Utilising a Massive Open Online Course (MOOC):

A narrative inquiry on the experiences of caregivers in special care centres with online professional development

By

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DECLARATION

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DEDICATION

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ACRONYMS

BNIM: Biographical Narrative Interpretive Method

DBE: Department of Basic Education

DoH: Department of Health

DSD: Department of Social Development

EWP6: Education White Paper 6

LMIC: Low-to-middle income countries

SCC: Special Care Centre

SPID MOOC: Severe to Profound Intellectual Disability: Circles of care and education Massive Open Online Course

SPID: Severe to Profound Intellectual Disability

WCFID: Western Cape Forum for Intellectual Disability

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ABSTRACT

Background

In South Africa in 2010, the High Court affirmed the right to education for children with severe to profound intellectual disabilities (SPID). Prior to this judgment, these children were considered ineducable and did not have access to education. Consequently, caregivers were often unprepared to shift from a social welfare care model to educational provision due to their limited training opportunities. This study examines experiences of caregivers with online professional development in the provision of education in care environments in the South African context.

Methods

This study utilised a narrative inquiry approach to explore and describe caregivers' experiences of engaging in the *Severe to Profound Intellectual Disability Massive Open Online Course* (SPID MOOC). The Ethics of care framework was identified as a valuable framework for examining development practices and processes, therefore considered suitable as a framework for exploring the care practices and professional development of caregivers of learners with SPID at Special Care Centres (SCCs). Purposive sampling was used to select three caregivers from special care centres and protective workshops. The Single Question aimed at Inducing Narrative was employed for data collection. Data were analysed both deductively and inductively. The Ethics of care framework comprising of four phases - *Attentiveness*, *Responsibility*, *Competence*, and *Responsiveness* - guided the deductive analysis, while subthemes were identified inductively.

Results

The findings revealed that participants demonstrated a significant gain in knowledge, skills and positive attitudes through the online course. Four predetermined themes emerged through the phases of the Ethics of care framework: *Attentiveness*,

Responsibility, *Competence,* and *Responsiveness*. The study highlights how the online course strengthened caregivers' resilience and creativity in facilitating education and care within resource-constrained environments with insufficient support from the state and community. Caregivers attributed their professional and personal development to their participation in the online course.

Conclusion

While caregivers found the online course beneficial to their professional development, it presented certain challenges for other caregivers. Caregivers had context-specific concerns that would affect the participation of those in rural areas, particularly informal caregivers. Their main concerns included limited language options tailored to the South African context, varying levels of computer literacy, device accessibility, and internet connectivity. While these concerns are not exclusive to the South African context, it affects those most in need of training and professional development options.

CHAPTER 1: INTRODUCTION

1.1 Introduction

Despite international and local educational policies, learners with disabilities experience challenges in accessing quality education. The educational needs of learners with intellectual disabilities, more specifically learners with severe to profound intellectual disabilities (SPID), have not been prioritised with little attention given to the training needs of caregivers of learners with SPID.

This chapter highlights the limited professional development opportunities for educators and caregivers which has had a negative effect on the education and care of learners with SPID. In this chapter, alternative training options are proposed which resulted from a call for training.

Furthermore, the researcher's encounters with learners with intellectual disabilities will be discussed. The disparity between policies and practices related to educators' training to provide effective care and education to learners with SPID will be covered in this chapter. The study's rationale, research question, aims and objectives, and summary of the research chapters will be presented as well.

1.2 Background of the study

Despite international policies such as the Salamanca statement (UNESCO, 1994), Convention on the Rights of Persons with Disabilities (CRPD), Article 24 (United Nations (UN), 2008) and the Sustainable Development Goals (SDGs) (UN, 2015) which promote quality education for all, including learners with disabilities, learners with SPID continue to experience challenges in accessing quality education. As a signatory of the CRPD, South Africa has committed itself to the pursuit of quality education for all learners (Du Plessis, 2013).

The South African policy, the Education White Paper 6 on Inclusive Education (EWP6) (Department of Education (DoE), 2001), is centrally situated within the agenda of education for all, seeking to ensure that social justice in education prevails (Du Plessis, 2013). The EWP6 promotes quality, lifelong learning and full participation of all children and adolescents, particularly those with disabilities (Du Plessis, 2013). EWP6 is

aligned with the South African Constitution (Republic of South Africa, 1996; DoE, 2001).

Despite the attempt to redress existing educational inequities through the development of the EWP6, there remains a disparity between policy and practice (Mckenzie, Pillay, Duvenhage, Du Plessis and Jelsma, 2017). Achieving quality education for learners with disabilities has been slow to progress (Kelly & Mckenzie, 2018). Learners with SPID have the same rights as any other learner; society needs to adapt to these learners' needs and facilitate their full participation (UN, 2008).

Amongst the most prominent reasons for the disparity between policy and practice is that educators are inadequately equipped to respond to the educational needs of learners with SPID. Educational rights of learners with disabilities can only be met through adequately trained educators with sufficient support. Educators within the South African contexts are lacking in professional and personal development (Frankel, Gold, Ajodhia-Andrews, 2010; Vergunst, Hansen & Mckenzie, 2021).

According to Mckenzie, Kelly and Shanda (2018), there are limited formal academic training opportunities for teachers at pre-service and in-service levels that focus on educating learners with disabilities. Educators' anxiety and lack of confidence in teaching learners with disabilities is related to their doubts as to the adequacy of their training (Vergunst et al., 2021). In a recent study, teachers acknowledged the need for formal teacher education focused on specialised education for learners with SPID (Mckenzie et al., 2018). Professional competency remains a huge concern amongst educators working with learners with disabilities (Forlin, Keen and Barrett, 2008).

1.3 Experiences of the researcher

While the rights of learners with SPID are not widely known, the disparities between policy and practice became evident to me as a programme manager at a skills centre for learners with SPID. Similarly to the educators, a lack of confidence in my competence to develop and facilitate learning programmes for these learners resulted in anxiety and a need for professional development opportunities. Subsequent to my position as a programme manager, I convened short courses for educators. Delving into the experiences of other educators in accessing professional development opportunities as a course convenor validated my experience as a facilitator. The need

for an in-depth understanding of these experiences ushered in a qualitative research study.

Research evidence would validate these experiences and prompt action towards accessible online professional development for educators and caregivers of learners with SPID in similar contexts and promote the value of online professional development opportunities.

More than ten years in working with learners with intellectual disabilities from impoverished backgrounds has given me an understanding of what it means to facilitate educational activities for learners with intellectual disabilities at a non-profit organisation in the Western Cape, without the necessary training.

The learners accepted into the creative arts and crafts programme developed by *High Spirits Skills Training Centre for the Intellectually*[1] *Challenged* included learners with cerebral palsy, learning disabilities, intellectual disabilities such as autism, Down Syndrome and brain injuries due to traumatic experiences. This programme which was developed as an extra-curricular activity and for post-school activities is tailored to the needs of learners with intellectual and learning disabilities. The impact of the programme was particularly evident in the behavioural shift of the beneficiaries.

> *Peter*[2] *exhibited behavioural issues and resisted participation in the art and dance sessions upon entering the programme. Due to his resistance and the limited space available to beneficiaries, he was replaced by a more willing participant. After much encouragement to adjust his attitude towards the programme, he became open to participation and became a valued participant receiving an award for excellence in every aspect of the programme. Today, he continues to dance with community dance groups and has shared his dance routines on social media*.

Even though we had the opportunity to witness the positive impact of the programme, the adverse effects of limited funding, minimal remuneration for staff, and lack of necessary resources and support remained a stark reality and hindrance to the continued development of our beneficiaries. Beneficiaries' challenges in accessing

[1] High Spirits Skills Training Centre focuses on training persons with intellectual disabilities in various arts and crafts whilst developing life skills which promote their self-confidence and provides opportunities to generate an income
[2] Pseudonym

development opportunities and the fear of their parents for their future compounded these effects.

It was evident that the staff were all passionate about the development of learners, but we were all untrained. While we had minimal control over certain external factors, we could explore the possible professional development opportunities available. In search of professional development opportunities and an interest in the progress of the staff competence, I pursued a postgraduate diploma in disability studies which resulted in a career adjustment. In my position as a researcher assistant within a research unit, I found myself working with online professional development opportunities in the form of short courses for educators of learners with disabilities, disability activists and others in the disability sector. This position gave me an opportunity to participate in the redesigning of online courses which piqued my interest in professional development opportunities for caregivers of learners with intellectual disabilities. These interests were particularly on the effect of these online courses on caregivers' ability to provide effective education and care, and what, if any, hurdles they experienced in accessing online professional development which began the exploration of the extent of the problem as explained below.

1.4. Problem statement

In South Africa, children with SPID were excluded from education as they were considered ineducable. Desperate for care for their children, mothers of these children established special care centres (SCCs) (Geiger, 2012). The Western Cape Forum for Intellectual Disabilities (WCFID), a forum for organisations working with intellectual disability in the Western Cape Province, challenged the notion that learners with SPID were ineducable through litigation against the South African government (Mckenzie et al., 2017). The High Court found that this was an infringement of learners' rights and respondents were directed to take reasonable measures to give effect to the rights of learners with SPID in the Western Cape (Mckenzie et al., 2017). The measures included making provision for the training of persons to provide education for learners with SPID (Mckenzie et al., 2017).

The shift from social welfare to educational provision within SCCs rendered caregivers inadequately trained (Vergunst et al., 2021; Mckenzie et al., 2017; Human Rights

Watch, 2015). Inadequate knowledge and skills have resulted in caregivers having limited knowledge in the care and education needed, and how and when to access and best utilise community and other resources (Vergunst et al., 2021; Reinhard, Given, Petlick & Bemis, 2008).

Currently training is limited to NGOs and learners with SPID teams from the Western Cape Education Department (WCED) offering professional development of caregivers at SCCs (Mckenzie et al., 2017). While there is a huge demand for training, there are limited training opportunities to meet the training needs of caregivers at SCCs. Given the urgent need and the limited training opportunities, we need to understand more about how to provide training that is wide reaching and cost-effective.

1.5. Rationale

The United Nations Educational, Scientific and Cultural Organisation (UNESCO) suggests that different training models should be considered to meet the current training demands (Batchelor & Lautenbach, 2015). It is critical to consider different training models with the limited training opportunities available to caregivers and the unprecedented COVID-19 limitations bringing about a change in the educational environment (Misra, 2018).

Massive Open Online Courses (MOOCs) are considered a potential solution, especially since they offer convenient, accessible and often inexpensive methods to update pedagogical expertise (Misra, 2018; Liu, Carr & Stroebel, 2009). MOOCs are suitable where there is a large demand and a shortage of means and methods to undertake professional development. MOOCs are seen as a useful option for sustainable education and studies suggest a need to examine the quality and outcomes of professional development training programmes (Misra, 2018; Sezgin, 2020; Forlin, Keen & Barrett, 2008).

Even though MOOCs have the potential to significantly expand training opportunities, they have not always been regarded as an ideal alternative in LMICs. However, a recent systemic review challenged this perception by revealing that MOOCs received positive evaluations in over 90 LMICs. Despite ongoing challenges such as limited internet access and widespread time constraints that hinder participation in online learning, the systematic review highlighted that innovative strategies employed by

course developers can mitigate these barriers. Key recommendations from the systematic review emphasises the importance of providing participants in LMICs with the option to access content offline, alongside implementing user-friendly instructional designs that accommodate learners' time limitations. Although language was not addressed in this study, it suggests that considering language as a factor in online learning could be valuable in guiding course developers' decisions regarding language options, particularly within specific contexts (Nieder, Schwerdtle, Sauerborn & Barteit, 2022)

TEDI[3] in partnership with the University of Cape Town's Centre for Innovation in Learning and Teaching (CILT) has responded to the call for training through the *Severe to Profound Intellectual Disability Massive Open Online Course* (SPID MOOC) (Coursera Inc, 2024) in their attempt to address the training needs of caregivers in SCCs. This study addresses the question of whether MOOCs are a possible solution in capacitating caregivers as facilitators of learning for learners with SPID.

1.6. Research question, aims and objectives

The following research question was thus posed:

How do caregivers experience MOOCs that aim to support their professional and personal development in facilitating learning of the learner with SPID in the Western Cape?

The aim of this study was to explore and describe caregivers' experiences of engaging in the SPID MOOC and the objectives of the study were as follows:

1.6.1. To explore the experience of caregivers of online learning with regard to content, structure and delivery of the MOOC and technological factors.

1.6.2. To understand how the content of the MOOC has facilitated change and transformation of caregivers in facilitating learning of learners with SPID.

[3] Teacher Empowerment for Disability Inclusion (TEDI) was a partnership between Christoffel-Blinden Mission, a global organization focused on the disability sector and the University of Cape Town. It aimed to empower teachers to provide quality education to learners with severe to profound sensory and intellectual impairments through training (University of Cape Town, 2024b)

1.6.3. To understand how growth in competence, personal and professional development has been supported by the MOOC.

1.7. Summary of the chapters

A summary of the chapters of this study are detailed below. The focus of each chapter and its purpose in relation to the overall study are highlighted. This dissertation consists of six chapters: an introduction, a literature review, methods, results and a discussion. The last chapter includes recommendations, study implications, the strengths and limitations of the study, and a conclusion.

Chapter one

The first chapter sets the scene for what the research entails. This chapter presents the background of the study, the problem statement and the rationale for this study. In this chapter, the research question, aim and objectives are presented. In addition, a summary of the chapter is covered. This chapter provides a broad overview of the study, what the research is about and what to expect in each chapter.

Chapter two

In this chapter, a review of the relevant literature on the topic is presented. This chapter provides a brief description of learners with SPID. This is followed by circumstances which gave rise to the court case in 2010. The WCFID vs the Government of the Republic of South Africa and Government of the Province of the Western Cape court case culminated in the transformation of the policies for the education for learners with SPID. This chapter also includes the description of the transition of the role of caregivers to educators as a result of the court case. It examines the availability of training opportunities and the accessibility of the alternative option of online learning for caregivers at SCCs. The chapter concludes with a discussion on the Ethics of care framework as a lens for professional development and how it relates to learners with SPID and their caregivers.

Chapter three

In Chapter Three, the research methodologies used in this study are presented. This chapter includes the research design, the selection of study participants, and the pilot study. The data collection and data analysis strategies are covered, as well as the data

management approach. The ethical considerations and trustworthiness and rigour of the research are all covered in this chapter.

Chapter four

In this chapter, the results of the study are presented. The results are categorised. This study made use of the inductive and deductive qualitative data analysis. As a result, the themes are derived from the Ethics of care framework, with sub-themes emerging from an inductive process.

Within the first theme of ‘Attentiveness’, there are the following subthemes: ‘attitudes towards the education of learners with SPID’, ‘attitudinal, behavioural and emotional shift toward caregiving practices’, and ‘identifying the needs of parents and communities’.

The second theme, ‘Responsibility’, includes subthemes such as ‘caregivers’ responsibilities’, ‘shared responsibilities’, ‘resources for the facilitation of learning’ and ‘training for the effective facilitation of education and care’.

‘Competence’ as a theme includes subthemes, ‘meeting learner needs’, ‘creating enabling environments which are conducive to educational provision and good care’, ‘skills development for learners with SPID and their caregivers’, ‘working with families and stakeholders’ and ‘self-care: an integral part of caregiving practices’.

Within the theme of ‘Responsiveness’, the following subthemes emerged: ‘different learners respond in different ways’, ‘fostering a relationship for good care’ and ‘parents’ response to caregivers’ care’.

Chapter five

In Chapter Five, a discussion of the findings is presented. In the discussion chapter, the following sections appear: Attitudes, Responsive environments, Family support, Responsibility, Communication, Local relevance of the online course for the professional and personal development of caregivers, and Cyclical nature of Ethics of care.

Chapter six

This chapter includes the study recommendations and suggestions for future research. The implications, study strengths and limitations are outlined. Chapter Six includes the conclusion of the study.

1.8. Chapter conclusion

This chapter provides an overview of the study giving the reader an understanding of what is to follow in this study. The various sections of the study are included in this chapter as an outline of the study as well. The next chapter provides more in-depth information on the literature available on the topic.

CHAPTER 2: BACKGROUND AND CONTEXT

2.1. Chapter overview

The purpose of this study was to explore the experiences of caregivers with online professional development. This chapter offers the background for the study and establishes the context needed to understand its significance and relevance. To understand their experiences, we need to explore why caregivers require training focused on education for learners with SPID, what their role is in their new capacity, and how they are supported by government interventions. It is also necessary to understand what training opportunities are available to caregivers and the alternative training options available. This chapter also describes the theoretical framework, Ethics of care, which has been described as a useful tool for exploring professional development, particularly in the South African context. Embedding this study in this theoretical framework gives further relevance to this study.

2.2. Defining severe to profound intellectual disability

In order to understand the role of caregivers to learners with SPID, it is necessary to define intellectual disability and the levels of severity. The definition which follows has been extracted from the Diagnostic and Statistical Manual of Mental Disorders, written, edited and reviewed by the American Psychiatric Association (APA). This is a reference book on mental health and brain related conditions and disorders used by healthcare professionals in many parts of the world as the authoritative guide to the diagnosis of mental disorders (APA, 2024). According to the APA (2013), intellectual disability is a disorder with onset during the developmental period that includes intellectual and adaptive functioning deficits in conceptual, social, and practical domains. Within this general definition, different levels of severity are identified. The focus in this study was on severe and profound intellectual disability. Severe intellectual disability manifests as major delays in development such that individuals can understand speech but have limited communication. Although these individuals are able to learn simple routines and engage in self-care, they require supervision in social settings and require family care. Individuals with profound intellectual disability cannot live independently and require help with self-care and close supervision. They have both limited communication and physical limitations (APA, 2013). The boundaries

between the two levels are often unclear, and for ease of reference are combined and and referred to as learners with Severe to Profound Intellectual Disability (SPID). While this terminology has been adopted in the Draft policy for the provision of quality education and support for children with severe to profound intellectual disability (Department of Basic Education (DBE), 2016b), and widely used in policy discussions in the DBE, learners with SPID are more commonly referred to as learners with Profound Intellectual and Multiple Disabilities internationally.

It is evident from this description that learners with SPID have reduced communication which makes it difficult for them to interact with their environment. These learners rely on non-linguistic forms of communication which may be very difficult to identify, interpret and understand. While it may be difficult to interpret the learner's communication efforts, it is the responsibility of the person interacting with the learner to recognise their communication efforts as efforts which if not acknowledged will result in the learners not attempting to communicate. It is the responsibility of the person interacting with the learner, like a parent or caregiver, to find ways to promote effective communication (Mutumburanzou, 2018).

Despite their low adaptive functioning, high support needs and frequently experiencing multiple disabilities (Mckenzie et al., 2017), learners with SPID are able to learn (DBE, 2016b). Their developmental delays might hinder their progress, but creating responsive environments contribute to their development.

2.3. Attitudes

Even though learners with SPID are able to learn, negative attitudes towards people with disabilities remain a hindrance to accessing quality education and community participation. These negative attitudes that exist across the wider social system lead to the isolation, marginalisation and social exclusion of learners with disabilities (Acheampong, Mprah, Owusu & Bediako, 2018).

In many African communities, impairments are attributed to curses, witchcraft and either punishment from ancestors, or the embodiment of sin and social deviance. The most widely held belief about persons with intellectual disabilities is that they are victims of witchcraft that need to be 'cleansed' of their condition before reintegrating into society (Ndlovu, 2016). These negative cultural attitudes affect learners'

participation in educational programmes thus reducing their learning opportunities. In various developing countries, learners with disabilities do not attend school as it is believed that they are disruptive and ineducable (Donohue & Bornman, 2014; Mulovhedzi, Thuketana & Luhalima, 2023).

In addition to hampering these learners' participation in educational programmes, it also affects relationships between stakeholders which are crucial to the education and care of learners with SPID. Caregivers need to build relationships with parents, service providers and community members to provide effective education and care to learners with SPID (Moosa-Tayob & Risenga, 2022).

It has been noted that there is a move towards a western understanding of disability. Traditional African beliefs are being displaced by rights-based approaches. The social model of disability asserts that disability is socially constructed through the attitudes and structures that exist in society. The social model of disability supports the view that persons with disabilities have the right to participation in society. Attitudinal and structural barriers result in the exclusion of persons with disabilities from participation in society. The limited participation of learners with disabilities in education and the exclusion of learners with SPID supports their notion that barriers to participation are a result of negative attitudes. The social model of disability calls for a change in the physical, attitudinal and social environments to enable the participation of people with disabilities in society (Barnes, 2019).

The medical model of disability is viewed as a contrasting approach to the social model of disability. The medical model of disability is less focused on the external barriers and more focused on the internal 'deficits' of the individual. While the medical model of disability supports the right of persons with disabilities to specialised services in specialised facilities, it views these specialised services as a way in which to rectify the 'defects' of the individual. Providing care for the physical needs of learners with SPID is a primary concern (Mckenzie & Macleod, 2012).

Even though these are both rights-based approaches, these dominant moral theories do not recognise the complexity of the needs of persons with intellectual disability. The social model of disability rejects services that are directed at the impairment and resists dependency that is correlated with power, domination of others and threat to exploitation. While the specialised services referred to in the medical model of

disability may be used to enhance participation, participation is not considered a priority for learners with SPID nor in the best interest of the person with SPID. Persons with ID bring a particular dimension of difference in that participation cannot be realised without support and assistance (Kittay, 2011; Mckenzie & Macleod, 2012). Therefore, these models should be considered complementary rather than contradictory.

An approach that views the models as complementary and counters the traditional beliefs and practices within the African context would be more suited to the needs of persons with SPID. Ubuntu, a South African value system, highlights the interconnectedness of people through the assertion that we are all part of a significant relational, environmental and spiritual world. Its focus is building and maintaining a community of mutual caring and support. Ubuntu emphasises collective responsibility, co-operation and recognition of human vulnerabilities (Mugumbate & Chereni, 2020).

Ubuntu represents the complementary nature of the social model of disability and the medical model of disability. It emphasises the importance of embracing diversity and fostering a caring, supportive community. This approach challenges the negative attitudes apparent in the African traditional beliefs and promotes building relationships that are rooted in care, support and co-operation which are crucial to the education and care of learners with SPID. While African beliefs may persist, the fluidity of culture suggests that practices related to the education and care of learners with SPID could be transformed when adopting the principles encompassing the Ubuntu value system.

2.4. Court case

In South Africa, children with SPID were excluded from education on the basis that they are ineducable. These children were not accepted into schools and thus remained at home and in certain instances guardians formed support groups and created informal spaces. Mothers of disabled children desperate for care for their own children responded to the exclusion of their children by starting SCCs. These mothers extended their care to other disabled children as well (Geiger, 2012; Mckenzie et al., 2017).

The WCFID challenged the notion that these learners were ineducable through litigation against the South African government. The applicant's case hinged on a lack of state provision for the educational needs of children with SPID and the assumption

of their ineducability, which they argued infringed on the educational rights of learners with SPID, their equality and human dignity (Murungi, 2011).

The respondents' argument that children with SPID were unlikely to benefit from education implies a narrow understanding of education. It is challenging to prove that a child is incapable of benefitting from education as education is aimed at fullest possible development of all aspects of the child (Murungi, 2011). Education should be responsive to the needs of the learner. To argue that the learner is incapable of benefitting from education implies an inflexibility and unwillingness to accommodate for diverse needs which is a violation of learners' right to education (Murungi, 2011). In addition, scientific literature has debunked the idea that learners are ineducable. These learners are capable of learning and therefore their right to education has to be acknowledged (Mckenzie et al., 2017; Vergunst et al., 2021; Molteno, 2006).

The judgement declared that the respondents (namely, the Government of the Republic of South Africa and Government of the Province of the Western Cape) have failed to take reasonable measures to make provision for the educational needs of learners with SPID in the Western Cape, in breach of their right to education (Murungi, 2011). The respondents were directed to take reasonable measures in order to give effect to the rights of learners with SPID in the Western Cape (WCFID, 2019).

The ruling applies to all relevant government departments in the Western Cape as well as the national departments responsible for various aspects of service delivery related to the needs of learners with SPID. For example, the DBE, Department of Health (DoH) and the Department of Social Development (DSD) are respectively responsible for the management of educational services, health services and services for the social well-being of learners with SPID. The measures the state was directed to take included: ensuring that learners with SPID have access to affordable, quality basic education, and making provision for funds to organisations providing education to these learners, including facilities, staff and the provision of transport. The two directives central to this study are enabling staff of SCCs to receive training and remuneration and making provision for the training of those providing education for children with SPID (WCFID, 2019).

To accommodate for learners' complex educational and care needs, the relevant departments should be working co-operatively and collaboratively in an effort to ensure holistic care and education. The fragmentation of service delivery and contrasting macro and micro policies are not conducive to the provision of holistic care and education to learners with SPID (DBE, 2016b; Wood, Essop, Watermeyer, & Mckenzie, 2019).

Despite the transformational court ruling declared for learners with SPID with its clear directives, DBE has been slow to progress in executing a concrete course of action and providing adequate support to caregivers and SCCs. Even though DBE has acknowledged the important role of SCCs in the education of learners with SPID, this shift from a medical model of disability to a social model of disability should be accompanied by a cultural change. The limited financial provision made for this shift clearly demonstrates that a foundational transformation has not occurred (Mckenzie & Jelsma, 2017; DBE, 2016b).

2.5. Financial provision

In the court case, the applicant stated that the state's financial provision for children with SPID was far less than that provided for other children. In the Western Cape, in 2010, the DBE spent R6632 each year per learner attending mainstream, and R26 767 each year per learner with a mild to moderate intellectual disability attending special schools, there was no provision for learners with SPID (Ngwena & Pretorius, 2012). As a contribution to their education, the DoH paid an annual subsidy of R5092. While the DoH and DSD contributed to the needs of these learners, it was insufficient to meet their educational needs (WCFID v Government of the Republic of South Africa and Government of the Province of the Western Cape, 2011; Murungi, 2011)

While all parties recognised that indirect provision made towards the education of children with SPID was much less than other children despite their needs being much greater, the respondent argued that it had limited resources and competing demands. According to the United Nations Committee on Economic, Social and Cultural Rights (ESCR Committee), free and compulsory education must be prioritised when allocating resources (UN, 1999). In addition, under section 29 of the South African

Constitution, the right of basic education is not limited to the availability of resources (Murungi, 2011).

The responsibility of the state to ensure the implementation of rights of persons with disability in the allocation of resources was reaffirmed in this case (Murungi, 2011).

As a result of the court case, adjustments were made to the allocation of resources for the education of learners with SPID. The DSD took the lead in the implementation of the court order and are currently contributing the following funds to the needs of learners with SPID (WCFID, 2019):

Table 2.1: Services to persons with disabilities funding grid: SCC care cost (DSD, 2022.2023)

	Caregiver: per person per month	Programme implementer: per person per annum	Transport: per child per annum	Unit cost: per child per month
2017/18	1250	76643	1093	1137
2018/19	1290	78942	1126	1171
2019/20	1355	82889	1182	1171
2020/21	1355	82889	1182	1171
2021/22	1355	82889	1182	1171
2022/23	1355	82889	1182	1171

The last column is the existing subsidy (prior to the court order) provided as means to cover the cost related to the provision of day care service for the learner. The first three columns represent the contribution derived from the court order (Right to Education subsidy (RTE). All SCCs receive the RTE subsidy, but the unit cost funding is only received by some of the centres (DSD, 2022).

In addition to contributing to the SCCs for learners with SPID, DSD granted an amount of R1690 to parents for the support of their children. While parents reported benefitting from the SASSA disability grant, the contribution by DSD is commendable but seems insufficient to cover the medical expenses, extra support, transport to medical facilities and quality education (Sefotho, Ferreira & Lushozi, 2021).

In the 2022/2023 annual report of the Department of Education, the WCED reported an expenditure of R36 859 000 on the provision of the necessary support, resources, and equipment to identified SCCs and schools for the provision of education for children with SPID (WCED, 2023). In 2023/2024 an allocation of R34 080 000, 13% of the national allocation of R260 424 000, was set aside for the education of learners with SPID. The committee identified 62 SCCs in the Western Cape, and 1755 learners with SPID in these centres in the Western Cape (Mweli, 2024).

Table 2.2: MTEF allocation – LSPID (Mweli, 2024)

	2023/24 allocation	2024/25 allocation	2025/26 allocation
Western Cape	34 080 000	35 420 000	36 630 000
National	260 424 000	272 120 000	284 311 000

The 2022/23 annual report reported spending in the range of R20 004 427 000 and R1 507 392 000 on public ordinary school education and public special school education as seen in the table below (WCED, 2023):

Table 2.3: Programme expenditure (WCED, 2023)

Programme Name	2022/23			2021/22		
	Final Appropriation	Actual Expenditure	(Over)/ Under Expenditure	Final Appropriation	Actual Expenditure	(Over)/Under Expenditure
	R'000	R'000	R'000	R'000	R'000	R'000
1. Administration	1,464,030	1,456,507	7,523	1,335,830	1,332,420	3,410
2. Public ordinary school education	20,015,866	20,004,427	11,439	18,948,876	18,940,004	8,872
3. Independent school subsidies	143,544	143,544	-	130,508	130,508	-
4. Public special school education	1,511,425	1,507,392	4,033	1,451,271	1,443,830	7,441
5. Early childhood development	986,010	986,010	-	621,102	621,102	-
6. Infrastructure development	2,539,794	2,539,794	-	1,711,264	1,711,264	-
7. Examination and education related services	1,505,247	1,491,257	13,990	1,189,397	1,176,773	12,624
Total	28,165,916	28,128,931	36,985	25,388,248	25,355,901	32,347

The allocation and expenditure of the Department of Education on learners with SPID and SCCs seems considerably lower than what is spent on the education of other learners, despite their significant educational needs.

According to the purpose of the grant, stipulated in the annual report, the conditional grant provides for the support, resources and equipment for the education of learners with SPID which includes human resources specific to inclusive education and the recruitment of staff, the transversal itinerant outreach teams, programmes that support teaching and learning and the facilitation of the use of the learning programmes. If we consider the 2023/2024 allocation of R34 080 000, the amount allocated for each learner's educational needs per month is approximately R1618 (Mweli, 2024).

These figures are indicative of the extent to which the state has prioritised the educational needs of these learners and the value given to the care work at the SCCs. This response to the needs of SCCs, carers and learners with SPID clearly indicates that learners with SPID and their caregivers remain on the periphery of the state's priorities.

Despite legislative transformation, there has not been sufficient improvement in the financial provision of the Department of Education towards the educational needs of these learners and action towards the realisation and practical implementation of their rights.

For a comprehensive understanding of the financial shortfall related to the needs of caregivers at SCCs and learners with SPID, we need to examine caregivers' role and responsibilities within these SCCs.

2.6. The role of the caregiver

Caregivers of learners with SPID are by no means a homogenous group (Moosa-Tayob & Risenga, 2022). Family members, health professionals and educators might provide care over varying periods of time to different extents at different times in the learners' lives. Paid caregivers, or formal caregivers such as educators and nurses, may or may not have formal caregiving training and might work in varied environments such as hospitals, clinics, residential homes, SCCs or protective workshops (Coetzee, 2016). Others who care for children with disabilities include more informal caregivers,

also referred to as unpaid caregivers such as family members like parents, grandparents, siblings and other relatives (Coetzee, 2016).

Caregivers and staff at protective workshops and SCCs are included in the range of formal, paid caregivers. Protective workshops are safe, disability friendly environments providing opportunities to develop and improve the skills of persons with disabilities. These environments give persons with disabilities an opportunity to earn an income to supplement their disability grants. Learners from SCCs where learners with SPID are cared for on a daily basis often transition from these SCCs to protective workshops dependent on the parents and learners' ability and willingness to participate in these programmes (Disability Workshop Development Enterprise, 2024).

Many of the community-based, small informal centres, which are started by mothers of children with SPID develop into large, formal SCCs. With the growth of these centres, mothers who seek care for their children begin working as volunteers and carers. The staff employed at SCCs provide physical care for learners with SPID, including feeding, toileting and washing, and are referred to as caregivers (DBE, 2016b). Due to caregivers' limited understanding of these learners' conditions and insufficient resources, learners with SPID in centres are often treated as sick patients. They are confined to high-sided cots, and simply fed, cleaned and medicated (Geiger, 2012).

Whether it be paid or unpaid caregivers, informal or formal caregivers, the caregiver role is a role with numerous duties and obligations towards the recipient of care. The role could be overwhelming and demanding as it encompasses many duties which place a great deal of responsibility on the caregiver. Caring for learners with disabilities places persistent psychological and physical demands on the caregiver, which could result in the caregiver experiencing high levels of stress (Moosa-Tayob & Risenga, 2022). Caregiver burden, described as the emotional, physical, social and financial implications of providing care to people with disabilities (Diameta, Adandom, Jumbo, Nwankwo, Obi & Kalu, 2018), results in a higher risk of providing poor quality care to care recipients (Moosa-Tayob & Risenga, 2022). In addition to these stressors, caregivers have limited resources which poses a challenge to the provision of optimal quality care to learners with SPID (Moosa-Tayob & Risenga, 2022). To further exacerbate this situation, negative attitudes towards the learner and their family result

in barriers to accessing the necessary care. Communities, caregivers and health workers project an attitude of blame and judgment on families. These attitudes have a direct impact on the accessibility of health, education and social services of learners with SPID and their families (Mkabile, Garrun, Shelton & Swartz, 2021).

In a study conducted on SCCs, Spangenberg et al. (2016) validated that many of the children at SCCs presented with health conditions and require medication. While the information on health conditions was available at these centres, they found that assistive devices for all impairments was not available. Wheelchairs for those in need of them were often available, but many learners with sensory impairments did not have access to spectacles and hearing aids. Augmentative and Alternative Communication devices were also absent from the necessary devices. Transport is of utmost importance to learners attending SCCs, and those who could not afford personal or public transport often did not attend. These gaps in services suggest insufficient support from state departments and community members. Although the responsibility to source the necessary assistive device does not lie with the caregivers, the caregivers would need to initiate partnerships with state departments and other stakeholders to ensure that learners have access to the equipment required. Caregiver-stakeholder relationships are crucial to caregivers knowing who to contact, and who can be relied on to deliver quality services and effectively resolve problems that arise (Kelly & Mckenzie, 2018; Spangenberg et al., 2016)

Caregivers need to build quality partnerships and good professional relationships with government departments and essential services. These partnerships and relationships need to include essential services such as police and nurses, and services in the community (van Beurden, Vereijken, Frielink & Embregts, 2024).

Adopting a family-centred approach to caring for children with SPID and collaborating is valuable to both the family and caregivers. Good communication can help with support interventions and activities, setting and reaching shared goals for learners with SPID, and help with the stress related to caring for learners and coping with the demands of learners with SPID. The well-being of learners with SPID is dependent on good communication between caregivers and parents (van Beurden et al., 2024).

It is important that caregivers recognise the value of learners with SPID and the important contribution that they make to their families. Caregivers should recognise that the perspectives and insights of family are valuable in contributing to their understanding of the learners and their development (van Beurden et al., 2024).

More recently, the role of caregivers has extended beyond meeting the physical, emotional and social need to facilitate learning for learners with SPID (Mckenzie et al., 2017). Prior to the High Court judgment, caregivers were responsible only for the care of learners with SPID. With the recognition of their right to education, caregivers need to ensure that learners participate in an integrated care and education programme (DBE, 2016b). To provide effective care and education to learners with SPID, learners with SPID should be at the centre of relationships, with stakeholders surrounding these learners in what is referred to as circles of care and education. These circles of care and education include family members, stakeholders from various sectors, government departments (legislative policies in SA), and the community. The implementation of policies, community attitudes, intervention from carers, and family life affect these learners, and in turn learners with SPID also influence the organisation of families, the role of carers in education, participation of community members, and the necessary policy revision and responsibilities of government departments. The inter-related relationships should make up the circle of care and learning (Kelly & Mckenzie, 2018; Mckenzie, Kelly & Shanda, 2018).

With this recent development where caregivers facilitate the care and education of learners with SPID, the human resources development for the care and education of learners with SPID is often insufficient with the staff being predominantly made up of ill-equipped and untrained mothers of learners with SPID. Even the most basic individual intervention plans, and basic care needed are challenging to implement (Geiger, 2012). Although there is tension between the roles of caring and teaching, it is important that carers view their role as a child-centred role, including caring and teaching as child-centred practices to achieve better outcomes for learners and carers, alike (Jennings & Greenberg, 2009).

Access to and acquisition of caregiving knowledge, skills and resources assist caregivers in rendering optimal services to learners with SPID (Soni et al., 2020). There is a correlation between caregivers overcoming the negative effects of

caregiving and increased positive feelings towards caregiving, and access to resources, knowledge and skills about carrying out all the caregiving tasks. For instance, where caregivers have access to knowledge and skills, they approach the education and care of learners positively and are often able to cope with the burden of care, but without this knowledge caregiving becomes burdensome and negatively impacts learners with SPID. In addition to resources, knowledge and skills, caregivers require recognition of their role as caregivers by their community and support to render optimal care and education to learners with SPID (Moosa-Tayob & Risenga, 2022).

To gain a full understanding of their role and responsibility towards learners with SPID, caregivers require training and support to perform their role successfully. A training manual developed for caregivers of learners with SPID in the South African context lists the following topics (TEDI, 2019):

Understanding disability

Acknowledging and supporting children with disabilities

Teaching and caring for learners with disabilities

Communicating with families affected by disability

Caring for the carer

Using community and support networks

Understanding the wider context of disability

2.7. Training

Subsequent to the court case, and even now, the training opportunities available to caregivers were either limited or inadequate for the African context. The limited training provided by NGOs was insufficient to assist caregivers in understanding their role as caregivers (Mckenzie et al., 2017). Even training programmes developed by international organisations for caregivers are inadequate as these programmes are not specifically tailored to the needs of caregivers at SCCs within the African context. These programmes provide content for primary caregivers in nuclear families, centre-based training in well-resourced, developed countries for low child-to-carer ratios and

local programmes for specific disabilities (Geiger, 2012). The programmes were found to have limited application in centre-based group contexts and local contexts of under-resourced and under-staffed centres with previously untrained carers for large groups of learners with diverse ages and levels of functioning (Geiger, 2012).

Many caregivers acknowledged that they lacked sufficient skills for caring for learners with SPID as a result of a lack of appropriate training for the provision of education and care to learners with SPID in our context. Caregivers felt that they did not have enough information about learners' disabilities, rehabilitation, and care needs (Vergunst et al., 2021).

Two noteworthy measures were taken to meet the needs of both caregivers and learners with SPID. These measures were a direct result of the directives of the High court judgment. An audit was conducted which provided information on the interventions necessary to provide a suitable level of care and education for learners with SPID. The intergovernmental forum (IGF)[4] proposed a curriculum for children with SPID. Their proposal stated that the curriculum should include learning of life-skills, emotional and social skills, fine motor skills, gross motor skills, communication skills and cognitive development. Following the proposed curriculum, the DBE developed the Learning Programme (LP) as a means for caregivers to practically implement the High Court judgement. The LP, a guide for caregivers to incorporate self-care, communication, social and all aspects of learning into a structure programme, would only be effective if accompanied by training (Spangenberg et al., 2016; DBE, 2016a; DBE, 2016b).

In response to the recommendations from the audit, the WCED decided to employ a multi-disciplinary team. Also referred to as Learners with Severe to Profound Intellectual Disabilities teams (LSPID teams), it consisted of an occupational therapist, physiotherapist, speech and language therapist, learning support teacher and psychologist. In terms of the court ruling, the team is required to provide information

[4] At national level, each department has an inter-governmental forum where ministers meet with MECs and SALGA. A Premier's Inter-governmental Forum (PIF) consists of the Premier, the local government MEC, other MECs, Metro and District Mayors and other Mayors where necessary. The PIF consults on broad development in the province, as well as on the implementation of national and provincial policy and legislation. It also seeks to coordinate the alignment of provincial and legislation. It also seeks to coordinate the alignment of provincial and municipal development planning and strategic planning (Malan, 2012)

on equipment and staffing of the centres as well as on children and families (Spangenberg et al., 2016; Mckenzie et al., 2017).

In addition, these teams were responsible for providing support to learners, carers and care centres. These LSPID teams were required to provide support through the transfer of scarce skills and working collaboratively (Mckenzie et al., 2017). They had an extensive range of responsibilities which included capacity building of care centre staff through direct training and workshops; parental support, counselling and training; screening and assessing learners; compiling group plans, facilitating and implementing learning programmes and activities; and monitoring the implementation of these support programmes, including support and guidance for care workers (Spangenberg et al., 2017). Their practices in the field of learners with SPID in the African context were referred to as innovative (Mckenzie et al., 2017).

Spangenberg et al. (2016) recommend significant measures for the enhancement of services for learners with SPID, for example guidelines and frameworks that respond to the diverse educational needs of children with SPID, appropriate use of measurement tools for individuals, regular assessments on the performance of children and self-care assessments, that takes into account the child's ability and context-specific elements. With training these measures could lead to appropriate interventions for learners with SPID. These recommendations suggest gaps in the system, but it might be premature for caregivers who are already lacking basic care skills.

A recent update provided by the Portfolio Committee on Basic Education indicated that non-accredited training was provided to 40 caregivers in the Western Cape, and 383 nationally. Accredited training programmes included 510 caregivers nationally and training on a 12-month ECD NQF level 4 and 5 programme commenced in January 2024 for caregivers in the Western Cape (DBE, 2024).

Despite having taken extensive steps in developing policies and programmes, many more caregivers at SCCs are in need of training. Caregivers remain motivated and passionate about providing care and education to these learners, despite the current situation of SCCs. SCCs continue to comprise of mostly untrained volunteers and carers taking care of learners with complex needs in severely under resourced settings

with a disproportionately high child-to-carer ratio for no or below minimum wage (Geiger, 2012).

2.8. Professional development

Professional development is perceived as the pathway to increased competence (Huberman, 1995). Guskey (2002) details this notion by suggesting that 'professional development' involves developing and improving skills to better meet the needs of learners. Similar views are shared by Tronto (1993) who refers to competence as knowledge about how to care and perform caring tasks. Professional development leads to attitudinal changes of educators and caregivers which results in positive changes in learning outcomes of learners (Guskey, 2002).

Based on literature, competence leads to increased confidence of educators and caregivers. Strengthening caregivers' confidence and competence ensures more positive responses to providing care because they perceive themselves as skilled in their ability to provide care and meet care demands (Sandy, Kgole & Mavundla, 2013; Reinhard et al., 2008, Vergunst et al., 2021).

While professional development of educators and caregivers is imperative to learners' development, it is in crisis in the world's poorest countries (Lawrie & Burns, 2013). Due to this crisis, the effectiveness of the traditional system is being questioned. Professional development should not be limited to formally structured approaches but rather allow participation in informal practice-based networks (Batcherlor & Lautenbach, 2015). Furthermore, the inefficacy of the traditional system has resulted in a call for more innovative training models and approaches to meeting the training demands (Batchelor & Lautenbach, 2015). In addition to this crisis in professional development, the recent health crisis has seemingly exacerbated this situation.

There was a global search for solutions to the educational crisis during the pandemic. Educators had to adapt to new pedagogical concepts and modes of delivery of teaching for which they had not been trained. To remain relevant, universities had to reinvent their learning environments. Although educators and students in a range of learning environments were deeply impacted by the educational crisis during the pandemic, this experience was not exclusive to these settings. Trainers and training

institutions across various sectors were also significantly affected (Jones & Sharma, 2020; Rodriguez & Cobo, 2022).

Despite the negative effect on the educational sector, it became evident during the COVID pandemic that new technologies and innovative teaching and learning practices required serious consideration. The effect inspired new ways of learning.

Education changed dramatically with a distinctive rise of e-learning. It resulted in the largest 'online movement' in the history of education which seems to have become firmly embedded in the learning environment. The literature indicates that a new hybrid model of education will emerge, and the integration of information technology will be further accelerated. Online education, which is rapidly becoming an integral component of education, needs to be seriously considered especially with the critical demand for professional development (Jones & Sharma, 2020; Rodriguez & Cobo, 2022).

We are in an era where information is no longer available to only a few. New knowledge is created and shared in new spaces supported by emergent technologies, and MOOCs have a firm foothold in this space (Batchelor & Lautenbach, 2015).

2.9. Massive Open Online Courses (MOOCs)

MOOCs are considered a potential solution, especially since they offer convenient, accessible, and often inexpensive methods to updating pedagogical expertise (Misra, 2018; Zakharov, Carr & Strobel, 2009). MOOCs are offered by over 950 institutions, cover a range of topics and are accessed by over 180 million participants across the world (Nieder, Schwerdtle, Sauerborn & Barteit, 2022).

MOOCs are organised courses with specific learning objectives. They have a set duration and are offered exclusively online through a platform which facilitates engagement between participants. Theoretically, these MOOCs can be taken by an unlimited number of participants, regardless of geographical locations (Batchelor & Lautenbach, 2015).

MOOCs can increase access to high quality education and can train untrained or less trained people to become more professional in their practices. Professional

development is therefore noted as one of the main reasons for enrolment (Batchelor & Lautenbach, 2015; Misra, 2018).

More specifically, for the educational sector MOOCs are seen as a tool to acquire knowledge, skills and competencies in economic, social and cultural realms of society (Misra, 2018). MOOCs are particularly beneficial to educators as professional development opportunities as the platform enhances their professional network, forming communities of learning, observing online learning and sharing ideas, best practices and lessons learned (Bakogianni, Tsitouridou & Kyridis, 2020).

For optimal effect, MOOCs should be endorsed by government and management, have relevance to the local context and form part of an existing educational structure. MOOCs has brought innovation and change to the field of education, but also certain challenges (Bozkurt, Akgün-Özbek & Zawacki-Richter, 2017; Zawacki-Richter, Bozkurt, Alturki & Aldraiweesh, 2018).

2.10. MOOCs in LMICs

MOOCs become more relevant for professional development in those countries having a shortage of means and methods to provide professional development opportunities to large numbers, especially in episodes of changing pedagogical practices (Misra, 2018). MOOCs should be especially appealing and have immense potential in developing countries given the admission, travel and housing costs involved in participating in university courses. In spite of the benefits related to MOOCs, such as engagement opportunities between participants across the globe, the number of participants attending in LMICs remains low (Pasha, Abidi & Ali, 2016)

There are contrasting views on participants' immersion in technology for educational purposes. Some consider these tools essential for learning strategies, others find it detrimental to learners if used excessively, while many find that disruptive technologies can create new learning opportunities and improve students' outcomes While these contestations exist, there are perspectives acknowledging the broader concerns related to access to and participation in MOOCs (Pasha, Abidi & Ali, 2016).

On a global scale, issues related to accessibility and participation in MOOCs include pedagogical issues, instructional design, resources, technologies used, engagement

patterns and learner dropout rates (Batchelor & Lautenbach, 2015). Specific to LMICs, technical limitations have been identified as one of the reasons for non-completion of courses and limited engagement. Technical limitations such as participants' limited access to computers or low computer literacy; internet access issues; high cost of internet access; technophobia or fear of embracing technology and even lack of interest in learning technologies hampers the participation of potential users. Internet access is a central issue and continues to be widely cited as issues related to participation in MOOCs. In additional to these technical issues, LMICs experience power shortages. In LMICs where this occurs, it is important that participants have alternative options in accessing online training materials such as offering an option to view course materials offline (Pasha, Abidi & Ali, 2016).

Time constraints is also considered a challenge for those from LMICs who would like to participate in online learning. These time constraints relate to completing work obligations, home and family demands and learning (Pasha, Abidi & Ali, 2016).

Language has also been identified as one of the main barriers to participation in MOOCs. 90% of the Coursera courses are in English which discourages some potential users (Sanchez-Gordon and Lujan-Mora, 2016).

Due to the abovementioned constraints, considerations need to be given to the course design for an audience in the LMIC. These considerations include level of computer literacy of the student, the availability of electricity and internet connection in their setting. The course design should be user-friendly, that is easy to navigate, and not too technically challenging. The course activities should be simple since independent learning which is an element of online learning might be fairly new to the student. Course videos should be downloadable ensuring flexibility, i.e. doing the activities in their own time (Pasha, Abidi & Ali, 2016).

Those who are acquainted with the technological debate suggest that some approaches can be taken to alleviate certain challenges to professional development in LMICs and make use of MOOCs a sustainable and effective option. The potential of MOOCs in developing countries needs to be identified, understood and tackled to have a greater impact and wider acceptance. This could be achieved through training institutions in LMICs offering MOOCs, thereby adding the voices from local contexts

to the narrative. It has been stated that researchers and educationists should come forward with better solutions to utilise the full potential of MOOCs for different segments of educators living and working in different economic, political, and social settings (Pasha, Abidi & Ali, 2016; Batchelor & Lautenbach, 2015).

In the next section, we see how the University of Cape Town (UCT) has responded to the call for caregivers' professional development, providing a concrete representation of what has been suggested for higher education institutions in LMICs.

2.11. Severe to Profound Intellectual Disability - Circles of care and education MOOC

UCT's Centre for Innovation in Learning and Teaching (CILT), in partnership with the Teacher Empowerment in Disability Inclusion (TEDI) project, has responded to this call for training through the development of MOOCs. CILT is an organisation that serves the UCT academic and student learning and teaching needs with a focus on staff development, course and curriculum design, and educational technologies (UCT, 2024a). TEDI, which has now evolved into a research unit at UCT, was a partnership between Christoffel-Blinden Mission, a global organisation focused on the disability sector, and UCT. It aimed to empower teachers to provide quality education to learners with severe to profound sensory and intellectual impairments through training (UCT, 2024b).

The research conducted by TEDI supported the development of *The Severe to Profound Intellectual Disability – Circles of Care and Education* MOOC which is specifically designed for the advancement of caregivers working in SCCs with learners with SPID (Mckenzie, Kelly & Shanda, 2018; Coursera Inc., 2024).

This course is about caring for and educating learners with SPID. This course adopts an ecological approach that positions the child at the centre of many levels of support need such as parents, family, caregivers, healthcare workers, business owners and community members. Each person plays an important role in the life of a person with an intellectual disability. The levels of support around the child are circles of care and education (Coursera Inc., 2024).

The course aims to provide the participant with a greater understanding about intellectual disability, levels of severity and the history of intellectual disability. The course looks at lifelong learning, the learning process and maximising opportunities for learning. It provides participants with an opportunity to gain an understanding of how to support learners with SPID, thus ensuring that these learners reach their full potential as participating members of society (Coursera Inc., 2024).

The range of experts on the course give consideration to how best learning can be facilitated through looking at learners' learning support needs, planning activities for learning programme and empowering multiple people who work in a team to care and educate learners with SPID. This course also focuses on rights, advocacy and relationships of care, and empowering and caring for caregivers themselves (Coursera Inc., 2024).

This is a four-week beginner course, requiring two or three hours per week. It is offered in English, and subtitles are available in French, Portuguese, Russian and Spanish. The completion of the course is based on the participant passing all graded assignments (Coursera Inc., 2024). It also offers platforms and activities which encourage interaction between participants such as the discussion forums and peer-graded assignments (Coursera Inc., 2024).

Data on course participants are available on the platform. This course data shows that in December 2024 more than 20% of the course participants are 'unemployed and looking', while more than 45% are 'employed full-time'. More than 40% of the participants have a qualification. Due to the global reach of the online course and broad statistical data, it is challenging to draw conclusions on the employment status and level of qualification of caregivers in South Africa. However, the online course offers caregivers access to an extensive network of participants with international experience and global perspectives (Coursera Inc., 2024).

The course development was guided by voices from our local context. The developers were cognisant that experiences and perspectives differ within the disability sector. To provide comprehensive content and a multiplicity of voices, a range of stakeholders collaborated on the development of the course. Collaborators with expertise in their respective fields, including CILT, TEDI, Division of Disability Studies and Disability

Services unit from UCT, and WCFID with their caregivers and professional therapists contributed to the content and design of the course.

To identify the hurdles with online learning and understand how the course contributed to the personal and professional development of caregivers, a study that focused on the experiences of caregivers was conducted.

2.12. Theoretical framework: Ethics of care

Ethics of care is aimed at flourishing of those who need care, particularly those who are inevitably dependent. It is defined as a moral theory which places our connections to others and caring relationships central to morality (Kittay, 2011). Fisher and Tronto define 'care' as a "species activity that includes everything we do to maintain, contain, and repair our 'world' so that we can live in it as well as possible. That would include our bodies, ourselves, and our environment" (1990:40). Since this moral theory is seen as a process of human existence, it would apply to the care practices of caregivers at SCCs and the processes and practices affecting their care practice.

From a disability perspective, 'care' is described as constituting three facets: Labour, attitude and virtue. As labour, care requires that caregivers have adequate skills to attend to their own needs as well as the need of the learners and their families. Care as an attitude refers to being invested in the well-being of these learners and includes a positive, affective bond with them and their families. As a virtue, care requires a shift from the caregivers' interest in their own life situation to that of the learners with SPID. While labour can be done without the appropriate attitude, good care cannot be achieved with an attitude which is not responsive to another as this is essential in understanding what the other requires. This approach to the 'care' is beneficial when exploring the attributes required of caregivers in providing good care to learners with SPID (Kittay, 2011).

Although Fisher and Tronto (1990) provide a broad perspective of 'care', and Kittay (2011) explores a more nuanced perspective of Ethics of care framework through a disability lens, they agree that care is a public and political activity (Bozalek et al., 2014).

Ethics of care alerts us to the fact that relationality and particularity are important considerations when exploring professional development of caregivers in relation to their care practices as well as the curriculum design and implementation of the online course.

Existing within these relations are significant power differentials. It therefore seeks to reveal the practices of power and allows a multiplicity of voices in relation to understanding intellectual disability in context. Rather than being bound to fixed notions of intellectual disability, Ethics of care encourages the adoption of a situational understanding that recognises competence in relation to context and collaboration with others (Bozalek et al., 2014; Mckenzie & Macleod, 2012; Held, 2006).

This is particularly relevant to learners with SPID and caregivers in our context considering the societal perceptions about the education and care of learners with SPID within a resource-constrained context and the critical role of and support required from stakeholders (Wood et al., 2019). Caregivers and learners with SPID are differently positioned in social relations and society as a whole as demonstrated by the perceptions and practices of the state and various stakeholders. To ensure a holistic and effective approach to the education and care of learners with SPID, collaboration between parents, stakeholders and caregivers is imperative. With limited support from stakeholders, contextual challenges in the provision of education and care to learners with SPID need to be given serious consideration (Bozalek et al., 2014; Held, 2006).

To be considered competent in the education and care of learners with SPID, caregivers need to be mindful of the contextual challenges within a resource – constrained context. In addition, they need to remain cognisant of how caregivers and learners with SPID are differently positioned in social relations and the value of various perspectives, particularly those of parents in gaining a deeper understanding of intellectual disability in pursuit of effective education and care for these learners. Collaboration between stakeholders within our context plays a crucial role in the provision of care and education of learners with SPID.

By bringing in the contextual complexities of situations and environments, it draws

attention to the moral issues that arise in contexts. These contextual complexities which include language proficiencies are particularly relevant when considering course content, structure and delivery of online courses for caregivers in resource-constrained environments where limited technological expertise, access to devices and care knowledge exists.

It is crucial to recognise the significance of the care work of caregivers in forming a healthy, well-functioning society and, therefore, important to extend care to caregivers as well (Kittay, 2011). Professional development of caregivers plays a pivotal role in the care required by caregivers.

Bozalek et al. (2014) highlights the *Ethics of care* as a valuable framework for examining development practices and processes aimed at addressing identified needs. In the South African context, this study demonstrates the framework's relevance, making it an appropriate lens for exploring the experiences of caregivers in SCCs. This framework provides insight into how the SPID MOOC has contributed to caregivers' professional development. This framework is particularly important since rights-based approaches and dominant moral theories have proven insufficient in resolving the problems caregivers contend with in their daily work with learners with SPID (Kittay, 2011; Mckenzie and Macleod, 2012).

Tronto (1998) describes four stages of practices and virtues which are helpful in understanding caregivers' experiences with online professional development:

Ethics of care is an integrated, holistic process which involves four phases of care which includes paying attention to the need for caring, assuming responsibility to meet the need, performing the necessary caring tasks and responding to the care received.

The corresponding moral qualities of each phase respectively are: attentiveness, responsibility, competence and responsiveness (Tronto, 1998). The cyclical nature of care is evident in how attentiveness and responsiveness relate to each other.

Attentiveness refers to suspending one's own suppositions and feelings to acknowledge and understand the person's need correctly, while responsiveness is a different way of understanding the needs of others. There will be some form of responses to the care given which will indicate whether the care received met the

identified need. While it is true that the distinguishing feature of Ethics of care is responsiveness of the care receiver rather than attentiveness of the caregiver, caring requires caregivers to recognise learners' needs in order to respond to them. Through examining the person's responses, one can determine which practices work best. Attentiveness and responsiveness can help to guide what caring practices are more effective than others (Noddings, 2013; Sevenhuijsen, 2018).

The cyclical nature of Ethics of care extends beyond the caregiver-learner relationship to encompass caregivers' interactions with the curriculum design and implementation of the online course. By examining caregivers' care practices after completing the course, it becomes possible to gain an understanding of how the online course supported the caregivers' professional and personal development in facilitating the learning of learners with SPID.

The phases of Ethics of care are as follows:

Phase one is caring about. This is the practice of recognising a need for care and is associated with the virtue of attentiveness. This phase involves identifying a need, then recognising that the need should be met, while taking into account that each person is differently located economically, socially and culturally. Tronto (1998) argues that ignoring this need is a 'moral evil'. This phase highlights the importance of emotions as a guide in determining what is morally right and its potential to enable moral action (Tronto, 1998; Barnes, 2012; Held, 2006),

The right to education for learners with SPID has been acknowledged through the court case but can only be realised through the virtue of attentiveness. Caregivers and other stakeholders like parents need to change their attitudes towards learners with SPID and develop an emotional attachment for the virtue of attentiveness to be applied to learners' care and education. The complexity of each learner's educational needs requires the attentiveness of caregivers and other stakeholders (Tronto, 1998; Kittay, 2011).

Phase two is taking care. This involves the practice of assuming responsibility for the need and is associated with the virtue of responsibility. Kittay (2011) and Held (2006) along with others like Tronto (1998) and Barnes (2012) agree that the practice of taking care is largely the responsibility of the state. The state needs to take responsibility for

how to address the need (Tronto, 1998; Barnes, 2012; Held, 2006; Kittay, 2011). Based on the public Ethics of care (Held, 2006; Kittay, 2011), it is the obligation of the larger society to enable and support the relations of dependency in intimate settings. Through the court case, it was made clear that these learners had a right to education and the state had to take the necessary steps to fulfil this need. As a result, the state allocated funds, human resources and support to the education of learners with SPID, but the steps taken thus far have been deemed insufficient to accommodate the needs of these learners and educators. Kittay (2011) takes this further by stating that it is not only the responsibility of the state, but the community and stakeholders to scaffold the agency attempts of these learners. Responsibility, from Bozalek et al. (2014) and Tronto's (1993:132) perspective, is 'embedded in a set of implicit cultural practices, rather than a set of formal rules or series of promises' which implies that the education of learners with SPID will continue to receive minimal attention, if our cultural practices towards learners with SPID are not modified. Furthermore, without the necessary support from state and stakeholders, these learners' right to education and the support required by caregivers will not be realised (Kittay, 2011).

Phase three is caregiving. This involves the practice of hands-on work of caregivers or stakeholders attending to the recognised need and is associated with the virtue of competence. The caregiver can only provide adequate caregiving if they have skills or competence to meet the need (Tronto, 1993).

With the shift from social welfare to educational provision, it is clear that caregivers are unable to meet learners' need for education. Caregivers were only able to provide basic care, having no experience or skills to meet the educational needs of these learners. Failing to provide good care, means the need is not met and taking care on a superficial level means that care is not actually taking place (Bozalek et al., 2014) which suggests that caregivers require training to meet these needs.

Professional development could provide the necessary skills and knowledge required to ensure that caregivers are able to meet learners' educational needs, but it is only meaningful if it results in an adjustment to their practices and meets the educational needs of learners with SPID. Competence is achieved when caregivers collaborate with parents and stakeholders, have gained a deep understanding of intellectual disability and demonstrate mindfulness of their context, and how to effectively apply

their knowledge and skills to accommodate for the education and care of learners with SPID.

Phase four is care-receiving. This practice involves the recipient's response to the care provided for the recognised need. Care-receiving is associated with the virtue of responsiveness (Tronto, 1993; Bozalek et al., 2014).

Care can only be complete upon the acknowledgement of the care recipient, in this case the learner with SPID. The learner with SPID could either provide a verbal or behavioural response to the need which has been recognised, taken care of and completely met (Tronto, 1993). For caregivers to be able to recognise verbal or behavioural responses and interpret these responses and then adequately meet the need, they would have to be open to different ways of communicating and responding and know how to address this need. Learners with SPID communicate in different ways and will only be willing and comfortable to communicate if they sense attentiveness from caregivers. Caregivers will be able to tell whether the need has been addressed, or alternative action is required through the response of the learner.

This cycle may continue and can only be continued when both caregivers and learners are confident and comfortable with the process.

2.13. Chapter conclusion

This chapter has explained the importance of training opportunities for caregivers at SCCs and protective workshops. This chapter has shown that caregivers need to be adequately trained and supported by relevant stakeholders and government to counter the barriers to facilitating effective good and education for learners with SPID. However, the support and training required has been minimal due to a lack of urgency, will and insight of government and other stakeholders and service providers. There is limited professional development opportunities available to caregivers, and it will continue to be so unless alternative options such as online professional development are taken seriously. For international and local policies, and more specifically the declaration of the High Court to be realised, alternative training options for caregivers need to be a priority of the government and higher education institutions. This chapter has indicated that further attention needs to be given to caregivers' experiences with online professional development opportunities. This chapter has introduced the idea

of viewing the professional and personal development of caregivers at SCCs through an Ethics of care lens and demonstrated the relevance of this framework for the purpose of this study. The next chapter describes the methods used to explore caregivers' experiences.

CHAPTER 3: METHODOLOGY

3.1. Chapter overview

This chapter describes the methodology used in this study. It includes sections on research design, recruitment and selection of study participants. It also includes the data collection process, the pilot study and data analysis, as well as the data management approach. This chapter concludes with ethical considerations and trustworthiness credibility, transferability, dependability and confirmability.

3.2. Research design

The aim of the study was to explore the perceptions and experiences of the participants with online professional development. Caregivers are often silenced because of the devalued position they hold in society due to their association with learners with SPID. We have been mindful of this exclusion in our selection of approaches and adopted approaches which value the voice of the caregivers, while supporting the aim of the study. The qualitative approach supports our ideals and aims for this study, as it facilitates the process of exploring the experiences of participants' perceptions of a phenomenon in their own voice, while empowering the participant (Guba & Lincoln, 1994; Creswell, 2007; Creswell, 2014).

Narrative inquiry, a qualitative approach, supports our pursuit towards hearing the voices of the participants and gaining insight into their experiences. As humans, we are natural storytellers (Butina, 2015). This is particularly true within the African context (Tuwe, 2016). Narratives provide a window into people's experiences. They delve into why a person acted as they did and how these actions have positively or negatively contributed to their goals (Polkinghorne, 1995; Polkinghorne, 1988). While the voice of the marginalised is often absent in academic research, narrative inquiry gives caregivers the ability to express themselves and have their voices presented as valued knowledge (McAlpine, 2016; Denzin & Lincoln, 2011).

The Biographical Narrative Interpretive Method (BNIM), a form of narrative inquiry, is specifically focused on enabling participants to express their life experiences. This process gives rise to a meaning-making process of individuals' life stories which is important to gain an understanding of or insights into their choices. While BNIM

provides researchers with a data generation framework to capture the experiences of the participant (Corbally & O'Neill, 2014), it continues to facilitate the empowerment of the participant (Peta, Wengraf and Mckenzie, 2018).

It is most important to note that this study is not an evaluation of the SPID MOOC, but rather an exploration of the experiences of the caregiver with online learning. As such, it was designed to create knowledge about how the structure, content and delivery mode of online learning could be used to empower caregivers.

Narrative inquiry including BNIM is largely associated with thick descriptions which result in in-depth data (Butina, 2015). Thick descriptions provide the details, the emotions and the complexities of social relationships (Denzin, 2001). With narrative inquiry opening up pathways for the voice of the participant, and Ethics of care focusing on the needs within relationships, we have a methodology which provides ethical guidance in this study. Ethics of care is considered a starting point for narrative inquiry, and acknowledges the importance of relationships, and promotes the well-being and maintenance of these relationships (Maio, 2018).

Care can be directed at strangers as well as those we have intimate relationships with. This approach has been used as a lens in the caregiver-learner relationships and extended to the research-participant relationships within this study with the selected participants.

3.3. Study population

In this study, we focused on caregivers at SCCs and protective workshops.

3.3.1. Sampling method

This study adopted a purposive sampling method to select three caregivers from SCCs and protective workshops to participate in the study. Purposive sampling is used in qualitative research to select and identify knowledgeable participants who are able to articulate their experiences related to the subject matter of the study (Rule & John, 2011; Patton, 2002; Creswell & Plano Clark, 2011).

Due to the difficulty in accessing and recruiting participants who met the criteria, the snowballing technique was used in which participants identify other potential

participants (Parker, Scott & Geddes, 2019). This proved to be effective in recruiting additional participants.

While the purposive sampling technique makes the most effective use of limited resources, the snowballing technique does not recommend large samples. With the limited participants, the combination of the purposive sampling technique and snowballing technique works well with BNIM (Valerio et al., 2016; Corbally & O'Neill, 2014).

Inclusion criteria: The participants were required to a) have completed 80% of the SPID MOOC; b) be employed and experienced as a caregiver at SCC; c) be 18 years of age or older, and d) be sufficiently conversant in English, as any meaningful engagement with the SPID MOOC is dependent on the caregiver being proficient in English.

Exclusion criteria: a) qualified teachers; and b) any caregivers who have less than 12 months experience.

3.3.2. Recruitment

Multiple strategies for recruitment were decided upon early on in the planning of the study as we were cognisant of the difficulty in accessing caregivers who met the inclusion criteria. As a qualitative research study, the emphasis for the study was on obtaining sufficient participants to reach data saturation, while ensuring that they were representative of the population. The following strategies were used:

Participants of the online course were invited to participate in research studies. A survey, posted by the CILT team and completed by all course participants, made it possible to identify the caregivers in South Africa who had participated in the course. The caregivers amongst those participants were contacted to participate in this study.

CILT agreed to post a survey inviting participants of the online course to participate in this particular study.

An invitation to participate in this study was also sent to organisations such as WCFID, and SCCs. Caregivers who had participate in the in-person training provided by TEDI

were added to a WhatsApp group and invited to participate in the study. Various networks such as the care workers' network were used to recruit participants.

While many of the caregivers were interested in the online course and this study, principals of the SCCs acted as gatekeepers. They were protective of their caregivers' free time. Others stated that they had time constraints and demanding work schedules and had not participated in the online course. Among the reasons for their lack of participation in the online course was limited access to devices and data, and internet connectivity. While caregivers revealed that they felt their technological skills would hinder their effective participation, others stated their preference for in-person training.

These hindrances to participation in the study developed an awareness of the demands on caregivers and their needs. As a result, new strategies were considered to accommodate the needs of the caregivers. Adopting new strategies required an adjustment to my attitude towards the recruitment process and the caregivers.

Where caregivers had not completed an adequate portion of the online course due to technical and financial difficulties, I offered to cover the data costs of the online training or cover the cost of the certificate on completion of the course. This resulted in delays in collecting data.

Each potential participant received an information letter (Appendix iii) and certificate of consent (Appendix IV) via email. Once they confirmed their participation in the study, negotiations around interview dates and online platforms took place, and data collection followed.

3.3.3. The profile of the participants

Table 3.1: The profile of the participants

Caregivers' pseudonyms	Gender	Age	Employment	Location (live)	Location (work)	Level of education

Sophia	Female	41	Programme implementer at SCC	Worcester, Western Cape	Worcester, Western Cape	NVQ[5] level 3
Nylethu	Female	29	Caregiver at a SCC	Worcester, Western Cape	Worcester, Western Cape	Certificate in homebased care level 1, 2, 3
Nokuthula	Female	38	Caregiver at a protective workshop	Philippi East, Western Cape	Mitchells Plain, Western Cape	Higher certificate in disability studies, matric

3.4. Data collection

The data collection process was based on BNIM which included a Single Question aimed at Inducing Narrative (SQUIN). A pilot study was used to refine the SQUIN for the first session.

3.4.1. Pilot study

A pilot study is a pretest of a research instrument, which allows a novice researcher to practise a research technique and make adjustments (Shakir & Rahman, 2022; Abdul Majid, Othman, Mohamad, Lim & Yusof, 2017). This pilot study was used to test the SQUIN which is a single, carefully designed question used to prompt the interviewee to provide a free narrative on the topic. The SQUIN is a useful means of eliciting data which empowers participants to begin, construct and end their narrative on their own terms and uncovers what participants want to say, not what the researcher wants them to say as can be the case in semi-structured and structured interview schedules (Wengraf, 2008). There is always the risk that the caregiver might go off topic, and the way in which this risk can be limited is through testing the SQUIN and implementing the necessary changes (Shakir & Rahman, 2022).

[5] National Vocational Qualifications (NVQs) are work-based awards in England, Wales, and Northern Ireland that are based on training and assessment. NVQs are a lifelong qualification that doesn't expire and are achieved by producing evidence relevant to your role and responsibilities (SVT Ltd, 2025)

For this study, the SQUIN was based on the objectives of the study. For the pilot, it was posed to a participant of an in-person course with similar content who had previously held a position as a caregiver at a special care centre. The SQUIN was also shared with peers who then provided input. As a result, the SQUIN was shortened and bracketed text and instructions were included.

This pilot study proved to be particularly helpful. Not only did it result in the refinement of the SQUIN, but the practice session made me aware of the challenges of conducting online interviews. As a result, I was able to prepare for these challenges which made me more comfortable and confident with the participants of the study and enabled me to create a relaxed, intimate online environment. The pilot study was also helpful in understanding the need to remain engaged with participants of interviews conducted online. This process was particularly helpful in preparing for these interview sessions and developing research skills.

3.4.2. Data collection method: Biographical Narrative Interpretive Method (BNIM)

BNIM interviewing is predominantly an open narrative interview process. This process (which can involve two or three sub sessions) always begins with a SQUIN, a single framing question which elicits an uninterrupted story from participants (Wengraf, 2001; Wengraf, 2008). Questions based on the Particular Incident Narratives (PINs) were posed in the second session. The first two sessions took the form of in-depth interviews with caregivers. In-depth interviews involve probing questions as a means to acquire data and gain a thorough understanding of the subject matter (Guest, Namey & Mitchell, 2013). The third session involved a focus group discussion including all caregivers. The interview process was based on the BNIM interview structure, with a few adjustments as described below.

While narrative inquiry is centred around human interaction and building trusting relationships, planning a research study during lockdown limited the options (Riesmann & Quinney, 2005). All interviews were conducted online. The participants chose their preferred online platform which was Zoom. When Zoom is configured for cloud recording, it generates automatic, live transcriptions which proved to be helpful

with timeous completion of transcriptions. While online interaction makes building trusting relationships with participants challenging, it afforded us the opportunity to reach caregivers in different regions which resulted in more robust data. Consistent and continuous engagement with caregivers via various communication channels, negotiating scheduling of interviews, regular updates on the progress of the study and regular check-ins proved to be helpful in building these relationships.

As part of the entire process, I gave the participants the opportunity to engage with code switching. Code switching refers to the use of two languages within a sentence or discourse (King & Chetty, 2014). It makes communication more meaningful between the interviewer and the interviewee. Caregivers felt comfortable enough to share in English and therefore declined the offer.

The first interview focused on the SQUIN which assisted participants in telling their story. In this portion of the collection of data, I had minimal control and focused on listening, supporting and reassuring the participant (Wengraf, 2013).

The SQUIN which was developed was:

I am particularly interested in ALL your experiences as a caregiver working with learners with SPID.

I am particularly interested in the events and experiences as a caregiver prior (before) you did the MOOC, during (while) you were busy with MOOC and after (once you had completed) or engaged with the MOOC (repeat). Any experiences with the content, structure and delivery of the MOOC (repeat). Any occurrences related to online learning and any matters related to you personally and professionally (repeat).

Your work at the special care centre (workshop) is significant to you, and all aspects are relevant. All your work at the special care centre before you started the MOOC, while doing the MOOC and once completing the MOOC is both relevant and significant to me too.

Please share any emotions, feelings and happenings in detail, in no hurry. Start wherever you like, I'll listen, take notes and ask questions later.

At the start of the interview, I read and explained the consent form and the information letter which included the purpose of the study, confidentiality and voluntary participation and withdrawal from the study. Participants were reminded that they had the option of code switching. Again, all participants declined the presence of an interpreter. I informed the participant that all interviews would be recorded with their consent and invited any concerns and questions from the participants with regards to any aspect of the study.

Prior to sharing the SQUIN, the interview process was shared with each participant. The participant was informed that I would pose one single question; this question would be posted in the chat box for ease of reference and there would be no further interruptions. I explained that I could repeat the question or parts thereof, but that would be the extent of the commentary.

Participants seemed uneasy at first with the idea of a single question, but as they continued, they became more comfortable with the format of the interview. Where participants seemed hesitant in their responses, I reassured them which motivated them to continue. Having the question in the chat box seemed to be reassuring to participants since they could refer to the question when necessary.

Once the caregiver had exhausted the narrative in the first interview, I was free to ask more probing questions in the subsequent interviews. In preparation of the second interview, I provided an explanation of the process of the second interview and discussed the scheduling of the second interview.

The second interview was focused on the Particular Incident Narratives (PINs). PINs are questions about issues that were raised in the first interview. These questions are asked in the order in which they are raised, using the words that are used by the participant (Wengraf, 2013). The questions are ordered in a particular way to maintain the initial shape (gestalt) of the narrative which has a certain relevance to the participant (Wengraf, 2013). PINs support the process of remembering and recounting of particular experiences, eliciting a more detailed narrative (Wengraf, 2013). At the second interview, I had the opportunity to ask participants to elaborate on what they had said in the first interview (Wengraf, 2013) and probed them on points of interest associated with the research study.

Instead of having a short interlude between the first and the second interview, as per the original structure of BNIM, they had an extended interval. The duration of the interval was dependent on the availability of the participant which meant it could last up to a few months. As per the original structure of BNIM, the short interlude between interviews provides the researcher with time to reflect on the narrative and formulate questions, but as a novice researcher who is not well-versed in the technique it made more sense to take time to examine the initial data and formulate questions at a slower, more relaxed pace with guidance from the my supervisor.

During the interval, I listened to the recordings and edited the automatic transcriptions from the Zoom recording. In preparation for the second interview, I formulated questions for each participant based on these transcriptions following the prescribed method of BNIM. The participant maintained control over their narrative as I continued to assume the position of an active listener.

The decision to have a longer period between interviews seemed to suit participants as they were able to take a break and reflect on their own input. In my view, this interval had a positive effect on the data as participants were neither rushed, nor exhausted, nor distracted. As participants became more comfortable with the process, they became less concerned with the time spent on the interview and proceeded confidently in their responses to my questions since the questions were shaped around their words. They realised that these interviews were about understanding their experiences and hearing their stories. Participants were focused on the research study and on providing rich data.

The third interview is an optional session (Wengraf, 2001). The third interview gives the researcher the opportunity to pose unstructured questions associated with the research question. These are usually related to issues which have not arisen in narrative, but necessary for the researcher to adequately respond to the research question.

The participants had provided sufficient data in the first and second interview, so we had thus reached data saturation. It was decided that the third interview would serve as a focus group discussion for any additional information and a member checking exercise. Once the interviews are complete and data saturation has been reached,

the researcher interprets the data, draws their understanding from this interpretation which is subsequently shared with the participants of the research study (Nyamba, Wilson, Derrick & Mukherjee, 2018; McKim, 2023). After concluding the interviews, these are the steps which were followed.

In this session, the findings were discussed. The participants were all contacted via a platform specifically created for this purpose, and a date and time was scheduled for this session. The findings were shared via this platform for caregivers to peruse prior to the session and then met on Zoom to discuss. All participants were not available for this session, but two out of the three were available to meet after much delay due to the third participant's unavailability. The preliminary analysis was shared for the purpose of member-checking and at this session participants had the opportunity to add any further ideas. The participants shared their views on the findings, and the general consensus was that their experiences were captured accurately. The third participant had access to the findings and did not oppose the accuracy of the findings. Authentication of the data is essential in the BNIM approach and is part of the co-creation of knowledge between participants and researcher (Corbally & O'Neill, 2014).

3.5. Data analysis: Inductive and deductive

BNIM has its own complex analytic strategy, but an alternative can be used to analyse data (Corbally & O'Neill, 2014). Rather than using a narrative analysis technique, I chose to use a thematic analysis. The Ethics of care framework was chosen to analyse the data as it provided a fitting framework to discuss and analyse the experiences of caregivers and assisted in pinpointing any problems in the caring process and relationships (Tronto, 1993).

The data were analysed deductively according to the phases of ethics of care. As discussed in Chapter Two, Tronto's (1993) Ethics of care has four phases of practices and virtues:

The first phase is the practice of caring about, associated with attentiveness.

The second phase is the practice of taking care of, associated with responsibility.

The third phase is caregiving, associated with competence.

The fourth phase is care-receiving, associated with responsiveness.

Thematic analysis using a deductive approach and an inductive approach was used to analyse the data. Deductive analysis uses defined categories and requires the application of theory to the data, while inductive analysis allows codes to emerge (Braun & Clarke, 2006). By applying the phases of the Ethics of care framework as the deductive approach, ethical issues related to relationality and particularity were identifiable, especially in the context of the complexities involved in facilitating learning for learners with SPID and care practices within a resource-constrained environment. An inductive approach allowed for a detailed account of each phase of the Ethics of care framework revealing unexpected results associated with the online experiences giving a voice to the caregivers, while the deductive approach based on the phases of Ethics of care assisted in developing an understanding of how caregivers evolved as caregivers of learners with SPID.

As outlined in Chapter Two, a correlation can be made between the caregiver-learner relationship and the caregivers' participation in the online course. This relationship provides the necessary data to understand how the MOOC supported the professional and personal development of caregivers of learners with SPID.

Familiarity with the data was the first step of the analysis and was an ongoing process which provided an understanding of the overall meaning of the information (Babbie & Mouton, 2001). The editing of the transcriptions of the interviews contributed in gaining insight into the data. The data were coded using the deductive approach. These codes were fitted into the predetermined phases of Ethics of care. Upon further analysis of the codes in each of these phases, subthemes emerged. The "New comment" feature in the "Review" tab was used to identify codes. The "Review" tab in Microsoft word is a section of the ribbon that contains tools for checking and improving a document's quality, adding comments and managing changes. The option to add "New comment" was used to include and track codes. In the deductive coding process, codes were identified and fitted into the predetermined themes using the phases of the Ethics of care framework. Within each of these predetermined themes an inductive coding process was followed developing new codes for subthemes. This was an ongoing process until all the data had been categorised accordingly.

In the first theme, attentiveness, the following subthemes were developed: 'attitudes

toward the education of learners with SPID', 'attitudinal, behavioural and emotional shift toward caregiving practices' and 'identifying needs of learners, parents and community'. In the second theme, responsibility, the following subthemes were developed: 'caregivers' responsibilities', 'shared responsibilities', 'resources for the facilitation of learning' and 'training for the effective facilitation of education and care'. The third theme, competence, included the following subthemes: 'meeting learner needs', 'creating enabling environments which are conducive to educational provision and good care', 'skills development for learners with SPID and their caregivers', 'working with families and stakeholders' and 'self-care: an integral part of caregiving practices'. In the theme of responsiveness, subthemes, 'different learners respond to different ways', 'fostering a relationship for good care' and 'parents' response to caregivers' care' were developed.

Once this data analysis had been completed, the draft analysis was shared with the participants for data authentication at the focus group discussion, and participants' feedback was implemented where necessary.

Upon the completion of the data collection process and the analysis of the data, it seemed that I had grown in my competence to conduct a research study. Caregivers were comfortable and forthcoming; they felt comfortable enough to ask questions, responded with confidence and spoke with ease. From recruitment to data analysis and write-up, my actions were guided by an Ethics of care. Attentiveness to the needs of the caregivers grew which allowed for a greater understanding of their experiences with online learning, and their participation and responses were indicative of growth in my competence as a researcher.

3.6. Data management

Once interviews were recorded and transcribed, the raw data were stored in a cloud storage and password protected. The recorded zoom sessions were also saved in a cloud storage. All recorded data and transcribed data were anonymised. Data were kept confidential and only accessible to me and made available to my supervisor. Analysed data were only shared for the purposes of member-checking. This data will be kept for a period of five years in case it is required for any purpose.

3.7. Ethical considerations

Consideration of potential ethical issues was sparked by embracing the values of Ethics of care. I reflected on what it meant to protect the privacy of participants, considered the power dynamics within the researcher-participant relationships and thought about what it meant to respect and do no harm within these relationships Ethical approval was obtained from the Faculty of Human Research Ethics Committee (HREC Ref 585/2021) (Appendix VI) at UCT. I adhered to the Ethical Principles for Medical Research Involving Human Subjects (World Medical Association (WMA), 2024).

In addition to ethical approval from the relevant bodies at UCT, the participants were assured of confidentiality, anonymity, voluntary participation and the ability to withdraw. Their participation was voluntary, and they could withdraw at any time. The ethical consideration of beneficence, non-maleficence and justice were all given consideration as well.

3.7.1. Confidentiality

To safeguard the participants of a study, every precaution must be taken to protect the confidentiality and privacy of the participants (WMA, 2024).

Participants were assured of their confidentiality and anonymity. Participants were informed in an information letter and consent form that the interviews would be recorded, but none of the raw data would be shared with anyone outside of this study. They were informed that to maintain confidentiality and privacy a pseudonym would be used. This information was shared in both the information letter and consent form, and the first interviews with each caregiver.

3.7.2. Non-maleficence

To minimise the risks of the study, measures must be taken. The researcher needs to monitor and assess these risks on a continuous basis (WMA, 2024).

The study caused no harm to the participants of this study, but telling their story could be very emotional. Therefore, these interview sessions required an appropriate plan e.g. a break, ending the interview or even identifying external support. If they required any support, we would support them in finding the necessary support they need. All

participants were informed of this prior to the interview in the letter and in the first interview session.

Online interviews were adopted as a precautionary measure during the COVID-19 pandemic to protect participants.

3.7.3. Beneficence

Beneficence refers to behaving in way which is beneficial to others (Barrow, Brannan & Khandhar, 2022)

The study had no direct benefits for the participants. Their participation would likely assist in understanding how the SPID MOOC could assist caregivers providing effective care and quality education to learners with SPID.

3.8. Trustworthiness and rigour

I opted to be guided by a commonly used approach taken by Lincoln & Guba (1985) which includes credibility, transferability, dependability and confirmability. Trustworthiness is aimed at establishing a sense of confidence in the research (Stahl & King, 2020).

3.8.1. Credibility

Member checking has been established as a validation technique (Birt, Scott, Cavers, Campbell & Walter, 2016). Member checking was done in the focus group discussions. These discussions provide the participant with the opportunity to confirm that their voices and the meaning of what they shared were skillfully and accurately captured. This process allowed for the correction of errors, confirmation that data had been accurately interpreted and reflected the experience of the participants.

3.8.2. Transferability

Transferability refers to the extent to which qualitative research findings can be generalised or applied to different contexts or settings (Stahl and King, 2020). While the researcher knows that findings will not be directly transferable, transferability is primarily the judgment of the reader attempting to make a judgement on the generalisation (Amankwaa, 2016). Findings are seldom transferable as people have

different experiences, but thick descriptions of the methods and methodology may make generalisation possible for the reader. I have made every effort to provide detailed descriptions of the methods and methodology (Stahl & King, 2020; Amankwaa, 2016).

3.8.3. Dependability

Dependability refers to the degree of consistency, reliability, and stability of findings and interpretations throughout the research process (Ahmed, 2024). A detailed description of the research process is clearly stated in this study. The report of the research process included the research design, data collection, how themes were derived and the basis of the research decisions.

3.8.4. Confirmability

Confirmability refers to a process where the results are checked and re-checked throughout the data collection and data analysis (Stahl & King, 2020). The transcriptions of interviews were shared with the supervisor. In addition, the supervisor confirmed the emergent themes of the data. My views and the voices of the participants were clearly identified during the process.

3.9. Chapter conclusion

This chapter provided a justification for the research design. The narrative inquiry approach was used, further characterised as the BNIM approach. The SQUIN was used to elicit an uninterrupted narrative from caregivers and a focus group discussion was used to authenticate the data. The data were analysed both inductively and deductively. This data generation method, BNIM, was particularly helpful in understanding the experiences of caregivers with online professional development and allowing their voices to be heard against a backdrop of consistently being unheard and devalued. Ethics of care assisted in the inductive analysis process and was valuable to guiding me in my conduct with these caregivers. This resulted in my own personal and professional development process. The next chapter presents the study findings. More importantly, it was clear that without the voices of the caregivers or participants, we are unable to accommodate their needs which are valuable to both the caregiver-learner relationship and the research-participant relationship.

CHAPTER 4: FINDINGS

4.1. Chapter overview

This chapter presents the study findings in response to the research question: “How do caregivers experience MOOCs that aim to support their professional and personal development in facilitating learning of the learner with SPID in the Western Cape?”. The results were structured using the Ethics of care framework described in Chapter Two. In summary, the framework consisted of the four phases: *Attentiveness, Responsibility, Competence* and *Responsiveness*.

Table 4.1: Themes and sub-themes

	THEMES	SUBTHEMES
4.2.	Attentiveness	4.2.1. Attitudes toward the education of learners with SPID
		4.2.2. Attitudinal, behavioural and emotional shift toward caregiving practices
		4.2.3. Identifying needs of learners, parents and community
4.3.	Responsibility	4.3.1. Caregivers’ responsibilities
		4.3.2. Shared responsibilities
		4.3.3. Resources for the facilitation of learning
		4.3.4. Training for the effective facilitation of education and care
4.4.	Competence	4.4.1. Meeting learner needs
		4.4.2. Creating enabling environments which are conducive to educational provision and good care
		4.4.3. Skills development for learners with SPID and their caregivers
		4.4.4. Working with families and stakeholders

		4.4.5. Self-care: an integral part of caregiving practices
4.5.	Responsiveness	4.5.1. Different learners respond in different ways
		4.5.2. Fostering a relationship for good care
		4.5.3. Parents' response to caregivers' care

While the table provides a detailed list of themes and sub-themes, the diagram represents the relationship between online learning and the circles of care and education.

Caregivers' participation in the online learning content set in motion the cycle of professional and personal development evident in their progression through the phases of ethics of care. As caregivers transition through the phases of ethics of care, their transformation impacts the circles of care and education. While the deeply interwoven entities of the circles of care and education of learners with SPID are affected by the transformation of an individual entity within the circles of care and education, caregivers' transformation is evident in their relationship with the entities within the circles of care and education.

The diagram depicts the relationship described above, followed by the themes and sub-themes which provide further clarity of caregivers' experiences with online learning.

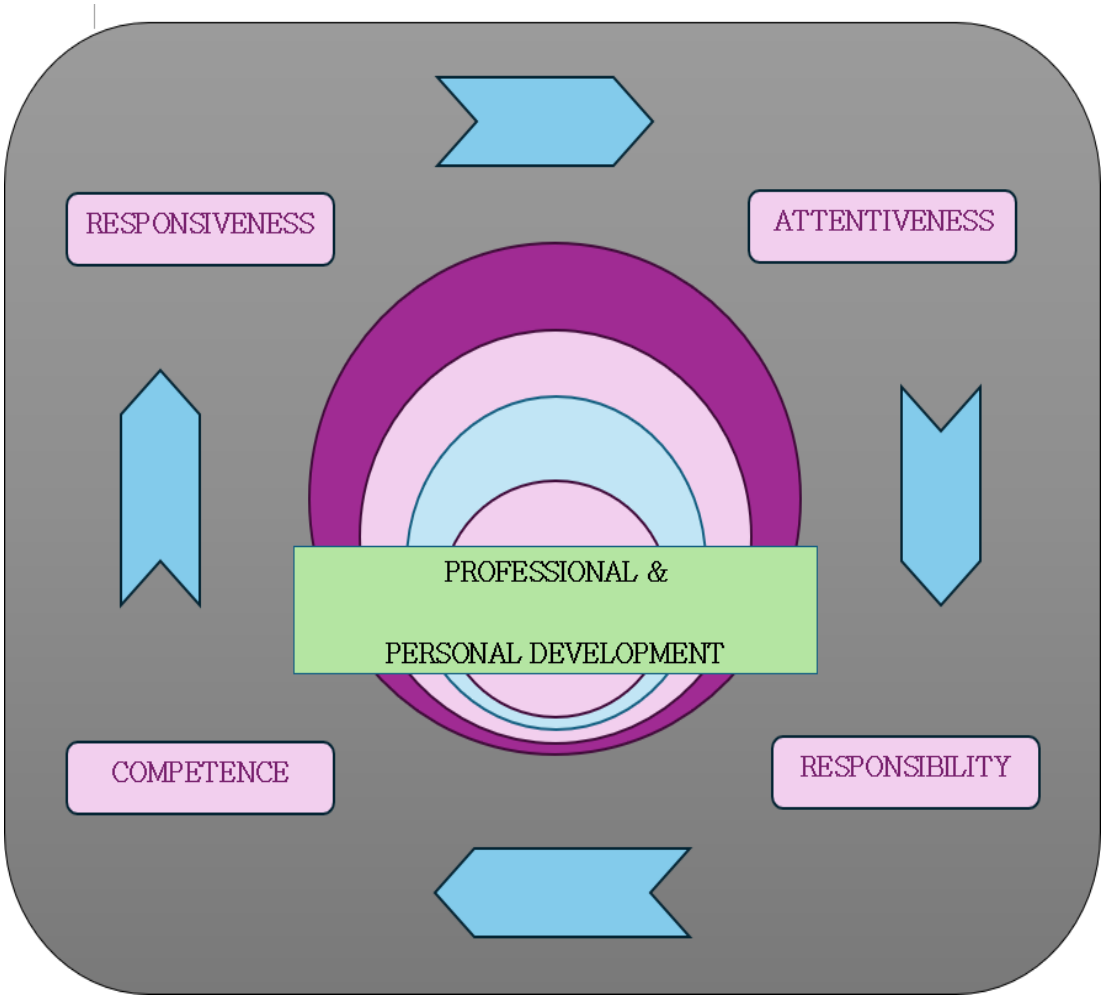

Figure 4.1: Caregivers' cycle of professional and personal development and how it relates to the circles of care and education of learners with SPID

4.2. Attentiveness

Table 4.2: The sub-themes discussed in this section on 'Attentiveness'

Theme	Sub-themes
4.2. Attentiveness	4.2.1. Attitudes toward the education of learners with SPID
	4.2.2. Attitudinal, behavioural and emotional shift towards caregiving practices
	4.2.3. Identifying needs of learners, parents and community

In relation to attentiveness, caregivers, like many parents and community members, held negative attitudes about the learning capacity of learners with SPID. Following their participation in the online course, caregivers noted a shift in their attitudes towards these learners. Their engagement with the content of the online course allowed caregivers to identify the specific needs of learners, parents, and the broader community. Caregivers found that learners with SPID benefit from opportunities for stimulation, communication, and the autonomy to make choices about their lives. In addition, a notable overlap between the needs of learners, parents and community members was reported by caregivers. While parents and learners required support and effective communication with caregivers, the community shared a need for training similar to that of parents.

4.2.1. Attitudes towards the education of learners with SPID

Caregivers acknowledged their initial negative attitudes towards learners with SPID at the SCCs. These attitudes were not only evident within their communities but reflected a broader, global phenomenon. Caregivers perceived learners with SPID as uneducable, viewing any efforts to teach them as futile.

> *"So, we tend to [have an] attitude [that] they can't learn. They can't do this, [or] they just must sit. Or they just must do whatever I want them to do. Or why must I teach them? Why must I teach them because they can't learn anything?"* (Nylethu*)*

Caregivers referred to their lack of recognition of learners' capacity to learn, and their negative attitudes about their ability to exercise decision-making and attain any form of independence.

> *"I had an attitude [towards] people [with] disability-they can't do anything [for] themselves, they can't make decisions or choice for themselves."* (Nokuthula)

Similar attitudes persist within their communities. Children with SPID are not recognized as 'normal' children, often go unnoticed in their own communities, and are excluded on the basis that they cannot contribute meaningfully to their community.

> *"like the community doesn't realise or recognise those children because they just there. They don't even know they are here, they are [at] home. They don't even realise they are children, like other children…..people have mentalities like excluding those children, saying they are nobody. They don't even [consider] what can they do, what can they contribute to the community."* (Nylethu)

As mentioned, these attitudes represent a global phenomenon. The online course participants from diverse regions shared their experiences through discussion forums which prompted dialogue. Through these conversations, caregivers could attest that negative attitudes towards learners with SPID were widespread. While these attitudes extend beyond the borders of Africa, they are especially rife within Africa.

> *"..when I did come [across] a topic [where] people were giving [their] views in different countries, [they] were saying, we used to call these children with disabilities maybe morons, maybe retarded. So, it came back to me, I have seen that most people don't [see] this children with disabilities as the same children, normal children. So mostly, not only in my country, [most] of the countries like African countries, people view those people like nobody, they view [them as] useless, they can't do anything."* (Nylethu)

Caregivers recognized that the negative attitudes they held towards learners with SPID prior to their participation in the online course were widespread. These negative attitudes affected their attentiveness and led to a lack of attentiveness to the needs of these learners.

4.2.2. Attitudinal, behavioural and emotional shift towards caregiving practices

This section examines the shift in attitudes and behaviour experienced by caregivers. The emotional responses associated with these changes extend to interactions with both learners and parents. This section reports on how this process unfolds.

4.2.2.1 Shift in attitudes and behaviours

As caregivers experience a shift in their attitudes and behaviours, they begin to identify the needs of these learners. Caregivers develop a deeper understanding of learners' individual needs and grasp the meaning of inclusivity. This shift has been partially attributed to the emotional bond that develops between the caregiver and learner. As caregivers gain a deeper understanding of learners' needs, they realise that these needs extend to education. Caregivers acknowledge that, if learners are restricted to care without stimulation, they would be complicit in hindering their progress. One caregiver reflects on her experience of this shift:

> *"What brought my change in my attitude [was seeing what] those children needs is and [that] they need to be taught every day. Like, I have learned they need to be independent. So, if I [have] an attitude towards something, I am hindering progress for those children, maybe I don't teach them."* (Nylethu)

Caregivers acknowledge that these learners have equal rights and should receive equitable treatment. As caregivers recognised learners' entitlement to equal rights, they experienced a significant shift in their perceptions on how they should interact with these learners.

> *"And also, my attitude towards disability, it has changed. Because now I know that a person with a disability have equal right, they are like everybody else. Now I have to [treat them] equally and to treat them like everyone else, like the way I would like to be treated."* (Nokuthula)

Through their online learning, caregivers developed a broader understanding of inclusivity. Central to inclusivity is acceptance. Inclusivity recognises and values diversity which forms the foundation of our society. Inclusion cannot be determined by any single characteristic.

> *"… according to the MOOC, what I actually learned is, you cannot accept without inclusiveness. So, no matter [whether] you are coloured, you are black, you are white, it affects you. So, if we have a common understanding, we include everyone."* (Sophia)

Caregivers extend their understanding of inclusion to providing learners with an opportunity to voice their opinions and views. According to caregivers, allowing learners to express their views would be beneficial not only to the learners but also to their caregivers.

> *"… to also include the people with disabilities, maybe to give them a platform to speak from their point of view. Because sometimes it's more, it will make much more impact to hear maybe a child with autism speak on behalf of children with autism, not everybody else speaking about them. To see how them as people, they feel, how they cope, what do they need the community to do. So, if we're able to get information from them as well and make them part, I think it can also be impactful."* (Sophia)

4.2.2.2. Care as an emotion

Accompanying caregivers' attitudinal shift is an emotional bond between caregivers, learners and their families. Caregivers found that the emotional connection with learners magnified learners' capabilities rather than their limitations.

> *"So, it [SPID MOOC] taught me how to love them, how to treat them in such a way that they can be independent. So, it [SPID MOOC] made me to accept them, to love them, to accept them every day regardless of what they go through, regardless of who they are, what disabilities they have. I see them as one. I see them as equal as my children."* (Nylethu)

The emotional bond that develops between caregivers and learners extended to learners' parents and families. This emotional connection with parents contributes to caregivers' understanding of their experiences, which is beneficial to the well-being and development of learners.

> *"So now it's actually a way of approaching things, a way of being calmer and being empathetic. And just putting myself in their shoes. That was actually a highlight for me and even noticing when they are not coping."* (Sophia)

A caregiver described her bond with a parent and how this connection with the parent benefitted the learner:

> *"So, it brings happiness to that child you see. Even during the day, after the visit you see the child who is smiling. That father, I love that father because he's dedicated."* (Nylethu)

As caregivers delve into the online content, they begin to experience a shift in their attitudes, emotions and behaviour towards learners with SPID. This shift, characterised by positive changes in both attitudes and emotions, leads to a corresponding change in their behaviour towards the learners. This transformation leads to a critical examination of previously held negative attitudes and behaviours which results in an increased attentiveness towards learners and their needs.

4.2.3. Identifying needs of learners, parents and community

This section shows how caregivers identify the needs of learners, parents and community members.

4.2.3.1. Identifying the needs of the learner

Caregivers identified the learners' need to be stimulated, and the importance of communication and the ability to make their own choices and decisions. Caregivers demonstrated a clear focus on the development of these learners, recognising that, while it's important to be cognisant of the limitations of these learners, caregivers must be able to recognise learners' potential. As noted below, caregivers acknowledged that these learners have diverse needs and must be treated in accordance with these needs.

> *"So, this course [SPID MOOC] helped me a lot to discover that we, as [caregivers should realise there are] a different lot of people who needs different care. I have learned that I can be able to see that this child needs [this] type of treatment or this child will need this type of care."* (Nylethu)

Different needs require a differentiated programme. Caregivers are clearly aware that these learners are not homogeneous and require individualised programmes tailored to their specific needs.

> *"So, it seems like every child have their own programme. We can't just say they are the same because they have different needs."* (Nylethu)

Due to the individual needs of learners, caregivers often work with learners separately rather than in groups. To address their individual needs, caregivers set personalised goals that align with their individual needs.

> *"…I think I'm now a better implementer because now I'm aware of each child's individual, educational and support progress. So, now I'm aware that I have to deal with each child as in case-by-case. This is why our classes are very small and as a programme implementer from time to time,....focus on the next developmental goal that they need to achieve."* (Sophia)

These caregivers demonstrate an understanding of the importance of both care and education in addressing these learners' needs. Caregivers recognise the importance of using caregiving moments as opportunities to teach these learners self-care skills. These interactions foster independence. In addition, caregivers are aware that learners can be further developed through various activities such as play.

> *"It [SPID MOOC] taught me a lot of things. It [SPID MOOC] taught me to teach those children to be independent because before I just know I have to take care of these children, nothing more. [I thought] I don't have to teach them how to eat. [I thought] I'm just [there] for the whole day. It [SPID MOOC] taught me also we should include different programmes like exercising. They also want to play, they also can do painting, they also can do a lot of things. So even new ideas, it gives me also kind of things that you can do with them for the whole day."* (Nylethu)

Despite the use of unconventional communication techniques, learners are able to express themselves. Caregivers, who initially were not aware that learners could communicate, acknowledge that learners can communicate through a variety of mediums, including images, videos, and tangible items. Due to their participation in

the online course, caregivers experienced a shift in understanding that foregrounded alternative communication methods.

> *"So, I didn't know how you [can] teach them, how you can speak with a child that can't speak back to you. Now I know that you can speak through different things like images, maybe videos, maybe showing them the actual thing."* (Nylethu)

Similarly to the importance of communication, caregivers are aware that offering learners the option to choose forms an integral part of their learning. Through this practice, caregivers demonstrate their focus on learners' development and gain greater insight into their needs. Caregivers are aware that the ability to make choices extends beyond the educational environment and developing the capacity to make decisions empowers learners to make decisions about their own lives.

> *"Like now, I know that now people with disability they have a choice, they have a right to have their own relationship. For instance, they can get kids, they can get married, they can decide for themselves."* (Nokuthula)

This is an indication of caregivers' clear understanding of the broad range of needs of learners with SPID. There is an emphasis on communication, the expression of choice, and goal setting with the aim to foster independence. Caregivers recognise the relational aspect of development of learners with SPID and recognise their role in facilitating this development. Learners' best interests remain at the forefront of their relationships as caregivers' principal focus is the development of these learners.

> *"… so that a child can develop holistically. By holistically, I mean the child has to develop physically, emotionally, socially, all of the aspects. We just don't look at one aspect of the child's development, we have to look at the child as a whole, and how best can we develop the child, … because our end goal is for child to be independent and for the child to participate, especially in daily activities. The child should be able to express themselves, even though they may not use speech. Because, it's not 'you can't do this'. [Our] approach is, how can I help you to achieve this?"* (Sophia)

4.2.3.2. Identifying the needs of parents and communities

Prior to the course, caregivers avoided communication with parents. However, through the online course, caregivers developed an understanding of parents' support needs and recognised the importance of maintaining ongoing communication with parents. While well-meaning acquaintances, family and friends may offer support, parents often require the support from a knowledgeable person who is able to provide guidance.

> *"Because, before we never really used to want to speak to our parents, maybe during weekends. But now I can say, maybe you can send me a WhatsApp message if maybe you need to ask something, if you are not coping or even if you just need to talk. Because what I noticed is, most parents they just need someone that can listen, that can understand them."* (Sophia)

Part of the reason for maintaining communication is that parents need to remain informed about the learners' well-being and progress.

> *"And also, being a carer also means like to communicate with the parents and the guardians of the learner to check and tell them [the] progress of their children and all that stuff. And also, [if] there is something wrong you need to get in touch."* (Nokuthula)

Caregivers recognise that parents of learners with SPID require training. It would be particularly helpful to parents in rural areas, as caregivers have identified them as being most in need of such training.

> *"Like I said before, I would like the MOOC to reach more parents, especially parents from rural [areas] because I've seen that. That is where most of the children with disabilities are impacted negatively."* (Sophia)

Caregivers claim that the needs of the community are similar to those of parents of learners with SPID. Caregivers assert that community members and other stakeholders require training to address their attitudes towards these learners, and educating community members would contribute to transforming these attitudes. Negative attitudes towards learners are particularly rife in African countries and rural communities.

"So, most of the African countries view those people like nobody. They don't see them, they don't include them. So, it's best we educate those people. We tend to [think we] know what these people are, they also people like us." (Nylethu)

The shift in caregivers' attitudes, behaviour, and emotions toward the learners, parents, and community highlights the contribution of the online course to their personal and professional growth. Through the course, caregivers' perceptions of learners' education, their role as caregivers, and their relationships with the parents of the learners have been reshaped. With these transformed perspectives and attitudes, caregivers have become more attentive to the needs of learners, parents, and the wider community, fostering stronger connections and a more supportive environment for all involved.

4.3. Responsibility

Table 4.3: The sub-themes discussed in this section on 'Responsibility'

Theme	Sub-themes
4.3. Responsibility	4.3.1. Caregivers' responsibilities
	4.3.2. Shared responsibilities
	4.3.3. Resources for the facilitation of learning
	4.3.4. Training for the effective facilitation of education and care

In relation to the second phase, the responsibilities of government, parents and community members towards caregivers and learners with SPID are intertwined. The responsibilities of the broader society include acceptance and advocacy, while context-specific resources and training are located with state departments and public institutions. While it is important to acknowledge that certain responsibilities overlap between stakeholders, there are duties that should be assumed exclusively by particular stakeholders. If stakeholders take on responsibilities that fall outside of their

scope of responsibilities in a resource-constrained context, they have additional pressure and their actual responsibilities receive less attention. Due to the limited attention given by public stakeholders to their responsibilities, these responsibilities have been relegated to caregivers.

4.3.1 Caregivers' responsibility

Taking responsibility for the provision of good care necessitates collaboration and co-operation with other stakeholders. Given the complexity of these learners' multiple support needs, community members, healthcare providers, educators, and social service providers play an integral role in the development of these learners.

> *"Because according to me, everybody who is involved in the child's life is a caregiver, be it you are a doctor, you are a parent, you are a therapist. Everybody in the child's life is a caregiver and everybody in the child's life has a responsibility for the positive growth of that child."* (Sophia)

Effective communication with the community and those responsible for services to learners with SPID is a critical component of collaborating with stakeholders and fulfilling their role as a caregiver.

> *"We need to communicate with whoever is providing."* (Nylethu)

Communicating effectively with parents of learners with SPID is particularly important in fulfilling their role as caregiver.

> *"The highlight for me was the communication and the ways that we communicate. Because sometimes when we spoke to parents, now in hindsight, now that I see it, I was speaking at them. So now, it came across as I was telling them what to do with their child."* (Sophia)

It is important for caregivers to understand the context of learners, including their home environment and the circumstances of their parents and/or guardians.

> *"I also learned that it's not just at the centre that we need to do stimulating activities. It is also important for me, as a caregiver to do home visits and when*

I'm doing those home visits, I have to bear in mind the environmental implications and the financial implications that the parents face." (Sophia)

Consideration of the home environment is crucial, as parents should be implementing these strategies within their home environments.

"Even if I have a new strategy…I can share it with the next person so that a child does not regress when they are not with me…" (Sophia)

Caregivers are aware that good care can only be achieved through co-operative efforts with community members, service providers and parents. Therefore, the responsibility for providing good care is influenced by and shared among these stakeholders. Caregivers acknowledged their contribution to the provision of good care for learners with SPID as working co-operatively within and outside of the centre with all stakeholders. They attribute their understanding of the distribution of responsibilities to their engagement with the course content.

4.3.2. Shared responsibilities

Community members, parents, and other stakeholders share the responsibility of recognising, supporting, and raising awareness of the rights of learners with disabilities, including the right to dignity which serves as the foundation for all rights.

" ..according to the MOOC.., you cannot accept without accepting that we are coming from a diverse community. [If] we have one goal, that is [to focus on] disability, we [will try] to help each other out. So that means [if] we are able to raise awareness, we are able to get accept[ance]." (Sophia)

Obtaining support is challenging in environments where stigma, discrimination and a lack of acceptance of learners with SPID are widespread. As a result of their association, caregivers' roles are devalued. Caregivers can only fulfil their role as effective facilitators of the development of learners with SPID if they have access to adequate support.

"So, I'm going, I'm doing this, I know now I get support from everybody. It helps if you have support..parents support..community support..it helps to deal with my work. I know now I have the support. So, it help. It keeps me motivated that

[when] this child is supported, the child is happy, the child can do a lot of things. You can facilitate learning." (Nylethu)

The effects of stigma are exhibited through the community's lack of acceptance of learners with SPID.

"… the community doesn't realise or recognize those children because they just there. They don't even know they are there, … there [in] that home. They don't even realise they are children, like other children. So, it helps me to realise most of the things like to accept them, like the community accept them." (Nylethu)

For a host of reasons, parents may struggle to accept their children with SPID. These children are often isolated and hidden due to stigma, discrimination and the negative attitudes prevalent in communities.

"Personally, they are children just abandoned by their parents because they can't accept who they are. So, it made me accept them, to love them, to accept them every day, regardless of what they go through, regardless of who they are, what disabilities they have. I see them as one. I see them as equal as my children. So, it made my work easier because I'm dealing with children, I'm not dealing with disabled children." (Nylethu)

Raising awareness and advocating for the rights of learners and caregivers could contribute to the eradication of stigma and foster acceptance of learners with SPID within their communities. This shift could consequently elevate the position of the caregiver and the facilitation of care to learners with SPID. Raising awareness could contribute to communities assuming responsibility for their duties towards these learners leading to increased participation of these learners in community activities.

"Even when they see them now, it's also a way to negate discrimination and stigma, because now they see them as part of the community. They even gave them the opportunity to participate even in community-based things. So those are positive things that can come out [of] raising awareness and even other people will learn how to work with a child with a disability." (Sophia)

When stigma, discrimination and poor attitudes towards the care of learners with SPID persist, stakeholders are often unable to recognise their responsibility toward learners with SPID and their caregivers. This impedes the support caregivers' need to provide good care to these learners. However, through their engagement with the online course, caregivers are more knowledgeable about the role and responsibility of stakeholders in the care and education of learners with SPID. This knowledge has motivated caregivers to deliver better care and improved their confidence in their interactions with stakeholders.

4.3.3. Resources for the facilitation of learning

The unequal distribution of resources for learners with SPID and under-prioritisation of their needs are partly a result of the devaluation of the role of caregivers. In response, caregivers have assumed the responsibility of mobilising resources to facilitate learning. Caregivers recognise that part of their role involves creativity in utilising available resources to create learning opportunities and experiences for learners with SPID. The DBE and DSD should take responsibility for providing the resources required by caregivers. In addition, other stakeholders such as community members could also contribute to resources required.

> *"So, I've been able to show people that even though we do not have resources, we just need to find a way of using what we have."* (Sophia)

Caregivers have even taken responsibility for sourcing assistive devices and equipment for learners with SPID. They understand the crucial role these devices play in the provision of good care and enabling learners to participate in learning activities at the centre and in their homes, as it facilitates the movement of these learners. However, despite caregivers assuming the responsibility of accessing these devices, it is the responsibility of the DoH.

> *"Even I found out most parents, they can't even take their children to the park because they don't have wheelchairs and they don't have buggies…a simple task like going to the grocery shop was very challenging, because now a parent has to carry the child on the back, so it's easier to leave a child locked at home. So, they gave us some old wheelchairs, they just put new cushioning. So now, our children can go to the park, they can go to the shop, they can experience*

what other children are experiencing and they are also now exposed to much more than when they didn't have those resources that would enable them to participate in just simple community activities." (Sophia)

For caregivers at SCCs, the provision of good care extends beyond physical and financial demands. Providing good care to learners with SPID includes significant emotional demands. Caring for learners with SPID is both physically and emotionally taxing due to their multiple support needs.

"Is difficult to watch someone, maybe someone is that [sick child] because it needs your attention. You are the one who have that job. So, it's so tiresome. You must take care of the child. You have to turn her because she can't do anything, she can't even turn, she can't even sit. So, she's laying all the day, its tiresome to look after those kinds of child, it's not like we don't want to, but it's a hard job to do… everyday…" (Nylethu)

Caregivers face workplace pressures and family demands which are further exacerbated by lack of resources and the complex support needs of learners with SPID. In addition, caregivers also contend with insufficient human resources.

"Because at the end, we are very busy people and there lots of life pressures that we have to go through. You have to work, you have children at home that needs to be helped out with homework and so much more." (Sophia)

Despite the limited provision of resources for the care and education of learners with SPID, the responsibility for these resources rests with state departments. Due to the resource constraints, caregivers have had to adopt creative approaches to creating suitable learning environments for learners with SPID. While these limitations foster caregivers' resilience, they also present significant challenges in delivering good care. State departments play a critical role in addressing these resource constraints and the inadequate support received from stakeholders and are ultimately responsible for ensuring a cultural shift towards greater support for learners and their caregivers.

4.3.4. Training for the effective facilitation of education and care

Resourcefulness is not the only skill required by caregivers to provide good care and education to learners with SPID. Caregivers acknowledge that, prior to the online course, they lacked specific knowledge relevant to the care and education of these learners. They recognised their need for additional training.

> *"… at work sometimes maybe we don't know what to do with this child, maybe we don't know what [they] want, maybe we don't know how to take care of this child..so I wasn't aware of most of the things, like what am I doing, what am I teaching, and especially the learning part. I didn't know that they must learn, they must go to school. So, it's best for us to engage in this course [SPID MOOC] and to know what [I am] dealing with every day."* (Nylethu)

Caregivers recognise the importance of training, understanding that insufficient knowledge and skills have a negative effect on learners and themselves. Insufficient training may lead to caregivers experiencing frustration and mental strain. Although training is not their responsibility and rests with the DBE, caregivers have taken it upon themselves to enhance their skills through training.

> *"… try to find out ways to help or ways to help yourself, you can actually drown in frustration…"* (Sophia)

Parents and community members also require training. For parents and caregivers to recognise their responsibilities and effectively support caregivers and these learners, they need to be informed and knowledgeable.

> *"..[learners] need us, especially in educating parents. Like parents, we need to really educate the parents, us caregivers ... it is like when you educate the community to get involved in [these] children life."* (Nylethu)

Caregivers are acutely aware of the training needs in remote communities and are committed to reaching a broader audience. Caregivers are often left to manage training needs without external support, even though the responsibility for training lies with trainers and course developers within state departments and higher education institutions.

> *"I think we have to look [for] ways in which we can reach more people. How best can we help them to learn what to do? So, we have to find ways to get information in the homes of children with disabilities."* (Sophia)

It is imperative that trainers understand the context in which caregivers function and consider ways to accommodate them accordingly. Greater accessibility to the online resources for caregivers in various contexts requires flexible options. In interviews, caregivers referred to reverting to videos and images provided in the MOOC when seeking clarification on the content.

> *"Because when you don't understand, if I didn't understand something, then I would [have a] look [at] the video and it would explain it better and the pictures will explain it better."* (Nokuthula)

When these challenges persisted, caregivers would make use of the discussion forum provided in the online course to consult with other participants on the content.

> *"No, it wasn't challenging because there's a discussion part that you could go and ask questions, other people can just respond."* (Nylethu)

Having a repository of online information also proved helpful as caregivers could refer to and revisit information whenever required.

> *"…if I didn't understand something, I could rewind it. I could be exercising a child and just put in my earphones and listen. So that was actually a good way of learning."* (Sophia)

For those caregivers who participated in the study, the course being offered in English was not a barrier to accessing the course as they were proficient in English. However, this may not be the case for all caregivers.

> *"So, for me it was learning, it wasn't a barrier. It was easy for me because if I come across a word that I can't understand, maybe go through what does this word mean. So it was easy to learn in English..."* (Nylethu)

The language in which the course is offered could easily be a barrier for parents and caregivers. Many caregivers who are also parents of learners with SPID are based in

rural communities and lack proficiency in English. According to caregivers, offering training in a familiar language could promote greater implementation of good practices.

> *"So, language is still a barrier as in they will still not be able to understand what is being said. So, if maybe we get interpreters that can interpret and put it in maybe Xhosa, isiZulu so that it can have a greater impact, especially in the communities here in South Africa, and especially in the more rural communities where some of the people they do not understand English...the language barrier inhibits the learning process for them. But if you can talk to them in their vernacular language, one-on-one, then they get to understand. That's when you start to see positive changes. But if you teach them to understand it first, then they're in a better position to implement it."* (Sophia)

Many parents either lack access to devices or are not computer literate. This should be taken into consideration when developing and offering courses for caregivers. Parents, who are often the caregivers working in SCCs, are often uneducated and live in communities where computer literacy is neither a priority nor affordable.

> *"Most of my parents, they don't have cell phones, they don't even know their way around the computer and the MOOC is computer-based, and you have to have data to even navigate and some of them are even illiterate, they cannot read and write."* (Sophia)

Rural communities often face challenges with connectivity and the cost of data. Government, service providers and trainers are responsible for ensuring that online content and platforms are accessible to caregivers, without being hindered by the expense of data.

> *"No, I didn't have any, because most of the time like, if I'm not at home I don't have wifi. So, I just maybe download most of the things I want or if I'm offline, I can go through it."* (Nylethu)

While the responsibility for training lies with DBE, caregivers have taken ownership of their learning and transferred their knowledge and skills to parents of their learners. Given the demands of caregivers' roles and responsibilities, the structure and delivery of the online course has been helpful. However, caregivers realise that the course may

not be accessible to all those in need of training. These caregivers foregrounded the context of parents, family members and other caregivers in need of training, and the responsibility of course developers and trainers in developing online courses which are accessible to the diverse communities within our context.

4.4. Competence

Table 4.4: The sub-themes discussed in this section on 'Competence'

Theme	Sub-themes
4.4. Competence	4.4.1. Meeting learner needs
	4.4.2. Creating enabling environments which are conducive to educational provision and good care
	4.4.3. Skills development for learners with SPID and their caregivers
	4.4.4. Working with families and stakeholders
	4.4.5. Self-care: an integral part of caregiving practices

In relation to competence, caregivers understand the importance of creating enabling learning environments for learners with SPID. In our context, caregivers need to be resourceful to effectively facilitate learning for learners with SPID. These caregivers adopt a range of different techniques to support the development of these learners. For example, caregivers use instructional images, hand-over-hand activities to develop learners' skills at various activities and offer learners the autonomy of choice. Caregivers also refer to 'learning concepts' which refer to the recognition of numbers or words through an appropriate process for their intellectual level. For the continuous development of learners, caregivers adapt activities within the centre and create suitable activities for their home environment. It is imperative that parents, community members and caregivers work co-operatively. Due to learners' high support needs, all stakeholders should be contributing towards the development of these learners as collaborative efforts have been found to have a positive effect on the progress of the

learner. All these activities are dependent on healthy caregivers, making self-care an essential component of effective caregiving practices.

4.4.1. Meeting learner needs

Caregivers feel that they are responsible for the education and stimulation of the learner with SPID. For caregivers to provide education, they need to be competent in the provision of education and stimulation for learners with SPID.

> *"So, as a caregiver ... I'm the one most responsible for stimulating this child."* (Sophia)

Being competent in providing care entails more than education; it involves being the voice of the learner with SPID. As caregivers, they believe they should be raising awareness and advocating for the rights of the learner with SPID.

> *"We speak for them, we analyse for them, we are the ones that need to make sure their human rights [are] exercised, it's through us. Awareness [has] the most impact and [teaches them] how to help, how to advocate for their rights, where to go, how to go about it, who is who in the lives of the children. All of those different aspects. They all come and count and they're all part of the process of the holistic development."* (Sophia)

Like all children, learners with SPID require holistic development. However, to facilitate their development, caregivers need to conduct individual assessments, identify their specific needs and set goals tailored to their individual needs.

> *"So, if you can identify the needs and the challenges, it is much easier to develop the child... as a holistic person… You have to work with them as an individual, because they have different needs and they have different goals."* (Sophia)

Caregivers must recognise that these learners have lifelong learning support needs. While all learners are lifelong learners, their lifelong learning support needs are different from those of neurotypical learners. These support needs include continuous, repetitive learning. This repetition should be continued until learners have fully grasped the concepts and are able to make progress.

> *"Because for our children, it's lifelong… It's something that we have to repeat every day, we need to reaffirm every day… once they know something and they catch on to it, it's very easy for them to adapt and start progressing."* (Sophia)

Competent caregivers are able to identify the barriers to learning faced by learners with SPID, recognising that it is not only the learners' intellectual abilities that hinder their development but also their environment.

> *"Positive development of a child holistically means to me, is looking at the child as a whole. ..and how best we can impact [them] positively. Because sometimes the barrier is the physical that hinders the intellectual. Because sometimes the learning barrier is because of the environment, not necessarily because the child is unable to be stimulable."* (Sophia)

Adapting activities and creating enabling environments to make learning more accessible are key to becoming a competent caregiver.

> *"I think I also mentioned counting. You cannot set a goal for counting one up to ten when a child cannot even count up to five. So, it's about grading, in adapting all of the activities."* (Sophia)

For caregivers to effectively meet the needs of learners with SPID they need to remain cognizant of learners' lifelong needs. To meet these learners' needs, caregivers should consider their individual needs, the environmental barriers that might affect their learning and the adaptation of the activities to suit their learning needs.

4.4.2. Creating enabling environments which are conducive to educational provision and good care

Caregivers are entrusted with the responsibility of caring for learners with SPID. As caregivers, their role and responsibilities extend to stimulation and development. To perform effectively, caregivers need to have an understanding of how these learners progress and set realistic and attainable goals.

> *"… maybe my goal is for that child to count up to number five. So it's actually very important to know the sequence of the progress of the child, because*

without that, then we set goals that are unattainable and then we frustrate ourselves so much that it looks pointless…" (Sophia)

Caregivers acknowledge that creating enabling, learning environments is integral to the provision of stimulation. Environmental barriers often hinder learners' participation, consequently limiting their access to stimulation.

"I also learned that it was very important to create an enabling environment for the children. Because most times, sometimes the learning barrier is because of the environment, not necessarily because the child is unable to be stimulable." (Sophia)

In LMICs, creating enabling environments could be challenging due to limited resources. However, being resourceful and creative with the available resources ensures that learners with SPID are able to access learning experiences that are impactful.

"... so I've been able to show people that, we can be resourceful and get the same impact as anywhere else in the world, that can be maybe store bought." (Sophia)

Being resourceful, a crucial skill for a caregiver in a resource-constrained context, means identifying environmental barriers and creating cost-effective solutions. These caregivers demonstrated resourcefulness by adapting activities at the centres and in learners' home environments. Adapting activities is essential to ensuring that learners with SPID are able to participate in activities. One caregiver provides an example of how these activities can be adapted to meet the learner's specific learning needs:

"Especially if it means that they are going to be able to learn, especially with daily routines, how can you add just a toilet seat, because some children, maybe they even afraid of the water in the toilet. Put food colour in the water that can help them just to enable that environment, so that when they look they see blue water and they love blue water. So, it's now a fun activity to go to the toilet. So, those small things. Just to have that activities and make sure a child can participate." (Sophia)

The absence of certain resources could result in learners being excluded from learning opportunities. However, resourceful caregivers find ways to become more self-sufficient and reduce their dependence on donors. Producing the product required to create a learning opportunity could be used as a learning opportunity. Turning the process of producing these materials into a learning opportunity benefits learners in two ways: learners participate in a learning activity, and it gives learners a sense of pride and accomplishment.

> *"We made a skipping rope out of plastic bags. So, this was a whole activity. We would gather plastic bags, and then we would… knit them to make a big rope... So, the children were very proud of it, because they made their own skipping ropes. We don't need to ask... because we can make our own "* (Sophia)

Caregivers recognise that learning must continue at home. Implementing centre practices and activities at learners' homes could be challenging, as their home might differ from the environment at the centre. It is crucial to assess the viability of implementing the centre activities at their homes through home visits and identify any adjustments to ensure successful implementation. This caregiver shares the importance of assessing the viability of the activity as it also would depend on the financial and environmental situation in their homes.

> *"I also learned that it's not just at the centre that we need to do stimulating activities. It is also important for me as a caregiver to do home visits and when I'm doing those home visits, I have to bear in mind the environmental implications and the financial implications that the parents face."* (Sophia)

This caregiver also shares her experience of adapting an activity to suit the home environment of a learner who had been potty training.

> *"So, now the mindset that I got in the MOOC was to go there and see the kind of environment that the child is staying in and trying to adapt. So, when I did the home visit I actually realised the activity that I gave them was actually nonsense to them because there's no flushing system, there is no toilet bowl. So, we actually adapted that activity by using a ten-litre container. So now, the child can still be trained [by doing] potty training at home with what is naturally available…So that means this child is now aware that when I'm at home, this is*

my toilet and when I'm at the centre, this is my toilet. Therefore, we see progress." (Sophia)

Being a competent caregiver of learners with SPID in an LMIC does not only refer to being able to set realistic and attainable goals but also creating enabling learning environments. With the limited resources available for the education of learners with SPID, caregivers need to be resourceful within the centre and adapt activities for learners' home environments. Caregivers describe how the content of the course motivated them to create enabling learning environments and how it shaped the ways in which they continued learners' development in their home environments.

4.4.3. Skills development for learners with SPID and their caregivers

Caregivers employ various techniques to engage with learners with SPID and foster their independence. They acknowledge the contribution the online course has made to expanding their knowledge on the adaptation of activities and understanding appropriate techniques.

> *"So, in our activities, we have to adapt them to include each child. For example, if you are reading a story to a blind child maybe you might want to use lights. So, there are different ways to adapt and be inclusive in class. So, all of those things we learned in the MOOC."* (Sophia)

One of the techniques employed by caregivers is the use of images. This allows learners with SPID the opportunity to participate through visual cues.

> "*So, we left a picture in front of the zinc. We have a picture like 'put your hands under the tap, then wash your hands'. So, some of them if they see a picture, they know now it's time to wash my hands. They know now I shouldn't drink water. So, it's how we teach them, teach them through pictures."* (Nylethu)

Another educational technique used by these caregivers is what they have described as mimicking, more commonly known as hand-over-hand activities. The process assists learners with SPID to experience the activity, offering them the opportunity to learn in a more suitably experiential way.

".. you have to make sure that the child is experiencing the activity... you have to ensure that their hands are experiencing the process, but it's actually your hands. They're actually mimicking from your hands. So, in this way they're experiencing it so that, when they have to do it next time, they have an idea of how to do it." (Sophia)

Caregivers provide learners with the opportunity to choose their preferred activity. Offering them the opportunity to choose not only increases their interest in the learning activity thereby improving participation, but it also offers them the opportunity to become more independent.

"And also, I told them that sometimes you must like give them choice. So, we take two or three activities in front of the training, so that they can choose which activity they want with them…it increases their interest in [the] activity because you give them choice." (Nokuthula)

Physical activity is crucial for their learning and participation. Similar to the other strategies and techniques employed for increased participation, physical stimulation improves their co-ordination, strengthens their muscles and increases their independence.

"And then we do our activities, like [in] the morning we do activities that will help them to stretch and strengthen the muscles of the hands and the fingers. So that will help them to increase their independence in the long run. Our learners, their hands are closed." (Nokuthula)

Reading, counting and spatial awareness are abstract ideas for learners with SPID. Through certain activities, caregivers are able to make these abstract ideas more concrete for these learners. Caregivers refer to these activities as 'learning concepts'. These activities help learners to understand and connect to everyday tasks. These learners are able to identify and make connections to certain words or numbers through songs and environmental print, that is written text that appears in everyday life, such as labels, or logos.

By becoming familiar with environmental print and its meaning, learners are able to meaningfully participate in everyday activities.

> *"We take maybe familiar things like the names of shops because they pass through the shop every day. They know this is the signage of Shoprite, though they cannot read it, they read through familiarity. So those are the concepts. [So, now] they are more familiar with their environment and they are more aware."* (Sophia)

Learners' chronological age often differs from their intellectual age. According to caregivers, it is necessary to 'start where they are' which means activities should be tailored to their intellectual age. This approach ensures that learners participate in appropriate and relevant learning for their capacity level. Caregivers describe how they help learners recognise numbers. Presenting numbers through a song makes it easier for these learners to grasp them. While they may not be able to identify isolated numbers, they are able to identify numbers when arranged in a sequence.

> *"So, even like I'm saying they can sometimes count from song. They can count 1234, but when you say what number is this individually, if you isolate the number then they are unable to say this is number two or they are unable to write number two. But they know number one, after number one comes number two. So, we just go to the level of the child, with [their] ability, then we adapt. That is what I mean by the learning concepts."* (Sophia)

Learners with SPID can develop spatial awareness. Caregivers use the combination of object positioning, physical activity and play to teach these learners about area awareness.

> *"Maybe we are skipping... or maybe we doing hoola-hoops and then the yellow hoop is on the left and the blue one is on the right. What I'm actually teaching you is left to right. You think you're playing. When I asked where is the yellow one, it's on my right. Now, you know the area, you're learning about area, you're learning about your space."* (Sophia)

In addition to professional development, caregivers also develop personally. One of the skills which they acquire through their exposure to online learning is technical proficiency, a valuable skill when sourcing online resources for the education and care of learners with SPID.

"It also makes you improve your technical skills" (Nokuthula).

The range of techniques and strategies employed by caregivers reflects caregivers' competence in the provision of education for learners with SPID. Caregivers attribute their knowledge of strategies, techniques and adaptation of activities to the online course. This course has not only enhanced their caregiving skills but also technical skills which are essential when offline resources are unavailable.

4.4.4. Working with families and stakeholders

For the continuous development and well-being of learners with SPID, caregivers recognise the importance of working closely with parents, community members and stakeholders. Collaborative efforts involve sharing information and creating a structured home activity programme. Caregivers acknowledge the importance of co-ordinated, collaborative efforts between parents and caregivers for the development and progress of learners with SPID. Effective strategies must be shared with parents to ensure that learners continue to practise at home what they have learned at the centre.

> *"So, it will make things easier if we link hands. Like I was saying, a carry-over activity of activities at home that we do in the centre. Because it does not help to have a structured routine at the centre and then at home, they do random things. So, it's very useful to just to create a small programme that they can use at home."* (Sophia)

Sharing information between stakeholders, parents and caregivers at the centres is essential to the well-being and effective treatment of learners with SPID. Co-ordinated efforts between parents, health therapists and caregivers make the job easier on all involved. It ensures timely treatment, avoids duplicated efforts, and helps caregivers feel confident and comfortable with the health care provided to the learner.

> *"So, as I mentioned previously that when a parent brings a child in, I ask them information. So, this information that I ask them is information that I need, that I also need to pass to various people that will help this children. Even when the children go to clinics, I've asked the parents to come and take a folder from the centre. They go there, whatever is written in their clinic file they make a copy*

and they also put it in the centre file. So that when therapists come, they have the same information of the progress of the child, sometimes a child is on medication. And they asked me, 'does this child take medication?'. So, if I don't have that information, I'm not able to share." (Sophia)

Working closely and systematically with parents, stakeholders and community members not only applies to health treatment, but any other issues related to the well-being of the learner.

"It's now much... easier to do my work because I even know who to approach, the stakeholders that can help me and how to quickly help a child. Even maybe there's a social issue in the child's life." (Sophia)

Sharing information and doing home assessments provides parents with the opportunity to become skilled and knowledgeable in the provision of education and care of their children and supporting other parents. Parents begin to form their own community of practice and develop their own strategies for effective teaching, learning and caring.

"…. and they actually share their best practices that is working for them. Okay, I learn from them as they learn from me." (Sophia)

Caregivers understand the value of building relationships with various stakeholders. They recognise that strong relationships with stakeholders are imperative not only for their educational progress and effective health treatment but also for addressing their social issues. Building effective relationships with stakeholders and parents for the development of learners with SPID is a key aspect of what defines a caregiver as competent in their role.

4.4.5. Self-care: an integral part of caregiving practices

Caregivers are acutely aware of the burden of care associated with caring for a learner with SPID. One caregiver shared this painful experience that accompanied the care of a learner, highlighting the emotional and physical demands of this responsibility:

> *"So, it's hard, really hard to see them go through that every day. Like you feel their pain… it's like it hard for us to accept that this child, all his life, all her life she is like this."* (Nylethu)

Caring for these learners has a negative effect on the health of the caregiver in instances where caregivers are overburdened. Self-care and support for caregivers are especially important for caregivers with the physical and emotional demands of the role.

> *"So, if you are not strong enough to stand for yourself …You can also have a mental health issue..."* (Sophia)

Without knowledgeable and affectionate caregivers who are healthy, learners with SPID would face limitations in the educational opportunities available to them. Caregivers recognise that prioritising self-care is an integral part to facilitating learning effectively.

> *"And also, when you are a carer, you need to take care of yourself too. Because if you are not yourself, you can't do a good job."* (Nokuthula)

Being empowered through the course content has brought about enjoyment in their work. Caregivers highlight how beneficial the online course has been to their empowerment, to the enjoyment of their role and, more importantly, their competence as caregivers.

> *"Maybe they must introduce different courses to us to learn, to empower us every time because it brings empowerment. You realise now, I am empowered, I have to do this. I can do this…it really helped me a lot in my work and it also brings enjoyment."* (Nylethu)

Being able to refer to content in times of doubt has helped to maintain their positive attitude and improved their confidence level.

> *"… but sometimes you are doubtful. So, when you have a reference point of view, that can also bring positivity and confidence in what you want to do."* (Sophia)

Knowing where to turn for support and who to reach out to has made their job easier. Caregivers note that their diminished caregiver burden and positive mindset can be attributed to their engagement in the online course.

> *"It's now easier to do my work because I even know who to approach, the stakeholders that can help me and how to quickly help a child. ..if I was not exposed to all of this information, I would not have known what to do, or what approach to take..."* (Sophia)

Caregivers have grown to understand that self-care is as important as knowledge about the educational development of learners with SPID. The knowledge gained through the online course has contributed to the well-being of caregivers. Understanding how to maintain their own well-being is a crucial part of demonstrating competence as a caregiver of learners with SPID.

Caregivers' growth is evident not only in their improved caregiving practices but also in the diverse techniques they now employ to effectively support the education of learners with SPID. The knowledge and skills acquired through the online course has contributed to their collaboration and co-operation with parents and stakeholders. Their personal and professional development is reflected in their facilitation of learning of these learners, relationships with stakeholders and their resilience and resourcefulness in a resource-constrained context.

4.5. Responsiveness

Table 4.5: The sub-themes discussed in this section on 'Responsiveness'

Theme	Sub-themes
4.5. Responsiveness	4.5.1. Different learners respond in different ways
	4.5.2. Fostering a relationship for good care
	4.5.3. Parents' response to caregivers' care

With reference to the fourth phase of ethics of care, responsiveness, learners with SPID respond in various ways, often using non-traditional forms of communication. Caregivers recognise the various gestures, including physical responses such as pointing to images and emotional responses like smiling. To be effective, caregivers need to be attentive to these gestures and reflect on their responses to make meaning of their responses. Caregivers highlighted their experiences with parents and how these parents responded to the care provided. This phase highlights the importance of building relationships, implementing effective communication strategies and the role of the MOOC, acknowledging the contribution of the MOOC in the education and training of learners' parents.

4.5.1. Different learners respond in different ways

Caregivers are aware that learners respond in different ways. Their gestures are a clear indication of their needs. Through these non-traditional forms of responses, caregivers are guided in how to support these learners and what support they need. This caregiver explained that even though the communication between caregiver and learner may be different, they are open to these forms of communication:

> *"So, even if they don't talk, they respond in something. They do something that show, I want this. We want to let them speak to us or communicate to us in a different way."* (Nylethu)

By being open to these forms of communication, caregivers are directed by learners enabling them to recognise and address these needs effectively.

> *"We should learn through them. We learn through them to realise what they need."* (Nylethu)

Through the continued communication between caregiver and learner, the caregiver was able to make meaning of their responses and provide the necessary support to the learner.

> *"So, it's best for me every day, and it helped me a lot to support these children, and I can see the difference in them that now I'm engaging with someone that*

needs this. So, it helps me a lot to know how to support that child, what kind of support that child needs." (Nylethu)

Caregivers are attentive to learners' different ways of communication which guides them in providing good care and supporting learners' needs. The responsiveness of these learners is a result of caregivers' attentiveness towards them, and the responsiveness of these learners leads to increased attentiveness of caregivers towards learners.

4.5.2. Fostering a relationship for good care

Acknowledging learners' ability to communicate and respond to care inspires caregivers to build relationships which are open to various forms of communication, creating opportunities for the voice of the learners to be heard thus nurturing meaningful engagement between the caregivers and the learners. For meaning-making to occur, caregivers need to be attentive to these gestures and reflect on the responses of these learners. These gestures include emotional and physical responses, for example responses to images and real-life items. Caregivers recognise the role of the online course in their receptiveness to different forms of responses from learners. This caregiver reflects on the learners' various forms of communication, and demonstrates their attentiveness to these responses:

> *"It's just how they respond. We speak to them maybe with words, maybe I can speak [to] them with pictures. They can respond, maybe we need to put something that they know to respond, maybe they can point, maybe they can laugh, maybe they can nod their head, maybe they can move their eyes, maybe they can try something to agree with me to let me know what they are saying... maybe they are dancing or maybe they are moving. So, they agree with what you are saying. So, through this course [SPID MOOC] I have learned a lot."* (Nylethu)

This caregiver highlights the use of images and real-life items, creating opportunities for the voice of the learner to be heard:

"…and then, when it's in lunch time or tea time we show them food. Or we show them the picture of food, or then you can like talk, and then show that it's lunch time now." (Nokuthula)

This caregiver recognises learners' participation in activities as a response to care. Caregivers should pay attention to their participation as this informs caregivers of learners' preferences. A positive response, such as active participation, is an indication that caregivers are meeting the learners' needs.

"it's important to have every child participate in everything because they need to be independent. They need to realise, they need to know who they are because in participating you can realise, maybe this particular child is interested in sports, maybe this particular child is interested." (Nylethu)

Negative responses inform caregivers about the learners' preferences as well.

"So, now I know this particular child needs this. So, some time ago I didn't know [he would] sometimes throw a tantrum, if you want to feed him. So, we have realised we [might be] doing things for [him] that he doesn't need. So, now we take time. Even if he doesn't feed right, maybe some food his throwing up. So, [it took] time to realise he doesn't need to be fed, he need[s] to feed himself. So, now we take time to see if he likes to feed himself. So, we give him [a] chance to feed himself." (Nylethu)

Inactivity should also be monitored. By reflecting on learners' inactivity, caregivers gain a better understanding of learners' needs, preferences, and the possible barriers to participation.

"So why is the child not responding, we are not doing the things that the child require or we are not doing exactly or treating the child according to her group or his group. Maybe his in awareness stage, maybe his in transitional stage, maybe we doing things wrong. So, it taught me to do things right according to what their special needs are, like the group stages… ." (Nylethu)

Learners' responses are not limited to their physical responses only as emotional responses are also indicators of learners' needs. Emotional responses serve as a

guide for caregivers, allowing caregivers to tailor their approach accordingly. These emotional responses can be powerful indicators of positive engagement, and acknowledging these responses can motivate learners to engage further.

> *"So, it brings happiness to that child. You see even during the day, after the visit [with the father], you see the child is smiling. I love that father because his dedicated."* (Nylethu)

Being attentive to these gestures and responses informs caregivers of the type and scope of the support required by learning and provides caregivers with the necessary guidance required to facilitate goal setting for learners. Rather than relying on rigid, prescriptive programmes, caregivers who observe and interpret these responses can provide more personalised, flexible care. Being guided by the responses of learners is key to creating appropriate activities and setting attainable goals that are flexible and align with learners' intellectual abilities and physical and emotional needs. Through this process, caregivers are able to ensure meaningful development.

> *"… maybe my goal is for that child to count up to number five. So, it's actually very important to know the sequence of the progress of the child. Because without that, then we set goals that are unattainable and then we frustrate ourselves so much that it looks pointless. Maybe a child, as a nine-year old child has an intellectual mind of a two-year old and you are doing things on the level of five-year old. So, in that way it's not attainable. So, you have to start with where the child is."* (Sophia)

This caregiver shares the progress of a learner with the implementation of an appropriate and relevant activity. For caregivers, these responses demonstrate how well the care aligns with the learner's needs.

> *"So sometimes maybe she can [comb with] a comb. So, you'll see this child is brushing her hair maybe. It helps us also a lot to deal with this children. So, sometimes they can teach themselves, sometimes maybe you see she's doing what [you taught her] last week. She's doing it. So maybe she's holding a comb, you know now that she know now the comb is maybe to brush [her] hair. So now maybe they realise that a comb is not maybe a toy, they realise [its] something that I can use."* (Nylethu)

Observing learners' responses assists caregivers in understanding the scope of the support learners need to foster their development. This caregiver shared how the response of the learner informed them of the need:

> *"Also, we give the child [a] chance to wash their hands by themselves. And [you] can see if you can help ... supervising that. And then you see that they can wash, and then you will help them to dry, also give a chance to dry. And [you] see where you can help, you can assist..then after that you go back to let them brush their teeth. Then we also do assist them. But we let them try to do it by themselves, and then we see where they struggle and then you help, you assist them."* (Nokuthula)

One caregiver described how a learner's gestures serve as indicators of the impact of the care provided. Their gestures reflect whether the support they are receiving meets their developmental needs. The response not only indicates the type and extent of the support, but also the impact of the care provided:

> *"..if I teach them, if they smile back, if I teach them, if they respond more, it helps to also see I'm making a difference in this child."* (Nylethu)

These learners often develop gradually. This gradual development needs to be monitored by caregivers. Monitoring gradual development as a response to care helps to identify effective strategies.

> *"So, it's part of learning. It's like we learn every day. They are developing something, we are learning as they are growing. We are learning maybe this child is changing in a particular way."* (Nylethu)

Learners' ability to actively participate in an activity serves as an indicator of the impact of the care provided on their development. Participation in activities reveals how learners are progressing in these activities, which supports caregivers in understanding where they are thriving and whether additional support is required.

> *"Also, you can see the difference with them. They [may] know how [to do it] tomorrow, they [may] know what we are doing now. Maybe we are playing [with] a ball, they know I can throw the ball to the next person. I'm throwing it. So, it*

helps develop their skills, also their social skills, how they engage with others, how they play with others." (Nylethu)

Below the caregiver eloquently shares not only how the process involved in meaningful engagement with the learner and the reflection of the caregiver results in responsive learners and more effective facilitation of learning, but also how the online course contributed to this process.

> *"It has helped me to find ways to be able to engage them. Also be able to teach them, like the grouping, like what stage is this child in…also it helps us to know what kind of activities, what kind of things I must do with this child. The child is involved.. also it helps to engage with the children, the children are happy."* (Nylethu)

As caregivers become more attuned to learners' responses, learners sense their attentiveness and develop a willingness to respond. Through the ongoing interaction between caregivers and learners, caregivers gain a deeper understanding of the ways in which learners respond and how to provide effective support. This ongoing engagement fosters trust and connection between caregivers and learners, cultivating a relationship rooted in good care, largely attributed to caregivers' engagement with the online course.

4.5.3. Parents' response to caregivers' care

Caregivers have come to understand the value of supporting not only learners but also their parents or primary caregivers, in the case where learners are not cared for by their parents. By supporting parents in navigating challenges they may face, providing coping strategies and being empathetic, caregivers are able to provide the support parents may require. Support groups, a crucial strategy for the development of learners and support of parents, are a source of emotional and practical support. Caregivers encourage the formation of these support groups.

> *"… because the neighbour doesn't have a child with a disability, they are not going to understand what is going on. So, just being somebody who can listen and even just share with them coping strategies. That's why I said, we created*

a parent group that are doing: how we can adapt, how they are coping." (Sophia)

Parents become more receptive towards caregivers, as caregivers relate to parents with empathy and understanding. This shift is instrumental in the development of the learner. A caregiver reflects on her growth, noting a transition from initially using ineffective communication strategies to embracing supportive, constructive approaches:

"So, when you speak from a point of understanding, a point of empathy, they are more welcome to receive information from you. Because, sometimes we don't talk to them as parents, we talk at them. Because we know what we want the children to develop and sometimes they don't understand why. So, if you are talking from an understanding point of view, it's much easier for a parent to receive that information from you." (Sophia)

Caregivers incorporated training sessions into their regular parent meetings. Through the content of the online course, caregivers were able to share strategies and practical knowledge with parents in their parent meetings. Caregivers were able to promote acceptance by parents of their children, while sharing practical solutions to challenges they may be facing.

"… it helped me also, especially to educate, especially those parents who are struggling with their children, who are struggling with their children, who are not accepting [their] children with disability." (Nylethu)

By communicating with parents in their vernacular language, caregivers contribute to the empowerment of parents in the application of learning techniques for their children. Parents become more open and confident, they are able to understand and implement the strategies which not only support parents in the continuous development of their children in their homes but also help parents feel more empowered in providing care in their homes.

"But if you can talk to them in their vernacular language, one-on-one, then they get to understand. That's when we start to see positive changes, even in the children. Because sometimes to tell someone to do something they don't

understand, they ignore it, because what is the use if I'm not understanding it myself. But if you teach them to understand it first, then they're in a better position to implement it." (Sophia)

As caregivers demonstrate commitment to assisting parents, their support leads to increased confidence in managing their children's needs. With this increased confidence, parents begin to formulate their own strategies and share these coping strategies with other parents.

"And I've actually seen that some parents that are coming up with strategies …sometimes it's something that it's not even coming from me." (Sophia)

By persevering in their support to parents, offering solid recommendations and providing training to parents, caregivers' unwavering support leads to parents becoming more empowered and adopting a positive approach to the provision of care to their children. The application of the techniques shared by caregivers and the formulation of their own strategies is a reflection of the effectiveness of the support caregivers provide to parents. Through adopting empathetic and supportive approaches towards parents, caregivers and parents build stronger relationships that promote the development of these learners.

As a result of their engagement with caregivers, learners have developed a willingness to engage with caregivers, and parents have developed confidence, resilience and created a cycle of mutual support through their engagement with caregivers.

Parents' and learners' responsiveness to caregivers can be interpreted as a reflection of the caregivers' ability to provide good care. The caregivers' engagement with parents and learners have elicited positive responses from parents and learners' willingness to engage. The responsiveness of the parents and learners has revealed the caregivers' capacity to build strong, effective relationships that promote supportive environments and foster development.

4.6. Chapter conclusion

The findings have effectively addressed the research question by demonstrating that online courses can significantly contribute to both the personal and professional

development of caregivers. These courses have equipped caregivers with the knowledge and skills necessary to support the education of learners with SPID, enhancing their understanding of how to facilitate learning, engage with diverse forms of communication, and foster strong relationships with service providers, the community, and parents.

Caregivers recognise and respond to the learners' needs, evident in their ability to effectively address learners' emotional and physical responses. The attitudinal and behavioural shift towards the educability of learners with SPID, and their use of a variety of strategies demonstrate the positive impact of the online course.

However, the disparity between the needs of learners with SPID and their caregivers, and the support and resources provided for the care and education of learners with SPID continue to receive minimal attention. The response from government remains insufficient to bridge the gaps, leaving caregivers to manage any challenges on their own. While the course content, structure and delivery were beneficial to these caregivers, they were concerned about language accessibility for those in rural areas who are not proficient in English. In addition, technical limitations and internet access may continue to hinder the ability of other caregivers to engage with the online course. Their concerns highlight the need for improvement in terms of language offering, technological support and accessibility to ensure that all caregivers are able to benefit from the online course

CHAPTER 5: DISCUSSION

5.1. Chapter overview

The purpose of this study was to explore and describe caregivers' experiences of engaging in the SPID MOOC. In this chapter, the discussion of the findings is presented demonstrating the contribution of the SPID MOOC to caregivers' professional development through the content, structure and delivery of the online course. This chapter also closely examines the cyclical nature of the phases of an Ethics of care as experienced by these caregivers. The shift caregivers experienced in their attitudes towards the education of learners with SPID results in greater competence in their roles which is demonstrated through their ability to create more responsive environments and their support for families. This chapter also discusses the importance of communication in realising these responsive environments. In this chapter, we describe the responsibility of various stakeholders and the affect when stakeholders do not take responsibility for their roles in the education and care of learners with SPID. This chapter includes the following sections: attitudes, responsive environments, family support, responsibility, communication, local relevance of the online course for the professional and personal development of caregivers and the cyclical nature of an ethics of care.

5.2. Attitudes

In their accounts in Chapter Four caregivers refer to their attitudinal shift towards learners, parents and even community members. Through their exchange with participants of the online course, caregivers realise that negative attitudes towards learners with SPID and their families extended beyond the African context and is in reality a worldwide phenomenon. The caregivers themselves demonstrated a shift from negative attitudes to care and education of learners with SPID to having a caring attitude towards these learners. These caregivers attribute their increased attentiveness towards learners' needs to their participation in the online course.

Despite legislative policies and frameworks articulating the basic human rights of persons with disability, it is often overlooked. As a result of this oversight, attitudinal

barriers are maintained and even fuelled by those closest to these learners. Negative attitudes towards learners with SPID thrive within African communities due to many superstitions held about learners with disabilities and the origin of the disability. It is often stated that disability in the family is due to a curse resulting from the actions of forefathers, witchcraft and retribution of God (Ndlovu, 2016).

Studies have shown that individuals involved in the care of children with SPID are devalued and experience significant challenges. Parents often experience isolation and a lack of support, while caregivers at SCCs contend with inadequate resources and assistance to deliver effective care and education (Moosa-Tayob & Risenga, 2022).

Despite the adverse effects these experiences have had on caregivers, these negative attitudes are manifested in caregivers' practices and interactions with learners and their families. Caregivers underestimated learners' capability to participate in society, their educability and ability to make choices. Caregivers acknowledge that their negative attitudes were a hindrance to the development of these learners. Through their encounters, caregivers realised that parents, other caregivers and members of the community shared these perceptions and consistently questioned the value of the learners' contribution to their communities and society as a whole.

For a shift to occur, caregivers needed to put aside their own preconceived notions, which often manifest as indifference and neglect of learners with SPID. By releasing these ideas, caregivers are able to recognise the diversity of each learner. This shift also applies to parents and family caregivers. As research consistently highlights the importance of family-professional relationships, this shift also applies to parents and family. Such partnerships are often seen as crucial to the developmental progress of these learners (Sevenhuijsen, 2018; Mckenzie, Kahonde, Mostert & Aldersey, 2020). Caregivers describe the attitudinal shift as moving from the belief that educating learners with SPID would be futile to understanding that denial of education hinders their growth and development. They discarded the idea that learners only needed care, recognising as well their potential and ability to be educated. Through their educational techniques, caregivers showed an awareness of learners' uniqueness and emphasised the importance of collaborating in providing education for learners with SPID.

The account provided by caregivers of their shift is closely related to Kittay's (2011)

description of caring attitudes which foster attentiveness. They attribute this shift in their attitude to their participation in the online course, but it is evident that a shift in attitude requires a deeper level of understanding fostered by embracing and practising the principles contained in the content of the course.

Kittay (2011) describes a caring attitude as a positive, affective bond between caregiver and care recipient. Emotions could be a motivator for altering beliefs which guide our actions and choices. Empathy gives rise to a variety of emotions. Empathy is both a precondition for care and the origin of our demand for justice. Attitudes could be adjusted by positive as well as negative feelings. For example, indignation and shame could result in self-correcting to avoid judgment of others (Pulcini, 2017). Caregivers display these qualities as they share their account of their attitudinal shift.

Firstly, a caring attitude enables the caregiver to be open to understanding and responsive to the learners' unique needs (Kittay, 2011).

It is clear from the thoughtful questioning of their deeply entrenched beliefs of learners' ineducability which has been replaced by the newly found knowledge on the rights and capabilities of learners with SPID that caregivers have released their own prejudices and opened themselves to a different understanding of these learners' capabilities.

The second attribute of a caring attitude is investment in the well-being of the care recipient (Kittay, 2011).

Caregivers are fully aware that learners with SPID have a range of complex needs and caregivers are limited in their capacity to meet all these needs. Caregivers understand the importance of building relationships for the purpose of ensuring the well-being of these learners. Caregivers' investment in the well-being of the learners extends beyond the learners to a range of stakeholders, including their parents.

The findings demonstrate that caregivers displayed feelings towards these learners which contributed towards the change in attitude towards the learners with SPID. These feelings aroused a need to view the situation in a different way and gain a better understanding of who these learners are and what their needs are with the view to responding to these needs. This bond encouraged feelings of acceptance.

Recognising a need requires attentiveness. To effectively address the needs of the

care recipient, caregivers must set aside assumptions about sameness and instead consider each person's unique situation. This involves thoughtfully questioning and reflecting on their interactions and reactions in order to better understand and interpret the needs of the other (Tronto, 1993; Sevenhuijsen, 2018). While it is important to recognise the difference, Norwich (2008) explains that recognising and responding to difference could also have negative risks. Caregivers need to be attentive so that they are able to balance the negative perspectives of difference against the positive views which recognises the learners' needs. The caregiver needs to recognise and respond to difference in way that supports inclusion, and barriers are addressed through impairment-specific approaches and strategies (Norwich, 2008).

This section presents a broad overview of caregivers' attitudinal shift. It demonstrates how caregivers abandoned initial perspectives about learners and adopted a caring attitude which contributed to their attentiveness towards learners' needs. This section also provides evidence of the emotional element and how it contributed to the adoption of a caring attitude. This next section takes a closer look at the transition of caregivers and their professional development. It shows how caregivers' attitudes and practices changed towards learners' needs and their learning environment.

5.3. Responsive environments

Prior to training, caregivers believed that learners with SPID were ineducable and found that these beliefs were shared by other caregivers through their discussions with the online course participants.

Education has been described as learning which happens within a particular setting with specific teaching methods and a specific curriculum. It is understood to equip learners with skills to be productive members of society contributing to the economic growth (Johnson & Majewska, 2022). Mental and intellectual faculties have been a focus of education. Being so closely associated with intellectual faculties and skills for economic growth means that those with a lower intellectual capacity are seen as a drain on the economy with little value to society. These interpretations limit education to scholastic learning and place more value on formal learning. This overriding interpretation of education has had implications on the learning of learners with SPID (Hanusek & Woessmann, 2008).

A more suitable interpretation of education for learners with SPID is meaningful knowledge which receives a response from learners. Education of learners with SPID does not imply 'formal schooling' but rather refers to a process of lifelong learning (DBE, 2016a).

The curriculum developed for learners with SPID contrasts with the curriculum for neurotypical learners in that it has different objectives or curricular outcomes. The curriculum for learners with SPID has been developed to respond effectively to their needs by ensuring that they acquire and apply knowledge and skills that are meaningful to their lives, for example an understanding of social interactions and the world around them, while the curriculum for neurotypical learners, described as prescriptive and a social-engineering domain, has been developed to serve the vision of society. It is designed to develop professional formation and academic discipline to cultivate desirable qualities for adult members of society. Even though it has been acknowledged that learning through educational programmes is a socialisation exercise, the curriculum of learners with SPID is more focused on the needs of learners with SPID while the curriculum of neurotypical learners serves the vision of society (Bobbitt, 1918; Smith, 2000; DBE 2016a).

While the curricular for neurotypical learners is prescriptive and described as a social-engineering arena, it is designed to develop desirable qualities for adult members of society, for professional formation and academic discipline. The curriculum for neurotypical learners is developed to serve a vision of society, while the curriculum for learners with SPID serves the needs of the learner (Bobbitt, 1918; Smith, 2000; DBE, 2016a). A conducive learning environment has been defined as a responsive environment in a natural setting (DBE, 2016a). The caregivers' description of a conducive, learning environment aligns with this description provided in the *Draft learning programme for learners with severe to profound intellectual disability* (DBE, 2016a).

It was evident that this online course had an impact on the caregivers' view of education. Caregivers released their pre-conceived views of the educability of these learners and were open to a different way of thinking. They put great emphasis on the importance of creating a conducive, learning environment. The learners are not homogenous and require a customised learning programme, participation in

meaningful activities and more importantly a responsive environment. The customised learning programme included a variety of teaching methods and techniques which they have described. Their curriculum focused on self-care and life-skills, communication and language and spatial and conceptual development.

A responsive environment or setting is less about the resources, and more about the attitudes of caregivers and other stakeholders towards these learners' capacity to learn. The responsive learning environment of learners with SPID not only includes caregivers and the learners, but parents as well. While government and the community bear the responsibility for addressing learners' needs, caregivers, learners and parents play a crucial role in creating responsive environments (Wood et al., 2019) (see figure 5.1). Attitudes of caregivers and parents could be a facilitator or a barrier to education for learners with SPID. For example, caregivers' resilience towards limited resources could be a facilitator in the learning environment, while insufficient support provided by government to parents could act as a barrier and affect how parents attend to the needs of their children.

The diagram below depicts the learners' educational environment and their context. It includes all the stakeholders who have an effect on their development and those whom they have an effect on.

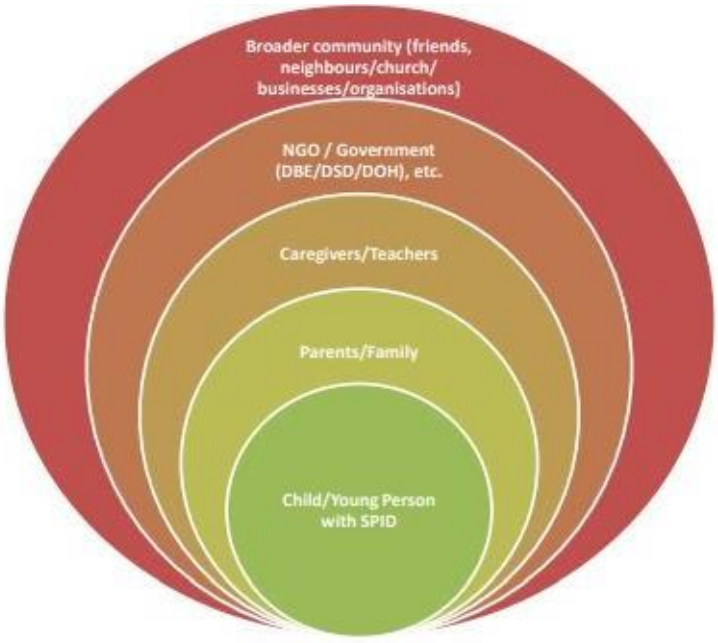

Figure 5.1: Circles of care and education – The circles of support for learners with

SPID (DBE, 2016a: 26)

Caregivers have provided evidence that knowledgeable, well-trained caregivers present positive attitudes towards these learners' education. They create effective, responsive learning environments for learners with SPID. Responsive environments are described as engaging teaching and learning environments in which learners obtain a response to their behaviour, actions or gestures. The learning environment should be structured in a way that it is sensitive to their actions and responds to their actions, demonstrating that learners' actions have meaning (DBE, 2016a), for example, awareness of learners' cues, enabling learners to perform certain activities and creating opportunities for learners to respond. Despite the resource-constraints experienced at SCCs, caregivers have managed to create responsive learning environments by their responses to the learning areas of learners. If no opportunities are created for a response from caregivers to learners, development will possibly be hampered. The guiding principle of the learning programme in the Draft learning programme for children with severe to profound intellectual disability is: "Development and learning takes place through the continuous integration of communication, spatial and conceptual development and life skills that the child is exposed to and experiences in his/her natural environment or daily programme on a daily basis" (DBE, 2016a:16). The following three components of the curriculum for learners with SPID are the focal areas when creating a responsive learning environment:

Table 5.1: The three subject components within the learning programme

This subject component is concerned with the following: Communication and language	This subject component is concerned with the following: Spatial and conceptual development	This subject component is concerned with the following: Self-care and life skills
Continuous development of symbolic communication in speech or gesture	Development of conceptual skills that involve the physical world rather than symbolic processes	Increasing independence on all aspects of daily physical care, health, and safety, with increasing participation

Understanding of simple instructions or gestures	Use of objects in goal-directed fashion for self-care, work, and recreation	Assisting with some daily work tasks at home and at the learning centre, like carrying dishes to the table
Expression of own desires and emotions largely through	Visuospatial skills, such as matching and sorting based on physical characteristics	Developing simple actions with objects as the basis of participation in some vocational
non-verbal, non-symbolic communication		activities with high levels of ongoing support
Enjoyment of relationships with well-known family members, caretakers, and familiar others	Sensory, motor and perceptual skills to explore and participate in their environment	Developing recreational activities that involve, for example, enjoyment in listening to music, watching movies, going out for walks, or participating in water activities, all with the support of others
Initiating and responding to social interactions through gestural and emotional cues	Basic problem-solving skills	Reducing maladaptive behaviours
Being consulted and indicating their own choices		Sexuality and relationship education
		Developing relationships with community members, family, caregivers and peers

5.3.1. Communication and language

In terms of the development of communication and language, the *Draft learning programme for children with SPID* highlights: continuous development of symbolic communication in speech and gestures; understanding of simple instructions or gestures; expression of own desires and emotions largely through non-verbal, non-symbolic communication; enjoyment of relationships with well-known family members, caretakers, and familiar others; initiating and responding to social interactions through gestural and emotional cues and emotional cues; and being consulted and indicating their own choices (DBE, 2016a).

The following are techniques used by the caregivers:

Techniques related to ‘Communication and language’ used by caregivers

Made use of images of handwashing at washbasins

Handwashing images were used as instructions

They observed emotions expressed by learners like smiles

Encouraged parents to visit the centre and visited home to demonstrate relationship-building

They observed learners’ responses to physical activities

They observed learners’ responses to a variety of activities, and learners’ gestures such as nodding, pointing. Caregivers also presented two or three activities to learners.

To develop communication and language skills, caregivers developed an understanding of their preferred mode of communication. These caregivers explained how they identified learners’ gestures, learned to understand and respond to them based on learners’ mode of communication. In Chapter Four, caregivers referred to a range of activities which elicited a response from learners. They explained how they used hand washing images to demonstrate the activity which took place at the washbasin. Caregivers explained that these images indicated that learners had to wash their hands rather than drink the water. Caregivers observed the emotion expressed by learners when parents were encouraged to visit. This not only indicated

how they felt about the visit but prompted them to encourage parents to continue visiting. Caregivers observed learners' responses to physical activities and often presented more than one activity to give learners the autonomy of choice. Their observation of learners' responses to activities gave caregivers an indication of how to respond to learners and what further action was necessary. Identifying, understanding and ongoing engagement between caregivers and learners helps learners to develop 'communication and language' skills.

While 'communication and language' is a subject component on its own, the subject components are integrated into other areas of learning creating an integrated, holistic programme. For example, hand washing signs are purposed for the development of 'communication and language skills' but fall under the development of 'self-care and life skills' as well.

5.3.2. Spatial and conceptual development

The *Draft learning programme for children with severe to profound intellectual disability* describes the development of conceptual skills as involving the physical world rather than symbolic process. It entails the use of objects in self-care, work and recreation. Matching and sorting, described as visuospatial skills, based on physical characteristics and perceptual, motor and sensory skills, are used to explore and participate in their environment (DBE, 2016a).

The following are strategies used by caregivers for the development of spatial and conceptual skills:

Techniques related to 'spatial and conceptual development' used by caregivers

Caregivers made use of physical items like food to indicate lunch time or tea time

Caregivers made use of self-care items to demonstrate the use of these items and adapting activities to encourage self-care skills

Made use of the environmental print to assist them in participating in their environment

Made use of ball games and hula hoop activities to develop visuospatial skills

Learners were able to develop spatial and conceptual skills through strategies used

by caregivers. Caregivers used various opportunities such as lunch time and tea time to assist learners in developing these skills. Caregivers signalled to food provided to indicate to learners that it was lunch and tea time. In instances where learners found toileting challenging, caregivers devised creative solutions. In Chapter Four, a caregiver describes how she responded to the learner's toileting issue with a simple solution by adding food colouring. This particular learner was persuaded to use the water as a result of the change in colour. Caregivers are required to assist learners in developing visuospatial skills. Ball games were used to develop these skills. In addition, learners were taught to identify and make associations with certain words through the use of environmental print which made it increasingly possible for them to participate in their environment.

Ball games and hula-hoop activities assist with both 'spatial and conceptual skills' and 'self-care and life skills' development as hula-hoop activities develop spatial awareness and allows for recreational activities demonstrating how caregivers integrated the subject components.

5.3.3. Self-care and life skills

Self-care and life skills refer to the holistic development of the learner with SPID and include self-care skills. They are central to supporting and teaching development and learning and include emotional, personal, sensory, perceptual and physical development. Life skills support and strengthen the development of communication and language, and spatial and conceptual development. The aim of life skills is to increase independence, assist with daily work tasks, develop simple actions with objects and, amongst others, include developing relationships with other individuals (DBE, 2016a).

The following are techniques related to 'self-care and life skills' used by caregivers:

Brushing or combing their own hair; washing and drying their own hands with support, then scaffolding support, brushing teeth

Making skipping ropes, knitting plastic bags to make skipping ropes, hand-over-hand activities

Participation in physical activities like ball games and singing songs

Learner expelled food: rather than feeding him when they thought necessary, allowed him to eat on his own at his own pace.

In this area of development, caregivers focused on adapting activities, hand-over-hand activities and producing items for physical activities like skipping ropes. Caregivers supported learners in increasing their independence through scaffolded self-care activities like combing their hair, washing and drying their hands and brushing their teeth. Expanding on this, caregivers used their lack of resources as an opportunity to develop learners' life skills. For example, caregivers supported learners in making skipping ropes. The production of these skipping ropes had a dual purpose, they were used for recreational activities and to create opportunities for participation in vocational activities. Learners participated in physical activities like ball games and singing songs for recreation. For those learners who demonstrated maladaptive behaviour like expelling food, caregivers made sure to monitor their behaviour and considered the possible reasons for this behaviour which assisted them in formulating a suitable response like allowing the learner to eat on their own.

The three subject components are delivered in an integrated way, and this is evident in the example on brushing or combing their hair which covers 'self-care and life skills' and 'spatial and conceptual skills' development.

While caregivers demonstrated the ability to create effective, responsive learning environments, learners demonstrated their ability to be educated. Despite the limited evidence we have on learners' responsiveness, caregivers claimed that learners were able to communicate their needs and preferences, acquired self-care skills and life skills, and developed conceptual and spatial awareness.

Responsiveness is at the heart of education for learners with SPID. Caregivers need to firstly adjust their attitudes towards the education of learners to become more attentive to their needs and gestures. Caregivers acknowledge that they need to reflect on these gestures to make meaning and acknowledge these gestures through their responses to ensure learners continue their attempts at communication. While their development is quite different to that of the neurotypical learner, there is learning happening which could easily go undetected if the caregivers were unaware or unable to recognise these responses (Mutumburanzou, 2018). The failure to create

opportunities for responses, accompanied by limited engagement with the learner, often lead to their responses going undetected. This, in turn, contributes to the perception that learners with SPID are uneducable.

This section provides evidence of caregivers' transition and how this transition contributed to the learners' development. In the next section we see how this transition in their attitudes affected their relationships with the learners' families as well.

5.4. Family support

Caregivers at SCCs are associated with community support structures as well as a professional community (Moosa-Tayob & Risenga, 2022). The participants in this study acknowledged their role and identified their responsibilities and their affective connections which motivated them to respond to the needs of learners and their families. In this section, they describe their transition from neglecting these families and their need for support to being fully engaged in the lives of these families, attributing this transition to their participation in the online course.

Caregivers' beliefs about learners had an effect on their engagement and interaction with their families. Prior to the training, caregivers and parents functioned in their own silos, even though parents were interested in a relationship and often reached out to caregivers for support. Despite well-meaning neighbours and family members offering their support, primary caregivers and parents required the support of knowledgeable, empathetic individuals who could provide coping strategies, such as the caregivers.

The value of this online course is evident in caregivers' realisation of the importance of building a relationship with these families, and the impact of this relationship on the progress of these learners. Caregivers collaborated with primary caregivers, maintained communication with them and supported parent groups. Caregivers' insight into the families' needs and how to respond have been attributed to their increased empathy towards families which developed from the knowledge gained through the course content and increased engagement with these families.

Caregivers demonstrated empathy in their behaviour towards the primary caregivers and parents. Empathy motivates us to respond to others and guides us on how to respond to others. When we perceive their reality, we are motivated to act in accordance with their reality and respond to their needs. Empathy transforms us and

guides an ethical response (van Dijke, van Nistelrooij, Bos & Duyndam, 2019).

While professionals often have the cognitive knowledge to provide services, cognitive knowledge lends itself to limited provision of support and services. Through empathy, caregivers are able to extend their support services and meet the full range of needs of family, thus providing comprehensive support services which reach beyond their mandate. Empathy generates a deeper understanding of the needs of learners and their families.

5.4.1. Communication with primary caregivers and parents

A study conducted by Modula and Chipu (2024) indicated that communication with care centre caregivers was essential to primary caregivers and parents. They felt the need to be informed on their children's well-being and progress.

As the relationship grew between the care centre caregivers and primary caregivers, communication extended beyond the expected information required on learners' well-being and progress. Care centre caregivers understood that primary caregivers required someone who would be open to listening and talking about their challenges when they were not coping. It was apparent that they set aside their perspective and stepped into the primary caregivers' reality since they were open to communication after hours, and even weekends. Caregivers understood that communicating with neighbours and family members was not enough; families and primary caregivers needed to communicate their challenges with knowledgeable care centre caregivers.

5.4.2. Home visits

Modula and Chipu (2024) made reference to the need for home visits. These home visits were essential to encourage and support primary caregivers, especially since primary caregivers found social grants inadequate to support their basic needs. The support provided by care centre caregivers described below aligns with Modula and Chipu's (2024) study on the needs of primary caregivers.

Home visits are essential to adopting the routines implemented at the care centres. Caregivers need to assess the viability of these activities in learners' home environments as continuing these activities in learners' homes contributes to their development. Due to the financial and environmental situation in the homes of these

learners, their home environment might contrast with the care centre environment and where this is the case, families and primary caregivers require the guidance and support of care centre caregivers. Caregivers became aware of the importance of these home visits to learners and their families and thus ensured that these home visits became part of the support provided to families.

5.4.3. Support groups

Despite parents prioritising communication with caregivers at SCCs, it is evident in studies that parents found community support essential in times of crisis. Primary caregivers often felt isolated, requiring community support from extended families, friends and neighbour, but found that they enjoyed emotional support from other parents. This highlights the need for support groups of families and suggests professionals facilitate and co-ordinate these support groups (Modula & Chipu, 2024).

These caregivers at SCCs displayed their attentiveness to the call for support by parents and primary caregivers through encouraging the formation of support groups for parents. Parents shared their coping strategies and best practices with each, thus learning from each other and feeling more empowered.

Creating responsive environments and supporting families forms part of the caregivers' responsibilities. Caregivers are able to confidently and comfortably fulfil their roles with the increased empathy. Although they have embraced their empathetic responses which motivate them to fulfil their responsibilities to others, it is necessary for others to increase their empathetic responses as caregivers are not solely responsible for the care of learners with SPID.

5.5. Responsibility

Our local and international policies, frameworks and laws have been developed to protect the rights of persons with disabilities and are pursued and supported by the disability movement (UN, 2008; 2015). While all persons are entitled to these rights, we acknowledge that there is a disparity between rights and practice. The disparity could be attributed to, firstly, who is entitled to these rights and, secondly, whether government is taking responsibility for the realisation of these rights. Mckenzie and Macleod (2012) argue that human rights approaches have been less effective for persons with intellectual disability due to their failure to recognise the complexity of

rights for persons with intellectual disability. The rights rhetoric is based on an understanding that individuals entitled to these rights should be rational individuals which requires an intellectual capacity which by the very nature of their condition they do not meet. This rights rhetoric pursues the idea of independency, autonomy and individualism which does not take into consideration the fragility of human beings and our dependency on one another. This focus on independence and autonomy has cultivated a culture of neglecting the responsibility we have to one another as a society. It is particularly evident in government's responses to their people (Kittay, 2011).

The disparity between policy and practice is evident in the 2010 court case of the WCFID vs Government of Republic of South Africa and Government of Province of the Western Cape (Southern African Legal Information Institute, 2011). According to the Constitution, learners with SPID are entitled to the right to education, but the government declared these learners 'ineducable' and therefore not entitled to education. The exclusion of these learners with SPID could be attributed to their inability to be considered 'rational' persons. The High Court acknowledged their rights when they declared their exclusion as an infringement of their rights. This court case demonstrates how the government had initially failed to acknowledge its responsibility towards these learners (Murungi, 2011).

As discussed in Chapter Two, various government departments are responsible for different aspects of fulfilling these learners' rights to education and care. DBE, DoH and DSD are respectively responsible for curriculum development, capacity building and support of care centre caregivers; assistive devices; and financial resources for children and their families. While departments have their specific roles to play, these departments need to work collaboratively to ensure effective support to caregivers at SCCs (DBE, 2016b). The respondents argued that they had limited resources and competing demands that could not be trumped by these learners' right to education; however, the South African Constitution states that learners' right to education is not subject to resource availability over a period of time. The implementation of their right to education is an immediate obligation (Murungi, 2011).

Prior to the online training, caregivers lacked an understanding of learners' capacity, teaching techniques and support services which had a negative impact on the learners. Upon completion of the online course, caregivers developed teaching

techniques at the care centre for these learners and adapted activities to suit their home environments. As a result of the minimal financial support received by families to accommodate these learners' needs, these adapted activities in their homes formed a pivotal part of their development (Sefotho et al., 2021). Under-resourced centres and poorly supported homes required caregivers to be more resourceful to ensure learners' participation in stimulating activities (Geiger, 2012). While co-ordination of government support services lies within the realm of DSD responsibilities, caregivers built relationships with various departments without the assistance of DSD (DBE, 2016b). As a result of these relationships, caregivers were able to arrange second-hand wheelchairs for these learners for their participation in everyday activities. Since participating in the course, caregivers have suggested participation in this course as a means of capacity building for other caregivers.

Through these examples, it is evident that the Department of Education, Social Development and Health were not adequately fulfilling their roles and responsibilities. In instances where one stakeholder does not fulfil their responsibilities, the result is additional pressure on another stakeholder. Whilst these examples have displayed and developed characteristics such as resilience and creativity, it could result in feelings of isolation, lack of support, burnout and neglecting their actual responsibilities (Wood et al., 2019).

Alongside government departments, academia and higher education institutions are responsible for professional development training for caregivers at SCCs on the needs of these children on a national level. The '*Draft policy for the provision of quality education and support for children with severe to profound intellectual disability*' states that short courses should be developed on addressing the needs of children with SPID and goes further by stating that the training should be developed and offered by HEIs and TVETCs. When developing national programmes, rural areas need to be prioritised (DBE, 2016b).

Even though caregivers found the training opportunities empowering and beneficial to their engagement with the learners with SPID, they were concerned about the accessibility of the course for other parents and families, especially those in rural areas. These online courses delivered in English could be considered a barrier to accessing online training opportunities since family members taking on the role of

primary caregivers might have limited skills in navigating online platforms and be limited in their proficiency in English. Caregivers were made aware of these challenges at parent meetings when sharing the content of the course. Caregivers were often required to translate the content. This demonstrated that, even when stakeholders attempted to fulfil their responsibility to learners and their families, caregivers often stepped in to accommodate for the needs of these families.

While there are overarching responsibilities, there are also sector-specific responsibilities which are interconnected and often overlap (DBE, 2016b). Achieving these responsibilities is often dependent on another stakeholder fulfilling their responsibility; therefore, all stakeholders need to work collaboratively and co-operatively towards the needs of learners and caregivers.

Adopting a value system which supports interdependence, community and responsibility could mitigate the effect of laws which promote independence, autonomy and individualism (Held, 2006; Kittay, 2011). Like ethics of care, Ubuntu, as described in Chapter Two is a collective rather than an individualistic worldview which upholds interdependence, connectedness and relations (Gouws & van Zyl, 2015). Unlike individualism which is believed to give rise to corruption in our society, care of members of a community is paramount as challenges are overcome through co-operation, collaboration and care and has a positive effect on the overall performance of the community (Magang & Magang, 2017).

Despite the belief that western ideologies are often not suitable for an African context, we need to acknowledge that seemingly oppositional worldviews could be complementary in nature and have similarities. Ethics of care refers to it as ‘relationality’; while Ubuntu refers to it as ‘I am because we are’. It has been claimed that Ubuntu nurtures the Ethics of care and refers to a collective responsibility. Both Ubuntu and Ethics of care value relationships and the interconnectedness of individuals. Ethics of care speaks about the dependency we have on one another and identifies responsibility as a key element of caring practices. Ubuntu encourages people to focus on the needs of the community rather than themselves and acknowledges one’s responsibility to one’s fellow humans and the world around them (Kittay, 2011; Gouws & van Zyl, 2015; Chisale, 2018). Ethics of care and Ubuntu share foundational elements acknowledged in the responsibility we have to one another.

Caregivers who were previously working in isolation have now learned the value of collaborating, co-operation and care for the progress and development of their learners. They collaborated with a range of stakeholders including social workers; they co-operated with parents through the adaptation of activities for learners' home environments and demonstrated care through encouraging parent support groups. They are acutely aware of their responsibility to these learners and the value of connectedness to creating conducive learning environments for these learners.

Even though policies promoting the rights of learners have been established, the realisation of their rights is evidently dependent on the adoption of a value system. The adoption of this value system, which they attributed to their participation in the online course, seems to have directed their actions which has led to the transformation in how they educate and care for these learners.

Similarly to this section, 'communication' demonstrates their creativity and resourcefulness. Despite the limited resources and support, caregivers' implementation of techniques and their attitude towards learners clearly show their professional development.

5.6. Communication

Communication is a fundamental right to everyone, including persons with SPID. The United Nations Convention on the Rights of Persons with Disabilities (UNCRPD) includes the rights of persons with disabilities to have access to communication and participate in their community (United Nations, 2008). Communication is central to all aspects of our lives; it influences our relationships, our independence and ability to make choices. It is essential to our quality of life and well-being (Goldbart, 2023).

The learners' development is dependent on the continuous integration of the three subject components in their daily programme and natural environment. Communication is one of the three subject components which intersect, as seen in the diagram below (DBE, 2016a). With the intersection of these three subject components, one subject component may affect the development of the other subject components.

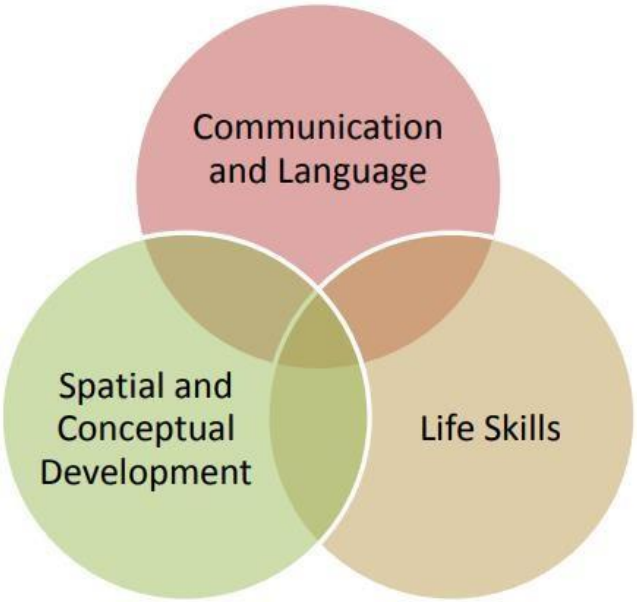

Figure 5.2: Communication as one of the three subject components intersecting (DBE, 2016a: 16)

Learners with SPID are often affected by severe motor disabilities and this combined with significantly limited cognitive abilities results in difficulty communicating and engaging with others. Learners with SPID have an idiosyncratic form of communication which results in the belief that they are unable to communicate. Learners' idiosyncratic language includes pre-symbolic communication such as gestures, vocalisations, facial expressions and body language and symbolic communication such as images, signs and symbols (Boardman, Bernal & Hollins, 2018).

This study supports the literature on these learners' ability to communicate. These learners used pre-symbolic communication and symbolic communication. For example, they would use physical gestures like pointing to indicate their preference; they would use emotional cues like smiling to show their happiness or their enjoyment of an activity. Learners also reacted negatively towards activities in which they were not interested. Certain learners were dependent on pre-symbolic communication, while others made use of symbolic communication in the form of images, signs, symbols and *real items*.

Caregivers apply Lumadi and Maguvhe's (2013) recommendation to present curriculum in an accessible format by incorporating these forms of communication into the curriculum. If the format in which the curriculum is presented is not easily understood by learners, the teaching-learning experience is futile (Lumadi & Maguvhe, 2013).

Effective communication with these learners is largely dependent on the communication partners such as caregivers and family members being involved in the Alternative and Augmentative Communication (AAC) intervention process, the process of supporting or replacing the spoken and written language with techniques which are easily understood by learners with SPID. For effective communication with these learners, caregivers need to integrate AAC into their communication, anticipate learners' needs and interpret their gestures (Goldbart, 2023; Mutumburanzou, 2018). Despite the need for caregivers to be empowered to support and facilitate meaningful interactions and optimal communication development for these learners (Geiger, 2012), SCCs have not been included in any form of strategic planning or budgetary provision for appropriate services or resources for basic stimulation and training provision (Wood et al., 2009). While non-profit organisations attempt to provide services, training and support, up-skilling of centre-based carers remains an urgent need (Geiger, 2012). The minimal attention given to developing communication skills of learners and providing training to caregivers to support the development of learners' skills infringes on learners' rights to meaningful interaction and communication. As a responsibility of the state, the necessary steps need to be directed and supported by the state with training of caregivers as the central focus.

Basic communication development of learners with SPID should be prioritised by the state with training of caregivers in the development of communication skills.

With all these constraints placed on caregivers, they were still able to create environments which facilitated the development of learners' communication skills. Their lack of targeted communication training, interventions and strategies was compensated by their knowledge acquired through the online training. Caregivers knew that learners had a right to effective, quality communication interventions, and learned to value learners' communication systems, and understood how to use environmental cues. They became more receptive and were able to interpret and

respond to learners effectively. These relationships between caregivers and learners were effective only where good communication practices were implemented, and good communication in turn can only be achieved where learner-caregiver relationships have a strong foundation.

Caregivers' competence in facilitating communication development strategies is evident in their communication with learners and transference of these skills to parents.

5.6.1. Communication development strategies used by caregivers at the SCCs

Even though the National Rehabilitation Policy addresses the provision of assistive devices and AAC devices in South Africa, the provision of assistive devices in underserved and low-income communities such as the Western Cape is inadequate (McConkey, 2005; Department of Health, 2000). In addition, formal speech therapy services remain inaccessible for learners with SPID (Geiger, 2012).

These caregivers made use of unaided AAC in their engagement with their learners. There is no indication that they have access to aided AAC, and this is possibly as a result of lack of resources provided to these SCCs. The lack of resources at SCCs has been compensated by the enhancement of their resourcefulness. Caregivers refer to making use of the resources which are available to them to use in their learning and teaching.

To be able to use unaided AAC effectively, caregivers had to determine what form of communication worked for which of the learners. For those learners who used pre-symbolic communication, caregivers focused on anticipating their needs and interpreting their behaviour and gestures. Caregivers used images, pictures and real-items as a form of instruction to determine the needs or preferences of the learners who used symbolic communication.

5.6.2. Inclusion of families in the communication development strategies

Studies support applying the communication skills learned in the classroom setting outside of the classroom. These skills must be repeated in a variety of settings. The family-professional relationship is important with the application of skills and the

continued development of communication skills in other settings. It is particularly important for successful, collaborative AAC interventions and family-centred approaches (Mutumburanzou, 2018; Goldbart, 2023).

The symbolic communication and pre-symbolic communication techniques used in the classroom should be shared with parents. The caregivers teach learners to identify words through association and this technique assists learners with their everyday functioning within their communities. For example, signage for a store would be used in this instance. Through this process of learning, abstract concepts become more comprehensible and concrete for learners, thus making these 'abstract' concepts more useful in their everyday activities. Identifying and understanding these concepts makes communication outside of the classroom possible.

While effective communication is dependent on good relationships between caregivers and families, the relationship between caregivers and families hinges on effective and efficient communication.

5.7. Local relevance of the online course for the professional and personal development of caregivers

Online courses, training and education have become the order of the day since the COVID pandemic and online learning has not only become embedded in how to deliver training but will continue to grow (Nieder et al., 2022). While the SPID MOOC (Coursera Inc., 2024) contributed to the personal and professional development of caregivers, there are further considerations and changes required to accommodate those living in rural areas where training is most needed.

In Chapter Four, caregivers demonstrate how their professional development aligns with the content of the *Draft learning programme for children with SPID* (DBE, 2016a). With the application and implementation of the content of the online course, caregivers have demonstrated personal development evident in their increased confidence in facilitating learning for learners with SPID, their resilience in a resource-constrained context and their understanding of the importance of relationship-building and collaboration. In Chapter Four, caregivers attribute their personal and professional development to this online course.

5.7.1. Content of the SPID MOOC

The table below provides an outline of the main topics covered in the online course. It is immediately evident that the course is succinct, making the course manageable for caregivers with their intense workload and family demands placing constraints on their time available for training.

Table 5.2: Topics covered in the Severe to Profound Intellectual Disability: Circles of care and education MOOC (Coursera Inc., 2024)

Week 1 (Module 1)	Who is the child with SPID?
Week 2 (Module 2)	Lifelong learning
Week 3 (Module 3)	Facilitating learning
Week 4 (Module 4)	Rights, advocacy and relationships of care

While this course may be succinct, it provides rich and robust content which is necessary to provide good care and facilitate learning for the learner with SPID.

The *Draft learning programme for children with SPID* states that caregivers should create responsive environments through a learning programme that is integrated into a structured daily programme. It raises the importance of collaboration between all stakeholders and goes on to describe the responsibility of the broader community in the education of learners with SPID. For learners to have meaningful development and learning experiences an integrated, holistic approach within a responsive learning environment and collaboration between stakeholders are crucial (DBE, 2016a). The content of online aligned with the content of the *Draft learning programme for children with SPID* which means that the online course contained locally relevant content (DBE, 2016a).

The phases of Ethics of care was particularly useful in demonstrating the process and transformation experienced by caregivers in facilitating learning for learners. The process was initiated by a shift in their attitudes and increased attentiveness towards the learning needs of learners with SPID. They understood the complexities that came

with facilitating good care and learning within an environment where barriers existed, such as a lack of support from the community and the state neglecting their responsibility towards learners with SPID. Caregivers demonstrated competence through their acknowledgement of the vital role of fostering strong relationships with learners, parents, and other stakeholders, especially in resource-constrained contexts. They recognise the importance of collaboration with stakeholders who are responsible for the health and well-being of learners with SPID. These stakeholders not only address the learners' physical and educational needs but also provide diverse perspectives on the needs of these learners allowing caregivers to gain a deeper understanding of learners' needs. Through co-operation and shared efforts, caregivers and stakeholders can effectively support the holistic development of learners with SPID. Caregivers demonstrated their competence particularly through their ability to adapt activities to accommodate for the needs of the learner, using various techniques and strategies to engage the learner, and consideration of their home environments and the needs of parents. Responsiveness of these learners also indicated caregivers' level of competence in the provision of care as it was evident that learners' needs are identified and attended to.

5.7.2. The structure of the SPID MOOC

One of the main barriers identified to online course participation in LMICs is the time constraints related to competing commitments around family life demands, work commitments and learning (Nieder et al., 2022).

The recruitment process made it clear that the demands placed on caregivers in their workplace makes the participation in activities outside of family life and work difficult. Many caregivers who were approached to participate in the study declined to participate and others could not even participate in the online course in preparation for the study due to their work and family life commitments.

The caregivers who participated in the study were able to balance work, family life and learning commitments. They attributed the completion of the online course to the structure of the course. The flow of the modules made it easy to follow which reduced the pressure on participants to gain a comprehensive understanding of the content. The discussion forums offered participants access to a diverse range of participants

who could support them when assistance was required. In addition, the course included content in various formats such as videos and text. When participants were not clear on the content in text format, they could utilise the videos for clarity. The online content served as a repository for participants who could revert to it when necessary. When additional resources were required, they could use the technical skills they acquired through the course to search for additional resources. They could even work and learn simultaneously as the video formats allowed participants to listen to the audio while working. The flexible options allowed participants to use their time efficiently and suited the work environment and demands of caring for learners with SPID.

5.7.3. The delivery of the SPID MOOC

MOOCs have the capacity to reach a large number of participants with diverse educational backgrounds regardless of their geographical location. These online courses are an attractive option for professional development since there is no cost to participate in the online course. However, the growing concern for participants in LMICs, especially in rural areas, is the cost of internet connections and data, as well as digital literacy of those in need of training in rural areas (Nieder et al., 2022).

Despite the challenges raised regarding the participation of participants from LMICS, none of these caregivers were affected by these challenges. They found the delivery of the course suitable to their needs. The online course has downloadable resources which allow them to view and engage with the resources even when they are offline. It could be possible that it was particularly suitable for them due to their access to devices, their digital literacy and their proficiency in English. Those most in need of training are based in rural areas where there are limited funds available for internet connectivity and devices. Most times the caregivers are not proficient in English and have limited digital literacy. Caregivers are concerned about the accessibility of these courses for those in rural areas and those who are not proficient in English.

The reach of this online course could be hampered due to these challenges and could be considered privileging certain communities and disadvantaging those who are already in a disadvantaged position. With considerations towards language and

internet costs, these online courses could contribute to enhancing the technical skills of those in rural areas, as it did for these caregivers.

5.8. Cyclical nature of Ethics of care

As noted, Ethics of care includes the four phases of attentiveness, responsibility, competence and responsiveness. Through attentiveness, the needs of learners and parents are identified; after assessing the need, caring is allocated appropriately by determining who is responsible for this need. Competence, which follows the allocation of the responsibility, is acknowledged when quality and appropriate care is provided by the caregiver to the learner with SPID and their families. Responsiveness is the phase that makes Ethics of care a cyclical process. The caregivers need a mechanism to direct the care provided to these learners and indicate whether this care met the need. Learners expect attention to be paid to their responses. The response requires further attention for the interactions to continue and for the development and growth of both caregiver and learner (Tronto, 1998; Maio, 2018; Tronto, 1993, Mckenzie, 2016).

It is evident that caregivers' caring attitudes helped them to develop attentiveness towards the learners and their needs. Caregivers became aware of their attitudes and the attitudes held around them and how this impacted the learners' care and education. Attentiveness of caregivers to the needs of learners is clearly demonstrated as caregivers ascertain learners' capacity to learn and establish the most effective environment for learners' learning. Through their attentiveness, they improved their understanding of learners' needs and consequently were able to create conducive learning environments for these learners. While there is not sufficient evidence in the study to demonstrate the responsiveness of learners since the focus was not on learners, we have evidence that caregivers used responsiveness of learners as a tool to develop and build their competence and create conducive learning environments for these learners.

While attentiveness and responsiveness are the distinguishing features of Ethics of care, caregivers need to assume responsibility for the identified needs and recognise that they can act to address these unmet needs to further the process towards understanding how to effectively fulfil the identified needs (Maio, 2018; van Nistelrooij

& Visse, 2019). They often took on the responsibility of fulfilling identified needs which were not necessarily their responsibility, like training.

Caregivers' competence is evident when performing the necessary caring tasks to fulfil the identified need (Tronto, 1998). However, competence needs to be recognised as an act of caring by the care receiver and can only be confirmed through a response from the care receiver (Noddings, 1999).

Caregivers' participation in the online course and application of the online content started to develop their competence in caring. The discussion on communication describes how caregivers applied their knowledge; however, there is not sufficient evidence in learners' responses to confirm caregivers' competence in fulfilling learners' need for communication.

Dialogue between caregiver and learner is representative of competence and contributes to the cyclical process of Ethics of care.

5.8.1. Not static, not oriented in one direction

The cyclical nature of care demonstrates that care is not static, but a reciprocal phenomenon which is not oriented in one direction. The cyclical process is also evident in that any single act may alter the situation and produce new needs for care, with responsiveness requiring more attentiveness (Maio, 2018; Mckenzie, 2016).

The aim of the caregiver to enhance their caring and the caring of others does not lie beyond the process, but is built into the process itself (Maio, 2018; Noddings, 2013). In care, the views of the person caring are broken down or suspended as caregivers confront the unfamiliarity of the care receiver. The interchange of responses based on demands depends on attentiveness and responsiveness. Through this process, the care provider expands their perspective and broadens their standpoint (Maio, 2018; Noddings, 2013). Even though the caring process comes full circle, we should remain cognisant that it often plays out in a complex fashion.

The cyclical nature of Ethics of care is evident in the caregivers' engagement with learners' communication needs. Traditional forms of communication are challenging for learners due to their cognitive levels. To effectively communicate with these

learners, caregivers need to be open to their idiosyncratic forms of communication. Caregivers have taken the initiative to participate in an online course and applied the knowledge they have gained through the online content using the environmental cues, interpreting and making meaning of their gestures whether it be inactivity, participation or emotional responses. These caregivers have come full circle demonstrating their receptiveness, attentiveness and responsiveness to learners' cues.

In this thesis we have explored the experiences of caregivers with online learning with regard to content, structure and delivery of massive open online courses. The content and structure of the MOOC have contributed to their knowledge of care and education for learners with SPID, while the delivery of the course has been instrumental in their access to the content on the effective education and care of learners with SPID and the perspectives of local and global participants of the online course.

The Ethics of care framework, with attentiveness and responsiveness as a guide to caring practices, has been useful in demonstrating the transformation and competence of these caregivers. Their attitudinal change towards the education of learners and their confidence in the provision of education and care to learners is clearly illustrated in Chapter Four and Chapter Five. In addition, caregivers have shown a broader understanding of care and education of learners with SPID with the adoption of a value system which focuses on collaboration, co-operation and care, driving the implementation and realisation of policies on the education of learners with SPID. Furthermore, Ethics of care has been described as a framework that is not one-directional. Instead, the personal growth and development of caregivers could be attributed to the learners with SPID and their engagement with the caregiver.

Caregivers have demonstrated a deep level of understanding of the needs of learners and their families. Their personal development is evident in their increased empathy as a motivator to understanding the needs of learners and especially their families in the facilitation of learning for learners with SPID.

5.9. Chapter conclusion

The discussion chapter argues for online learning as a contributor to the professional and personal development of caregivers at SCCs of learners with SPID. While there may be challenges which hamper caregivers' access to the online course, the benefits

are evident in this chapter. Caregivers have experienced a shift in their attitudes towards learning of learners with SPID and their understanding of education. They have also demonstrated an understanding of the importance of collaboration which is evident in their contrasting experiences with various stakeholders. While the challenges persist within this resource-constrained environment, caregivers' perseverance has contributed to the development of characteristics such as resilience and creativity which are necessary in the South African context. The chapter demonstrates the professional competence of the caregiver as well as personal development of caregivers with regards to their emotional bonds, ethics and moral principles.

CHAPTER 6: STUDY RECOMMENDATIONS, IMPLICATIONS, STRENGTHS, LIMITATIONS and CONCLUSION

6.1. Chapter overview

This chapter will present the study recommendations for caregivers' professional development. The chapter includes the study implications, strengths, limitations and conclusion.

6.2. Recommendations

6.2.1 Consideration of the cyclical process and policy development

The cyclical nature of Ethics of care should be given consideration when developing policies for learners with SPID, their caregivers and educational policies as a whole. These policy developers should take into account the circumstances of learners, caregivers and educators. With any policy development pertaining to training, courses should be a consideration from the start.

6.2.2 Incorporating Ethics of care in our practices in society

Ethics of care has proven beneficial in analysing the data for this study, but this framework should also be promoted and applied in our practices in society. The application of the Ethics of care framework could extend to business and government practices. It should be adopted and become an integral part of the implementation of policies as well.

6.2.3 Collaboration and co-operation between stakeholders for the effective care and education of learners with SPID

Caregivers and learners with SPID remain on the periphery of society, their needs are not prioritised and the lack of will and insight of government remain evident in issues related to learners with SPID and their caregivers. Collaboration of stakeholders and co-operation between stakeholders has been an ongoing conversation in literature. This study clearly demonstrates the fragmentation of state department and the impact this has on services for learners with SPID.

Creating responsive environments requires the engagement of all stakeholders across the health sector, sectors responsible for the social well-being of learners and the education of learners, as well as communities and parents. Caregivers and their learners are dependent on the resources, skills and knowledge of all stakeholders to create an environment which responds to learners' needs. Partnerships with higher education institutions, collaboration with and between government departments and co-operation between government departments and other relevant stakeholders are required to ensure that practices reflect the policies developed in South Africa.

6.2.4 Support and respite for caregivers at SCCs

Caregivers have workplace pressures and family demands which are exacerbated by the limited staff, lack of resources and the multiple, lifelong support needs of learners with SPID. In addition to the abovementioned challenges, caregivers are faced with insufficient human resources. This could be resolved through greater consideration of the support needs of caregivers. The DSD, DoE and DoH could collaboratively assist with this matter and caregivers could receive the necessary support and respite they require.

6.2.5 Stakeholder support of professional development of caregivers

Caregivers' work needs to be valued and supported considering the valuable contribution made by caregivers to the development of learners with SPID. For caregivers to provide effective care and education to learners with SPID, their professional development should be supported by relevant stakeholders such as government departments.

6.2.6 Enabling caregivers to participate in professional development opportunities

The studies' recruitment challenges are indicative of the overwhelming nature of the demands of the job. Caregivers who were unable to participate in the study mentioned reasons such as inspection by government officials, LSPID team visits, and administrative tasks as reasons for their inability to commit to this study. Principals of these care centres declined the invite to caregivers to participate in an effort to protect their personal time and space, allowing them a much needed respite. While it is important to have government support for the training, it is even more important to

ensure that caregivers have the necessary time to dedicate to professional development.

6.2.7 Further consideration of the distribution of LSPID teams and alternative options for training

Government should give serious consideration to the training options and where these options would best serve the specific community. With the inclusion of language options suitable to the South African context, the SPID MOOC could be promoted as a source of training in the urban, semi-urban and rural areas where connectivity is not too problematic. This could work with the downloadable options available on the SPID MOOC. The LSPID teams could then focus their attention on remote rural areas, thus making sure that more efficient use is made of the limited in-person training resources available.

6.2.8 Endorsement of the SPID MOOC

In this study, caregivers found the online course a valuable contribution to their attitudinal adjustments, skills and knowledge in providing effective care and education to learners with SPID. The online course ushered in the potential for increased attentiveness, competence and responsiveness to the educational needs and care of these learners. This course could be beneficial to parents, health workers and government officials to understanding disability issues and education related to learners with SPID. For this course to be an integral part of the training opportunities available to caregivers at SCCs, government and management in various sectors should endorse this online course.

6.2.9 Local relevance of the SPID MOOC

While the course has been beneficial to their professional development, caregivers stated that the course developers need to be more cognisant of the diversity of caregivers and the constraints of our local context. Despite the availability of foreign language subtitles in the online course, the course does not cater for African language speakers. In addition to the language constraints, many caregivers may experience issues with access to computers, technophobia and computer literacy, and internet connectivity. Even though the online course includes downloadable materials, course

developers need to give serious consideration to the delivery and accessibility of this online course, especially for those caregivers, parents and health workers in rural areas.

6.2.10 Evaluation of the SPID MOOC statistical data

This online course has a wide reach, with caregivers and educators across the globe participating and providing valuable engagements with our local caregivers. While these engagements are beneficial to caregivers, it distorts the course statistics purposed for local research. The course statistics could be valuable to understanding the demographic of caregivers in our local context, the local reach of the course and the possible impact of the online course. The categories included in the course statistics might require an evaluation. This is a consideration for course developers.

Further studies in South African context should be conducted on a larger scale on the accessibility and delivery of online courses for caregivers at SCCs, while government departments should consider their responsibility towards the development of learners with SPID and their caregivers at special care centres to ensure the continued professional development of caregivers through online courses and effective education and care of learners with SPID.

6.3. Study implications

The main aim of the study was to explore and describe caregivers' experiences of engaging in the SPID MOOC. The study shows that caregivers are willing to participate in professional development and found the content, delivery and the structure of the MOOC useful in acquiring the necessary knowledge and skills to be effective as a caregiver for learners with SPID. As the researcher on this study, I believe this study provides insights into alternative training options for caregivers working at SCCs.

I believe that this study contributes to the pursuit of achieving the SDGs, and South Africa's commitment to the realisation of the Convention of the Rights of Persons with Disabilities. More importantly, this study contributes to the High Court judgment directives in 2010. It provides details about how an online course could contribute to the effective education and care of learners with SPID.

This study has also shown how the professional development of caregivers and the development of learners with SPID remain on the periphery of society and the minimal priority given to their needs by the South African government. The negative implications of this should be mitigated by a more responsive government as this impacts the value of care work, and the dignity and realisation of the rights of learners with SPID.

This study has shown how effective the Ethics of care framework is in the evaluation of the professional development of caregivers of learners with SPID.

6.4. Study strengths and limitations

The study has exposed some insightful information that may help government, communities, and course developers at higher education institutions and other training institutions at large to facilitate the effective education and care of learners with SPID and professional development of caregivers at SCCs. The study has identified certain facilitators and barriers that may hinder the professional development of caregivers at SCCs through online learning and effective education and care of learners with SPID.

The study used the BNIM approach through online interviews to collect the data and FGDs to authenticate the information. The study only involved a few caregivers, and not all caregivers were able to attend the FGDs to authenticate the data. This study should be considered as a preliminary study from which further research can stem.

6.5. Study conclusion

A qualitative research design was used to explore and describe the experiences of caregivers at SCCs with online professional development. The study has identified various gaps that contribute to the professional development of caregivers and effective care and education of learners with SPID. The study shows that caregivers are eager to develop their skills and knowledge on caregiving responsibilities for the effective care and education of learners with SPID, but require additional support from government, communities and higher education institutions to grow professionally and personally in their ability to assist parents with their children and educating and caring for learners with SPID. Furthermore, it is evident that online learning should be given serious consideration in the professional development of caregivers at SCCs.

The study recommends further studies on a larger scale. It also recommends greater support for caregivers and the endorsement of this course by government.

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Appendices

Appendix I: Survey posted by CILT

1. Do you live in South Africa?
2. Have you completed at least 80% of the *Severe to Profound Intellectual Disability – Circles of Care and Education MOOC* (SPID MOOC)?
3. Have you been employed as a caregiver at a special care centre working with learners with severe to profound intellectual disabilities for more than one year?
4. Are you over the age of 18 years?
5. If you have responded 'yes' to questions 1 to 4, we would like to ask you if you would be willing to participate in a research study. If you would like to participate, please provide us with your name and email address.

Appendix II: Recruitment letter for organisation(s) and Facebook

Dear .....(*potential participant*)

My name is Chantal Samuels studying at the University of Cape Town in South Africa.

I am carrying out a research study on the experiences of caregivers who have done the *Severe to Profound Intellectual Disability: Circles of Care and Education Massive Open Online Course*.

The purpose of the study is to explore the experiences of caregivers with the *Severe to Profound Intellectual Disability: Circles of Care and Education Massive Open Online Course* and how it supports your ability to care for and teach learners with SPID.

Interviews will be conducted online.

I am inviting you to be part of this research study and hope that you are available and willing to participate in this research study.

Selection criteria

Inclusion criteria:

The participant must a) have completed 80% of the SPID MOOC; b) be employed and experienced as a caregiver at a special care centre; c) be 18 years of age or older; and d) be sufficiently conversant in English, as any meaningful engagement with the SPID MOOC is dependent on the caregiver being proficient in English

Exclusion criteria: qualified teachers; and b) any caregivers who have less than one year's experience

Appendix III: Information letter (respondents of the survey, the organisation and Facebook)

Introduction:

My name is Chantal Samuels and I am studying at the University of Cape Town in South Africa.

Purpose

I am carrying out a research study on the experiences of caregivers who have done the *Severe to Profound Intellectual Disability: Circles of Care and Education Massive Open Online Course*. I am inviting you to be part of this research study and below you will find information about the study. If there is anything that you do not understand, please ask me to explain, where it might be necessary.

What will be required of you

This research will involve your participation in three individual interviews for an hour. Each interview session will be done online. You will be able to choose which platform you would like to use. The online platform's video recording option will be used to record and capture the interview. All interviews will be scheduled according to your availability. In this research I would like to ask you some questions which will be based on the purpose stated above.

The research takes place over three sessions. The research requires one session of approximately an hour to start, followed by a second interview and then a third interview to ensure that the information I have collected reflects your experiences. The entire time commitment will be approximately 3 hours on the three interviews, over a period of five weeks and an hour on emails exchanged. The interviews will take place between the months of March and September 2022. In addition to the individual interviews, a 2-hr focus group discussion will be conducted via zoom.

Participation at your own free will

It is our choice whether to participate or not. Any choice you make will not have a negative effective on your job. You may change your mind later and stop participating even if you agreed earlier.

Risks

Telling your story may be very emotional. Therefore, it requires an appropriate plan e.g. a break, ending the interview or even identifying external support for you. If you require any support, I will help you find a place where you can get the support that you need.

Benefits

There will be no direct benefit to you, but your participation is likely to help us gain a better understanding of how the Severe to Profound Intellectual Disability Massive Open Online Course assists you with care of and teaching of learners with Severe to Profound Intellectual Disability.

Funds made available for involvement with the research study

You will not be provided any form of payment to take part in the research

Confidentiality

Even though the interview is recorded (video recording), there will not be sharing of information about you to anyone outside of this study. Agreeing to be part of this study means that you have agreed to have the sessions recorded. This recording is important to make sure we get our story correctly. Any information about you will be replaced with a pseudonym (another name) instead of your name. Only the researcher will know what your pseudonym (a name assigned to each participant to ensure confidentiality) is and it will not be shared with or given to anyone. I am asking you to share personal and confidential information about your views, opinions and experience and therefore you will remain anonymous. The views will be shared but no-one will know where specific views come from.

Any research assistant assisting in language matters will be bound to confidentiality by a confidentiality agreement.

Sharing the Results

Only anonymised (utmost attempts will be made to remove information which could lead to your identity) and analysed (the process of cleaning and transforming data to discover useful information) data will be shared. Although only anonymised and analysed data will be shared, the risk of identification remains. Nothing will be noted as information that you have provided i.e. your name will not be included as the person who provided the information.

Raw data will only be shared with the researchers i.e. nothing will be noted as information that you have provided. Your name will not be included as the person who provided the information.

Right to Refuse or Withdraw

You do not have to take part in this research if you do not wish to do so, and any choice made will not have a negative effect on your job. I will give you an opportunity at the end of the interview to review your remarks with a further follow-up, and you can ask to modify or remove portions of those, if you do not agree with my notes or if I did not understand you correctly. You will also have a chance to review my interpretations of the information you have shared with me.

Preferred language

I will have a Xhosa speaking colleague and an Afrikaans speaking colleague available for ease of expression during the interviews. If you require someone who speaks your mother tongue to avail themselves during the interviews, please inform me and indicate which language. We could make an appointment to discuss.

Who to Contact

If you have any questions, you can ask them now or later. If you wish to ask questions later, you may contact me at chantalleslenesamuels@gmail.com. The UCT FHS

Research Ethics Committee can be contacted on 021 406 6338 in case you have any questions regarding your rights and welfare as research subjects on this study.

Appendix IV: Certificate of Consent

I have been invited to participate in this study focusing on experiences of caregivers with the *Severe to Profound Intellectual Disability: Circles of Care and Education Massive Open Online Course* (SPID MOOC).

I have read the information, or it has been read to me. I have had the opportunity to ask questions about it and any questions I have been asked has been answered to my satisfaction. I freely agree to being a participant in this study and understand that I am free to withdraw at any time. I understand that the interviews will be recorded and agree to the recording of the interviews.

Head of Human Ethics Committee: Marc Blockman

The UCT FHS Human Research Ethics Committee can be contacted on 021 406 6338 in case participants have any questions regarding their rights and welfare as research subjects on the study.

Supervisor for this study: Judith Mckenzie

Email address: judith.mckenzie@uct.ac.za

Mobile number: 083 500 0464

Print Name of Participant_____

Signature of Participant_____

Date_____

Day/month/year

Statement by the researcher

I have accurately read out the letter of invitation to the potential participant, and to the best of my ability made sure that the participant understands that the following will be done:

Interviews will be conducted and recorded

I confirm that the participant was given an opportunity to ask questions about the study, and all the questions asked by the participant have been answered correctly and to the best of my ability. I confirm that the individual has not been coerced into giving consent, and the consent has been given freely and voluntarily. I confirm that every endeavour will be made to keep the study material confidential.

Print Name of Researcher_____

Signature of Researcher_____

Date_____

Day/month/year

Head of Human Ethics Committee: Marc Blockman

The UCT FHS Human Research Ethics Committee can be contacted on 021 406 6338 in case participants have any questions regarding their rights and welfare as research subjects on the study

Supervisor for this study: Judith Mckenzie

Email address: judith.mckenzie@uct.ac.za

Mobile number: 083 500 0464

Appendix V: Confidentiality agreement

Statement by those involved in the process of code switching (assistants)

I confirm that every endeavour will be made to keep the study material confidential.

Print Name of code switching assistant_____

Signature of code switching assistant_____

Date_____

Day/month/year

Appendix VI: HREC approval

UNIVERSITY OF CAPE TOWN

FACULTY OF HEALTH SCIENCES
Human Research Ethics Committee

FHS016: Annual Progress Report / Renewal

HREC office use only (FWA00001637; IRB00001938)			
This serves as notification of annual approval, including any documentation described below.			
☑ Approved	Annual progress report	Approved until/next renewal date	28.02.2025
☐ Not approved	See attached comments		
Signature Chairperson of the HREC/ Designee		Date Signed	13/2/2024

Note: Please email this form and supporting documents (if applicable) in a combined pdf-file to hrec-enquiries@uct.ac.za
Please clarify your plan for research-related activities during COVID-19 lockdown.
Please use the latest form found on our website:
http://www.health.uct.ac.za/fhs/research/humanethics/forms

HUMAN RESEARCH ETHICS COMMITTEE
- 8 FEB 2024
HEALTH SCIENCES FACULTY
UNIVERSITY OF CAPE TOWN

Comments to PI from the HREC
Thank you for your Study Deviation SR 5/24

HREC Chair Signature
Date: 13/2/2024

Principal Investigator to complete the following:

1. Protocol information

Date (when submitting this form)	8 January 2024		
HREC REF Number	585/2021	Current Ethics Approval was granted until	28.02.2023
Protocol title	A narrative inquiry on the experiences of caregivers in special care centres with online professional development: Utilising a Massive Open Online Course (MOOC)		
Protocol number (if applicable)			
Are there any sub-studies linked to this study?	☐ Yes	☐ No X	
If yes could you please provide the HREC Reference number for all sub-studies? **Note:** A separate FHS016 must be submitted for each sub-study.	N/A		

(Note: Please complete the Closure form (FHS010) if the study is completed within the approval period)

Principal Investigator	Prof Judith Mckenzie
Department / Office Internal Mail Address	Judith.mckenzie@uct.ac.za

1.1 Does this protocol receive US Federal funding?	☐ Yes	☐ No X
1.2 If the study receives US Federal Funding, does the annual report require full committee approval? **Note:** Any annual approvals for **Full Committee** review MUST be submitted on the monthly HREC submission dates. (Please send electronic copy for full committee review to hrec-submission@uct.ac.za)	☐ Yes	☐ No

If yes in 1.2 please complete section 1.3 below for invoicing purposes

1.3 Ethics Renewal Fee

Please **(tick ✓)**appropriate box for billing purposes:

Submission Type	***Description***	***New fee (Vat Incl.)***	***tick ✓***
Research funded solely from UCT departmental/ divisional/group budget	Annual evaluation of research progress report for re-certification	**R0,00**	☐
Non-sponsored student research for degree purposes at UCT/Other Universities & Colleges	Annual evaluation of research progress report for re-certification	**R0,00**	☐
Annual re-certification / Progress report (FHS016 Form)	Clinical Trial & International Grant Funded Research - Annual evaluation of research progress report for re-certification for Full Committee Approval	**R7000,00**	☐
Annual re-certification / Progress report (FHS016 Form)	Clinical Trial & International Grant Funded Research - Annual evaluation of research progress report for re-certification for Expedited review	**R3 710.00**	☐
Annual re-certification / Progress report (FHS016 Form)	National grant funded research - Annual evaluation of research progress report for re-certification for Full Committee Approval	**R6000.00**	☐
Annual re-certification / Progress report (FHS016 Form)	National Grant funded research for Annual evaluation of research progress report for re-certification for Expedited review	**R1 500,00**	☐

NB: Protocols funded by UCT (e.g. departmental funding / student research) and by certain grant funding organizations (e.g. MRC, NRF, CANSA,) are exempt from these charges.

Please provide details for Invoicing, either complete section 1 or 2 :

1. Invoice billing – Directly to Sponsor

Sponsor's name	

(Note: Please complete the Closure form (FHS010) if the study is completed within the approval period)

Billing Address of Sponsor:	
Vat Number:	
Contact person	
Telephone number	
Email Address	
2. **Internal Journal Billing:**	
Fund Number:	
Cost Centre Number:	
Account Holder Name:	
Division of Account Holder:	

2. List of documentation for approval

3. Protocol status (tick ✓)

☐	Open Enrolment
☐	Closed to enrolment (tick ✓)
☐	Research-related activities are ongoing
☐	Research-related activities are complete, long-term follow-up only
☐ X	Research-related activities are complete, data analysis only
☐	Main study is complete but sub-study research-related activities are ongoing
☐	Study is closed → Please submit a Study Closure Form (FHS010)

4. Enrolment

Number of participants enrolled to date	3
Number of participants enrolled, since last HREC Progress report (continuing review)	3
Additional number of participants still required	0

(Note: Please complete the Closure form (FHS010) if the study is completed within the approval period)

5. Refusals

Total number of refusals (participants invited to join the study, but refused to take part)	**Approx. 8**

6. Cumulative summary of participants

Total number of participants who provided consent	**3**
Number of participants determined to be ineligible (i.e. after screening)	1
Number of participants currently active on the study	3
Number of participants completed study (without events leading to withdrawal)	3
Number of participants withdrawn at participants' request (i.e. changed their mind)	0
Number of participants withdrawn by PI due to toxicity or adverse events	0
Number of participants withdrawn by PI for other reasons (e.g. pregnancy, poor compliance)	0
Number of participants lost to follow-up. Please comment below on reasons for loss of follow-up.	0
Number of participants no longer taking part for reasons not listed above. Please provide reasons below:	0

7. Progress of study

Please provide a brief summary of the research to date including the overall progress and the progress since the last annual report as well as any relevant comments/issues you would like to report to the HREC:
The data collection, data analysis is close to completion. Member checking needs to be completed. Findings chapter completed, findings to be shared with participants. Working on discussion chapter.

8. Protocol violations and exceptions (tick ✓ all that apply)

☐ X	No prior violations or exceptions have occurred since the original approval
☐	Prior violations or exceptions have been reported since the last review and have already been acknowledged or approved
☐	Unreported minor violations that have occurred since the last review, as well as significant deviations not yet reported, are attached for review

(Note: Please complete the Closure form (FHS010) if the study is completed within the approval period)

9. Amendments (tick ✓ all that apply)

☐	No Prior amendments have been made since the original approval
☐ X	Prior amendments have been reported since the last review and have already been approved
☐	New protocol changes/ amendments are requested as part of this continuing review (See note below)

Note: If new protocol changes are being requested in this review, please complete an amendment form (FHS006).
Specific changes in the amended protocol and consent/assent forms must be **bolded**, *italicised* or tracked and all changes must include a rationale.

10. Adverse events

10.1 Please provide below or attach a narrative summary of serious adverse events and/ or unanticipated problems since the last progress report. Please indicate changes made to the protocol and informed consent document(s) as a result (if not already reported to the HREC). Please comment on whether causality to any study procedure or intervention could be established.
N/A

10.2 Have participants received appropriate treatment/ follow-up/ referral when indicated (e.g. in the case of abnormal or incidental clinical findings, distress or anxiety)?		
☐ Yes	☐ No	☐ X Not applicable
If yes, please describe:		

11. Summary of Monitoring and Audit Activities (tick ✓)

11.1 Was this study monitored or audited by an external agency (e.g. SAHPRA, FDA)?		
☐ Yes	☐ No	☐ X Not applicable

11.2 Did a Data and Safety Monitoring Board publish a report?		
☐ Yes	☐ No	☐ X Not applicable

11.3 If yes, please identify the agency and attach a summary of the findings.					
Agency Name		Report attached	☐ Yes	☐ No	☐ X Not applicable
		DSMB report attached	☐ Yes	☐ No	☐ X Not applicable

(Note: Please complete the Closure form (FHS010) if the study is completed within the approval period)

11.4 Has there been any agency, institutional or other inquiry into non-compliance in this study, or any finding of non-compliance concerning a member of the research team?	
☐ Yes	☐ X No
If yes, please explain:	
N/A	

12. Level of risk (tick ✓)

12.1 In light of your experience of this research, please indicate whether the level of risk to participants has:	
☐	Increased
☐	Decreased
☐ X	Shown no change
If there has been a change, please explain:	
N/A	

12.2 Please provide a narrative summary of recent relevant literature that may have a bearing on the level of risk.
"There was a potential foreseeable minimum risk of harm, which was minor and may have arisen when caregivers discussed the challenges they experienced when caring for children with disabilities." (Moosa-Tayob & Risenga, 2022)

13. Insurance

Please confirm that valid no fault insurance is still in place? **(tick ✓)**			
☐ Yes	☐ No		☐ Not Applicable – N/A
If yes, please complete the following:			
Insurer's name:	N/A		
Policy no.	N/A	*Coverage Period:	**N/A**
For UCT sponsored studies please liaise the Insurance office via fhs.sponsorship@uct.ac.za regarding the required documentation and information required obtain a renewed UCT No-fault Insurance Certificate.			

14. Statement of conflict of interest

Has there been any change in the conflict of interest status of this protocol since the original approval? (tick ✓)

☐ Yes	☐ No X
If yes, please explain and if necessary, attach a revised conflict of interest statement (Section #7 in the New Protocol Application Form FHS013):	
N/A	

15. Signature

My signature certifies that the above is complete and correct.			
Signature of PI		Date	08 February 2024