South African context. Fourteen studies published between 2003 and 2022 were added to the review and synthesised using Schalock's (2010) QoL model of intellectual disability and Jones and McEwen's (2000) model of intersectional theory to identify relevant themes. As intersectional factors, service users' IDD and service provider attitudes towards IDD and LGBTQIA+ identities impact the services available and accessible to service users. There is an opportunity for sexuality education that incorporates LGBTQIA+ identities to be made available to service users, their providers, and families. However, policies and training programmes that can aid in the provision of LGBTQIA+-inclusive care for individuals with IDD with potential LGBTQIA+ identities remain unclear, absent, or not known about to service providers.

Chapter Four: Interview Findings

4.1 Introduction

This section details the results from the SSIs held by the researcher with the key informants who participated in the study. The section first shows the codes that were interlinked to produce the main themes and sub-themes. Following this, the main themes and sub-themes are illustrated through a graphic, and written up with quotes from the interviews to elucidate them. Member checking focus groups were conducted with a selection of the participants and the results of these focus groups were integrated into the findings where participants focus group input provided further insights to the analysis conducted by the researcher.

4.2 Characteristics of the Participants

The characteristics of 13 study participants are summarised in Table 7, with participants' names having been replaced with pseudonyms. Most participants are registered social workers (n=7), with the remainder being health practitioners (n=4) or in managerial posts (n=2).

Table 7

Characteristics and experience of participants

Pseudonym	Gender	Respondent's role at work	Experience in disability/IDD services	Experience with LGBTQIA+ clients with IDD
Amelia	Female	Social Worker at Disability NGO	4 years (IDD)	Gay, Transgender
Anne	Female	Social Worker at IDD residential facility	11 years (IDD)	Gay, diverse SOGIESC
Bandile	Male	Social Worker at Department of Social Development	1.5 years (disability/2 clients with IDD)	None
Carlyn	Female	Social Worker at Disability NGO	27 years (disability/IDD)	Transgender, diverse SOGIESC
Kamala	Female	Social Worker at Disability NGO	13 years (disability/IDD)	None
Kashiefa	Female	Social Worker at Disability NGO	1 year (disability/2 clients with IDD)	Gay
Landon	Male	National Programmes Manager at SOGIESC/LGBTQIA+ NGO	No disability/IDD	Diverse SOGIESC
Lydia	Female	Clinic and Outreach Nurse at SOGIESC/LGBTQIA+ NGO	8 years (2 clients with IDD)	Lesbian, Transgender
Lynette	Female	Social Worker at IDD residential facility	10 months (IDD)	Gay
Nicky	Female	Programme Director at LGBTQIA+ residential facility	4 years (disability/no IDD)	LGBTQIA+
Patricia	Female	Registered Nurse at IDD residential facility	5 years (IDD)	Diverse SOGIESC
Roberta	Female	Sexual Education Expert	25 years (IDD)	Sexuality (no LGBTQIA+/SOGIESC)
Rudi	Male	Health Officer at SOGIESC/LGBTQIA+ NGO	No disability/IDD	Diverse SOGIESC

Most participants have experience working in the disability sector, many of whom have had IDD service exposure spanning a wide range of time (10 months - 27 years). Some participants worked in settings where there are multiple conceptualisations of sexual orientation, sexual identity and gender expression, so that the term LGBTQIA+ was too narrow for their exposure in their organisations and the more inclusive term 'diverse SOGIESC' was used where a service users' sexual orientation was not explicitly identified as LGBTQIA+ by participants.

4.3 Themes

Analysis of the interviews yielded 32 codes, as captured in Appendix 14. Through an iterative process, the 32 codes were interlinked to produce three main themes, as indicated in Table 8.

Table 8

Interlinked codes, main themes and sub-themes

Interlinked Codes	Main Themes and Sub-Themes
Self-determination; Experiences of abuse; Family views and interventions; Diverse SOGIESC Presentation and Issues; Experience with diverse SOGIESC in people with intellectual and developmental disability; Understanding sexuality and LGBTQIA+ terms; Community and societal views; Service responses to diverse SOGIESC; Relationships and support; Contextual factors against SOGIESC; Service provider responses to diverse SOGIESC; Awareness & information on LGBTQIA+; Awareness & information on intellectual and developmental disability; Service provider background	Main theme: 'Double Whammy': Sexuality Rights of People With IDD Sub-theme 1: 'Forever Children' And Decision-Making Sub-theme 2: Responses to Diverse SOGIESC In Individuals With IDD
Available social services; Personal development; Physical and sexual well-being; Sexuality support; Post-education, psychoeducation, and protective workshops; Health and gender affirming care	Main theme: Availability of Services Sub-theme 1: "Vicious, Slow-Moving Cycle" of Sexuality Education Sub-theme 2: Sexual and Reproductive Health
Service users' experiences of challenges; Emotional well-being; NGO services; Accommodations in due process; Service provider challenges with available services; Governance at NGO and national level; Service provider competency; Education services; Service user skills and education levels; Justice or police services; Behaviours that challenge; Lack of, and recommendations for, adequate services; Health and gender affirming care, Access to social services	Main theme: Access to Services Sub-theme 1: Discriminatory Attitudes Sub-theme 2: Service Providers' Skills in Managing Mental Health Issues Sub-theme 3: Economic and Material Services Sub-theme 4: Barriers to Gender Affirming Healthcare Sub-theme 5: Justice Services

The three main interview themes focused on: the participants' perspectives regarding the sexuality rights of individuals with IDD and LGBTQIA+ identities; the services available to this group; factors that may influence access. The QoL domains and intersectional aspects that are influenced by each of these themes, as identified by the participants, have been interwoven into the relevant theme to provide a clearer and more concise illustration of how service availability, access to services, and intersectional factors influence the QoL and well-being of LGBTQIA+ people with IDD in the Cape Town region of the Western Cape.

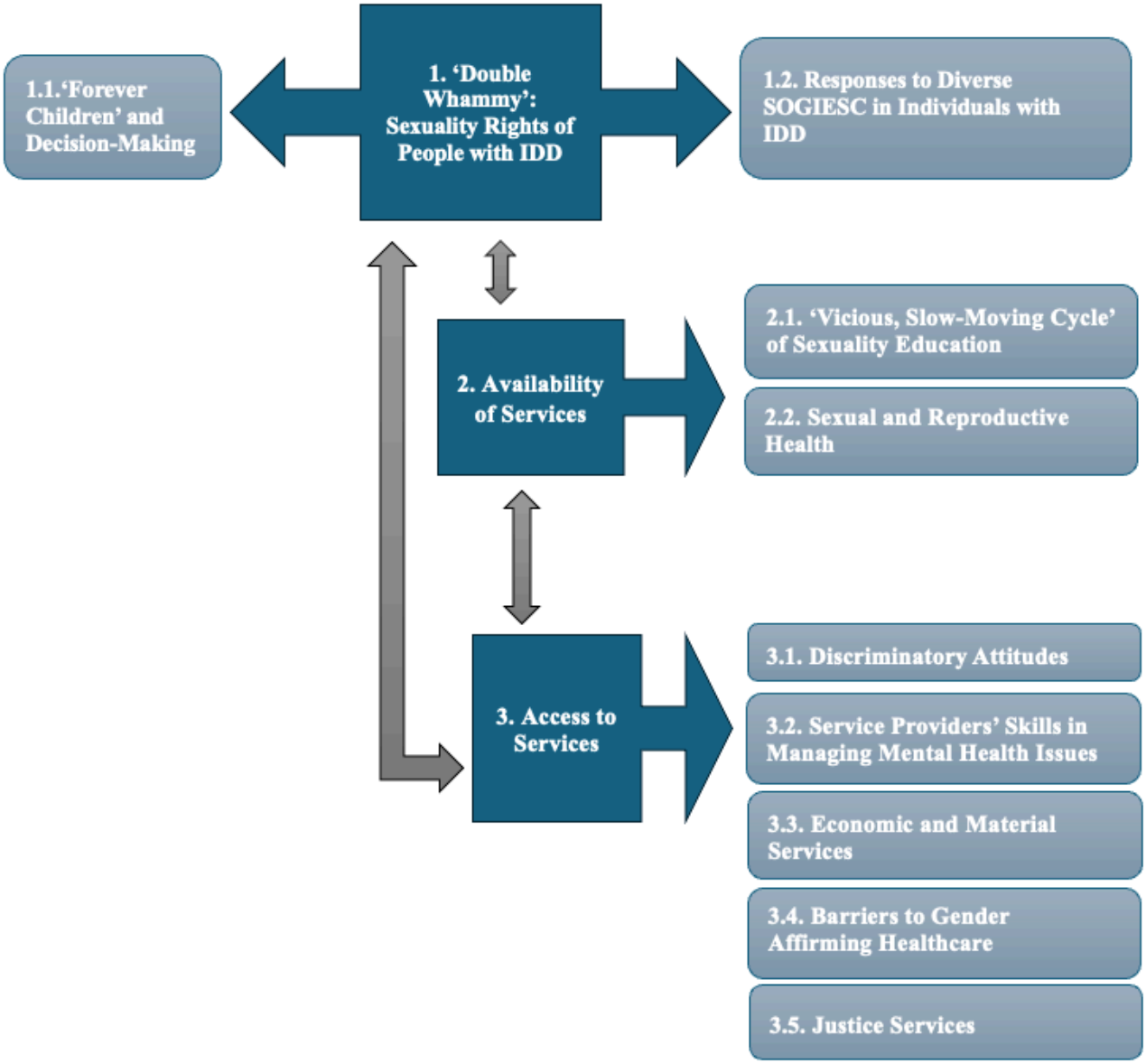
Participants in the **member checking focus groups** in general agreed with the main themes presented during the focus groups. They also supported how the data had been

understood under each theme in most instances, but also expressed views which provided additional, clarifying comments which further enhanced understanding of the themes.

To illustrate these view, findings of the SSIs analysis are presented, and where additional supporting, elaborating or refining views were coded from the focus groups during member checking, these are integrated into the write up of the themes. Figure 3 provides a brief summary of each theme, with the findings below.

Figure 3

Themes and sub-themes identified from SSIs and focus groups



In the figure, the sexuality rights of individuals with IDD are presented as theme one with the lack of adequate inclusion of, and attention to, the rights and needs of people with (intellectual) disability and SOGIESC identities reflected in inadequate availability (Theme Two) and accessibility (Theme Three) of services. The arrows between Theme One and Theme Two and Themes One and Three are bi-directional because lack of adequate services and lack of accessible services to meet the needs of people with IDD who are LGBTQIA+ individuals can negatively impact on upholding the rights of these individuals and the quality of life which may be experienced by these individuals. Additionally, the arrow between Theme Two and Theme Three is bi-directional because a failure to provide services can lead to limited access, just as a lack of access can result in the non-availability of services. Further, though noted as separate themes, each of these themes intersect and impact on the other.

4.3.1 'Double Whammy': Sexuality Rights of People with IDD

Several respondents noted a trend in the general community and in service institutions for people with IDD, to be regarded as being without sexuality rights, generally discriminated against, and specifically denied acknowledgement of their sexual orientation.

> *"Within the community with regards to them, it's very sad because they don't... I think there's a lack of knowledge, man, they don't understand that this is, let's say... to me, it's normal if someone identifies as gay, if someone identifies as lesbian it's normal, but to them it's not." (Amelia, SSI)*
>
> *"I've never come across where they would say 'Oh no, no, maybe or even that this is a relationship between the two, you know, 'same-sex'. It's never been that. It's always been, and this is my experience… that people are almost like they are villains, they become the villains because, you know they're doing something that they should not be doing. So already there's this whole thing about people with intellectual disability*

having sex. It's still- within our communities, it's a no… And then to even go further and do it in terms of same-sex." (Carlyn, SSI)

Review of this theme during the member-checking focus groups confirmed participants views, with participants emphasising that intersectional discrimination contributes to poor emotional well-being.

"Looking at people with disabilities - it's a double whammy that, you know, aside from the disability thing, if they do present with any kind of sexuality, they're seen as demons. Simply, within our field, this is how it's seen at the moment." (Carlyn, focus group 1)

Most participants agreed that when presenting with an LGBTQIA+ identity as a person with IDD, the marginalisation is deepened at the intersection of the individuals' sexual orientation and disability.

"Sometimes they would have this perception that 'The person already has a challenge, how can the person decide for him or herself what they want to identify with?'" (Lynette, SSI)

In the focus groups, some respondents confirmed the problem of marginalisation as they spoke of their personal experiences as members of the LGBTQIA+ community, and reflected on the possibility of experiencing more marginalisation if they also had IDD.

"As a well person without any disabilities, it was hard enough for me to come to terms with who I was and the life that I was going to lead. I can't even imagine what that must be like. If you have an intellectual disability." (Lydia, focus group 1)

4.3.1.1. 'Forever Children' and Decision-Making. The sexuality rights of individuals with IDD are further undermined when parents and other supporters infantilise adults with IDD, which limits their self-determination. A few participants showed frustration towards this infantilisation, which was attributed to socio-cultural and religious factors.

> *"Families see the residents as their kids, as their forever children, even though they are actually adults and they are allowed to make their own choices. The family sees them as my child, and my child will not do this or that … almost all the families being stuck in … the child is six years old and I have to be their voice - where the child is actually not six years old anymore, where they do have their own voice." (Anne, SSI)*

Agreeing with this, a few focus group participants noted that as a result of the infantilisation, the decision-making processes of their adult clients with IDD are usually informed by the client's family, since the client's participation in decisions about themselves is still seen as impractical. This further indicates that the family is an intersectional limitation to self-determination.

> *"People with intellectual disabilities don't get to make a lot of decisions about their own lives. Sometimes it depends on the level of disability. So, within the higher functioning people, they would be able to make their own choices and all of that; but there is still going to be a lot of supervision, a lot of monitoring, a lot of parent interference. Not involvement - interference." (Carlyn, focus group 1)*

Some interview respondents spoke of the limited choice-making, for clients with IDD, where choices were tailored by well-meaning service providers and parents, so that whatever choice was available to them was dependent on the approval of the service provider and family.

> *"We provide options, and they can choose. We don't just leave it open, because sometimes what we'll see then is they'll just choose the easiest or the one with less resistance, instead of helping them to develop a little bit by trying something new." (Anne, SSI)*

4.3.1.2. Responses to Diverse SOGIESC in Individuals with IDD. According to a few respondents, families who fail to accept the potential LGBTQIA+ identity of a relative with IDD are influenced by religion.

"The first one that is transitioning, his mother is very much involved with the church and to this day it's still very hard to accept (his transgender identity)." (Amelia, SSI)

"Our families, specifically at this centre, is very, very Christian. Religious. So, to them it's not okay." (Anne, SSI)

Many of the respondents who participated in the focus groups corroborated this and further illustrated cases where individuals with IDD hide their LGBTQIA+ sexual orientation because of a fear of rejection from their families.

"Interviewer (in focus group): Lydia in the chat box mentions culture, religion and a whole lot of other factors as having an influence on, I suppose the coming out or experience of being LGBTQI+ in people with intellectual and developmental disability and the acceptance or support from their families?

Kashiefa: It's not allowed in the religion, so that and the person knows that there's certain values that they need to adhere to. So that's why they all stay in the closet. Because they fear rejection or whatever. So, like they will remain in the closet because there is always when you come from a very religious background these values play a big role… They can sometimes disown people also sometimes. So that's why the person prefer to remain in the closet." (Kashiefa, focus group 1)

In several instances, parental and family rejection was reported to result in experiences of physical and emotional abuse for the LGBTQIA+ community, people with IDD, and individuals who held both identities mutually. The main reasons for this mistreatment were the rejection of an LGBTQIA+ identity, and the family's limited understanding or lack of awareness that clients with IDD have potential to choose a same-sex relationship.

"There is a case now, with the most recent carer that he lived with, this carer actually … how do I say, she threw him with boiling water. She actually locked him in the bedroom. She took the handle off the door, so he has to use his finger to open the

door. And then he came out and she will tell him - she used to tell him things like, 'Get on your knees and beg for food'." (Amelia, SSI)

4.3.2 Availability of Services

4.3.2.1. 'Vicious, Slow-Moving Cycle' of Sexuality Education. About half the respondents mentioned that sexuality education programmes at skills-focused or special education schools are largely limited to understanding external sexual organs, consent, and autonomy, with no focus on diverse SOGIESC.

"We teach different body parts, for males and for females - just anatomy, not what it's used for, or who can use it with who. Only when specific residents then ask do we then educate further." (Anne, SSI)

Knowledge of different sexual orientations would help service users develop a better understanding of their gender and sexuality, as explained by the few respondents who found LGBTQIA+-friendly sexuality education to be an essential service that has the potential to help ensure the safety of people with IDD.

"I then have to render psychoeducation with regards to what is the term, the various identities, so that he can understand." (Amelia, SSI)

Corroborating this, a participant in the second focus group emphasised the need for all people with IDD to receive sexuality education that is not only focused on anatomy, rights, and consent, but also on the often-excluded LGBTQIA+ identities.

"All people with intellectual disability and including that group, they need education, so they need education about their bodies, they need education, about their rights and consent. And that's the same no matter what group you belong to. But we need to include information about LGBTQ and that, and that's often invisible." (Roberta, focus group 2)

However, a few service providers felt that parents remain opposed to these ideas, which affects the nature of the services provided as well as service users' self-concept and autonomy.

> *"So, it's a super, super frustrating and slow process at this point in time, because every time we're trying to introduce something that is maybe just a little bit away from Adam and Eve. The parents, it's again a big thing, and we have to remind them that they have the right to know this, that they are not children. So, it's like a vicious, slow-moving cycle." (Anne, SSI)*

Many participants in the focus groups also expressed this frustration at families, highlighting the challenging disapproval from families when they initiate the introduction of learning materials focused on educating service users with IDD about the important topic of sexual abuse and acceptable or unacceptable sexual behaviours.

> *"People with intellectual disabilities are very prone, are vulnerable in terms of sexual abuse so we would then want to say you know let's just educate our people with intellectual disabilities about their rights, you know 'What is sexual abuse? What is acceptable? What is not acceptable?' Then our parents say no. So, if you then can't even open up that discussion, how do you open up this sensitive discussion in terms of, you know, not only saying but actually the person has a right to do what they want to, to practise whatever they want to but that the family should also be supportive of them?" (Carlyn, focus group 1)*

In a few instances, resources to eliminate the stigma and educate the community and service providers on LGBTQIA+ identities have already been made available by NGOs.

> *"You'll also see on our website, there's a [name of LGBTQIA+-friendly resource]. I always use that when I teach Med students … It's in Afrikaans, English and isiXhosa, and it is in collaboration with stakeholders. So that was another way we facilitated*

organisations together to make a change. I hope you get the over-arching idea of how we're trying to implement people-level experiences into system-level change." (Rudi, SSI)

These NGOs emphasised the importance of partnering with organisations that offer different services to them as an opportunity to improve and make their services accessible by adopting an intersectional approach, in this instance, a need to partner with organisations with IDD experience.

"We would need to have a conversation with the Department of Social Development just because of 'what is the criteria, what is the requirements to have disabled persons in the Safe House?' Right. So, we can have those things in place. And then once that is approved, then we can approach organisations that work with disabled persons … Instead of them coming to us and staying at the shelter, we can go to them and render the service. I think practically that would work and it's also just less cost." (Nicky, SSI)

A few respondents expressed their perception that some sexuality-related concepts may be too abstract for people who have IDD and noted a need to structure sexuality education programmes at a pace and level of complexity that takes into account the individual's capability, and reduces the likelihood of these programmes being a barrier to effective sexuality education.

"They are so concrete that if you don't start with the simple basics, like anatomy, just two, and then go from there, it'll probably go over their heads. And then they won't understand. And then they will be more confused, instead of starting with their base." (Anne, SSI)

Only providing people with IDD with sexuality education that is inclusive of LGBTQIA+ identities was thought to be problematic. Several providers suggested that families and

communities also be sensitised to these identities, in order to promote social inclusion, especially in non-urban areas, where the high likelihood of low socio-economic status can potentially contribute to limited education.

> *"This is my role and this is what I need to do in support and be there for them and render psychoeducation for their families and awareness…" (Amelia, SSI)*
>
> *"They're not educated, they need to talk. I mean, for, for communities and the societies to talk about it. But it's a lot of work needs to be done in terms of that." (Carlyn, SSI)*

4.3.2.2. Sexual and Reproductive Health. A few providers raised a concern about the lack of involvement of people with IDD in reproductive health decisions that affect them, in violation of their right to be included in reproductive decisions. They noted that some individuals present for care with their reproductive organs having been removed, or using contraceptives without understanding the purpose of these.

> *"When they come here, they're already on the stuff; we just continue all of them. So, at home, whoever looked after them took them to the doctor or clinic, and we just continue. Some of uterus are out, so we stop the family planning; but other than that most of them are on family planning." (Patricia, SSI)*

Corroborating this in the focus group, Carlyn also mentioned that the families of individuals with IDD often make the decision to get the individual on contraceptive medication as a family planning measure that is administered without any sort of education beforehand.

> *"Very often it's the family who makes that decision. It's not the choice of the person with the disability… And like I said earlier that if you, if there's any symptom that you are presenting with any kind of sexuality or sexual behaviour in a very difficult not understanding family, you will be taken to the hospital to be medicated… this is a way*

of ensuring that the person doesn't fall pregnant, nothing else happens. There's no education, there's nothing except every quarter or something the person goes for the injection." (Carlyn, focus group 1)

The view below also reflects partial understanding of the law that, again, can impact on provider responses to reproductive health interventions in place for their clients, possibly resulting in uncritical continuation of services without consideration of other alternatives.

"*It is recommended, but it's not forced. It is recommended just for girls … Yeah, by law … Anyway, that person has to give consent, so you can't force it … Sterilization Act stipulates that person must give informed consent. So, yeah, we can't go against the law." (Anne, SSI)*

Another respondent felt that legislation does not always protect people with IDD from reproductive rights violations, although there are supportive mechanisms in place to protect other vulnerable citizens as well as keep them informed within the bounds of their capabilities.

"The National Health Act is very clear on the right to informed consent - even if you can't read, you have the right to things being explained to you. And also, a child also has the right to consent. The Children's Act also says that things need, you know, information needs to be provided in an accessible way to children and all children have the right to know about their bodies … I don't know whether they would have been asked, so it would have been assumed in your best interest. So, this is what you must do." (Roberta, SSI)

4.3.3 Access to Services

4.3.3.1. Discriminatory Attitudes. In terms of QoL, about half the respondents agreed that individuals with IDD, as well as those who are LGBTQIA+, experience poor emotional

well-being because of stigma from society and other service providers who may lack sensitivity to these identities.

> *"I haven't experienced discrimination with regards to my gender and what I identify as, but I've seen it with my clients, especially when going to- let's say [City Hospital], or when going to the hospital in [residential area] because the healthcare professionals don't really understand, especially the nurses." (Amelia, SSI)*

To echoe this viewpoint, in the focus group, Lydia spoke of the prevailing challenges they experience at her organisation as they conduct psychoeducation programmes to desensitise and make the general community aware of LGBTQIA+ and SOGIESC identities.

> *"I absolutely agree with the prejudice and the bias, and you know, it's very hard to change people's minds of how they think and what they believe. I mean, we know that because it's our day-to-day work. So, you know, we can give training as much as we can, we can do awareness. You know, we speak from a personal space so that we at least try to get people to interact with us. But you know, there are some people that you will never, ever, ever change their opinions. So yeah, that's very difficult." (Lydia, focus group 1)*

This discrimination was also evidenced in service institutions where the overt dimensions of an individual's identity took precedence over the more covert. Additionally, when covert identity dimensions became public knowledge, they were discriminated against, which led to hesitance in accessing services. This is illustrated in the quote by Carlyn where a transgender individual with IDD's request to receive gender affirming healthcare was dismissed and viewed as a symptom of the IDD.

> *"It just became this kind of thing that it was said that he was using this to take attention away from his behaviour or whatever... So, it was never going to be given an opportunity. He was not there when - nobody was interested in looking at: 'Is there a*

possibility? Would this help him a little bit?' It was just said 'No, we're not gonna look at it.' and almost like you know it, it's a non-issue. That is how it was dealt with." (Carlyn, SSI)

In the focus group, Lydia expressed agreement to this one-sided view of identities as she leaned in on her own experience as a former emergency healthcare practitioner.

"I've seen it with intellectual disabilities and that I've nursed, so I've also been a paramedic. So, I've seen this in my life and absolutely I agree with Carlyn... Always the disability is seen first, the person within that is very seldom even spoken to." (Lydia, focus group 1)

Discriminative attitudes also extend to service provision for mental health and well-being services. The mental health and well-being of people with IDD, and those from the LGBTQIA+ community is prioritised even less, and significantly so if the person is someone who has both identities. This is due to currently under-resourced health and social well-being service providers.

"I'm the only medical person, the others are carers, so I need to give them in-service training all the time, but I don't go deep, deep, deep because they only carers. They need to know what they need to know here about these patients." (Patricia, SSI)

Several providers also highlighted family support and other supporters paying attention to the individual to be potential mediating factors when service users experience negative emotional well-being.

"They get in a slump. And that's why I say support is very much important, especially from their family alone." (Amelia, SSI)

"I think when people listen to him. You know, so it's not just the 'No, you can't do this'." (Carlyn, SSI)

4.3.3.2. Service Providers' Skills in Managing Mental Health Issues. Respondents noted that the limited knowledge and skills of service providers can also impact their ability to manage distress expressed as behaviours that challenge in individuals with IDD. Self-harm may indicate a need that the person is struggling to communicate or be a response to service provider behaviour that has escalated, rather than contained distress experienced by the client.

> *"For attention, if you punish them or they did something wrong and you punished them, then some of them (not all) will go and cut here. They will put needles somewhere. One choked herself - she almost died in front of me - with a scarf. I had to cut her loose and she was blue already. Ten stitches in the head. She cut because her family didn't wish her on her birthday." (Patricia, SSI)*

Limited clinical knowledge, along with poor understanding and poor management of clients with an IDD's style of communication when distressed, including stress related to their own struggle with understanding SOGIESC-related issues, can be compounded by other factors such as language and cultural differences, as well as other mental health related factors that intersect with these two dimensions of the individual's identity.

> *"There's so much writing about how different cultures express anxiety, and some people say, 'My chest feels tight', or 'Wow, my feet are heavy', you know. And everyone in your village will know what you're talking about. But when you go to the doctor, the doctors will be like, 'Oh my God, what's going on?' So, that is definitely something I even see in clinics." (Rudi, SSI)*

4.3.3.3. Economic and Material Services. Where individuals with IDD were staying in residential homes, there appeared to be varying degrees of accommodation for a potential LGBTQIA+ identity, from some institutions going as far as evicting those with potentially diverse SOGIESC, to some offering the same services regardless of SOGIESC.

"The one that's so, like the male - you can sort of see when you see her, she wants to be a male. She's the one that is a dangerous one here, that wanted to use everybody here with her roll-on. So, we sent her away." (Patricia, SSI)

"All our residents, regardless of how you label yourself, use the same services." (Anne, SSI)

A few participants in the focus groups also echoed the challenges experienced by individuals with IDD who may face expulsion from a residential facility when they share their LGBTQIA+ or SOGIESC identity openly.

"You mustn't disclose [LGBTQIA+ identity] because I know of one residential facility it's not disclosed. But there are things happening, but they can't like, put the person out, but it's not actually encouraged." (Kashiefa, focus group 1)

Given that there are limited and lower levels of employment available to both LGBTQIA+ people from marginalised communities and people with IDD, it is no surprise that the income levels reported by a few respondents were low for individuals who had both identities individually and mutually.

"He's got this job since the end of May … And it's quite sad, actually, because they pay him so little. They pay him so little - I think it's like R500 in a week. And he's working in a butchery, and it's for cleaning." (Amelia, SSI)

"We used to link people with intellectual disability with special schools, maybe they do Arts craft, do you understand? They end up being, becoming carpenters and all those things." (Bandile, SSI)

Many of the focus group participants also emphasised this aspect of the economic lives of individuals with IDD.

"I know some people work in Spar packing shelves and bakeries, coffee shops. I think there's lots of potential there. It's like it's more about opportunities and people being

given a chance. And I think it probably depends also a lot from what your social economic status of your family is, which reflects what opportunities that perhaps you get." (Roberta, focus group 2)

4.3.3.4 Barriers to Gender Affirming Healthcare. Another issue highlighted by two service providers is the delay in transgender individuals being allowed to access gender affirming healthcare. Healthcare professionals and those involved in the process of evaluating suitability and readiness for this service sometimes struggle to make a decision when the individual seeking care also has IDD. This situation is worsened by administrative processes that are not designed to be friendly to service users with IDD, as well as the common act of pathologising diverse SOGIESC in both neurotypical and neurodiverse individuals, which undoubtedly contributes to poor emotional well-being while evidencing limited social inclusion.

"It was really difficult because you didn't know whether this person actually really wanted to… because on the one hand, you had staff members saying 'But he's very serious about it. This is what he wants to do. Please allow him to do it', and on the other hand, you had the fraternity, the medical fraternity, saying 'No, shouldn't even look at it. It's not an issue to be discussed anymore' so, it became a bit difficult in terms of that management." (Carlyn, SSI)

4.3.3.5. Justice Services. A few service providers mentioned that individuals with IDD often struggle to access judicial services - including for gender-based violence - as officials require levels of information that they may struggle to provide. This is coupled with a lack of the financial resources needed to obtain legal aid that can help ensure fairness, as well as a lack of expertise in accommodating the individual's need for support.

"Our justice system fails our people massively, because unless you spend sixty thousand rand to get somebody by the court stated as mentally incapacitated, they go

through the system as adults. And if you get a judge who's not sympathetic and understanding, it's quite hard … It is difficult with the police reporting, because the police go into technicalities like day, time, place, how big was the room, how many times - and our residents and ID people can't always say that detail, and they often wait very long to report something." (Anne, SSI)

In the focus group, a few of the participants confirmed this and noted that judicial services can be regarded as discriminatory towards disability (IDD) in such instances.

"The issue is you are not a really reliable witness because you have an intellectual disability, you don't even know what day it is so that is you know that they're discriminated against in terms of their disability first if they interact with our stakeholders." (Carlyn, focus group 1)

However, it did become apparent that service users' experiences with justice services are not consistently negative. A few respondents mentioned instances in which individuals with IDD, and sometimes an LGBTQIA+ identity, experienced judicial and police services positively.

"But I've had another beautiful case where we also went to court and the judge realised, okay … but you can't trial this as a normal adult mental capacity. So, we took the resident in-camera and … we had a mediator, an interpreter. So, it depends on the judge." (Anne)

For this supportive approach to go beyond the individual behaviour of certain officials to a systemic approach, some providers mentioned collaboration aimed at educating and sensitising officials on LGBTQIA+ identities, as well as IDD, as being an important aspect in bettering public services and NGOs.

"And we've just recently partnered with the Department of Justice, because they've basically created a team - National Task Team that is solely focused on LGBT people.

And they want to be trained or given some sort of education around the LGBT community that - in order for them to better their work, and especially when it comes to LGBT legal representatives, what pronouns to use; what can you say not to offend this person?" (Nicky)

4.3.4 Conclusion

The aim of the interviews was to explore the perceptions of service providers regarding the need for, availability of, and access to services for individuals with LGBTQIA+ individuals with IDD in the Cape Town region of the Western Cape Province. Service providers expressed varying attitudes regarding the potential or proclaimed LGBTQIA+ identities of their clients with IDD. Some respondents felt that some service providers and families contribute to the infantilisation of people with IDD, and limit access to LGBTQIA+-friendly services. To improve available services, the respondents suggested that LGBTQIA+ NGOs partner with IDD organisations to educate service users, their families and providers, and the broader community on IDD and LGBTQIA+ identities.

Chapter Five: Implications of the Study

5.1 Introduction

The results show that service providers have varying views concerning the quality of life and well-being of people with IDD from the LGBTQIA+ community. Many are supportive of service users' possible LGBTQIA+ identities, while some are non-supportive, and mirror reported family perceptions. Similar to the results reported in previous research, many services are hindered by non-inclusive policies and training programmes, and biased views, which mean that providers are unable to offer services that cater to the intersectional identities of individuals.

The ScR results provided an overview of global existing literature on the study, while the interview findings provided a deeper account of service provider perspectives in the South African context. This led to the adaptation of Schalock's Quality of Life model of intellectual disability, as seen in table 9, where exemplary indicators, highlighted in bold text, have been added to some domains to indicate what might be useful to promote the QoL and well-being of LGBTQIA+ individuals with IDD.

Table 9

An adapted conceptual framework of the service needs and availability of services that affect the quality of life and well-being of people living with IDD from the LGBTQIA+ community

Factor	Domains	Exemplary indicators
Independence	Personal development	Education status, personal skills, adaptive behaviour (Activities of daily living/instrumental activities of daily living), ***sexuality education***
	Self-determination	Choices/decisions, autonomy, personal control, personal goals, ***interdependence***
	Interpersonal relations	Social networks, friendships, social activities, interactions, relationships
Social participation	Social inclusion	Community integration/participation, community roles, supports, ***inclusive policies and training programs, supportive attitudes and competent allies***
	Rights	Human (respect, dignity, equality) Legal (legal access, due process)
Well-being	Emotional well-being	Safety and security, positive experiences, contentment, self-concept, lack of stress
	Physical well-being	Health and nutrition status, recreation, leisure, ***sexual and reproductive health***
	Material well-being	Financial status, employment status, housing status, possessions

Note: Adapted from Schalock, 2010.

As the study was underpinned by intersectionality and the Quality of Life model of Intellectual Disability, the section below discusses the additional exemplary indicators indicated in Table 9 in relation to both theoretical frameworks, and with consideration of the South African context.

5.2. Independence

The independence factor of Schalock's (2010) Quality of Life model of Intellectual Disability is concerned with the individual's personal development and self-determination, which are indicated by the individuals' education status and autonomy, as well as other indicators.

5.2.1 Sexuality Education

The study results foregrounded the importance of the availability and accessibility of inclusive sexuality education for service users and service providers. Sexuality education, as evidenced in the literature review and interviews, is important to prevent abuse and inform individuals with IDD of their legal right to consent, as supported by the Sustainable Development Goals (SDGs) (UN, n.d.). Even so, families are often against sexuality education programmes and refuse to allow service users autonomy by employing monitoring tactics to safeguard the nature of the content delivered, which translates into learning about LGBTQIA+ identities being unavailable (e.g. McCann et al., 2016; Whittle & Butler, 2018).

Existing policies also do not support service providers when parents are uncomfortable with a service user's exposure to diverse SOGIESC; therefore, the reluctance by service providers to offer sexuality-focused discussions (Clare, 2021) is unsurprising. This articulates the challenges experienced by individuals with these intersecting identities where family background is a contextual factor in determining accessibility to LGBTQIA+-inclusive sexuality education. However, the interviews did provide evidence that existing sexuality

education programmes are accessible, as they considered IDD. Most respondents mentioned a need for service providers, users and their caregivers to be provided with sexuality education that is inclusive of LGBTQIA+ identities, in order to help them understand sexuality-related concerns better.

In the Western Cape, various organisations have produced accessible resources for individuals with IDD and their families and carers (e.g. Western Cape Forum for Intellectual Disability (WCFID), South African Medical Research Council (SAMRC), University of Cape Town (UCT) and Christoffel-Blinden Mission (CBM)). Although useful and developed recently, these resources do not include information on LGBTQIA+ identities and can be rendered inaccessible to individuals who hold both identities mutually. This is at odds with the International Technical Guidance on Sexuality Education (UN Population Fund, 2018), which is an evidence-informed approach that speaks to the inclusion of diverse SOGIESC in the creation of sexuality education programmes. Furthermore, the exclusion of LGBTQIA+ identities in provider-focused programmes like the Teacher Empowerment for Disability Inclusion (TEDI) project (TEDI, 2019) is a clear indication of the deprioritisation of LGBTQIA+ identities in sexuality education. It also confirms the literature review findings (Sommarö et al., 2020; Abbott & Howarth, 2007; Abbot, 2015) that emphasised limited training for service providers to be a barrier when it comes to this topic, as they have limited knowledge and lack confidence in sexuality-related discussions (Echezona-Johnson, 2021; Kahonde, 2022).

As a first approach to making sexuality education more accessible to this group, their families and providers, inclusive and sensitive training (Treacy et al., 2018) that fosters personal reflection in service providers is needed (Nowaskie, et al., 2020; Kahonde, 2022). Secondly, there is a need to adapt existing programmes that have proven to be successful (e.g.

Marks et al., 2020) in promoting positive emotional well-being and social participation for service users.

5.2.2 Interdependence

The study found family interference to be a recurring factor in the lives of individuals with IDD, by placing limitations on this group's independence and reinforcing the thinking that they would remain 'forever children'. These "restraints of freedom" (Van der Meulen et al., 2018, p. 55) can also be seen on a larger scale in the country, as evidenced by the recent national elections, where no provision was made for individuals with IDD (Electoral Commission of South Africa, n.d.). This automatically excluded them from participating in decision-making processes about the country's governance (Combrinck, 2014) and goes against article 29 of the UN Convention on the Rights of Persons with Disabilities (UNCRPD) (UN, 2008).

This indicates wide-spread limited autonomy and social inclusion, and is at odds with the African value of Ubuntu. (Ubuntu alludes to interconnectedness and the view that "a person is a person through other persons" (Mji et al., 2011, p. 365)). As indicated in the study findings, interdependence is appropriate and needed in instances when an individual might face difficulty making more complex decisions. The lack of support for interdependence in the country is surprising, considering that the origins of Ubuntu can be traced back to the Bantu people of southern Africa, and that the philosophy was also significant in the improvement of public services in post-Apartheid South Africa (Bolden, 2014).

As a philosophy, Ubuntu aims to empower individuals regardless of neurodiversity or diverse SOGIESC, and inform them of togetherness, rather than isolation and restriction (Mji et al., 2011). Therefore, employing the philosophy of Ubuntu – and the value of interdependence - might improve service access and social participation, not only for individuals with IDD who are LGBTQIA+, but for everyone.

5.3 Social Participation

Schalock's (2010) QoL model of intellectual disability states that social participation is a factor that focuses on the interpersonal relations, social inclusion, and rights domains. These domains are underpinned by various indicators which have been adapted to include inclusive policies and training programmes, and sexual and reproductive health rights.

5.3.1 Inclusive Policies and Training Programmes

The two main concerns highlighted in both the literature review and interviews was the lack of inclusive policies and training for service providers, which resulted in incompetency when working with individuals who have IDD with potential LGBTQIA+ identities.

Policies are absent, not known about, or unclear and therefore contribute to services that are informed by a service provider's core beliefs (Lines et al., 2020). The existence of non-inclusive policies is unsurprising (Meyer & Keenan, 2018; Concannon, 2022), given that individuals with these combined identities are already excluded from research (Abbott, 2013; Concannon, 2022). Researchers might justify this by citing the challenge of finding LGBTQIA+ people who openly identify as such and have IDD (Harley et al., 2002). This is because they are an "invisible group" (Löfgren-Mårtenson, 2009, p. 21; Sommarö et al., 2020, p. 1202), due to stigmatisation and abuse experienced when they openly identify as LGBTQIA+ (Leonard & Mann, 2018; Tallantire et al., 2016), and because, until recently, sexuality was not allowed as a topic of discussion alongside IDD (Abbott, 2013).

The lack of relevant services for service users is also due to the lack of awareness amongst policymakers and service funders, and the absence of proper training programmes for service providers. Limited and deprioritised training hinders service providers from offering services that speak to the overall quality of life and well-being (Atkinson et al., 2022) of service users with diverse identities, and it reflects higher management's incapacity to provide holistic services that include everyone (Concannon, 2022). Service providers are obligated to provide

care that is inclusive, regardless of the service user's intersectional background and identity (Peña et al., 2016).

Providing LGBTQIA+-sensitive training is important, as equipping service providers and higher management with the necessary training promotes awareness and leads to social inclusion for service users (Concannon, 2022; Ikhile et al., 2024), which provides them with a space that allows for confident expression of identity, which speaks to positive emotional well-being. It is also important to ensure that the need for sexuality education that is accessible to this group is provided for in policies and procedures (Pound et al., 2017; Echezona-Johnson, 2021).

5.3.2 Supportive Attitudes and Competent Allies

Services were also said to be governed by policies and laws that speak to equal access and treatment for all. However, this was not always applied, as when individuals present to service providers (both NGOs and government services), their disability often comes before their sexual orientation and their sexual orientation is ignored. Healthcare providers' lack of sensitisation to LGBTQIA+ issues may sometimes cause people in this community to have anxiety about accessing health services and having to disclose their sexual orientation (Hubach et al., 2022). This is problematic and influences the individual's access to services and self-concept negatively, and could be due to the generally conservative attitudes associated with the sexuality of people with IDD (Deffew et al., 2021). Sexual orientation is not always overt, which means this fault is understandable in some instances (IOM, 2020). The literature (e.g. Newman et al., 2018) reflects this finding, since organisations have been noted to always aim at assisting with one aspect of an individual's identity, instead of the individual as a whole.

It is important to consider a holistic and intersectional approach that is underpinned by a biopsychosocial model of care to eliminate the invisibility of individuals' identities in

services. The biopsychosocial model states that an individual should be perceived as dynamic with biological, psychological, and social factors that interchangeably contribute to their quality of life (Lehman et al., 2017) and personhood. Services should also review their admission and exit forms, policies and procedures (Charitou et al., 2023; Robinson et al., 2020), and aim to create inclusive environments (Echezona-Johnson, 2021; Pound et al., 2017). Education and exercises focused on improving service planner, provider and family views and competency through self-reflective assessments would be useful in this instance too (Echezona-Johnson, 2021; Nowaskie, 2020).

5.4 Well-Being

The well-being factor focuses on three domains of an individual's well-being, namely, emotional, physical and material well-being. Various exemplary indicators underpin these domains, with the study having found an additional indicator for the physical well-being domain - sexual and reproductive health.

5.4.1 Emotional Well-Being

Both the literature review and interviews indicated low levels of emotional well-being for LGBTQIA+ people with IDD, due to frequent experiences of double marginalisation in the community and in terms of services. This was referred to as a 'double whammy' by the respondents. These said experiences of double marginalisation are predictable and concur with the minority stress model, which emphasises identity-based challenges as leading to poor emotional well-being in minority individuals (Echezona-Johnson, 2021; Geiger, 2019).

Service providers also illustrated marginalising attitudes and the idea that same-sex sexual behaviours in individuals with IDD are sexual abuse, which is not unexpected, considering that the historical views that affection between individuals of the same sex is "problematic, threatening or misplaced" (Abbott, 2013, p. 1081), and that people with IDD are asexual (Atkinson et al., 2022; Kahonde, 2022).

Although predictable, the ‘double whammy’ and biased attitudes are a breach of this group’s rights, as they highlight limited access to respect, dignity, and equality (Republic of South Africa, 1996a). This leads to invalidation of potential LGBTQIA+ identities in service users (Treacy et al., 2018; Wilson et al., 2016), which affects self-concept and freedom of being. It could also lead to feelings of otherness and to poor development (Clare, 2021; Meyer & Keenan, 2018), since sexuality is entrenched in the formation of self-identity, well-being, and self-esteem (Brown & McCann, 2019), and so also means limited access to suitable services. In a South African context, the public sector has been noted to be “institutionally fragmented” due to poor service provider attitudes and skills shortages, among many problems (De la Porte, 2016, p. 2). Ultimately, service users’ identities are an intersectional factor that mean limited access to inclusive services and contribute to poor emotional well-being, as shown in the literature review and interviews.

To allow for proper access to services and a welcoming context for service users, it is important that service providers: recognise their internal biases that contribute to incompetency (Marchia & Sommer, 2019); leave personal beliefs at home, so that they are on the same level as other service providers in supporting service users (Clare, 2021); and receive inductive and ongoing gender sensitivity training (Deffew et al., 2021).

5.4.2 Material Well-Being

The double discrimination experienced by LGBTQIA+ individuals with IDD also means this group has impoverished material well-being. The findings indicated that intellectual disability residential facilities and the families of neurotypical individuals evict and reject individuals with diverse SOGIESC. Reasons cited for this were religion, race, socio-cultural and socio-economic factors, which were again unsurprising, given that society generally has negative attitudes towards LGBTQIA+ identities (Pew Research Center, 2013; The Other Foundation, 2016).

These negative and intolerant attitudes have evidenced as being rampant in many African societies (Statista Research Department, 2022), including South Africa (Lawyers for Human Rights, 2021). This comes as a challenge, given that the South African constitution advocates for the rights of all individuals (Republic of South Africa, 1996a) and the Employment Equity Act (No.55 of 1998) (Republic of South Africa, 1998a) advocates for equal treatment in the workplace regardless of disability and sexual orientation, and almost half the South African population is already unemployed and cannot afford basic living expenses (StatsSA, 2024). Additionally, where NGOs were willing to assist individuals with both identities, it was indicated that resources to do so were limited, with the Department of Social Development already having cut resource-constrained NGO funding in the province at the time of writing (Johnston, 2024).

5.4.3 Sexual and Reproductive Health

Regarding physical well-being, the respondents relayed that people with IDD are almost always on contraceptive medication without full knowledge as to why. Literature supports this, claiming that women with IDD are often exposed to inaccessible clinical settings with biased healthcare professionals (Horner-Johnson et al., 2021; Shreshta et al., 2022).

Apart from the bias, service providers often showed a misinformed understanding of who decides that individuals with IDD should be on contraceptive medications or have a sterilisation procedure performed. In South Africa, the Sterilisation Act (No. 44 of 1998) (Republic of South Africa, 1998b) and Choice on Termination of Pregnancy Act, 1996 (Republic of South Africa, 1996b) both allow a panel of expert providers to decide on the sterilisation of an individual, should they be regarded as incapable of giving consent due to IDD.

Contrarily, the National Health Act (Republic of South Africa, 2003) and Children's Act (Republic of South Africa, 2018) both advocate for an opportunity for an individual to obtain

clear and accessible consent-seeking procedures. Therefore, regardless of who makes the decision, without the individual's prior consent, contraceptive medication and sterilisation procedures may be invasive, as they have the potential to remove part of a person's autonomy (Johnston et al., 2022) and have reproductive health implications (Shreshta et al., 2022). The findings showed that the lack of consent for this group, when it comes to their reproductive health, may result in mental health and behavioural issues that are often translated as challenging behaviour (Echezona-Johnson, 2021) that also needs to be medicated.

To ensure people with IDD have access to services that are good for their physical well-being, they must be given the autonomy to participate in decision-making processes regarding policies and procedures that are designed to meet their sexual and reproductive needs (Johnston et al., 2022) and ensure a more positive quality of life and well-being. Also, expert service providers and advocates for people with IDD should provide training to other professionals who are responsible for the well-being of these individuals, in order to eliminate existing bias and discrimination (Johnston et al., 2022).

5.5 Limitations of the Study

The ScR was conducted as part of a master's degree, but with limited resources and time constraints, which meant that all kinds of grey literature that could have been included in the review could not be explored. Some of the studies spoke to sexuality and not sexual orientation, which was, at times easy to confuse, so the researcher and research assistant had to carefully define the two terms and note the differences.

Only studies published in the English language were included, as this is the researcher's language of instruction, and no resources for translation were available, so there is a possibility that viable studies in different languages may have been missed. Additionally, all the studies that were included employed a qualitative research approach, which is good, as it considers individuals' life experiences (Bhandari, 2020). However, the lack of quantitative

research means that the findings may not be applicable to a larger population (Holton III & Burnet, 2005). For the ScR, a quality assessment of the included studies could have added further depth to the review, although this was not required.

Additionally, there was a paucity of research on this population pre-2003. All the studies, except for one (Kramers-Olen, 2016), were conducted in HIC, which speaks to the more pronounced expression of these identities in those countries and the resources available to researchers to conduct research in this area. The reviewed studies largely focused on lesbian, gay, and bisexual people, and only briefly mentioned people who are transgender, which is a limitation for the rest of the LGBTQIA+ community, as their needs are under-represented even in research (Dinwoodie et al., 2021). It also possibly speaks to the lack of access to the services that transgender people with IDD might need (Zirnsak, 2022).

Several potential interviewees who could have added value to the study's findings because of their work within justice, health, and gender affirming services were identified for the interviews but could not be recruited to participate in the interviews. Additionally, given that five of the participants worked for the same NGO, it is possible that the data reported lacked diversity. Some of the study respondents had only worked with individuals with only one of the identities that the study focused on, which may have limited their responses relative to LGBTQIA+ people with IDD.

It is also important to consider that not all the individuals that the respondents worked with were proclaimed to be LGBTQIA+, as some of them only showed diverse SOGIESC. Because the researcher is a member of the LGBTQIA+ community, this could have provided insider insight to the focus of the study, but it might also have introduced personal perspectives that could have impacted on the interpretation of the findings.

5.6 Contributions of the Study

This study has the potential to improve the inclusion of LGBTQIA+ and IDD communities in society, and of public and NGO services accessible to them. This study highlights the ways service providers, communities, and families can ensure service users' QoL is improved. Awareness about the needs of this group and barriers to service access have been highlighted and will aid in improving the attitudes and competence of supporters.

Contextual considerations in undertaking relevant research directly with LGBTQIA+ people with IDD have also been highlighted, with illiteracy of families and individuals regarding diverse SOGIESC being the main considerations. Although interviews with participants from the DoJ&CD could not be secured, a few of the participants spoke to service users' service needs being required at justice and police services, which can also be used to inform what is needed to improve access to justice for this group.

5.7 Recommendations for Future Research

The findings of the study yielded a number of recommendations, which are detailed below.

Although the key participants of the study spoke to service users' access to health and related services in the province, a study should be done on the primary views of these individuals to highlight their views on policy and training issues and the opportunities related to meeting these needs (Marshall et al., 2012). Experience gained in doing this study suggests that this research with this group needs to take proper care to ensure that available, positive support systems are mobilised to participate in the research, and that individuals, their families, and other caregivers receive preliminary orientation and training on LGBTQIA+ identities prior to the research being done (Burns & Davies, 2011; Stoffelen et al., 2013). Recruitment of potential participants with IDD through supportive allied organisations and providers is key (Marshall et al., 2012), as is ensuring adequate follow up for participants

who may experience emotional distress when participating in this type of research (McCann et al., 2016).

To promote the development of evidence-based, accurate policies and training programmes for service users, service providers, and their families; more research must be conducted on the service needs of LGBTQIA+ people with IDD (Abbott, 2013; McCann et al., 2016). This study has noted, in particular, the need for research to inform: gender affirming healthcare; participation of service users in decision-making about their healthcare, for example, the use of contraceptives, and the implementation of the sterilisation legislation; the development of LGBTQIA+ inclusive educational resources. Regarding consent-seeking procedures for people with IDD, research to determine whether there are education and other accommodations that can be introduced to appropriately elicit the views of the person with IDD, on the recommendation for sterilisation and other reproductive health issues, could assist in making supported decision-making a reality in this area of affected people's lives (Tilley et al., 2012).

Society and the research community have largely ignored neurotypical and neurodiverse individuals who are transgender; therefore, future research should focus on the inclusion of this community to ensure social participation and assist in improving service provider competency (Brown & McCann, 2019; Dinwoodie et al., 2021).

Key issues highlighted by this study could inform future research with a quantitative research design, conducted in different contexts, to promote more generalisable recommendations regarding service provision for this population (Brown & McCann, 2019; Atkinson et al., 2022).

Given that discrimination continues to be an integral experience for IDD individuals with LGBTQIA+ identities even with South Africa having protective legislation, there should be "active efforts to improve attitudes" among service providers in the education and health

fields (Kempapidis et al., 2024, p. 59). A shift in service provider attitudes, and educating them on inclusive approaches (Ikhile et al., 2024), will help alleviate discrimination and ensure equal access to healthcare and education services.

It is also recommended that employment practices become more inclusive to mitigate the employment discrimination experienced by IDD individuals with LGBTQIA+ identities (Ikhile et al., 2024). Educational and social services should establish education and awareness initiatives to promote the understanding and acceptance of intersectional identities, particularly IDD and LGBTQIA+ (Egner, 2018). Such initiatives may help cultivate inclusive mindsets towards the community of people with IDD from the LGBTQIA+ community, thus bettering the quality of life and well-being.

5.8 Conclusion

This study has tapped into an under-explored area and has indicated service provision limitations for LGBTQIA+ individuals with IDD. The use of the QoL model of Intellectual Disability and intersectional theory has aided in providing a wide perspective from which to investigate QoL and access to services for people with IDD from the LGBTQIA+ community.

Various intersectional factors (such as family background and the individual's identity) influence the availability of, and access to, services for LGBTQIA+ people with IDD. Education for both this community and its supporters is necessary to improve QoL and well-being. The South African government has conceptualised inclusive policies and legislation that currently does not explicitly include these intersectional identities. It is important to ensure that current exclusionary policies are adapted to LGBTQIA+ people with IDD needs.

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Appendices

Appendix 1: Preferred Reporting Items for Systematic reviews and Meta-Analyses extension for Scoping Reviews (PRISMA-ScR) Checklist

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

SECTION	ITEM	PRISMA-ScR CHECKLIST ITEM	REPORTED ON PAGE #
Critical appraisal of individual sources of evidence§	12	If done, provide a rationale for conducting a critical appraisal of included sources of evidence; describe the methods used and how this information was used in any data synthesis (if appropriate).	
Synthesis of results	13	Describe the methods of handling and summarizing the data that were charted.	
RESULTS			
Selection of sources of evidence	14	Give numbers of sources of evidence screened, assessed for eligibility, and included in the review, with reasons for exclusions at each stage, ideally using a flow diagram.	
Characteristics of sources of evidence	15	For each source of evidence, present characteristics for which data were charted and provide the citations.	
Critical appraisal within sources of evidence	16	If done, present data on critical appraisal of included sources of evidence (see item 12).	
Results of individual sources of evidence	17	For each included source of evidence, present the relevant data that were charted that relate to the review questions and objectives.	
Synthesis of results	18	Summarize and/or present the charting results as they relate to the review questions and objectives.	
DISCUSSION			
Summary of evidence	19	Summarize the main results (including an overview of concepts, themes, and types of evidence available), link to the review questions and objectives, and consider the relevance to key groups.	
Limitations	20	Discuss the limitations of the scoping review process.	
Conclusions	21	Provide a general interpretation of the results with respect to the review questions and objectives, as well as potential implications and/or next steps.	
FUNDING			
Funding	22	Describe sources of funding for the included sources of evidence, as well as sources of funding for the scoping review. Describe the role of the funders of the scoping review.	

JBI = Joanna Briggs Institute; PRISMA-ScR = Preferred Reporting Items for Systematic reviews and Meta-Analyses extension for Scoping Reviews.

* Where *sources of evidence* (see second footnote) are compiled from, such as bibliographic databases, social media platforms, and Web sites.

† A more inclusive/heterogeneous term used to account for the different types of evidence or data sources (e.g. quantitative and/or qualitative research, expert opinion, and policy documents) that may be eligible in a scoping review as opposed to only studies. This is not to be confused with *information sources* (see first footnote).

‡ The frameworks by Arksey and O'Malley (6) and Levac and colleagues (7) and the JBI guidance (4, 5) refer to the process of data extraction in a scoping review as data charting.

§ The process of systematically examining research evidence to assess its validity, results, and relevance before using it to inform a decision. This term is used for items 12 and 19 instead of "risk of bias" (which is more applicable to systematic reviews of interventions) to include and acknowledge the various sources of evidence that may be used in a scoping review (e.g. quantitative and/or qualitative research, expert opinion, and policy document).

From: Tricco AC, Lillie E, Zarin W, O'Brien KK, Colquhoun H, Levac D, et al. PRISMA Extension for Scoping Reviews (PRISMAScR): Checklist and Explanation. Ann Intern Med. 2018;169:467–473. doi: 10.7326/M18-0850.

Appendix 2: SPIDER extraction sheet

Author, Year, Title of Study, Location & Journal	Sample, sample size	Phenomenon of Interest	Design	Evaluation (Study Outcomes: Service Providers' Experiences, Perceptions & Attitudes)							Research Type
				Need for Health & Well-being services	Availability		Access		Availability	Access	Intersectional considerations	Impact on QoL Life
					Availability of services	Barriers to availability	Access to services	Barriers to access	Improvement opportunities to availability	Improvement opportunities to access		

Appendix 3: Key findings from Scoping Review

Author, Year, Title of Study, Location, Journal, Research Type	Sample, sample size, Design	Phenomenon of Interest	Need for Health & Well-being services	Availability		Access		Availability	Access	Intersectional considerations	Impact on Quality of Life
				Availability of services	Barriers to availability	Access to services	Barriers to access	Improvement opportunities to availability	Improvement opportunities to access		
Abbott & Howarth, 2007 "Still off-limits? Staff views on supporting gay, lesbian and bisexual people with intellectual disabilities to develop sexual and intimate relationships?" United Kingdom Journal of Applied Research in Intellectual Disabilities Qualitative	71 staff From 20 intellectual disability service organizations. Semi-structured interviews	Explored views of service providers working with LGB people who have intellectual disabilities, regarding these clients' sexuality, sexual expression and relationships with people who have intellectual and developmental disability at residential facilities.	Service users have choice in expressing themselves sexually in a relationship. Provide the same support as heterosexual individuals.	Sexuality/relationships ignored until a "crisis". Few proactive in supporting with relationships and sexuality issues. Sex education material not informed by service users' concerns as service providers fear looking agenda driven. Programs on service users' sexuality/relationships not available in higher education institutions, topic is included, nonetheless. Supporting interpersonal relations/social inclusion is service providers' responsibilities. LGBTQIA+ friendly service environments allow service users sense of safety. Service users express sexual contact not related to sexual identity, but to need for sexual contact in limiting environments making services question if relationships are exploitative or abusive. Men who have sex with men (MSM) are not gay but only have men to choose from. No consideration of lesbian/gay identity when women have sex with other women and men. Several interviewees in a service were young support workers in small residential homes.	Lack of training and prioritization, & lack of policy guidance and experience hinder sexuality/relationships work. Unawareness of organizations' policies on sex and sexuality. Available policies unlikely state how service providers should work around sex and sexuality. Useful to have policies that support service users' relationships; unclear how policies will become actionable deliverables. Service providers' non-proactivity in sexuality/relationships conversations is problematic as users are not aware of available support. Caregivers' possible negative reactions make service providers anxious and hinder sexuality/relationships work. Raising issues related to sexuality/relationships is intrusive and inappropriate. No right balance in sexuality education as discussing LGBTQIA+ issues without sexuality basics is problematic and having sexuality education alone marginalizes LGBTQIA+ community.	41% providers support development of same-sex relationships.	76% providers support PWIDD to develop heterosexual identity. General belief that service users are asexual. Service users' confusion about own sexuality makes it difficult to know how to support. Uncertainty and confusion about service users' sexuality. Avoid presuming service users' relationship and sexuality needs. Fear doing relationships/sexuality work due to lack of confidence, experience, or willingness. Lack of confidence/experience means choosing to ignore service user needs. Difficulty responding to MSM incidents. Asserting equal treatment regardless of sexual orientation often means treating everyone as hetero- or asexual. Policies are challenging when service providers have own beliefs and must reserve them to follow policy. No need to discuss sexual identity unless problematic behaviours.	Training programs helpful and service providers feel positive about them. Want policies and training regarding work on sex/sexuality. Training is main mechanism in challenging attitudes. Policymakers should recognize importance of service users' emotional and sexual needs too. Policies helpful, offer legitimacy, and allow to be assertive with parents. Policies allow same-sex relationships if there is consent and understanding. Having policies, training, managerial support creates confidence, liberal perspectives, and allows work with service users.	Service users should acquaint with policies too, service organizations should make policies accessible. Accept their professional responsibility to assist with sex/sexuality. Training, policy development & sex education essential for competency. Need for policies on sexuality issues to aid decision-making after training on sexuality issues.	Context: family background, programmes, services, policies Core sense of self: intrinsic values Identity dimensions: sexual orientation, intellectual and developmental disability	Self-determination: Personal development Interpersonal relations Rights Physical well-being Social inclusion: supports attitudes, competency Emotional well-being: self-concept

Abbott, 2015 "Love in a Cold Climate: changes in the fortunes of LGBT men and women with learning disabilities?" United Kingdom British Journal of Learning Disabilities Qualitative	71 staff in 20 learning disability services and 20 women and men with learning disabilities who were in or wanted to be in a same sex relationship. Semi-structured interviews and photovoice	Study aimed to see how people with learning disabilities who identified as LGBT had been supported by services and professionals; and to identify ideas and produce resources, for training and policy development.		Female service providers more likely to discuss empowerment. Services call for experienced service providers to assist bullied service user. Available services jeopardize service users' emotional and physical well-being by failing to care. Few service providers proactively engage with sexuality-related issues.	Service providers disinterested in training/group discussions by researchers. Stories from and research about service users not found in literature. Spending cuts mean cessation of service user support groups. Anxieties about sexuality-related work because of concerns about families' views/reactions. Research encourages self-advocacy organizations to create media resources about material pertaining to and for service users in Sweden. Minimization of research on health/well-being of service users unless advocates are present.	Learning that service users want to love and be loved changes negative perceptions.	Disapproval of lesbian, gay and bisexual identities. Anxieties about sexuality work because of lack of policies, training, experience and confidence & own biased views about LGBT persons. Many are aware of LGB individuals who have intellectual and developmental disability.	Training on responses to bullying of gay service users. Research on health/well-being of service users allows researchers to speak to and advise service users. Research publishing allows support groups/training programs to emerge, and creates interest for change. Research on service users' health/well-being disseminated in extensive way at +15 conferences/workshops in various UK countries.		Context: family background, services, policies, training, research, government Identity dimensions: gender, sexual orientation Intrinsic values: biased, hostile, prejudicial, and uncertain views	Social inclusion: supports, supports attitudes Emotional Physical well-being Personal development
de Wit et al, 2022 "Sexuality, Education and Support for People with Intellectual Disabilities: A Systematic Review of the Attitudes of Support Staff and Relatives" The Netherlands Sexuality and Disability Qualitative	31 studies Systematic Review	Overview of research focused on the attitudes of support staff and relatives concerning the sexuality of both LGBTQIA+ and cisgender people with intellectual disabilities, considering both supportive and restrictive attitudes.	Sex education important for people with intellectual disabilities. People with intellectual disabilities should choose their sexual identity. Support sexual orientation and its expression. Sexual orientation topic should be explored frequently.	Doubts about LGBT service providers being best suited to support service users. Male to male sex is a result of male-only residences.	Sex education should be introduced when sexuality becomes problematic, and to prevent abuse and unwanted pregnancies.	People with intellectual disabilities also have sexual rights. People with intellectual disabilities have same sexual feelings as everyone else.	Sexuality remains taboo topic. Difficulty recognizing sexual feelings of individuals with intellectual disabilities. Those uncertain about sexuality of people with intellectual disabilities concerned about sexual abuse risks. Intellectual disabilities make it difficult for service users to understand and accept sexual identity and orientation. Gay identity is inappropriate for people with intellectual disabilities because it's the same sex. Insecure about supporting/providing sexuality education.	People with intellectual disabilities should be given support regardless sexual orientation. More training, clearer guidelines & permission from management needed.		Services: policies, training manager support, compulsory homosexuality Identity dimensions: sexual orientation, sexual orientation of SPs, Intellectual and developmental disability Core sense of self: intrinsic values	Personal development Social inclusion: supports, attitudes self-determination: need for services that respect autonomy Emotional well-being: self-concept physical well-being Rights
Dudek et al., 2006 "Institutionalized Queers: Homosexuality in Residential Facilities for People with Cognitive Disabilities" USA and Germany USA and Germany Disability Studies Quarterly Qualitative	10 experts and 25 care workers and program managers Semi-focused interviews and focus groups	This study aimed to, 1) analyse qualitative data from a pilot study that observed staff and residents with intellectual and developmental disabilities in 2 cooperating residential facilities where people with mild, moderate and severe intellectual disability live; and 2) to develop a programme for service providers based on the results of the research.	Residential facilities ought to assist gay residents too. Service providers should normalize discussions on same-sex relationships.	Some are open and use gender-neutral speech. Service providers initiating the topic of sexual orientation fosters support. LGBTQIA+ service providers good for promoting LGBTQIA+ identity visibility and acceptance. View same-sex relationships as "compulsory homosexuality" (p. 7). Residents in same-sex relationships do not get support.	LGBTQIA+ identities often omitted from literature, or if not, ideas presented are old.	Some do not view same-sex relationships negatively. All sexualities will be treated equally if nobody is coerced against their will. No assumptions about sexual orientation, service providers ask about a girl- or boyfriend instead of assuming.	Non-acceptance of lesbian/gay identities and view as being taboo and inferior. Lesbian and gay identities an "exploration phase". Distant and reserved attitudes towards lesbian and gay identities.	Service providers should get training that raises awareness on diverse sexual orientations. Training should include explorations of personal attitudes as they have been noted to be largely negative. Professionally trained supervisors should be made available to service providers. Service providers should be aware of where and how to get support and information if someone comes out.	Develop teaching models that allow service providers to respond to discrimination and encourage sexuality development. Service providers who have issues with service users' same-sex relationships should be educated or transferred to a different section of the residence.	Services: policies, lit informs policies, pronouns Intrinsic values Identity dimensions: sexual orientation	Social inclusion: supports, attitudes Interpersonal relations Personal development Emotional well-being

Kramers-Olen, 2016 "Sexuality, intellectual disability, and human rights legislation" South Africa South African Journal of Psychology Qualitative	Included studies focused on people with intellectual disabilities, family members, and residential support workers. Systematic Review	Review of existing literature on sexuality and the factors that act as barriers to sexual expression for individuals with intellectual disabilities.		Lack of sexuality education limits development of LGB identity in individuals with intellectual disabilities. Limited opportunities to promote sexual exploration limit development of LGB identity. Heterosexist attitudes limit development of LGB identities.	No literature on sexuality among transgender, intersex and asexual individuals with intellectual disabilities.		Heteronormative attitudes limit capacity to fathom that people with intellectual disabilities may not be heterosexual. Negative reactions and discriminatory behaviour toward gay and lesbian identities limit free expression of sexuality.	Policies and legislation that support sexual diversity needed to facilitate expression of diverse sexuality.	Needed paradigm shift in training for health care providers/caregivers to challenge existing heteronormative sexuality attitudes. Accessible educational materials that show diverse sexuality in individuals with intellectual disabilities needed to challenge service users' heterosexist attitudes.	Identity dimensions: sexual orientation, intellectual and developmental disability Services: policies Core sense of self: intrinsic values [Stigma] Literature	Personal development Emotional well-being: self-concept Rights: legislation Social inclusion: supports, attitudes
Lofgren-Martenson, 2009 "The Invisibility of Young Homosexual Women and Men with Intellectual Disabilities" Sweden Sexuality and Disability Qualitative	13 youths and young adults (16–27-year-old people with intellectual and developmental disability), 13 staff members (working within recreational environments, group homes, student homes and short-term homes) and 11 parents. Qualitative Interviews	Aimed to identify the experiences and attitudes of service providers and parents regarding the gay, lesbian, and bisexual identities of people with intellectual disabilities.	Teaching about different sexual orientations at special education schools is important.	LGB identities are uncommon in service users because development of an LGB identity in requires a lot of unavailable support. Teachers in special education classes and schools do not focus on variations in sexuality. Shedding light on LGBTQIA+ behaviour such as men having sex with men is done in a "marginalizing or dismissive manner" and is framed as sexual abuse. Same-sex behaviours between individuals who have intellectual disabilities interpreted as expressions of friendship instead of sexual desire.		Service providers do not have overtly negative attitudes towards same-sex relationships.	Teachers do not have clear understanding of what teaching curriculum should entail. Expression of a gay or lesbian identity in teenagers is "exploration". Belief that heterosexuality is more "normal". Service providers reprimand the expression of affection in same-sex couples. Intellectual disability an already enough "deviation" affecting freedom to explore unconventional SOGIESC. There is possibility of people with intellectual disabilities being LGBTQIA+ but expression would be challenging given vulnerability and challenges understanding themselves.			Services Core sense of self: intrinsic values Identity dimensions: sexual orientation, intellectual and developmental disability	Personal development: education Social inclusion: supports; attitudes Emotional well-being: self-concept Self-determination: interdependence, autonomy
Marks et al., 2020 "Where's the human dignity in that?': LGBTQIA+ people with intellectual disability exploring sexual lives and respectful relationships." Australia Journal of Gay & Lesbian Social Services Qualitative	9 LGBTQIA+ people with intellectual disability taking a pilot LGBTQIA+ program. 3 program presenters (Peer Educator with intellectual disability who identified as LGBTQIA+; Program Partner with experience in sexual assault and domestic violence; and National SL&RR coordinator.) Interviews and focus group.	Aimed to report on a revision of the Sexual Lives & Respectful Relationships (SL&RR) program by Frawley & O'Shea (2017) which was originally developed for cisgender people with intellectual disability, and specifically adapted to support sexually and gender diverse (SGD) people with intellectual disabilities.	Sex education should be provided as service users expect it.	SL&RR program turned out differently (from usual program) because of nature of group which was calmer. Service users nervous on first day of focus group but soon became relaxed as they "felt at home".	Peer Educator noted connection with service users was not because of bisexual identity, but rather it was on a mental level with mutual understanding.			SL&RR program was satisfactory. Peer Educator asked about implementation of SL&RR program for LGBTQIA+ people with intellectual disability because interested in doing it.		Context: services, adapted programmes Identity dimensions: The Peer Educator's LGBTQIA+ and intellectual disability identities Core sense of self: personal identity	Social inclusion [SP attitudes] Interpersonal relations [Peers] Emotional well-being/safety & security [Similar individuals present]

Newman et al., 2018 "A Transgender Woman with Intellectual Disability and Borderline Personality Disorder" United States of America American Journal of Psychiatry Qualitative	Service providers at care facilities. Case study	Psychiatrists' clinical reflections on the receptivity of service providers and systems available to assist a 23-year-old transgender woman who has intellectual disability, foetal alcohol syndrome, and borderline personality disorder.	To support client's mental health, treatment team identified importance of proper correct gender treatment.	Individual with intersectional identities received care and support from regional intellectual disability agency and had inpatient hospitalizations. Police services brought service user to residential home after suicide attempt. Individual's misidentification seldom dealt with. No services that provide hormone and surgical treatment to help with transition for transgender youth. Within intellectual disability community, few opportunities for peer support/dedicated resources for transgender individuals with intellectual disability. Residential homes segregated by gender, homes for females do not accept transgender [m to f] people. No known resources that can meet all individual's gender, intellectual, and mental health needs.		Treatment team aiding in changing transgender person's gender in identification documents to prevent misidentification.	Ignore transgender identity of people with intellectual disability completely. Service institutions often aimed at assisting with one issue at a time, forcing service users to choose one treatment over another. No use of correct/preferred pronouns for transgender individuals with intellectual disability because of uncertainty and hostility.	Review of gender policies and initiation of sensitivity training done to develop more transgender sensitive services.		Identity dimensions: gender, sexual orientation, IDD, BPD, FAS Context: services, policies, programmes/training	Emotional well-being: BPD, FAS, self-concept Social inclusion: supports/attitudes Rights: policies, reasonable accommodation (legal documents) Self-determination: interdependence Interpersonal relations: social networks
Smith et al., 2022 "Social inclusion of LGBTQ and gender diverse adults with intellectual disability in disability services: A systematic review of the literature Published for the British Institute of Learning Disabilities" Australia Journal of Applied Research in Intellectual Disabilities Qualitative	9 articles: LGB people with intellectual disability (n = 57) Transgender people with intellectual disability (n = 2) Parents (n = 2) and residential support workers (n = 2) Cisgender people with intellectual disability (n = 22) Systematic review	Aimed to explore experiences of social inclusion and exclusion for people with intellectual disability who identify as LGBTQ in disability services and how social inclusion for this population is promoted in these services.		Contact with LGBTQ service providers important for service users' self-determination.			Service providers' reluctance and sexuality stigma instead of people with intellectual disability's needs shapes nature of sexuality support. When service providers accept gender/sexuality support as within role, they encourage service users to develop heterosexual identity. Service providers in disability services ill-equipped to assist with SOGIESC issues. Services have no support for service providers to navigate lack of cultural literacy *and* have limited time to engage with service users on SOGIESC, leading to limited focus on service users' sexuality issues. Service providers lack LGBTQ cultural literacy. Supporting people with intellectual disability in development and expression of LGBTQ identity will make them more prone to sexual violence. Little time to assist clients with gender/sexuality-related issues. Little manager/organization guidance about acceptable/appropriate activities to discuss in sex/sexuality education. No understanding of transgender issues and enforcing of heteronormative gender ideals on transgender service users.	Services should have clear policies service providers can use facilitating sexual exploration/managing risk. Training important to challenge poor attitudes/provide mechanisms to support service users better/improve service users' self-determination. Sex education important to challenge poor attitudes/provide mechanisms to support service users better/improve service users' self-determination.	Awareness raising exercises to improve understanding that LGBTQ identities are possible in people with intellectual disability. Responsibility of disability organizations/service providers to support people with intellectual disability with self-determination to pursue diverse gender and sexual identities.	Identity dimensions: sexual orientation; IDD Intrinsic values: personal identity Context: services, policies	Social inclusion: supports attitudes Self-determination Rights

Sommaro et al., 2020 "A deviation too many? Healthcare professionals' knowledge and attitudes concerning patients with intellectual disability disrupting norms regarding sexual orientation and/or gender identity" Sweden Journal of Applied Research in Intellectual Disabilities Qualitative	19 healthcare professionals working with children (n=12) and adults (n=7). Two interview guides Focus groups	Aim was 1) to establish knowledge levels of healthcare professionals in habilitation centres regarding LGBTQ identities of residents with intellectual and developmental disability, 2) to explore the perceptions concerning the sexuality and gender identities of people with intellectual disabilities, and 3) the way service providers create LGBTQ-affirmative practices at habilitation centres.	Educate healthcare professionals on LGBTQ issues, frequently have follow-ups to reduce chances of reverting to old methods.	Interested service providers initiate discussions on sexuality issues. Service users have more difficulties expressing sexuality/gender identity than people without intellectual disability. Problematic to only cater to needs of LGBTQ individuals when other minority groups are present. Service users are described as an "invisible group" in the rehabilitation facilities.	Non-awareness of existing LGBTQ training courses plans of action or policies pertaining to LGBTQ issues at rehabilitation centres. At rehabilitation centres new employees do not receive information on policies/goals regarding LGBTQ training or approach that is LGBTQ-affirmative for employees. Issues related to LGBTQ identities rarely raised. Only including unconventional sexuality and/or gender identity in policy documents would have negative impact on other minority groups at risk of not being named and noticed. Disability hinders provision of sex education. Sexuality only mentioned when clients show problematic sexuality behaviour. General perception that topic of sexuality is delicate/difficult; providers worry that service users will be offended if they initiate topic and feel comfortable when service users initiate discussion.	Service users' LGBTQ identities do not affect nature of services provided.	Unconscious risk of addressing service users from heteronormative perspective. Healthcare professionals feel uncertain if topic of LGBTQ issues/gender identity comes up, they have varying levels of knowledge on topic. Sexuality topic more relevant to adolescent/adult clients than children, younger service users do not appreciate sexuality discussions.	People with intellectual disability with diverse sexuality and/or gender identity be included in policy documents. Addressing LGBTQ issues will be easy if work documents directly mention how LGBTQ issues should be addressed. After LGBTQ training, service providers reviewed waiting room literature, facilitated introduction of gender-neutral signs and appointment of LGBTQ representative.	Materials (i.e., paperwork, forms, & questionnaires) should be made inclusive and gender-inclusive restroom signs should be made available.	Identity dimensions: sexual orientation, age, gender Context: services, policies Core sense of self: intrinsic values/stigma and stereotypes	Social inclusion: supports, attitudes Rights
Stoffelen et al., 2017 "Sexuality and individual support plans for people with intellectual disabilities" The Netherlands Journal of Intellectual Disability Research Qualitative	187 ISP documents of people with intellectual disability from 7 service providers Content analysis	Content analysis of Individual Support Planning (ISP) documents with aim to identify 1) extent to which sexual health and sexual rights are mentioned, 2) what subjects or issues are covered in the instance that these issues are mentioned, and 3) how support related to sexual health is provided to people with intellectual disabilities.			People with intellectual disability are not always included in process of ISP documents creation, as is supposed to be. Only 2/187 ISP documents mention same-sex relationships.					Identity dimensions: sexual orientation, IDD Context: Non-inclusive policies and non-existent programmes	Social inclusion: supports attitudes

Wilkinson et al., 2015 "'As Normal as Possible': Sexual Identity Development in People with Intellectual Disabilities Transitioning to Adulthood" United Kingdom Sexuality Disability Qualitative	4 people with intellectual disability who had verbal competence and their carers (2 parents and 2 residential support workers) Semi-structured interviews	Attitudes of adolescents with intellectual disability as well as their carers (parents and residential support workers) were explored to provide a triangulated and enriched perspective as well as highlight the role of the patient-carer relationship and how it affects the development of sexual identity.		Non-provision of LGB sex/relationship education and support to young individuals with intellectual disability which hinders sexual exploration.		Stigma around people with intellectual and developmental disability being sexual beings, or even being LGB.		Identity dimensions: sexual orientation, IDD Intrinsic values Context: services	Social inclusion: attitudes, supports
Winges-Yanez, 2013 "Why All the Talk About Sex? An Autoethnography Identifying the Troubling Discourse of Sexuality and Intellectual Disability" United States Sexuality Disability Qualitative	Researcher who is a service provider with experience in intellectual disability field and a relative with intellectual disability. Autoethnography	Author set out to highlight the limitations that people with intellectual disability experience with focus on diverse SOGIESC client.		Chosen to work with male person with intellectual disability who had been "hitting on men" because she (researcher) was an out queer person with experience working with individuals who have "concerning sexual behaviours". Service users engage in same-sex behaviours because residential facilities only have the same sex.		Parents deny service users access to LGBTQIA+ friendly services.		Identity dimensions: sexual orientation, gender Core sense of self: personal identity and experience of SP Context: services	Social inclusion: SP attitudes, support Personal development: Adaptive behaviours not being displayed as individual has been noted to "hang out in men's bathrooms to meet guys" Interdependence: The guidance in managing the concerning sexual behaviours
Yool et al., 2003 "The Attitudes of Medium-Secure Unit Staff Toward the Sexuality of Adults with Learning Disabilities" United Kingdom Sexuality Disability Qualitative	4 service providers (i.e., consultant psychiatrist (male), senior care-worker (female), advocacy worker (female), and a domestic staff member (male)) Semi-structured interviews	To explore the attitudes of service providers regarding the sexuality of people with learning disabilities.	People with learning disabilities should have same-sex relationships if that is their need.		Conservative attitudes toward people with learning disabilities being included in decision-making processes regarding their sexuality and same-sex relationships.	Same-sex relationships between people who have learning disabilities will be discouraged and uncertain about policies related to this.	Training that focuses on same-sex relationships/sexual behaviours other than masturbation.	Identity dimensions: sexual orientation, intellectual and developmental disability, service providers' gender Core sense of self: intrinsic values Context: policies, services, socio-cultural conditions	Social inclusion: attitudes. supports Self-determination: decision-making processes Personal development: SP training

Appendix 4: Information Sheet for Research Participants

Exploring the perceptions of service providers regarding the need for and availability of services that affect the well-being of LGBTQIA+ individuals living with intellectual and developmental disability in Cape Town, South Africa.

I would like to invite you to participate in a research study. It is important for you to understand the purpose of the research and what it would mean for you before deciding to participate. Please take your time and carefully read the following material. If something you read is unclear or you would like additional information, please ask questions. Spend some time deciding whether to participate or not.

Who am I and what is this study about?

My name is Nathi Poswa, and I am a candidate for the Master of Philosophy (MPhil) in Intellectual Disability programme at the University of Cape Town (UCT) which is a research degree. I am doing this research study because I want to learn more about the service needs of and availability of services that affect the well-being of people living with intellectual and developmental disability who are from the Lesbian, Gay, Bisexual, Transgender, Queer, Intersex, and Asexual (LGBTQIA+) community. I hope to document this by exploring the perspectives of service providers who work with this group.

What will participating involve?

Participating in this research study will involve your participation in a semi-structured interview and a focus group discussion where we will discuss the quality of life and well-being needs, social participation, and independence of persons living with intellectual and developmental disability from the LGBTQIA+ community. The interviews will be recorded using an audio recording device.

Why Have You Been Invited to Participate?

Service providers who interact with people with intellectual and developmental disability from the LGBTQIA+ community are likely to be the best informants for the study given their experience of working with this group of people.

Do You Have to Participate?

Participating in this study is completely voluntary and you may refuse participation, or having agreed to participate, you may withdraw from the study at any point. You are also free to refuse to answer any questions put to you during the interviews.

What Are the Possible Risks and Benefits of Participating?

This study should not pose any harm to you as a participant. Though there may not be any direct benefits to you from participating in the study, possible benefits of the research are that it could provide information that can help in the drafting of policies and service provision for persons living with intellectual and developmental disability from the LGBTQIA+ community which in turn may support service providers in their work to provide services that are suitable for this group of service receivers.

Will participating be confidential?

Your anonymity and confidentiality will be ensured for the individual interview. Confidentiality of views reflected in the information collected from the focus group discussion

will also be ensured. Anonymity for the focus group will not be possible. Participants in the focus group will be asked to respect confidentiality; however, this cannot be assured. The interview audio recordings, transcripts and signed consent forms will initially be kept in a password protected computer which I will only be able to access.

How will information you provide be recorded, stored and protected?

The audio recordings from the interviews will be transferred to the researcher's password protected personal computer and stored in a secure folder. After the researcher has finished transcribing the audio recordings, the files will be deleted from their personal computer and any tangible copies of written notes will be destroyed. Transcripts of the audio recordings will be saved in a secure location within the Department of Psychiatry and Mental Health at the Neuroscience Centre, Groote Schuur Hospital. To maintain the participants' anonymity, their names will be deleted. The researcher, supervisors, and transcribers are the only individuals who will have access to the data. No confidential information will be disclosed to parties outside of those listed above, and the transcriber will be asked to sign a confidentiality agreement. The final data set will be stored in the Department of Psychiatry and Mental Health research depository for 5 years before shredding.

What will happen to the results of the study?

Once the interviews are done and the data has been analysed, I will write reports in the form of a dissertation and articles, and I will submit these to the University of Cape Town. No identifying information will be included in. this research report. I may also publish the findings in an academic journal. Should the opportunity for a conference present itself, I will present the research findings there.

For more information or to express interest in participating in the study please contact me here:

Cell number: +27787323093 email address: pswnat002@myuct.ac.za

You may also contact my research supervisor, Prof. Sharon Kleintjes, here:

Telephone: +27216502147 email address: sr.kleintjes@uct.ac.za

Department of Psychiatry and Mental Health. University of Cape Town, Neuroscience Institute, Groote Schuur Hospital, Observatory Cape Town.

You may also contact Prof. Marc Blockman who is Chair of the Health Research Ethics Committee at the Faculty of Health Sciences should you wish to communicate any complaints or concerns about the study or research practices.

Telephone number: +27214066626 email address: hrec-enquiries@uct.ac.za

Faculty of Health Sciences, Room G50 Old Main Building, Groote Schuur Hospital, Observatory 7925 University of Cape Town.

Appendix 5: Informed consent (Semi-structured interviews)

INFORMED CONSENT FORM FOR RESEARCH PARTICIPANTS

Research study about the perspectives of service providers regarding the service needs and availability of services that affect the well-being of LGBTQIA+ persons who live with intellectual disability.

I would like to invite you to participate in a research study. It is important for you to understand the purpose of the research and what it would mean for you before deciding to participate. Please take your time and carefully read the following material. If something you read is unclear or you would like additional information, please ask questions. Spend some time deciding whether to participate or not.

Purpose of the study: This study is to document the views of service providers regarding the service needs and availability of services that affect the well-being of Lesbian, Gay, Bisexual, Transgender, Queer, Intersex, and Asexual (LGBTQIA+) persons who live with intellectual disability.

Description of the Research

The research study is undertaken by me, Nathi Poswa, a candidate for the Master of Philosophy (MPhil) in Intellectual Disability programme at the University of Cape Town (UCT) and is for a research degree. I am doing this research study because I want to learn more about the service needs of and availability of services that affect the well-being of people living with intellectual

and developmental disability who are from the Lesbian, Gay, Bisexual, Transgender, Queer, Intersex, and Asexual (LGBTQIA+) community. I hope to document this by exploring the perspectives of service providers who work with this group.

Participation

If you decide to participate in the study, you will be asked to sign a consent form that states your agreement to participate in the study. You will have a semi-structured interview with the researcher. The views of all participants will be documented by the researcher and participants will then be contacted for a focus group discussion with the other study participants to advise on and discuss whether the key themes identified from the semi-structured interviews reflect the views of participants well. Semi-structured interviews will take 50 - 60 minutes.

Potential Risks and Benefits

This study should not pose any harm to you as a participant. Though there may not be any direct benefits to you from participating in the study, possible benefits of the research are that it could provide information that can help in the drafting of policies and service provision for persons living with intellectual and developmental disability from the LGBTQIA+ community which in turn may support service providers in their work to provide services that are suitable for this group of service receivers.

Confidentiality

Your anonymity and confidentiality will be ensured for the individual interview. Confidentiality of views reflected in the information collected from the focus group discussion will also be ensured. Anonymity for the focus group will not be possible. Participants in the focus group will be asked to respect confidentiality; however, this cannot be assured. The interview audio recordings, transcripts and signed consent forms will initially be kept in a password protected computer which I will only be able to access.

The audio recordings from the interviews will be transferred to the researcher's password protected personal computer and stored in a secure folder. After the researcher has finished transcribing the audio recordings, the files will be deleted from their personal computer and any tangible copies of written notes will be destroyed. Transcripts of the audio recordings will be saved in a secure location within the Department of Psychiatry and Mental Health at the Neuroscience Centre, Groote Schuur Hospital. To maintain the participants' anonymity, their names will be deleted. The researcher, supervisors, and transcribers are the only individuals who will have access to the data. No confidential information will be disclosed to parties outside of those listed above, and the transcriber will be asked to sign a confidentiality agreement. The final data set will be stored in the Department of Psychiatry and Mental Health research depository for 5 years before shredding.

Publication of Results

Once the interviews are done and the data has been analysed, I will write reports in the form of a dissertation and articles, and I will submit these to the University of Cape Town. No identifying information will be included in. this research report. I may also publish the findings in an academic journal. Should the opportunity for a conference present itself, I will present the research findings there.

Decision to Participate in Study

Participating in this study is completely voluntary and you may refuse participation, or having agreed to participate, you may withdraw from the study at any point. You are also free to refuse to answer any questions put to you during the interviews.

For more information or to express interest in participating in the study please contact me here:

Cell number: +27787323093 email address: pswnat002@myuct.ac.za

You may also contact my research supervisor, Prof. Sharon Kleintjes, here:

Telephone: +27216502147 email address: sr.kleintjes@uct.ac.za

Department of Psychiatry and Mental Health, University of Cape Town, Groote Schuur Hospital, Observatory, 7925.

You may also contact Prof. Marc Blockman who is Chair of the Health Research Ethics Committee at the Faculty of Health Sciences should you wish to communicate any complaints or concerns about the study or research practices.

Telephone number: +27214066626 email address: hrec-enquiries@uct.ac.za

Faculty of Health Sciences, Room G50 Old Main Building, Groote Schuur Hospital, Observatory 7925 University of Cape Town.

If you agree to take part in the interviews, please sign below to confirm your participation.

I _____

declare that:

- I have read or someone has read this information and consent form to me.
- It is written in a language which I can speak well.
- I understand what the project is about and the possible benefits and risks/discomforts for me.
- I have had a chance to ask questions, and all my questions have been answered fully.

- I understand that I can choose to take part in this study, or I can choose not to. I have not been pressured to take part.
- I also understand that I do not give up any rights by signing below.
- I may choose to leave the study at any time and will not be penalised or prejudiced in any way.
- I have received an unsigned copy of this form to keep.

Participant signature _____ Date: _____

Name of person taking consent: _____

Signature of person taking consent: _____ Date: _____

Appendix 6: Semi-structured interview schedule

Interview guide for service providers who work with individuals living with intellectual disability, LGBTQIA+ persons, and LGBTQIA+ persons living with intellectual disability: Service needs and availability of services that affect well-being in the Western Cape (for degree purposes).

Questionnaire: Documenting the views of service providers regarding the service needs and availability of services that affect the well-being of Lesbian, Gay, Bisexual, Transgender, Queer, Intersex, and Asexual (LGBTQIA+) individuals living with intellectual and developmental disability in the Western Cape.

Introduction: Thank you for agreeing to take part in this interview. As I mentioned in the consent form, the aim of our discussion today will be to help me understand your views about the service needs and availability of services that affect the well-being of LGBTQIA+ individuals living with intellectual disability. I will ask you to think about what should be included in the policies that guide the day-to-day service provision of individuals who identify with both LGBTQIA+ and intellectual and developmental disability identities. Do you have any questions before we start the interview?

Personal details

Could you briefly introduce yourself?

Could you briefly share your understanding of the term LGBTQIA+ in the context of your work?

Please can you describe briefly what work you have done and are currently doing with people with intellectual and developmental disability from the LGBTQIA+ community? (Explore if not noted: what profession, what kind of service provision, how long, in what context?)

Questions:

Thank you, I am now going to ask you a few questions about your experience of and views on the health and wellbeing of people with intellectual and developmental disability from the LGBTQIA+ community.

1. What are some of the physical considerations for LGBTQIA+ persons with intellectual and developmental disability?

   (Explore if not mentioned, health and nutrition status (access to proper food), access to physical health resources, recreation and leisure activities, potential impact of level of intellectual and developmental disability on physical well-being, physical wellbeing of transgendered persons, physical (dis)ability, and sexual life?)

   _____

   _____

   (If not mentioned ask for solutions: From your experience what might be done to improve the physical wellbeing of these individuals in regard to the issues we have just discussed? What issues need attention for transgendered individuals?)

2. What would you say contributes to positive emotions in LGBTQIA+ persons with intellectual and developmental disability?
   (Explore if not mentioned, positive and negative experiences, the impact of context (family, work, culture and society) on the person's self-concept, any frequent stressors to persons who live with intellectual and developmental disability and identify as LGBTQIA+ face in particular, and coping with mental illness?)

   _____

   _____

   (If not mentioned ask for solutions: From your experience what might be done to improve the emotional wellbeing of these individuals in regard to the issues we have just discussed? What can be done to improve the coping mechanisms of this group in terms of mental illness and psychosocial disability?)

3. How would you say the financial state of LGBTQIA+ persons with intellectual and developmental disability is? Do you mind elaborating on that, please?
   (For example, would you say LGBTQIA+ persons who have intellectual and developmental disability have sufficient money, employment, or possessions?)

   _____

   _____

Thank you, the next set of questions will focus on your experience of and views on the independence of people with intellectual and developmental disability from the LGBTQIA+ community.

1. What would you say is the impact of contextual factors on the personal development of LGBTQIA+ individuals with intellectual and developmental disability?
   (Explore if not mentioned, education status, personal skills, adaptive behaviour (Activities of daily living/instrumental activities of daily living))

   _____

   _____

   (If not mentioned ask for solutions: From your experience, what might be done to improve the personal development of this group with regards to the issues we have just discussed? What strategies could be used to promote interpersonal skills?)

2. How would you say the self-determination of LGBTQIA+ persons with intellectual and developmental disability has been affected by contextual factors?
   (Explore if not mentioned, choices/decisions, autonomy, personal control, personal goals)

   _____

   _____

   (If not mentioned ask for solutions: From your experience, what might be needed to improve the self-determination of this group with regards to the issues we have just discussed? (Explore if not noted the interplay of self-determination and dependence? Independence? Interdependence?)

This final section of questions will look at the social participation of people with intellectual and developmental disability from the LGBTQIA+ community.

1. What kind of relationships have you observed in your work with LGBTQIA+ persons with intellectual and developmental disability?

   (Explore if not mentioned, social networks, friendships, social activities, relationships)

   _____

   _____

   (If not mentioned ask for solutions: From your experience, what might be done to improve the interpersonal relations of this group with regards to what we have just discussed?)

2. How would you say LGBTQIA+ persons with intellectual and developmental disability are made part of society?

   (Explore if not mentioned, community integration, community roles, supports, and supports attitudes/competency)

   _____

   _____

   (If not mentioned ask for solutions: From your experience, what might be done to improve the social inclusion of LGBTQIA+ persons with intellectual and developmental disability with regards to the issues we have just discussed?)

3. To what extent have you observed the rights of LGBTQIA+ persons with intellectual and developmental disability being protected?

(Explore if not mentioned, Human Rights (respect, dignity, equality), Legal Rights (legal access, due process), capability and accommodation for participation in due process)

_____

_____

(If not mentioned ask for solutions: From your experience, what might be done to improve the access to and accommodation of this group with regards to the issues we have just discussed? How could people with intellectual and developmental disability and different capabilities be accommodated in institutions? What might be done to improve access to rights for LGBTQIA+ individuals?)

Thank you so much for participating in the study. Are there any issues which you would like to comment on in closing which I might not have asked you about which you feel is important to address in the study?

Appendix 7: Semi-structured interview: Post Interview Form

Research study about the service needs and availability of services that affect the well-being of LGBTQIA+ individuals living with intellectual and developmental disability in Cape Town, South Africa (for degree purposes)

Interview date	
Respondent's role at work	
Respondents experience of working with people with intellectual and developmental disability from the LGBTQIA+ community (Years)	
Respondent's gender	
Consent form signed	
Interview location	
Interview start time	
Interview end time	

Appendix 8: Researcher interview notes

Completed all interview aspects	
Identification and marking of files	
Backing up of files	
Observations (Provide an overview of the interview):	
Will this interview contribute to the analysis? (Participant views are clearly expressed and verified by interviewer.)	
Might any of the ideas that emerged from the interview contribute to our thinking? (Hint: new, contradictory, confirming ideas, trends.)	
What key themes emerged from this interview?	
Are there any other observations?	

Appendix 9: Transcriber's confidentiality agreement

Name of study: *Exploring the perceptions of service providers regarding the need for and availability of services that affect the well-being of LGBTQIA+ individuals living with intellectual and developmental disability in Cape Town, South Africa.*

Master's Dissertation Research

I am aware that as the project's transcriber, I will be exposed to audio recordings of private and confidential interviews. Participants in this study have voluntarily disclosed the material captured on these audio recordings and have asked for strict confidentiality. I am aware that upholding this non-disclosure agreement is a duty on my part.

I acknowledge that the research team providing the audio is the only party with whom I may speak about or share any information contained there.

I, ……, agree to transcribe the digital recordings provided to me and to keep all information obtained from the research team for this study completely confidential.

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

Signature: …… **Date: ……**

Appendix 10: Focus group discussion interview schedule

Interview guide for service providers who work with individuals living with intellectual and developmental disability, LGBTQIA+ persons, and LGBTQIA+ persons living with intellectual and developmental disability: Service needs and availability of services that affect well-being in the Western Cape (for degree purposes).

Questionnaire: Documenting the views of service providers regarding the service needs and availability of services that affect the well-being of Lesbian, Gay, Bisexual, Transgender, Queer, Intersex, and Asexual (LGBTQIA+) individuals living with intellectual and developmental disability in the Western Cape.

Introduction: Thank you for agreeing to take part in this group interview. As I mentioned in the consent form, the aim of our discussion today will be to help me ascertain my understanding of your views about the service needs and availability of services that affect the well-being of LGBTQIA+ individuals living with intellectual and developmental disability. I will ask you to reflect on the ideas that you shared in the semi-structured interviews regarding the quality of life of people with intellectual and developmental disability with LGBTQIA+ identities and what should be included in the policies that guide their day-to-day service provision. I will also be recording this interview audio on my phone. Do you have any questions before we start the interview?

Personal details:

Can everyone please introduce themselves (your name and the nature of your work).

Questions:

1. In speaking about sexual well-being and the rights associated with people who have intellectual and developmental disability most people felt that they rarely have a right to sexuality. What is your view on that and what do you think to improve this along with individuals' knowledge of their sexuality rights?

   _____

   _____

2. Can you speak to people with intellectual and developmental disability's understanding of the acronym LGBTQIA+ and what needs to be done to improve this understanding?

   _____

   _____

3. Interdependence was expressed to be a common theme in the lives of people with intellectual and developmental disability who are LGBTQIA+. Might you speak more to this?

   _____

   _____

4. In the interviews ostracism from social environments and relationships appeared to be a common theme for people with intellectual and developmental disability who are LGBTQIA+. Can you speak more to the level of social inclusion this group has in terms of friendships and in trying to access services?

   _____

   _____

5. As per our last interviews, what do you remember as being the emotional challenges experienced by people with intellectual and developmental disability who are LGBTQIA+ and what reasons can we attribute to those?

6. In your experience how would you say people with intellectual and developmental disability who are LGBTQIA+ deal with unpleasant situations that may affect their emotional well-being and what environmental factors contribute to positive well-being?

7. Physical abuse was mentioned quite a few times in the semi-structured interviews as something that individuals with intellectual and developmental disability from the LGBTQIA+ community usually experience. How much access to justice services do you think people with intellectual and developmental disability have?

8. From the interviews it became clear that individuals sometimes go on contraceptive medication voluntarily or involuntarily. In your context, would you say that sterilisation is done on a voluntary or involuntary basis, and what might you say about the individuals getting educated about the reasons they are getting sterilised?

9. It was apparent in the interviews that people with intellectual and developmental disability who are LGBTQIA+ have limited access to material well-being services such as education, employment, housing, and a steady income. Can you speak more to this and

what needs to be done to change it?

_____

_____

Appendix 11: Informed consent (Focus groups)

INFORMED CONSENT FORM FOR RESEARCH PARTICIPANTS

Research study about the perspectives of service providers regarding the service needs and availability of services that affect the well-being of LGBTQIA+ persons who live with intellectual disability.

I would like to invite you to participate in a research study. It is important for you to understand the purpose of the research and what it would mean for you before deciding to participate. Please take your time and carefully read the following material. If something you read is unclear or you would like additional information, please ask questions. Spend some time deciding whether to participate or not.

Purpose of the study: This study is to document the views of service providers regarding the service needs and availability of services that affect the well-being of Lesbian, Gay, Bisexual, Transgender, Queer, Intersex, and Asexual (LGBTQIA+) persons who live with intellectual disability.

Description of the Research

Thank you for participating an interview for my study for the Master of Philosophy (MPhil) in Intellectual Disability programme at the University of Cape Town (UCT) which focuses on the service needs of and availability of services that affect the quality of life and well-being of

people living with intellectual and developmental disability who are from the Lesbian, Gay, Bisexual, Transgender, Queer, Intersex, and Asexual (LGBTQIA+) community.

Subject Participation

Participants who participated in the semi-structured interviews were also requested to participate in a focus group discussion with the other study participants to review and provide feedback on the findings of the study. For this part of the study, therefore, I am inviting you to participate in the focus group along with other service providers to LGBTQIA+ persons, persons living with intellectual disability, and LGBTQIA+ persons living with intellectual and developmental disability in the Western Cape who were interviewed. The focus group discussions will take approximately 1 hour and 30 minutes.

Potential Risks and Benefits

This study should not pose any harm to you as a participant. Though there may not be any direct benefits to you from participating in the study, possible benefits of the research are that it could provide information that can help in the drafting of policies and service provision for persons living with intellectual and developmental disability from the LGBTQIA+ community which in turn may support service providers in their work to provide services that are suitable for this group of service receivers.

Confidentiality

Participants in the focus group will be asked to respect confidentiality. Anonymity for the focus group will not be possible. Participants in the focus group will be asked to respect confidentiality; however, this cannot be assured. The interview audio recordings, transcripts and signed consent forms will initially be kept in a password protected computer which I will only be able to access.

The audio recordings from the interviews will be transferred to the researcher's password protected personal computer and stored in a secure folder. After the researcher has finished transcribing the audio recordings, the files will be deleted from their personal computer and any tangible copies of written notes will be destroyed. Transcripts of the audio recordings will be saved in a secure location within the Department of Psychiatry and Mental Health at the Neuroscience Centre, Groote Schuur Hospital. To maintain the participants' anonymity, their names will be deleted. The researcher, supervisors, and transcribers are the only individuals who will have access to the data. No confidential information will be disclosed to parties outside of those listed above, and the transcriber will be asked to sign a confidentiality agreement. The final data set will be stored in the Department of Psychiatry and Mental Health research depository for 5 years before shredding.

Publication of Results

Once the interviews are done and the data has been analysed, I will write reports in the form of a dissertation and articles, and I will submit these to the University of Cape Town. No identifying information will be included in. this research report. I may also publish the findings in an academic journal. Should the opportunity for a conference present itself, I will present the research findings there.

Decision to Participate in Study

Participating in this study is completely voluntary and you may refuse participation, or having agreed to participate, you may withdraw from the study at any point. You are also free to refuse to answer any questions put to you during the interviews.

For more information or to express interest in participating in the study please contact me here:

Cell number: +27787323093 email address: pswnat002@myuct.ac.za

You may also contact my research supervisor, Prof. Sharon Kleintjes, here:

Telephone: +27216502147 email address: sr.kleintjes@uct.ac.za

Department of Psychiatry and Mental Health, University of Cape Town, Groote Schuur Hospital, Observatory, 7925.

You may also contact Prof. Marc Blockman who is Chair of the Health Research Ethics Committee at the Faculty of Health Sciences should you wish to communicate any complaints or concerns about the study or research practices.

Telephone number: +27214066626 email address: hrec-enquiries@uct.ac.za

Faculty of Health Sciences, Room G50 Old Main Building, Groote Schuur Hospital, Observatory 7925 University of Cape Town.

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

I _____

declare that:

- I have read or someone has read this information and consent form to me.
- It is written in a language which I can speak well.
- I understand what the project is about and the possible benefits and risks/discomforts for me.
- I have had a chance to ask questions, and all my questions have been answered fully.
- I understand that I can choose to take part in this study, or I can choose not to. I have not been pressured to take part.
- I also understand that I do not give up any rights by signing below.

- I may choose to leave the study at any time and will not be penalised or prejudiced in any way.
- I have received an unsigned copy of this form to keep.

Participant's signature: _____ Date: _____

Name of person taking consent: _____

Signature of person taking consent: _____ Date: _____

Appendix 12: Human Research Ethics Committee (HREC) Approval

UNIVERSITY OF CAPE TOWN
Faculty of Health Sciences
Human Research Ethics Committee

Room 45 E-52-E-Floor- 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

19 January 2022

HREC REF: 006/2023

Prof S Kleintjes
Division of Intellectual Disability
Department of Psychiatry & Mental Health
Email: s.kleintjes@uct.ac.za
Student: pswnat002@myuct.ac.za

Dear Prof Kleintjes

PROJECT TITLE: EXPLORING THE PERCEPTIONS OF SERVICE PROVIDERS REGARDING THE NEED FOR AND AVAILABILITY OF SERVICES THAT AFFECT THE WELL-BEING OF LGBTQIA+ INDIVIDUALS LIVING WITH INTELLECTUAL AND DEVELOPMENTAL DISABILITY IN CAPE TOWN, SOUTH AFRICA.
(MASTER'S DEGREE – MS NATHI POSWA)

Thank you for submitting your study to the Faculty of Health Sciences Human Research Ethics Committee (HREC) for review.

It is a pleasure to inform you that the HREC has **formally approved** the above-mentioned study, subject to the following -
"The researcher aims to accommodate participants who are not fluent in the English language or IsiXhosa by using the services of a translator during the interviews. The translator will be required to sign a consent form ahead of the interviews".
This needs to be a confidentiality agreement as opposed to consent form as provided for in Appendix K.

Approval is granted for one year until the 28 February 2024.

Please submit a progress form, using the standardised Annual Report Form (FHS016) 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: Ms Nathi Poswa will also be involved in this study.

Please quote the HREC REF 006/2022 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

pp VBurgess

PROFESSOR M BLOCKMAN
CHAIRPERSON, FACULTY OF HEALTH SCIENCES 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 2020), 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 13: Letter to request permissions

Division of Intellectual Disability

Department of Psychiatry and Mental Health

Faculty of Health Sciences,

University of Cape Town

Cell no.: +27787323093

Email address: pswnat002@myuct.ac.za

[Contact person]

[Organisation name]

[Organisation address]

[Date]

Dear Sir/Madam,

RE: Permission to conduct research at [insert organisation name].

My name is Nathi Poswa. I am studying for a Master of Philosophy in Intellectual Disability at the University of Cape Town. I am seeking permission to do research at [insert organisation name].

I am conducting research on the perspectives of service providers regarding the service needs and availability of services to Lesbian, Gay, Bisexual, Transgender, Queer, Intersex, and Asexual (LGBTQIA+) individuals who live with intellectual and developmental disability in the Western Cape. I am doing this research because the needs of the minority individuals belonging to these 2 groups usually go unnoticed in service-providing institutions, and it would be beneficial to get the views of service providers regarding this group's needs so we can improve the services that affect their well-being. I have chosen [organisation name] because the staff working here may have had clients who live with intellectual and developmental disability and identify as LGBTQIA+.

I will invite health professionals such as psychologists, occupational therapists, social workers, and other health professionals who may have worked with LGBTQIA+ clients with intellectual and developmental disability from this organisation to participate in this study. If they agree, they will be asked to be interviewed and to participate in a focus group discussion. The interview and the focus group discussion will take place on different days at the University of Cape Town Department of Psychiatry. An audio recording device will be used to record the interview and focus group discussion for accurate analysis of the information provided.

Before the research gets started, participants will be prompted to provide their written or verbal consent. Their comments will be kept private, and unless otherwise stated, identities (including their names and the name of the organisation) will be kept anonymous. All data from the study that is published or written will respect the privacy of everyone.

The results will be communicated in a dissertation and academic journals.

Participants in the study are not likely to experience any advantage or disadvantage. They will be reassured that they are free to revoke their consent at any time without incurring any costs over the course of this project. There are no known dangers associated with taking part in this study. The study's participants will not receive any compensation.

All study materials will save in a secure location within the Department of Psychiatry and Mental Health at the Neuroscience Centre, Groote Schuur Hospital.

I therefore request permission in writing to conduct my research at your organisation. The permission letter should be on your organisation’s letterhead paper, signed and dated, and specifically referring to myself by name and the title of my study.

In support of my application, please find attached a copy of:

1. my ethics clearance for the study from the University of Cape Town,
2. a synopsis of my study protocol,
3. the information sheet for recruiting participants, and
4. the informed consent forms for the study.

Please let me know if you require any further information. I look forward to your response as soon as is convenient.

Yours sincerely,

Nathi Poswa

Nathi Poswa

Cell no.: +27787323093

Email address: pswnat002@myuct.ac.za

Prof. Sharon Kleintjes (Research Supervisor)

Tel no.: +27216502147

Email address: sr.kleintjes@uct.ac.za

Appendix 14: Initial coding framework

Name	Files	References
Self-determination	11	70
Personal development	11	69
NGO services	9	65
Emotional well-being	11	57
Health & gender affirming care	7	57
Diverse SOGIESC presentation & issues	11	55
Service provider challenges with available services	10	55
Family views and interventions	9	54
Accomodations in due process	10	53
Awareness of & info on LGBTQIA+	12	49
Community & societal views	10	44
Governance at NGO and national level	8	41
Experience with diverse SOGIESC in pwIDD	11	38
Access to social services	7	37
Contextual factors against diverse SOGIESC	9	37
Posteducation, psychoeducation & protective workshops	9	37
Sexuality support	6	35
Relationships and support	10	34
Lack of, and recommendations for, adequate services	10	32
Service provider background	11	32
Available social services	10	28
Justice or police services	8	25
Physical & sexual well-being	9	25
Awareness of & info on IDD	11	22
Service provider responses to diverse SOGIESC	10	21
Behaviours that challenge	5	20
Service users' experiences of challenges	5	15
Understanding sexuality & LGBTQIA+ terms	6	15
Experiences of abuse	6	14
Service provider competency	5	13
Education services	6	11
Service user skills & education levels	7	9