CAREWORKERS' LIVED EXPERIENCES AND THEIR PERCEPTION OF THE PROGRAM FOR LEARNERS WITH SEVERE TO PROFFOUND INTELLECTUAL DISABILITIES.

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A Dissertation Submitted to the Faculty of Health Sciences, University of The Witwatersrand, in fulfilment of the requirements for the degree of Master of Science in Occupational Therapy.
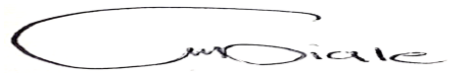
Johannesburg

March 2022

DECLARATION

I, <u>Galetshetse Vallery Diale,</u> declare that the work contained in this research report is my own work, except to the extent indicated in the acknowledgement sections. All the utilised sources have been thoroughly referenced.

This research report is being submitted for a degree of Master in occupational therapy, at the University of the Witwatersrand, Johannesburg, South Africa.

This work has not been submitted for any other degree or examination in this or any other university.

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DEDICATIONS

To my late father, you passed just when this project took off ground, and you were so looking forward to the graduation ceremony. Please grace us with your presence on graduation day. I hope you pick quite a sly suit in heaven. Love you forever papa.

To mama, thank you for the divine prayers, upon which I greatly depend, and for taking care of the baby so that I could dedicate the time towards completing this degree. You are simply the best.

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Ramasedi wa go loka, ditheto le ditebogo ke tseo.

ABSTRACT

Background: The children with severe to profound intellectual disabilities(SPID) had no access to education facilities, as they were referred to as uneducable, a discrepancy with the South African constitution and bill of rights that led the Western Cape Forum for Disabled people to take the Department of Basic Education (DBE) to court. In response to a court order, the DBE introduced the learning program for children with SPID to capacitate the careworkers to offer a formal and funded education to these children. It is unknown whether the program meets the expectations of the careworkers and how they perceive and experience this newly introduced program.

Aim of study: To explore the perceptions of careworkers in stimulation care centres of Nkangala District in Mpumalanga province about the learning program and the training provided by the education outreach team.

Methodology: A qualitative research method using a descriptive explorative design was used. Twelve research participants were purposefully selected and engaged in one-on-one in-depth interviews. The data were thematically analysed, using open coding.

Findings: The careworkers in Nkangala District of Mpumalanga province appreciate the learning program of LSPD for affording the children who have barriers to access education facilities an opportunity for them to be trained by a multidisciplinary rehabilitation team and education specialists to offer comprehensive intervention to the children in their care. The careworkers shared their lived experiences of how they started and grew over the years in their services and also appreciate the learning program for SPID for sharpnening their skills and capacitating them to carry out their duties. On the negative side, the careworkers feel side-lined and undermined based on their level of education as the DBE did not seek their collaboration in major decision making of the program and they do not get remuneration for the additional set of responsibilities and duties emanating from the learning program for LSPID.

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OPERATIONAL DEFINITIONS

Careworker- service provider at the stimulation care centre, sometimes a biological parent of the child at a centre, provides care on voluntary basis or employed by the centre and receives payment for his/her services.

Education team- Intersectoral collaborations as wella s transdisciplinary teams of health and education professionals to address the complex needs of children with severe to profund intellectual disabilities.

Learning program- Formal educational provision program for children with severe to prodound intellectual disabilites aged 0-18.

Severe to profound intellectual disabilities- Persons with IQ level below 40, and developmental age between 1 and 4.

List of Acronyms

CP- Cerebral Palsy

DBE- Department of Basic Education

DSD-Department of Social Development

HIC- Higher Income Countries

ID- Intellectual disability

LMIC- Lower to middle Income countries

LSPID- Learners with Severe to Profound Intellectual Disability

LTSM- Learner Teacher Support Material

MOHO-Model of Human Occupations

NGO- Non-Governmental Organisations

NQF-National Qualification Framework

SCC- Stimulation care centres

SPID- Severe to Profound Intellectual Disabilities

WCED- Western Cape Education Department

CHAPTER1: INTRODUCTION

1.1 Background to Study

Prior to 2010, few educational services for children with severe and profound intellectual disabilities (SPID) existed in South Africa. The Department of Basic Education (DBE) in South Africa did not cater for the children wth SPID even though the Constitution of South Africa and the Bill of Human Rights, supported by government policies, emphasise the right to education for all children irrespective of disability (Murungi 2011). The services which existed were often under-resourced and lacked competent staff. Nationally, children with SPID were found to have been excluded from educational services as they were termed uneducable (Kleintjes et al. 2010).

In 2007, the Western Cape Forum for Intellectual Disability laid charges and took the South African Government to court, following the Western Cape Education Department (WCED)'s neglect to ensure access to affordable education for learners with SPID (Western Cape High Court 2007). The court found in favour of the Forum for Intellectual Disability. The WCED embarked on a project to provide the learners with severe to profound intellectual disabilities (LSPID) access to basic quality education. They were to monitor the progress of the project and report back to the high court after implementation and frequently update the court with the progress (Spansberg et al. 2013).

As a result, educational multidisciplinary teams were employed by the WCED to service 35 stimulation care centres (SCC) following the ruling made in 2013. The appointed teams included occupational therapists, physiotherapists, speech therapists, education psychologists and senior education specialists. Part of the multidisciplinary education outreach team's mandate was education. They were expected to build rapport with the careworkers employed in the SCCs, to consult with parents/primary caregivers, and train the careworkers to provide educational stimulation to learners with SPID (Spansberg et al. 2013).

As the project made progress in the Western Cape, in 2016 the court order was expanded to mandate all basic education departments in all nine provinces. This was to ensure the fulfilment of the right to education for learners with SPID (DBE 2016).

The project was officially piloted in 2017 country wide and officially introduced to the Mpumalanga care centres (including the Nkangala District) in 2018.

The Policy for the Provision of Quality Education and Support for Children with Severe to Profound Intellectual Disability (DBE 2016) indicates that the learners with SPID definitely benefit when their education is aimed at developing communication, personal and self-care, as well as practical and conceptual skills rather than in academic skills. While it is accepted that learners with SPID can learn and develop with appropriate input, they also require full-time care as they have physical and cognitive limitations and thus are dependent and/or require assistance in activities of daily living. Careworkers employed in the SCCs, where these children access education, are mandated to provide physical care for them including changing nappies, feeding, administering medication, facilitating mobility, and monitoring postural and positioning requirements. They also have an educational role in promoting independence as part of the learning program for LSPID.

Following the court ruling, these care facilities are expected to offer a daily program that is intended to provide not only care but also stimulation using a learning program for LSPID that guides the careworkers in creating an enabling environment, so that the learners with SPID may develop to their full potential (DBE 2016).By nature of their daily job and responsibilities, the careworkers spend considerable time with the children and understand and know them well. They are also the main executors of the learning program since they interact with the children daily as opposed to the education outreach team that only comes per scheduled visits. Currently, there are education outreach teams deployed in all nine provinces to provide training to the careworkers for them to implement the learning program. The careworkers are seen as the drivers of the project, and the education outreach team as the navigation system as the multidisciplinary education outreach teams are currently providing training to the careworkers. It is important to bring the careworkers on board as active participants, not underestimating the contribution they make regardless of their level of education or ability to express themselves in English, which is sometimes an exclusion criterion for taking part in formal studies.

This study engaged with the careworkers in Nkangala District of Mpumalanga Province to explore their feelings about the learning program for LSPID and the

training by the education outreach team introduced in 2018, and their experiences implementing the learning program for LSPID in their SCCs. The intention was to show how the careworkers experience being trained, provided with tools of the trade, and how they viewed the vision and mission of the learning program. It is hoped that the careworkers' views will shape the approach taken by DBE to cater for their needs and those of the children in the stimulation care centres. The careworkers' inputs would function as a review of progress made, to give an indication of whether the learning program for LSPID is achieving its goals, review effectiveness, and acknowledge the positive contributions of the education outreach team training from the perspective of the careworkers.

The importance of involving the careworkers cannot be overemphasised. Their involvement in intervention as active participants and decision makers, fully enlightened of the targets, can potentially improve outcomes and give the careworkers tools to confidently address challenges that will be encountered along the way.

1.2 Research problem

An audit of staff in SCC in the Western Cape found that 40% of careworkers were parents with a child in the centre. They and other staff had no formal training in early childhood development or health and rehabilitation knowledge required to provide educational support to the learners with SPID which is prevalent in Nkangala district of Mpumalanga Province. Therefore, a learning programme was developed by curriculum specialists and therapists to train the careworkers in the SCC country-wide (DBE 2016). However, the experiences and expectations of the careworkers are not known, as scant research has been conducted in this context, with these stakeholders, and within this scope. For example, it is unknown to which extent the training introduced in 2018 provided meets the needs of the careworkers. It will therefore be beneficial for the DBE to join forces with the careworkers by exploring their experiences and creating a platform for them to make inputs and inform policy.

Careworkers were excluded from executive planning which affects the outcomes of the LSPID program; even though the careworkers are the key role players whose buy-in is required to implement the strategies and activities by the DBE. Therefore, there may be reluctance to follow through the plans of the learning program for LSPID and

training received should the careworkers feel that they have not actively influenced the decision making and outcomes.

1.3 Purpose of the study

Before the effectiveness of the training offered to careworkers can be established, it is important to determine if the training meets the needs of the careworkers in terms of their expectations and ability to implement their skills and training. This study aims to provide evidence for the role of the learning program outlined in Policy for the Provision OF Quality Education and Support for Children with Severe to Profound Intellectual Disability(DBE 2016) in the SCCs of the Nkangala District in Mpumalanga. The perceptions of the careworkers about the learning program for the LSPID and the training and its effect on the intervention for LSPID can be used to improve their experience since the successful implementation of the program depends on the careworkers. A relatively new introduced program, exploratory data is needed to provide a basis for further research to ensure the sustainability of the program.

1.4 Research question

 What are the perceptions of the careworkers about the services they offer for the children with SPID as well as the learning program for LSPID and the training on the program received from the multidisciplinary education outreach team?

1.5 Study aim

The aim of the study is to explore the perceptions of the careworkers about their role in the development of services for children with SPID in their communities and the training on the learning program for LSPID, provided by provided by the multidisciplinary education outreach team, in the Nkangala District of Mpumalanga.

1.6 Study Objectives

●To explore the perceptions of the careworkers about their role in the development of services for children with SPID in their communities

●To explore the perceptions of the careworkers about the expectations and experience of the training provided by the LSPID education outreach team in the Nkangala District of Mpumalanga.

●To explore the perceptions of careworkers on the effectiveness of the training after six to twelve months of implementation by the LSPID outreach team.

1.7 Significance of Study

The study will hopefully contribute formal feedback on the learning program in terms of appropriateness, effectiveness, training and the alignment with the role of the careworkers as well as create a platform for the identified challenges to be addressed towards improved implementation of the learning program for LSPID.The outcomes of the study will enable the DBE to get a review that may be utilised across the country to meet the respective needs of the careworkers in the stimulation centres and thus ensure productivity and work satisfaction that occupational therapy promotes and strives for.

> "Only clients [careworkers] can identify the occupations that give meaning to their lives and select the goals and priorities that are important to them. By valuing and respecting clients' [careworkers'] input, practitioners help foster their involvement and can more effectively guide interventions (AJOT,2020, p22)."

1.8 Research design and methodology

A qualitative research method using a descriptive explorative design was used (Bengtsson, 2016). The research explored a relatively new introduced learning program for LSPID and as no previous research on the appropriateness, effectiveness, training and the alignment of the role of careworkers is available, this approach to understand the perspectives of the careworkers is appropriate. The researcher followed the Cresswell and Cresswell (2017) steps of thematic data analysis.

1.9 Ethical considerations

The researcher obtained ethics clearance (M200983) from the Wits Human Research Committee (WHRC) (Appendix A) and permission from Mpumalanga DBE authority to conduct research (Appendix B).

1.10 Dissertation Style and Outline

The researcher made use of the Mendeley Cit-O-Matic- Plug in on the Microsoft 2013 program with the Harvard referencing. The outline of the chapters is as follows:

Chapter 1: Introduction and overview

The first chapter provides the overview of the study, and includes the introduction, problem statement, purpose of study, research question and significance of the study. In this chapter, the researcher introduces the acronyms for a lot of terms that will be used throughout the dissertation, i.e., the Learners with severe to Profound Intellectual Disabilities is shortened as 'LSPID', the team that works with these children is referred to as the education outreach team and the program as the learning program for LSPID.

Chapter 2: Literature review

The second chapter discusses sub-topics and concepts related to the study with current and previous studies: local and international and compares the occurrences in terms of setting and contexts. As careworkers and children with disabilities are the most prevalent concepts for multidisciplinary intervention, literature that was reviewed encompassed sources from occupational therapy, and sources from other rehabilitation professions including speech therapy, physiotherapy, social work, psychology, nursing, and medical sources. In this chapter, close attention is paid to foundational occupational therapy literature such as the Model of Human Occupational Therapy (MOHO) and occupational justice concepts to depict the unique role occupational therapy contributes to this context.

Journal articles were obtained from electronic data bases including PubMed, CINAHL, Scopus, and the search engine Google Scholar.

Chapter 3 Research Methodology

In the third chapter, a comprehensive overview of how the study was conducted is provided. It covers the data collection procedure, steps followed to analyse and manage data, as well as the important considerations for validity, reliability, and ethical concerns.

Chapter 4: Findings and discussion

In this chapter the findings and the discussion are concurrently addressed. This was done deliberately to be authentic to the nature of qualitative epistemology where

findings standing alone make little sense without concomitant explanation and contextualization. As part of presenting the findings, the researcher attempted to follow the same pattern introducing the theme/category/subcategory; proceeding with a description of the concept; then finally giving significant and related quotes from interviews and supporting literature. The themes are captured as Pedi proverbs to illustrate the depth, weight and embedded nature of culture in the participants' experiences, in a manner that resonates with their identity and diversity. The researcher painted a picture of the participants' expressions of experience and used relevant literature to compare the South African reality with other parts of the world, with similar and different economic presentations. The chapter closes with a discussion of the findings in line with triangulating and/or dissimilar literature from relating to the delimitations of the study.

Chapter 5: Conclusions

The fifth chapter concludes the dissertation by addressing the extent to which the research question was answered, objectives met, and realistically stating the study limitations. Finally, the loop is closed with reflections and recommendations for future practice, research and other relevant fields, such as policy and legislation with respect to learners with SPID.

CHAPTER 2: LITERATURE REVIEW

2.1 Introduction

This literature review is put forward regarding the main concepts relating to the study. The purpose of this study was to explore the experiences of the careworkers about the learning program provided by the LSPID team in the Nkangala district of Mpumalanga Province. The researcher used data bases such as PubMed, Scopus, Cinahl and the search engine Google scholar to build a broad overview of what happens in South Africa and around the globe regarding the stimulation and care for severe to profound intellectual disabilities, careworkers in the stimulation care centres, and the training/ outreach programs. The researcher organised the literature review themes to contextualise the outreach project in the research setting (low socio-economic status, under-served and under-resourced), education for children with SPID, as well as careworker experiences of their work and their training. The chapter concludes with a summary of key points.

2.2 The child with severe to profound intellectual disability

2.2.1 Clinical presentation and prevalence of intellectual disability in children

The Diagnostic and Statistical Manual of Mental Disorders (DSM V) (American Psychiatric Association (APA) 2013) defines intellectual disability as significant limitations in general intellectual functioning or conceptual skills and adaptive behaviour including communication and engagement in activities of daily living. Children with severe intellectual disability (IQ 20–34) or profound intellectual disability (IQ 19 or below) need significant assistance from a careworker, and supervision, as they are unable to independently care for themselves. Salojee (2007) highlighted that about two-thirds of disabled children in South Africa have either a motor or cognitive disability, in some cases both, and cerebral palsy was found to be the most prevalent in child disability statistics. A recent study conducted in Cape Town also reported that most of the children with severe to profound intellectual disabilities' main diagnosis was cerebral palsy (McKenzie, Duvenhage, du Plessis and Jelsma 2017). Cerebral palsy is rated the leading chronic disability that is comorbid with intellectual disability in children before the age of 2 years (Tseng, Lee, Chou, Sheu & Lee 2018).

Studies indicate that In the United States the prevalence of CP is 1.5 per 1000 live births, which is far less in comparison with the 4.6 per 1000 live births in Cape Town, South Africa (van Toorn, Laughton and van Zyl 2007) and 10 per 1000 in rural parts of South Africa in Kwa -Zulu Natal (Couper 2002; Donald, Samia and Kakooza-Mwesige 2014; Health Systems Trust 2018). The evidence suggests that the prevalence of CP is higher in Low to Middle Income Countries (LMIC) than in High Income Countries (HIC).

2.2.2 Occupational Performance challenges experienced by children with severe to profound intellectual disabilities

Functional concerns with disabled children include feeding and swallowing difficulties, motor impairments, immobility, speech, visual and hearing impairments as well as incontinence (Kuper, Smythe and Duttine 2018). For children with SPID, health complications persist into adulthood: children with neurological disabilities need a lifetime of various healthcare services (Kuper et al 2018). Throughout the lifespan, people with severe to profound learning disability will for the rest of their life be dependent on self-care and other activities of daily life (Spansberg et al. 2013). Thus, parents adjust and replace academic expectations with a need for independence in activities (Janse Van Rensburg 2019).

With the children with SPID, the emphasis is on functional ability instead of treating symptoms, facilitating independence and community integration(Govender,Christopher and Lingah 2018).The DBE alludes to the potential key role that occupational therapy plays in promoting independence, self-reliance, and community re-integration of children with disability. Through stipulating a grant framework that education for children with SPIDs should be provided in condition that are dignified, promote independence, self-reliance and facilitate active integration into the community (DBE 2016).

Table 2.1 The 3 subject Components, their development areas and content

1.Communication and Language	2.Spatial and conceptual development (Cognition)	3.Life skills
Develop and support communication using whatever mode the child with SPID is capable of;	*Develop the understanding, thinking and problem solving abilities through the use of senses and experiences;*	*To understand himself physically, emotionally, socially and sexually and relationships with others*
In order for communication/ language to develop the following pre-linguistic (language) skills need to develop: Content: ● Attention ● Eye contact ● Turn taking ● Cause and effect ● Imitation ● Gesture ● Communicative intent **Development area: Understanding**	**Development area: Perceptual/ Pre-conceptual Content:** ● Readiness to engage ● Memory ● Cause and effect ● Categorisation **Development area: Spatial and conceptual Content** ● Basic concepts ● Patterns and sequence ● Spatial concepts	**Development area: Gross Motor Content** Reflexes ● Strengthening muscles ● Use large muscles to move ● Sit ● Stand ● Walk ● Run ● Kicks a ball ● Movement and music ● Jump **Development area: Fine Motor Content:** ● Grasps with hand ● Use fingers ● Eye-hand coordination

(Receptive language) Content:	● Time	Development area: Sensory and perceptual Content;
● Responding to sound		●Hearing,Seeing,Tasting,Touching
● Responding to name		**Development area: Self-help and activities for daily living (ADL)**
● Shows understanding of several words		Content:
● Following one step instruction		● Dressing, Feeding,Toileting,Washing hands/face,Brushing teeth
● Understanding no		**Development area: Sense of Sexuality Content:**
Development area: Expressive Language (Using sounds/ gestures/ pictures/ symbols/ words to indicate needs and communicate) Content:		● Body privacy
		● Social skills
● Gesture		**Development area: Social skills and relationships Content:**
- Greeting routines		● Relating to familiar people
- Performing actions		● Relating to friends/peers
● Verbal		● Playing and leisure time Development area; Emotions
- Vocalising		
- Imitating and copying sounds		

Table 2.1. illustrates the three subjects that should be offered by the careworkers to the children with SPID in SCC's as recorded in the Draft Learning Program for Children with Severe to Profound Learning Disabilities, October 2016, page 29-30.

The emphasis of the learning programme for children with SPID is on care, development and learning requirements of this population between the age of three (3) and 18. To ascertain that the learning program is aligned with national education standards. The 3 Subject components of the learning programme are guided by and adapted from the CAPS, Gr R to 3 and the NCF 0 – 4. Furthermore, it is recommended that for the development of child and group specific learning programmes, the learning programme should be congruent with the NCF 0 – 4, since the developmental age of the children with SPID is at this level. However, the chronological and physical age must be taken into consideration.

Figure2.1 Structure of learning Program

CAPS	NCF0-4	LP for children with SPID
• Language • Maths • Lifeskills	• Coomunication • Coomunicative/Explorative Maths • Life skills	• Communication and Language • Spatial and Conceptual Development • Life Skills

2.2.3 Role of Occupational Therapy for Learners with Severe to Profound Intellectual Disabilities

Occupational therapy may assist in improving people's lives, occupational performance and social engagement through employing/applying various strategies such as remediation or development of skills, task adaptation, area structuring and compensatory strategies(AOTA,2020).The core of occupational therapy practice is to assist people to participate in activities that have meaning and value to them, aimed towards social participation, having a role in the community and enjoying the quality of life. The activities include activities of daily living (ADL), rest, sleep, education, work, play, leisure, and social participation (American Occupational Therapy Association(AOTA) 2014; AOTA 2020).

An essential aspect in child health, development, and wellbeing is participation in occupations, defined as involvement in life situations (WHO, 2001). Occupations for children include eating, bathing, playing, learning and participating in the routines of

family life (Valvano and Rapport, 2006; McKenzie,Pillay,Duvenhage,Du Plessis & Jelsma, 2017).

According to Petrenchik and King (2011) all children have a need to take part in activities in conducive environments that present them with the just right challenge, social involvement, sense of belonging (to be accepted for who they are) and freedom of being (autonomy).

It is through occupation that these individuals, grow on a daily basis and can endeavour and envisage to have a future. Occupational injustice thus occurs when there are inequities preventing others to participate in activities that are worthwhile, due to low functioning and the incapacity to meet the demands of their environment(Townsend and Wilcock 2002).Considering the above, occupational therapists are advocates for occupational justice, as they apply the term enable to cover participation, and empowerment in occupations that enhance doing, being and becoming.

The tables below summarise occupational needs and wellbeing with regards to client care and occupational therapy intervention. Table 2.2 illustrates aspects that yield occupational wellbeing and serve as a guide on causal factors of occupational wellbeing and occupational challenges. With respect to this study, these factors in relation to occupational needs and wellbeing should be considered to implement the learning program for children with SPID in the SCCs in determining the outcome for the children with SPID.

Table 2.2 Occupational needs for occupational wellbeing

Occupational Need	Description	Occupational Need	Description
Accomplishment	Addressed when individuals generate evidence indicating that they are learning and mastering skills, meeting performance expectations, and achieving goals	**Coherence**	Occurs when individuals' occupational experiences are aligned with their values, personal desires, goals, and the occupations they engage in generate evidence that confirms who they are and want to become.
Affirmation	The need for individuals to recognize and have others	**Companionship**	Fulfilled when individuals engage in occupations with others who share

	recognize that their occupational choices and occupational performances are important, worthwhile, and valued and thus contribute to their self-worth. When individuals do things with and for others, they are more likely to receive affirmation.		common experiences, interests, Values, or goals, such occupations enable individuals to feel a sense of belonging and sometimes even intimacy.
Agency	Addressed when they perceive that they exert influence or control in important or valued aspects of their occupational lives. Agency may be experienced when individuals choose what occupations they do, and how, when, where, how often, and with whom they perform the occupations.	**Pleasure**	This ranges from the simple satisfaction derived from small daily rituals to the intense pleasure people feel in pursuing their driving passions and thus includes contentment, happiness and joy
Renewal	Experienced when individuals engage in occupations that provide a sense of inner peace, abandon, relief, and mental clarity, and leave them feeling refreshed, re-energized, and rejuvenated.		

Occupational therapists perceive people as occupational beings. Conceptual occupational therapy models, useful in understanding the internal and external factors that determine the occupations people choose to engage in and how this affects wellbeing can be extrapolated. The first published model in occupational therapy was the Model of Human Occupation (MOHO) by Keilhofner explained in table 2.2 (Doble and Santha 2008, p.186; Ramugondo 2017).

Table 2.3: MOHO Concepts (Forsyth and Keilhofner 2011; Turpin and Lwama 2011)

Concept	Description
1. Person	
Volition	The processes that motivate people to do what they do. The volitional processes consist of a cycle of anticipation, choice making, experience and interpreting actions.
Personal Causation	People's sense of their current and potential abilities to act with purpose and produce outcomes. It includes personal capacity, people's thoughts on their capabilities and self-efficacy and a sense of the extent to which they can control outcomes.
Values	The beliefs that people have about what is good, right, important, and worth doing. Values include personal convictions, a person's view of what matters in life, and a sense of obligation, which is a drive to act in accordance with ones' values.
Interests	Attraction to certain activities based on anticipated enjoyment.
2. Habituation	This is readiness to behave in a consistent way according to what is fitting for the time, place and social situation
Habits	Patterns of behaviour that are often performed automatically. Habit formation decreases the conscious effort to perform a task and frees up cognitive capacity
Roles	Taking on an identity, outlook and activities related to your position in society, and relationship with others. Society has expectations of what is expected of a person in a particular role. Examples of roles include friend, mother, careworker, therapist.
3. Performance Capacity	The way the systems in your body interact that allows you to do things.
Objective components	Capacities of bodily systems such as musculoskeletal, cardiovascular systems as well as cognitive capacities
Subjective Experience	How persons experience their performance in specific activities.
4. Environment	People and their environments cannot be separated. The environment affects the opportunities people have available for their occupation. Equally, the people affect their environments through their choices of activities
5. Occupational performance	
Skill	Quality of discreet purposeful actions during an activity such as reaching for a key and then manipulating it in your hand.
Occupational Performance	Ability to successfully complete a task or activity
Occupational Participation	Engaging in occupations that are part of a person's context and contribute to wellbeing.
Occupational Identity	A person's sense of who they are and who they want to become as influenced by what they do.
Occupational Competence	The extent to which a person can participate in occupations that reflects their occupational identity.
Occupational Adaptation	Constructing an occupational identity and achieving competence in that identity over time.

The MOHO concepts are the cornerstone of occupational wellbeing, which extensively elaborate on the personal, environmental, and occupational performance components that affect occupational wellbeing. The MOHO holds a conviction that careworkers possess innate factors such as volition, habituation and performance capacity that shape how they take or not take part in activities and how they handle the outcomes or consequences of their choices (AOTA, 2020; Forsyth and Keilhofner 2011; Turpin and Lwama 2011).

2.2.4 The role of Occupational Therapy with Careworkers of Learners with Severe to Profound Intellectual Disabilities

The therapists assist and facilitate the careworkers who provide care to the children with SPID in identifying challenges and making adaptations to maximise the performance of these children (Missiuna, Pollock, Levac, Campbell, Sehagian, Bennett and Russell 2012). King, Teplicky and Rosenbaum (2004) stated that carers of children with challenges want what is best for the children and therapists need to address the careworkers concerns about the children's participation in occupations. Odman and Oberg (2005), Gilson et al. (2018) as well as Douglas et al. (2020) concur that the careworkers know the children, and that the best way to improve the child's functioning will be through empowering their care through training and capacitation and enhancing their everyday environment in which they execute their occupations.

They also provide support for those that care for these children to alleviate occupational risk factors such as occupational deprivation, alienation, imbalance, injustice, and insufficiency (Keysor 2006; Watson and Fourie 2004).

In the case of careworkers as explained by Townsend and Wilcock (2002), creating opportunities for meaningful participation in terms of remuneration, recognition of effort, approval and celebration of achievements are all enablers of justice.

Reid, Chiu and Wehrmann (2016) further expand on the that occupational therapists' key role for learners with SPID as careworker training, making recommendations and referrals, and helping with putting the recommendations into practice. The occupational therapist equips the careworker with skills and knowledge to facilitate the child's functional ability, to observe progress and adjust

the learning program accordingly (Janse Van Rensburg, Van Der Merwe and Erasmus, 2019; Govender et al. 2018). Concisely, the occupational therapist serves as the link that connects the health and education sector (Missiuna et al. 2012).

Occupational therapy has a role to play in eradication of social ills that include discrimination, stigmatization and social exclusion. It is through ongoing education, advocacy and community mobilisation that emancipation and occupational justice of the children with disabilities and their careworkers can be realised. Community reintegration and social participation cannot be attained by addressing only those who are excluded without sensitising the community that instigate these problems (Townsend and Wilcock,2004).

2.3. Challenges of providing services for children with disabilities including Severe and Profound Intellectual disabilities

2.3.1 Burden of care on parents

In South Africa (Stats SA 2020) most children (43%) lived with only their mothers. Parents of children with disabilities in LMIC regions experience various challenges, including poor or no antenatal care, more children in the family/ household, dehydration, malnutrition, and poor health management – these contribute to the high prevalence of cerebral palsy in underserved areas (Barratt 2007).

The parents' main problem, however, is how to manage their child's chronic health demands effectively and still be able to juggle this role with other requirements of daily living (Raina et al. 2005). The families of children with disabilities also experience further financial distress due to the high medical costs or lost employability, as they care for the child full time (Kuper, Smythe and Duttine 2018).

Similarly, parents in Kenya face challenges beyond financial constraints over essential needs due to poor access to information about the medical conditions and healthcare services, resulting in parental stress. There is a correlation between child disability and parenting stress, and between disability and household socioeconomic status (Hunt, Laurenzi, Skeen, Swartz, Sundin and Weis 2021). Kuper et al.(2018) caution that it is too much to expect parents to

tend to their children with demanding needs whilst they (parents) have little exposure of and are uninformed of their child's condition, have poor support systems, and are undergoing emotional distress.

Caring for disabled children poses psychological strain on the family structure, related to sequelae such as fathers leaving the household and mothers suffering mental ill health. Findings from Zuurmond et al. (2019) concur that the burden of caring for a disabled child also bears the setback of social isolation, feeling alienated by the family and the community, and abandonment and departure of the father/husband. Fathers tend to abandon a family where a child is born with disabilities and do not provide financial support (Bannink, Stroeken, Idro and Van Hove 2015). Salojee (2007) suggests that the high unemployment rate in low socio-economic setups, where household incomes are extremely low, coupled with single parenting or lack of financial support (especially from fathers),are significantly contributing as factors affecting the ability to care for the whole family while singling out the child with a disability as a priority. Malaysian parents reported having a greater social support system as their immediate family members, friends and colleagues were helpful and considerate (Mohd Nordin et al.2019; Gladstone, McLinden, Douglas et al.2017)

As an example, 80% of children in Mamelodi, South Africa, were recorded as living in large family setups (extended family), and almost all surveyed children (94%, n=119) came from single parent households or no parent at all. These factors are linked to an ability to provide opportunities for the children to reach developmental milestones and fulfil potential to thrive later when they come of age (Du Toit, Van der Linde and Swanepoel 2021).

Mohd Nordin et al. (2019) uncovered that the parents are heavily laden and disheartened by the chronic nature of their children's disabilities, where delayed or no improvement is witnessed despite the number of intervention sessions attended. Provision of support by health professionals, like ongoing counselling and debriefing, was recommended by the parents as caring for their children with disabilities was experienced as emotionally draining (Mohd Nordin et al. 2019).

Parents hold faith and hope in prayer, exercises, and specialised equipment and medication to yield better prognosis, but lack the insight to the permanence of

disability and absence of cure(Paget, Mallewa, Chinguo, Mahebere-Chirambo and Gladstone 2016). There is high inclination towards religion and spiritual beliefs in Africa, not only because they are highly valued in this context, but perhaps because it is something to sustain hope (Mkabile, Garrun, Shelton and Swartz 2021). Parents of children with disabilities, especially mothers, experience daily hardships for the rest of their lives and this affects all areas of their lives with no exception of their physical and mental health, employability, and sociability (Gilson et al. 2018).

Mothers were found to experience mental ill-health including anxiety and stress owing to limited access to resources and poor custodial care. Seemingly, the anxieties stem from perceived treatment by society's beliefs pertaining to the causes of ID (Mkabile et al.2021). This is exacerbated in some cultures where children with disabilities are viewed as a curse and a burden. The community's negative mentality in relation to the children with disabilities led to their parents feeling unwelcome. The mothers experience pity, stigmatization, discrimination, and social exclusion. These feelings can and do lead to mothers isolating themselves to protect themselves from guilt, shame, and humiliation of having not birthed a 'normal child' (Nyante and Carpenter 2019).

These mental health issues which arise from these experiences along with social negativity and misconceptions about disability: sadly result in some parents venting their frustrations onto their children (Nyante and Carpenter 2019). Parents expressed that caring for a disabled child, robs them of the time to attend to other children, complete chores at home, socialize and participate in remunerative activities. These parents indicated a loss of opportunity to study or work as they receive no help to care for the child from family members. Parents explained that transporting their child with disabilities is expensive as regular public transport is not accessible for people with disabilities, thus they tend to hire or rent transportation. Health workers have raised concerns that mother's burden of care leads to burnout and depression, which is a risk factor to abuse or neglect of their disabled child (Paget 2016).

Nyante and Carpenter (2019) found that parents were incredibly desperate and thus at risk of being exploited, prepared to whatever it takes to find cure for their

children. Fund, already scarce, were (mis)used in the pursuit to find a cure, paying traditional and spiritual healers, seeking western medicine that can permanently cure the child.

2.3.2 Burden of caring on careworkers

Zuurmond et al. (2019) highlighted that child with disabilities have greater care demands owing to their impaired sensory, intellectual, and communication abilities, as well as an increased likelihood of epilepsy and motor dysfunction, which poses burnout on those that care for them. Like the parents, careworkers of children with SPID are prone to burnout, which is detrimental to the institutions and the children. Consequently, there is a high turnover of staff at care centres for children with disabilities which results in increased costs to training of new staff(Van der Linde 2014).

Raina et al. (2005) found that the careworker's job is not popular and seldom desirable, thus it is highly unlikely that careworking may be an appealing job prospect. Furthermore, Raina and colleagues (2005) emphasise that the careworker's stress is exacerbated by several factors and not just the taking care of the children. Income was found to have an overall effect on the physical and psychological health of the careworker.

Overall, careworkers are typically adults who have less capacity to thrive in the labour market, or do not identify themselves as pursuing a career. The impact of careworking on the open labour sector differs on the basis of the type of care being provided (Van Houtven, Coe and Skira 2013). For instance, assisting with self-care activities such as bathing, eating/feeding, and cleaning is more strenuous and time consuming compared to other activities that allow flexibility, can be executed during convenient times of the day, or even over other days - unfortunately, tending to self-care activities like changing diapers, cleaning the child, and feeding the child should be done timeously (Van Houtven et al. 2013).

Ngubane and Chetty (2017) projected that research on careworker's satisfaction and perception over rehabilitation is lacking in LMIC like South Africa. They Found that careworkers experienced their jobs as physically strenuous, for instance, having to do transfers with overweight, older children who are completely dependent. Therefore, careworkers described caring as increasingly tedious and

physically strenuous as children with disabilities such as SPID grow older and become heavier, and that the neurological complications such as spasticity and musculoskeletal problems add on to the handling challenges: bathing the children, changing diapers, washing soiled linen, and feeding the children were described as most demanding and tiring (Nyante and Carpenter 2019).

The effect on psychological and physical health arises from these essential, yet difficult demands to manage the child's health (Raina et al. 2005). The time that careworkers spend with the children at the centres precipitates a conviction in parents that the careworkers understand the children better and are better positioned to take care of the children, hence the parents shunt the care responsibilities unto the careworkers (Hasan et al. 2020).

Zuurmond (2019) argues that the hardships that careworkers face are not fully captured by standardised assessments, and the aim of empowering the careworkers cannot be achieved without addressing pressing issues of stigma, social exclusion, poverty, gender inequality, illiteracy and lack of resources. Kuper et al. (2018) stressed that it is pointless to conduct programs that aim at capacitating the parents/carers with knowledge and change in practices without dealing with their core problems such as emotional burnout, financial constraints, and poverty as this compromise the effectiveness and sustainability of caring programs.

2.3.3 Education for children with disabilities

Access to education for children with disabilities is a global concern. In Malaysia, parents voiced their frustrations of struggling to find placements for their children, and so were forced to take them to private schools (Mohd Nordin, Hui Shan and Zanudin 2019). The lack of access to resources are often taken for granted in other parts of the world is common in LMIC (Mkabile et al. 2021). About 25 % of children of school going age in LMIC are out of school and attributed to poor health (Bright et al. 2018).

Van der Linde (2014) highlighted that the children with SPID have cognitive impairment and neuro-motor dysfunction. The severity of the impairment can be exacerbated by comorbidities such as behavioural impairments, epilepsy, sensory impairments, gastric reflux, and chronic respiratory disorders. Lack of education

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affects the health and wellbeing of a child (Van der Linde 2014). This is compounded because children with SPID often reach the service points quite late, when they have already developed related complications such as contractures, deformities, and fixed behavioural patterns. Children with disabilities do not access early intervention benefits as their parents are uncomfortable to seek help due to fear of harsh judgement and being stigmatised by the community (Mohd Nordin et al. 2019). Johnson and Boxall (2021) explain, recommend, and advocate for full inclusion in early childhood education, facilities, and early childhood intervention for younger children with learning disabilities as highly recommended.

Despite the challenges, Gough, Dryden, Wolff and Williams (2019) attest that paying close attention to children with disabilities helps to ascertain that every child is recognized as an individual with unique needs, and that they may be accommodated to learn to participate in some activities to a limited extent which they are able.

2.3.4 Poor access to services for children with disabilities including Severe and Profound Intellectual disabilities

According to Stats SA (2020) more than half of the South African population lives in poverty. In LMIC the intersection between poverty and disability is glaring - destitution exists alongside malnutrition, even inaccessible basic public health services, such as vaccination. The scarcity and insufficiency of basic needs like safe water and proper sanitation all there exacerbate the ill health of people with disabilities (Kuper, Smythe and Duttine 2018). Risk factors for delayed development in children are also prevalent in these circumstances: coming from a large family size, low family income, and unemployment; these are indicators of living in poverty (Du Toit et al. 2021). Child dependency grants were reported to be the only income in 40% of the households headed by single mothers, subjecting her and her dependents to high food insecurity. It is noteworthy that poverty is accompanied by social ills such as unemployment, crime, drug abuse, domestic and child abuse as well as broken family structures. Even with low resources areas, access to services for children with disabilities is not equally distributed in South Africa. The rural areas are generally poorly resourced and underserved, with many inhabitants, with low socio-economic status as

businesses and services are easier to access in urban areas. Research continues to uncover that people living there are typically living in areas with poor housing and transportation, economic deprivation, poor access to health and community facilities which is tantamount to lack of care as these are integral for people with physical and mental health challenges (Kaufman, Kosberg, Leeper and Tang 2010).

The rural population often has little to no access to basic needs such as health services and have to travel to cities with already constricted funds, to access better health services. The SCCs where the study was conducted are situated in these communities with low socio-economic status.

2.3.4.1 Scarce rehabilitation services

Careworkers of children with disabilities face a variety of challenges and they are even greater in rural parts of South Africa where resources are scarce (Barratt 2007; Pahuwa 2012). Adugna, Nabbouh, Shehata and Ghahari (2020) reported that there is a lack of scientific databases collecting information on disabled children's access to health facilities, and that may be due to lack of research in childhood disability. Additionally, the government is found to pay poor attention to the accessibility and rendering of services to children with disabilities. In parts of South Africa with constrained resources, only a quarter of children in need of therapeutic rehabilitation services were found to be recipients of any form of relevant services (Salojee 2007). The prevalence of childhood neurological disabilities is four times higher in Africa compared to high income countries countries(Adugna et al. 2020). Transport and geographic challenges also obstruct access to health facilities: instead, they are located in central urban areas, creating further logistical challenges for those living in rural areas (Adugna et al. 2020). This is a strain added onto issues of money and time taken to get to facilities.

A greater number of people living in rural areas coupled with a shortage of health workers in these areas create a substantial barrier in providing rehabilitation services (Palisano, Almarsi, Chiarello, Orlin and Maggs 2010). The African continent has a scarcity of trained health and rehabilitation workers, with a few that are specially trained in the tools required to care and to manage a child with

CP in rural areas. In addition, where infrastructure is available, there are usually other hindrances such as lack of cultural- and language-specific, validated clinical assessment tools; illiteracy in caregivers; and lack of appropriate facilities and equipment for rehabilitation (Donald et al. 2014). On the other hand, Arnodottir and Egilson (2012), pointed out that there was a lack of professional expertise in some health facilities in rural areas. The situation has not changed significantly since then, the shortage persisting, reinforcing the need for local health workers to be trained and upskilled. Orlin and Maggs (2010), Palisano et al.(2010) concluded that health professionals have the responsibility to avail services in their users' communities. In other words, through outreach programmes. Outreach programmes are of immense value to these underserved areas (Grut, Mji, Braathen and Ingstad 2012).

In Zimbabwe, these challenges are counteracted by the services of community-based rehabilitation workers that conduct home visits and can effectively offer intervention to disabled children in their homes since the early 90's. Community health workers and outreach services have played a significant role in decentralizing health services and increasing upscaling health service delivery and thus bettering access for people in the rural parts of the LMIC (Bright, Felix, Kuper and Polack 2018).

Challenges of negative attitude, poorly trained health workers, poverty, and physical inaccessibility are frequent barriers to accessing health care for children with disabilities in the low- and middle-income African Countries. Ameliorating the barriers to accessibility include informing policy, enhancing physical accessibility, and raising disability awareness in the community as well parental and professional support (Adugna et al. 2020).

Community mobilisation in Ghana addressed stigma and misconceptions in the family and community at large, increasing positive health-seeking behaviours in the population (Bright et al 2018).

2.3.4.2 Lack of resources and fragmented services

Children with disabilities need rehabilitation centres and specialised medical equipment to ameliorate physical limitations, improve the quality of life, and become integrated into the community (Wang, Chen, Zhang, Li, Guo and Hailey

2008). It is unfortunate that in most cases, parents cannot afford assistive devices. In Malaysia, parents appealed for funding to procure assistive devices for their children - they are mostly imported into low socio-economic settings as there are limited or no local manufacturers and thus are costly and unattainable to parents (Mohd Nordin et al. 2019). Parents of children with disabilities in Pakistan revealed that their main concern and obstacle is the lack of government provisioned infrastructure, lack of disability friendly transportation and untrained personnel lacking expertise to work with disabled children (Qayyum, Lasi and Rafique 2013).

Qayyum, Lasi and Rafique (2013) argue that the care of children with disabilities does not solely rest on health professionals imparting information on how to care for the disabled, but also requires social networking, quality education, capacitating of careworkers and availing support services. In Malaysia, parents indicated that the social welfare department could improve its service as it only assists with items of daily use such as diapers (Mohd Nordin et al. 2019).

In South Africa, the Department of Social Development (DSD) provides reasonable service to the children with disabilities, inclusive of feeding subsidy and paying careworker stipends for providing care services. The DBE has developed a policy that imposed a teaching role in the centres and employed the education outreach team to conduct the training to the careworkers and provide rehabilitation services to the children. The DBE also provides learner teacher materials (LTSM) to ensure implementation of the learning program (DBE 2016). Salojee (2007) reported that as major sectors that should be in the frontline of child disability, the lack of collaboration between the departments of Basic Education, Social Development and Health consequently leads to parents being misinformed of resources available to them. Cloet et al. (2017) concurred that poor child development and integration in the family can be attributed to fragmented social, health and education systems that are not aligned to support children in middle- to low-economic settings.

2.4 Stimulation care centres

It is undeniable that in low socio-economic settings, there are discrepancies between the needs of children with disabilities and the services provided to them (Couper 2002). Therefore, in the underserved rural areas where children do not

have access to regular therapy, it is crucial to ensure that the intervention or outreach program offers therapy that will make a meaningful difference (Couper 2002).

Donald et al. (2014) highlighted that strategies implemented in Africa to manage children with disabilities include usage of pliable low-cost materials, community health careworkers, parent support groups, and multidisciplinary outreach services – these are often provided by NGOs, private or missionary funded centres, and some government subsidised programs. The community-based centres are often the only accessible means where children with disabilities in the area can receive rehabilitation and education, in some parts of Africa. The careworkers assume the role of program implementers and ensure that there is carryover of the services. The careworkers are the prime drivers of capacitating the families of children with disabilities, and the community at large, on matters of rehabilitation (Hasan, Abdul and Aljunid 2020). It is important to note that the community based SCCs were making up for the lack of service provision by professional stakeholders (Hasan et al. 2020; Ngubane and Chetty 2017).

Hasan et al. (2020) distinguished between active and passive community-based centres. Passive care centres are characterised by not being goal-oriented towards self-reliance and community integration. Active care centres are those that strive for education, vocational training, independence, and social participation. A typical passive centre is identifiable by personnel that lack formal training or non-professional staff, and only provides shelter and meals to people with disabilities (Hasan et al. 2020).

In the endeavour to deliver therapy that is effective, the education outreach team target to provide intensive block therapy, in other words, therapy provided over a minimum of five days, with careworkers being trained to ensure continuity in the absence of therapists (Geiger, 2012). This is, however, not always possible as the education outreach team covers a substantial district with a vast number of centres to cover, compromising the teams' turnaround times (Mckenzie et al.2017).

2.4.1 Co-creating and collaborating with careworkers

As stakeholders in the SCCs, careworkers are directly affected by centre proceedings, more so than government officials. The careworker's buy-in, involvement and commitment are integral for achieving objectives and smoothly executing their activities. Careworkers experience being a part of the development and evaluation of the intervention they provide to children with disabilities through active involvement, this gives them feelings of capability and competency in their care work (King et al. 2004; Palisano et al. 2010). Careworkers gain knowledge and become empowered to make informed decisions and take ownership of their roles and responsibilities. It is thus crucial that careworkers have ample opportunity to express their concerns and what they deem as priorities for intervention (King et al. 2004; Palisano et al. 2010; Bester 2020).

The success of an intervention program in a SCC depends on the calibre of its facilitators and their skill in building relationships with the caregivers. Furthermore, it may be the facilitators' responsibility to employ engagement skills to achieve collective collaborations, as well as afford the program end users some leadership roles. Zuurmond et al. (2019) argue that without this, the careworkers do not have the capacity to influence change in practices and societal behaviours as they are already poor, illiterate, stigmatised, discriminated, and excluded. Active involvement of careworkers as co-facilitators of the training program should be encouraged, as they have shared lived experiences and it is suggested that this practice may heighten the outcomes of intervention. Therefore, to address stigma and alleviate the already burdened female caregivers, Zuurmond et al. (2019) suggest that the programs should engage community leaders, faith-based leaders, extended families and strive for a gender balanced involvement.

Perhaps part of the problem is that careworkers are not seen as equal knowers. Galvaan and Rauch van der Merwe (2021) argue that health care professionals should innately consider all persons/stakeholders as an equal counterpart in the healthcare relationship. Furthermore, Ndlovu-Gatsheni (2018), elucidates that one way of dehumanisation occurs when one repels a person's epistemic virtue, and wittingly if not, portray another person as either having little knowledge, not being knowledgeable, or with invaluable knowledge.

Gladstone et. al (2017) reiterate that it is imperative to give recognition and acknowledgement to the careworkers for their pre-existing commendable practices. Paget et al (2016) concurs and stresses that the success of any program depends on the active involvement of the end users as they can contribute worthwhile ideas and recommendations that may sustain the program over long term. Thus, integration of the perspectives of both the service recipient and service provider is highly recommendable (WHO,2011). Interactions over knowledge-sharing and information imparting should incorporate service users in decision-making platforms (Galvaan and Rauch Van der Merwe 2021).

It is overtly clear that parents careworkers are not afforded the platform to make contributions. Bester (2020) established that parents and carers of children with disabilities yearn to be listened to and to be actively involved in the planning of interventions. Bester (2020) recommends that collaboration should be conducted with special consideration of the information needs, learning styles of the parents and careworkers aligned with adult teaching principles. Furthermore, Bester (2020) established that there is a need for careworker specific education and training program that is designed through a collective team work between the careworkers and the service providers and enhanced by opportunities for social support, thus occupational therapy can take the key role in facilitating careworker-centred, careworker-specific education and training and engagement in peer support groups as well as matters pertaining to mobility devices, equipment and policy informing.

2.5 Training the Careworkers

Ludici et al. (2019), stresses that to close the gap between the disabled and able-bodied, the community at large and careworkers, should be empowered to foster inclusivity and opportunities that will improve the participation of the individuals and assist in reducing discrimination. Van der Linde (2014) found that the training of staff working with SPID children yielded improved and sustained job satisfaction for the careworker. Salojee (2007) concurs and projected that there is no need for highly specialised staff to meet the basic needs of children with disabilities, however capacitating the carewokers could alleviate some burdens on the systems by allowing the careworkers to connect the families of disabled children to public resources.

Gladstone et al. (2017) uncovered that regular visit by support staff may be more disruptive than helpful unless the carers are supported and trained on how to manage their daily activity demands. Concurring results were found in a study conducted in Ghana on a support programme rendered to careworkers of children with disabilities, the parents reported that even though they appreciated home visits from health professionals, they experienced the gesture as being 'checked on' to establish whether they were following the home program or carrying out recommendations (Zuurmond et al. 2019, pg50). To prevent frustrations and disappointments, realistic feedback is needed. For example, careworkers need to be assured that they have done their best in all their endeavour to get the children to walk when this is not possible, and that it is sufficient to allow their child to crawl or use a wheelchair to maximise the functional mobility goals (Gibson 2013). According to Gibson (2013), reiterates the importance of a change in careworkers mindset from emphasising mostly on motor recovery , as it only subjects them and the children to unrealistic goals and ultimate feelings of failure. This change in mind-set should encourage the careworkers to strive more for the children's improved participation in activities as opposed to motor recovery. King et al. (2004) state that health professionals can be impactful in the lives of children with disabilities and their careworkers by looking at therapy beyond their own technical expertise. In other words it is not what the health professional observes that matters but that which the careworker identifies as a main concern.

The careworkers expressed a need to be educated and informed on their children's medical conditions and the implications of the condition on their learning abilities from health professionals, they felt they learned more from the internet and other parents raising children with disabilities (Mohd Nordin et al. 2019). Gladstone et al.(2017) deduced that training in the communities should cover medical information on a range of childhood disabilities..

2.6. Understanding disability

The health practitioner's perspective of disability is informed by science putting theory into practice, whereas the careworkers' and parents' understanding of disability is influenced by the communities they live in, the shared experiences and the challenges encountered. Hence it is thus important to understand what knowledge they already possess to guide their training.

In previous studies careworkers of children with cerebral palsy are particularly interested in finding out if there is a possibility that the children will be able to walk, regardless of how severely their milestones may be affected (Rosenbaum 2003). Ketelaar (2000) argued that careworkers were at risk of frustration if their demands from therapy were unrealistic, and their goals could not be achieved. In Ghana, participants only associated the success of a program and improved quality of life with the child attaining the ability to walk - the child's inability to walk after intervention increased levels of anxiety and dissatisfaction (Nyante and Carpenter 2019).

Noticeable change and improvement in the clinical presentation of children with disabilities was reported to a greater facilitator than awareness, in changing attitudes and perceptions, and even improved health-seeking behaviours (Bannink, Stroeken, Idro and Van Hoven 2015). A general perception is that disability is fixed and that no change can be brought about by intervention. This leads to instances of high motivation solely primarily in cases with observable changes (Adugna et al. 2020).

Ludici, Favaretto and Piero (2019) found that the careworkers perceive and define disability as a non-changing condition. Their general opinion is that a disabled person will live a life of challenges, characterised by lack of independence and needing assistance with everything. Careworkers' perception of disability explains their reluctance to implement strategies and methods developed to reduce the differences between disabled and able-bodied people.

There is also reluctance in seeking rehabilitation as people perceive disability as a permanent and non-changing condition. Parents become discouraged paying for transport to rehabilitation practitioners (therapists), only for the child not to show major change after years of consultation and intervention. There are discrepancies in outcomes measures and evaluations for improvement between the health practitioners and the parents.

2.6.1 Comprehensive training programs and their contribution

Willis et al.(2018) pointed out that time is a useful resource that can heighten the results of intervention for children with disabilities, as time opens room for repetition, shared learning and creates security within settings. Wills et al.(2018)

reiterate that understanding the collaborations between how a program yield results and under which settings, is important to customise and carry out successful.

A study by Chocarro et al. (2021) revealed that a training program was effective in improving the knowledge and skills required by careworkers of children with disabilities, in improving their confidence in their skills and knowledge and subsequently had improved self-perception following positive impactful careworker training (Chocarro et al. 2021). A positive change of behaviour and practice was found after by training by Adams et al. (2011) to primary carers addressing nutrition, by adapting food consistency to be consumed orally with ease, using correct utensils, and positioning devices to align the child for being fed or self-feed in a sensitive yet highly responsive manner.

With the improved self-perception after the training, the careworkers are empowered to do more than what they did before and became bold to undertake complex activities of which they had previously required approval of the professionals (Chocarro et al. 2021). To achieve the above, Chocarro et al. (2021) further emphasised the importance of a dedicated training site, with the correct equipment and training on equipment that are of high level of technology. Careworkers training takes more of a psycho-educational approach where peer learning and shared experiences take place, this assists with peer perception of their unique contribution. The careworkers see that they are in similar situations and can help one another (Chocarro et al. 2021).

On the other hand, it is emphasised that regardless of how well a program is planned and executed, the outcomes will always be compromised should the challenges at the immediate family and residing community not be addressed. It cannot be ignored that a positive mental state, food security and shelter are basic needs that will consequently affect the quality of care offered to a child with disabilities (Gladstone et al. 2017).

Kuper et al. (2018) emphasise the importance of attending to primary issues such as community exclusion, poverty effects and psychological distress above training on skills set and behavioural change. A recommendable careworker support program should be strategic and holistic in attending to ill health, stigma, isolation

and poverty by skilling the careworkers on health promotion and facilitation of development through primary activities that include feeding, positioning, communication play and early stimulation towards social participation and community integration. Furthermore, a comprehensive program will not only focus on attaining change in careworker's practice change and child's health condition but also strive towards advocating for the rights of the disabled children and their careworkers, inclusion in the education and health sector as well as access to disability benefits.

Paget et al. (2016) suggest that programs that train carewokers should be integral with existing services to combat inaccessibility to rehabilitation services in LMIC and put the emphasis on 'training the trainer' (Paget et al. 2016). In addition, an effective program should seek to equip parents with knowledge and empower them to disregard myths and misconceptions from the community.

The health workers caution that a program should from the onset manage the expectations of careworkers. Thus, the correct management of careworker's expectations will prevent giving them false hope or losing their active participation. Hunt et al. (2021), emphasised that efforts of training programs should be invested in supporting careworkers or parents to handle matters of child disability and stress management as opposed to dwelling on the child's disability as the reason for parenting stress.

Aspects that hinder the success of a program were identified as the community that is misinformed of available services, distorted communication, poor referral system, and lack of standardised operational measures. Even in countries with low to middle income, funding a program was not necessarily the issue, but the issue was managing the program effectively, with accountability (Paget et al 2016).

2.6.2 Occupational Therapy Concepts Applicable to Training Careworkers

The careworkers have shown to have low skills and inadequately trained to provide appropriate stimulation and eduction for the children with SPID even though they are passionate and enthusiastic to do so (Mckenzie et al. 2017).When collaborating with and training careworkers, occupational therapist identify and support ability in a conducive environment while appreciating the occupational

profile and skills of the careworkers in supporting the provision of education to careworkers of children with SPID. Their skills regarding feeding, seating and communication, play, and learning amongst others, are shared needs within a collaborative model where careworkers are taught skills and provided with knowledge that they can implement the learning program with the guidance of therapists DBE (2016).In the core of occupational therapy evaluation lies determining the careworker values and priorities for occupational participation, desired outcomes of intervention and creating goals in collaboration with the careworkers that address the desired outcomes of intervention.

Joint planning, observation and action based practices were highly commendable over reflection and feedback practices (Douglas, Meadan and Kammes 2020).

Douglas et al (2020), expanded that joint planning entails collaborating with careworkers during brainstorming, problem solving and extrapolation of challenges. The participating occupational therapist further alluded that questions such as 'what is the most important hurdle' or 'what is the priority' helps to establish the careworker's prime concerns.

The findings of this study are indicative of the value of careworker training and how it benefits the children, their parents and careworkers as well as early intervention providers.

The trainers emphasised the importance of pre-training tactics to support the careworkers who may be hesitant or unacquainted to the training strategies employed. However, the trainers reported that their undergraduate or pre-working exposure to careworker educating was insufficient.

Sawyer and Campbell (2017) confirmed their hypothesis that trainers would be prone to conduct purposeful training to careworkers who are engaging and participative. Purposeful training is more beneficial as it is goal directed and enables the trainers to unpack the course content with elaborative explanations and practical demonstrations. The careworkers get the opportunity practice implementation, seek clarity, and receive feedback on their application of strategies learned, to build their confidence for independent practice.

On the other hand, Sawyer and Campbell(2017) also found that careworkers did not show interest were trainers worked directly with the children without actively involving the careworkers nor taking them through what they are executing.

Sawyer and Campbell(2017) hypothesised that that there would be a correlation between purposeful training and level of careworker's education, however the study did not yield any significant results in this regard. It could be assumed that trainers are of the notion that less educated careworkers would not show interest or have the skill to grasp what is being done during a session, hence the trainers opt for directly working with the child without explaining what they are carrying out. Or it could be the lack of confidence in less educated careworkers to be fully engaged or that the trainers themselves lack the skill of actively involving carerworkers that seem reluctant to participate during training sessions.

2:7 Conclusion

This literature review covered the main concepts associated with the study such as intellectual disability, care centres, careworker job experiences, outreach, training programs, rehabilitation and education challenges in low to middle income countries and contribution of occupational therapy in this setting. There is vigorous literature on parents, careworkers and children with disabilities. The literature reviewed is presented chronologically to demonstrate the gap between this study findings and what is happening around the world. It is evident that occupational therapy has a focal role to play in ensuring occupational wellbeing and occupational justice for diverse populations. The journey ahead is still long in the South African context with respect to careworker job satisfaction, education for children with disabilities and implementation of programs that bring forth solutions to identified challenges as opposed to merely setting objectives and making mitigating recommendations without endorsement.

It is comforting to establish that the systems are being put into place and that the needs of careworkers and children with SPID have finally achieved the recognition that they deserve. What is left is implementation of strategies towards realisation and achievement of the objectives. Occupational therapy is featured as a frontline in supporting persons to be agents in therapy and their own lives (Townsend and Wilcock 2004, p83).

The literature review helped to reinforce that in order to establish the effect of training on the LSPID learning program offered to careworkers in special stimulation centres of Mpumalanga, it is crucial to determine if the program meets the expectations of the careworkers and their requirements to implement the program. This study contributes knowledge towards closing the gap of not knowing the careworkers' actual needs and how they experience the LSPID learning program.

CHAPTER 3- RESEARCH METHODOLOGY

3.1. Introduction

In Chapter 3, the researcher will describe the methodological processes undertaken to answer the research questions. The researcher will describe the research paradigm, study design, context, and the targeted population to emphasise why the specific study type and design was suitable.The chapter will clarify in detail how the data were analysed, what ethical considerations and measures were taken to ensure trustworthiness and rigour,producing chapter 4.

3.2. Study Design

This study employed a qualitative research method in the form of a descriptive, explorative design, where the researcher describes 'what 'and 'how' the participants experienced a phenomenon (Bengtsson 2016; Cresswell and Cresswell 2017; Cresswell and Poth 2018). According to Cresswell and Cresswell (2017) descriptive study design is ideal to systematically gather information on a current existing condition, whilst an exploratory design is used where there is no previous study conducted or only a few studies conducted for a research problem. The researcher deemed this design as suitable for the study problem as there are no studies conducted on the learning program for LSPID in Mpumalanga and on the lived experiences and perceptions of the careworkers in the country thus far. In other studies conducted on LSPID (Geiger 2012; Van Houtven et al. 2012; Mckenzie 2013; Mckenzie et al. 2017), a qualitative approach was effective in obtaining rigorous and rich data from participants. In this study, the researcher explored how careworker training on a learning program for LSPID introduced in 2018 in Nkangala district was experienced, from the perspective of the careworkers themselves.

To obtain an understanding of their perspectives, descriptive explorative design was effective in extracting rich data from detailed reports including what worked best, where the limitations of the learning program are, how the work of careworkers compares before and after training, and what the careworkers wish could be done to mitigate their challenges and improve their work performance.

3.3 Study Paradigm

Research paradigm referes to a philosophical framework that the research is based on. This study followed the constructivism paradigm, which entails that people form their own concept and perception of the world they live in through experiences and reflecting on their experiences(Denzin & Lincoln 2018).

The research paradigm of constructivism follows a subjectivist epistemology and relativist ontology. Subjectivists epistemology suggests that understanding stems from interaction and collaboration between the researcher and participants. Concurrently, relativist ontology implies that people's experiences are their reality which exists independent of the researcher's knowledge but dependent on those with first hand experience and giving interpretation of their reality (Denzin & Lincoln, 2018; Creswell & Creswell, 2017). Thus the researcher and participants have collaborated on generating new knowledge by engaging in a formal process of reflecting and sharing their experience of the program for children with SPID.

3.4. Research Setting

The SCCs are located in the rural parts of the Nkangala district of Mpumalanga Province, where participants have challenges with basic resources like water and sanitation.

There are a total of 10 SCCs, 107 careworkers and 476 learners serviced by the outreach team. Four out of these 10 SCCs are well-established and built by foreign missionaries from the United States of America. Others are in informal structures like tin huts, and others are still under development through donations by the South African private companies. The research participants come from a predominantly low socio-economic setting. The researcher was part of an outreach team that services the area. The researcher chose to conduct the study in this area to highlight the issues in the area, for research participants whose opinions may not be afforded a formal platform due to language barriers, and to contribute to the body of knowledge about the new LSPID learning program.

3.5. Researcher positionality

The researcher worked in this setting as part of the education outreach team deployed by the DBE under the learning program for LSPID. The outreach team

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is composed of a speech therapist, physiotherapist, educational psychologist, educationalist, and the occupational therapist/ researcher.

In the beginning of the project, the outreach team invited the centre careworkers to the provincial cluster training sessions that were conducted quarterly. The team, including the researcher, intensified the training thereafter by conducting more onsite, hands-on sessions.

The researcher occupies the positions of both insider and outsider. As an insider, she provided services and was experienced in similar settings. As an outsider, she conducted research in this setting, searching for information that was not readily available or noticed by group insiders. It was precisely because of the insider position that the researcher could identify the gap addressed in this research. Potential biases are addressed in the section of trustworthiness later in this chapter.

3.6 Population and Sample

The researcher used purposeful sampling to approach participants who fitted the main criteria of being careworkers in the SCCs of Nkangala district Mpumalanga Province. The careworkers needed to have interacted with the education outreach team and received both centralised cluster and onsite training from the team on the learning program for LSPID for a period of 6 to 12 months. Only once ethics approval was provided (Appendix A), the researcher recruited participants telephonically following the most recent training attendance registers. The careworkers, whom in the experience of the researcher from several training sessions and practical implementation on site, could give rich information and who had shown keen interest in the program, were contacted telephonically. As the researcher interacted with these group members regularly, as part of job portfolio, she had access to their work contact details. Upon approach, the researcher gave an overview of the study, highlighted that permission has been obtained from DSD as the department in authority as well as ethical clearance, and offered the choice to the person to participate, or not (Appendix D). The researcher also indicated that participation is not compulsory and that the participants had the choice not to take part or withdraw at any time without penalty (Appendix C). All participants chose to be part of the interviews and research procedure until its completion.

The researcher recruited twelve (12) careworkers that showed interest and increased understanding of the learning program for LSPID from the (10) SCCs in Nkangala district. According to literature it is not always possible to predetermine the correct sample for a qualitative study (Hennink, Kaiser and Marconi, 2017; Hennink, Kaiser and Weber 2019; Sim, Saunders, Waterfield, and Kingstone, 2018). In this respect, the researcher continued with interviews until inductive coding saturation was reached.

Eligibility Criteria

The criteria used for careworker selection included: careworkers who

- are willing to participate

- Understand the content under discussion

- had exposure to training by the education outreach team on the learning program for LSPID for at least six months

- Have attended both cluster and onsite trainings

3.7 Research Tools

The research project was discussed in detail with the SCC managers, the researcher produced ethics clearance and the permission letters to the SCC managers. A room with a measure of privacy was requested, with a table and two chairs. A schedule for using the room was created centred on the appointment date for each interview.

3.7.1 Demographic Questionnaire

A short demographic questionnaire (Appendix E) created by the researcher was used to collect information on personal details, place of residence in relation to the centre, level of education as well as information on the careworkers experience with LSPID.

3.7.2 Interview Schedule

The interview schedule (Appendix F) created by the researcher was used in a structured one-on-one interview to explore the experiences and opinions of the

careworkers on the training they receive, its impact, their feelings about the project, and what their thoughts were on what needed improvement. The researcher was trained to conduct interviews by her research project supervisors, and then practised on two colleagues who had knowledge of the field. An informal pilot on one careworker was conducted.

The interviews were scheduled at a time convenient for the participants, ensuring that their work was not affected. All interviews were conducted over a period of three weeks as the centres are scattered across the district. In each week, the researcher targeted a subdistrict and visited two or three centres for interviews. In the interview, work background information was gathered. This included the level of education obtained, and how many years were worked in this field. The main content of the interview focused on the careworker's experience of the training carried out by the education outreach team on the learning program for LSPID and concluded with the careworker's recommendations. The researcher asked open ended questions and made use of probing and attending to gather enriched data (Whiting, 2008). The interviews lasted 45-60 minutes and the two longest took 90 minutes.

3.8 Research procedure

To recruit participants, the researcher interacted with possible, purposefully selected candidates and explained the study background and its purpose. Several careworkers volunteered, but only those who met the selection criteria were interviewed. The interviews took place on a one-on-one basis in the room that was requested. The researcher is fluent in Sepedi and English and conducted the interviews in whichever of the two languages the participant preferred. Based on the researcher's experience of conversations with the careworkers, some participants used both languages interchangeably, and they were accommodated.

3.8.1 Data Collection

Data were collected using the following tools: the interview schedule printed on a sheet of paper, a digital voice recorder in view of both participant and researcher, a writing pad for notes, and a laptop. The recorded interviews were transcribed verbatim by the researcher (Hennink, Kaiser and Marconi 2017). Selected responses were translated by the researcher into English and back into Sepedi, a

common translation checking method, and reviewed by a co-supervisor who is fluent in Sepedi.
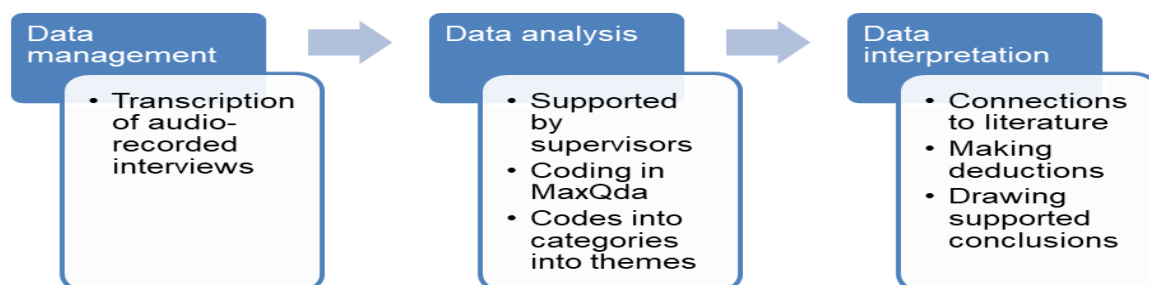
Figure 3.1 Research data procedure

Figure 3.1 outlines data management and analysis after collection.

3.9 Data Management

The audio files were transferred to and saved on a password protected computer and were deleted from the recorder within 24 hours of the interviews. Over a period of four weeks, the voice records were transcribed verbatim by the researcher and saved on the same password protected computer. The demographic questionnaires and consent forms were locked in the researcher's home office. Only the researcher had access to the hard copies and the password protected computer. The deidentified transcriptions and voice record links were shared with the supervisors during the process of assessing for trustworthiness through a password accessible electronic file. Data will be stored for six years should there be no publication ensued from the study and for two years should there be a publication from the study. Data will only be available to the researcher and the supervisors within the ambit of the University of the Witwatersrand Department of Occupational Therapy, Data Mangement Plan.

3.10 Data Analysis

The researcher coded the 12 interview transcriptions using MaxQda 2018 software. This process was overseen throughout by two supervisors with postgraduate degrees and experience in using the software. Regular meetings were held with them for guidance and following up on the progress of coding through repeated reading of transcriptions and arranging the codes into

subcategories. The subcategories were grouped into categories through mind mapping similar and connected ideas. In the final stage, themes were derived from these categories that were systematically carried out repeatedly.

The Creswell and Creswell (2017) method was used to analyse data, as described below:

Step one: *Organise and prepare the data for analysis*

All interviews are transcribed and translated into English.

The English translated transcripts were de-identified and coded for any similarities. The similar responses were then grouped under different categories.

Step two: *Read or look at all data*

The data was repeatedly scrutinised alongside the observational notes taken during fieldwork. The participants' general feelings, tone, and expressions were highlighted, as potentially, they could support or illustrate their deeper impressions.

Step three: *Coding of all data*

A code book was created for listing all codes and their definitions. Using MaxQda, sections of the data were labelled with the codes. Frequent discussions took place with the supervisors to collate independent scrutiny of the codes and carefully consider divergent or differing coding.

Step four: *Generate a description and themes*

A narrative describing the participants, their environment, and some events occurring during the study was written to create a broad and contextualising picture on individual participants and on the group at large. Verbatim quotes were carefully selected to enrich and rigorously illustrate discussion.

Step five: *Representing the themes and their description*

The researcher discussed participants' expressions and made mention of the transpired events in a sequential order. Pedi proverbs are incorporated to connect the themes.

Data were analysed using the inductive thematic content analysis and MaxQda horizontal analysis (Hennink et al. 2019; Creswell and Creswell 2017).

3.11. Rigour of research

The following step were taken to meet standards of trustworthiness

3.11.1 Credibility/Truth Value

The researcher kept a journal from the beginning of the research and recorded all preconceived ideas, expected responses, experiences of each session, in order to conduct a retrospective introspection. This practice of *reflexivity* serves to minimise bias through active self-awareness and reflection on how the researcher's role as an occupational therapist working for the education outreach team may influence the participants and interpretation of the data (Krefting 1991).

Credibility was ensured by following the interview procedure consistently for all the participants in the different SCCs. The researcher also requested a colleague and assistant supervisor for *analyst triangulation* by reviewing the findings and analysing independently of the researcher's influence. *Theory triangulation* was also used during data analysis in addition to attention to *negative case analysis*. Lastly, the researcher conducted *member checking*, by sharing the findings and interpretations with the participants to clarify their intentions, and make editions where necessary (Hennink, Kaiser and Marconi 2017; Krefting1991; Botma et al. 2016).

3.11.2 Transferability/Applicability

The researcher used knowledge and familiarity of the study setting to her advantage in describing behaviour, expressions, and experiences of the participants in their context, thus providing the readers with enough detail to allow transferability into different settings (Hennink, Kaiser and Marconi 2017; Krefting 1991). Additionally, the researcher aimed to reach data saturation by virtue of the number of participants and method of analysis that was also presented by thick and rich description of the data (Botma et al. 2016).

3.11.3. Dependability/Consistency

Dependability refers to the consistency and reliability of the research findings and the degree to which research procedures are documented, allowing someone outside the research to follow, audit, and critique the research process(Cresswell

and Cresswell 2017). The researcher applied code and re-code procedures to check for consistency in data analysis. Category recording was done after two weeks of initial coding (Krefting,1991). Pertaining to the aspect of trustworthiness, triangulation in terms of theory was one of the measures taken (Botma et al. 2016).

3.12. Ethical Considerations

The Human Research Ethics Committee (HREC) at the University of the Witwatersrand issued an ethics clearance certificate (M200983). The researcher sought permission to conduct research from the Mpumalanga Department of Education and the Department of Social Development (Appendix C). Participants were provided with information sheets (Appendix D), and they were asked to sign consent forms for participation and to be audio recorded (Appendix E). When potential participants were approached, it was made clear that participation was voluntary, and that they had the freedom to withdraw from the study without repercussions, even if they had already commenced participation. The study did not pose risk of harm to the participants, and it was emphasised to participants that their identifying information would be removed. The researcher explained that this project intended to improve the working relationship of the care- workers and education outreach team members (beneficence), by understanding their experiences as stakeholders. Additionally, the researcher respected confidentiality through de-identification of the transcriptions and protection of data by storing the recordings and transcription on a computer with a password. Only the researcher, transcriber/co-coder and supervisors had access to the data, and only the researcher had access to any identifying information.

3.13. Conclusion

In this chapter, this study's methodology was laid out and it covers the planning, data collection and data analysis processes. The researcher explained the steps taken to answer the research question, and how the data were analysed and interpreted for final presentation. The findings are discussed in Chapter 4 and compared with the literature to illustrate the contrast and the resemblances.

CHAPTER4- FINDINGS AND DISCUSSION

4.1 Introduction

In this chapter, data from the interviews are presented and discussed. The 'stand out' emphasis of participants' expressions were combined into three broad themes. These were further broken down and discussed in cluster categories and subcategories.

To embrace the context of the participants, the themes are presented as Pedi proverbs. The exuberant, figurative illustration helps to amplify this writing through proverbs meaningful to the participants and their culture.

4.2 Demographics and participants

A concise description of the participants provides information on gender, age, education level, and tenure as a careworker (Table 4.1).

The structure of this discussion first states the theme, provides a brief description of what it means, and how it resonates in the categories. Greater detail is focused on the findings and discussion thereof with literature comparisons.

Table 4.1: Description of participants - biographical details

GENDER DISTRIBUTION					
11 Females			1 Male		
AGE DISTRIBUTION					
25-30	30-35	35-40	40-45	45-50	50-55
1	1	3	1	2	4
LEVEL OF EDUCATION					
Below Grade 12	Grade 12	Early childhood development course	Home based care	Computer literacy	Security Guard Training
2	10	3	2	1	1
TENURE AS A CAREWORKER (YEARS)					
1-5	5-10	10-15	15-20	20-25	25-30
1	6	3	1	-	1

The careworker field is predominantly female since, care for children falls to women, as it entails activities traditionally ascribed to women/wives: feeding, bathing and toilet training (Budlender 2005). Four of the careworkers who were the founders of the SCCs were mothers with a disabled child at the centre.

Most of the careworkers were older and participants stated that the younger community members frequently leave for greener pastures. It is noteworthy that some careworkers have retained this job up to and beyond their retirement age (60 years of age).

Ten out of 12 careworkers have matriculated (grade 12). Only 3 out of 12 have been trained in early childhood development, and two have been trained in home-based care. Only one out of 12 has been formally trained in computer literacy. Half of careworkers in this sample have been working in the SCCs for 5 to 10 years. A quarter have been working for 10 to 15 years, and one for 25-30 years. All these participants have been exposed to training by the education outreach team on the learning program for LSPID for at least 6-12 months. The training sessions were conducted as formal cluster workshops that lasted for three consecutive days per quarter in a year, along with onsite training at least once a month at the SCC. The orientation to learning program for LSPID cluster training was initially conducted as provincial workshops where all four districts of the province would send one or two careworkers for training. Training was later decentralised to district level for one cluster training per quarter and regular intensive onsite training. The district based sessions had higher attendance rate than the provincial based ones, all the participants in this study attended more than half of the district based sessions.

4.3 Themes, categories, and subcategories

Three themes were constructed from the data. These themes are labelled according to Sepedi proverbs to emphasise the careworkers' expression.

1) "Monatlala oa ema" -hunger compels you to go out and hunt.

2) "Mollo yo sa o orego o ka se go ntshe dipale" - If you do not face the fire, you will not know it's heat.

3) "Go ba Komana Madula a bapile"- Be prepared for anything.

These themes, their categories and subcategories, are represented in Table 4. 2.Quotes are presented in the language used by participants during the interview. The interview schedule (APPENDIX F) was translated from English to Sepedi and back by the researcher and a research supervisor fluent in Sepedi.

Table 4.2.Themes,Category,Subcategory,code

Theme	Category	Subcategory	Code
Theme 1: **Monatlala oa ema ema Hunger compels you to go out and hunt.**	1.1 Unique Role in our communities.	n/a	Advocating for children's rights
			Fighting stigma
			Offering relief (to mothers)
			Pushing community integration
	1.2Challenges	1.2.1 Careworker challenges	Knowledge
			Skills
			Motivation
			Well-being
		1.2.2 Community and end-user challenges	Stigma
			Lack of knowledge
			Communication
			Dealing with disability
		1.2.3. Resource challenges	Infrastructure
			Assistive devices
			Learning materials

Theme	Category	Subcategory	Code
Theme 2: **Mollo yo sa o orego o ka se go ntshe dipale.** **If you do not face the fire, you will not know its heat.**	2.1. High expectations on careworkers	2.1.1. "Old tasks" revisited	Care routine
			Assistive devices.
			Administration
			Clinic/hospital f/u
		2.1.2. "New task" added	Stimulation & teaching
	2.2. Perceived low value of our work	2.2.1. Malalignment of perceived needs and actual needs	Resources
			Teaching materials
			Skills training
		2.2.2. Poor recognition of pre-existing knowledge	
		2.2.3. Job (in)security	Remuneration
			Qualifications
Theme 3: **Go ba Komana Madula a bapile.** **Be prepared for anything.**	3.1. Noticeable changes	3.1.1. Careworker capacitation	Improved knowledge
			Practice changes
			Careworker well being
		3.1.2. Learning programme Community and end- users	Status of centre
			Benefits
	3.2. Careworker recommendations	3.2.1. Nothing about us without us	Planning platforms/stakeholder sittings.
			Procurements for the centres

4.3.1 Theme 1: Monatlala oa ema ema - hunger compels you to go out and hunt

The first theme captures the service offered by the careworkers in the inception of the stimulation care centres before any government department was involved. The proverb 'monatlala oa ema ema' translates 'hunger compels you to go out and hunt' means that the one who is directly faced by a problem will seek a solution to it. The proverb for this theme astutely verbalises the events that led to the inception of the SCCs on the face of challenges which still exist.

There was a need in each of the careworkers' communities to provide services for children with severe disabilities that were not being filled by government services. Thus, these women went out on a 'hunt 'for services and started the centres. The careworkers and care centres existed and provided much needed services with the assistance from the DSD with regards to provision of food for the children and payment of stipend for the careworkers, however without professional training or monetary support, long before the department of education acknowledged the issues faced by these children and their parents. This theme comprises two categories: 'unique role in our communities' and 'challenges.' Both explored the highs and lows of service provision in poor communities without any external support.

4.3.1.1 **Category 1.1: Unique role in our communities**

The right to education for all children is echoed in the constitution of South Africa, and for the children with severe to profound intellectual disabilities in this district, the careworkers stood up for them and made it a reality by establishing the SCCs in their communities. The main service offered was a care routine that included feeding, administration of medicine, and toilet training. The operation of these SCCs enabled the parents of these children to go to work and at least get time to attend to household duties and brief reprieve from continuously caring for their disabled children.

<u>**Participant 1: Offer relief to parents**</u>

> *Ge re bana le meeting, ba tla batswadi ba ba bonang di-improve mo baneng ba bona, ba raiser their hands. Ba re nna ngwanaka o changitse, o so, o so, ba*

bangwe ba raiser their hands ngwanaka o tseba gore o na le mengwaga e me kae, for how many years, o tlhaga ore mara a sa tsebe mengwaga ya gae, ba ba ngwe at least nou ba kgona go ngwala le lebitso la bona.

When we hold a meeting, the parents come and raise their hands to share the noticed improvements, one would say may child has changed like this and like that, he knows his age, it has been long that we struggled to get him to know how old he is, for many years, and other parent would say at least my child is now able to write her name.

The careworkers' unique contribution in the community is visible as they hold a job that is not popular and not financially rewarding, but fulfilling in different ways, including emotionally.

Participant 6: Unique role

mmereko ore o dirang mo ga se mang le mang a ko o dirang, and then ga se mang le mang a ka o kgotlellang ka gore ba teng batho ba fitlha mo ba bereke, 1 day, 2 days ba tlogele ka gore mmereko o o boima.

Not everyone can do this job, some people come here for a day or two and then leave as this is a hard job.

Participant 8: Unique role

See me for me, I am a disability worker and the work I do is extraordinary

Their work puts them in a better position to advocate for the rights of children with ID, to improve utilisation of the available services by the community. Their choice to do this work challenges the prevailing stigma and misconceptions about children with disabilities, and levels the ground for these children to enjoy social emancipation and participation.

Participant 4: Advocacy

Yoh ah, role yaka ke dilonyana tse ntshinyana but, ntho e botlhokwa is to make sure gore persons with disabilities di right tsa bona eh di tseiwa tsiya. Kgotsa ga di eh gatellwe, because re a tseba gore batho ba ba nang le disability ba na le di rights but the way re ba treatang ka teng. Le the way re ba bonang ka teng re felletsa re gatella di rights tsa bona, ka tsela e e itseng, so nna one of my roles ke go maker sure gore di rights tsa bona ga di gatellwe.

My role is quite a few things, but the most important aspect is to ensure that the rights of persons with disabilities are being acknowledged and not tramped on, we know that people with disabilities have rights, but the way they are being treated is contrary to their rights, so one of my prime roles is to advocate for their rights.

Participant 9: pushing community integration

re a tseba gore batho ba ba nang le disability eh ga ba fitlhelle education eh ka tsela e e tshwanetseng, so stimulation centre ke e nngwe ya di vehicle e e leng gore e kgona go thusa bona bana ba gore ba kgone go filthella thuto.

We know that the people with disabilities do not access to education, so the stimulation centre is one of the vehicles that helps these children to access education.

Participant 9: Fighting stigma

because if go na le ngwana a a nang le disability ka mo familing, and the community ka bo yona ena le go ba tsea ka tsela e nngwe, like eh ga ba ba bone byana ka batho go tshwana le batho ba ba normal, and ntho e, e dira gore ngwana ola or motho o a nang le disability a tinyatse and once ena a thoma a tinyatsa e dira gore le motswadi wa gage a skaba le tshepo mo ngwaneng ola, and le ena motswadi oo ga a sa ba le confident ya go tsamaya le ena ngwana oo, mo tseleng,

Because if you have a disabled child in the family, the community looks at him differently from everyone else, as though he is not a normal person, and that is what causes that child to look down on himself. Once the child has poor self-identity, then the parent loses hope in the child and then the parent does not want to be seen in the streets with that child.

Townsend and Wilcock (2002) pointed out that it is through occupation that individuals, families, and communities continuously grow, endeavour, and envisage a future. Life is characterised by occupations that encompass play, rest, self-care, and care for others, which is what people engage in, in pursuit of doing, being and becoming. This speaks volumes for the careworkers who employed their human praxis to change and impact their communities by advocating for the

rights of disabled children to belong and have access to education. The careworkers decided themselves to provide care to these children, facilitate their engagement in occupations, and create situations where both the careworkers and the disabled children can experience doing, being and becoming. Townsend and Wilcock (2004) further stressed that occupations are central to human life, and that individuals suffer injustice when they experience occupational alienation and marginalisation. Careworkers, without being affiliated with occupational injustice terms, identified a gap in their societies and strived to make a difference by opening the SCCs.

Occupational justice and social justice are intertwined ideas which have the common perception that a society requires a set of ethical, moral, and civic principles associated with fairness, empowerment, an equitable access to resources, and sharing of rights and responsibilities to be governed justly (Townsend and Wilcock 2002). Which is what prompted the women in the communities to advocate for the rights of the children who were deprived of their constitutional rights to education and right to co-exist with their fellow men having access to resources. This is the act that earned them the title careworkers.

As the SCCs are often the only facility accessible to the children with disabilities, the careworkers' assumption of the roles of initiators and program implementers ensures that those who require such services have access to them. It is specifically the careworkers who capacitate the families of children with disabilities and the community at large on matters of disability and rehabilitation (Hasan, Abdul and Aljunid 2020). These centres are often the only means to ameliorate the lack of service provision by professional stakeholders (Hasan et al. 2020; Ngubane and Chetty 2017). In South Africa, rehabilitation services, such as occupational therapy and educational psychology, are regarded as scarce skills and not readily available in rural areas but concentrated in urban areas and academic hospitals. Stimulation centres are often the only place where children with disabilities can access education, rehabilitation, and outreach services.

McKenzie et al. (2017), highlighted that parents also suffer lack of support, thus they struggle to find employment as caring for their children is a full-time job. Children with disabilities cannot be admitted into day care centres or nursery

schools because of their high support needs and due to the community stigmatisation (Geiger 2012). With children being enrolled at the SCCs, their parents get a break from the 24-hour care and have the chance to attend to other responsibilities (Raina 2005). This relief from constant care duties means that they are open to possibilities of other activities, including recreation (Paget et al. 2016). Through providing care for these children, the careworkers are thus an enabling tool for parents to manage their distress and obtain skills to better care for their children (Kuper et al. 2018).

The children who experienced social isolation and had nowhere to belong were now afforded a place to come to for stimulation and integrate into society. The careworkers identified actively decided to address the marginalisation in the community, counteracting it by availing themselves to provide care, which is at the core of their service. The majority of the careworkers who participated in this study project their role as unique and with impactful contribution to the society. They described it as not easy and not for the faint hearted, some careworkers also surprised that they stayed on for so long, that it grew on them as they initially thought they would not last in this field. The careworkers perceive themselves as pioneers of great invention that ensures social participation and community integration, that in turn makes them activists of children with disabilities in their communities.

4.3.1. 2 Category 1.2: Challenges

The second category describes the challenges as experienced by the careworkers before the introduction of the LSPID program to the centres. This category captures three subcategories: Careworker challenges; Community and serviced user challenges; and Resource challenges highlighting the hardships faced by the careworkers.

Subcategory 1.2.1 Careworker challenges

Careworker challenges described under this category are the careworkers' abilities and characteristics that require enhancement and, if wanting, can create barriers in provision of services strived for. Examples of these required characteristics include knowledge, skill, motivation, and wellbeing (Appendix G). For instance, before the training, limited knowledge directly impacted the skills

careworkers were able to execute. It is noteworthy that the careworkers were afraid of the unknown over their job of caring for disabled children, they thought it would be more difficult for them to cope with the disabled children and the work intensity.

Participant 3: Lack of knowledge

so dilo tse ka moka ne re sa ditsebe as macaregiver, ne re no tseba gore ngwana vroeg ge a tla skolong, o a tla, o tlo mo tlhokomela, wa no re a robale, wa mo fa dijo, a tsoga a namela a boela gae.

As caregivers we did not know any of the things we know now, we just knew that a child would come to the centre in the morning, for us to take care of him, put him down to sleep, give him food and return him home.

Participant 3: lack of skill.

*I mean as the child if you didn't eat ""***tswalla nko(pinch the child's nose)*** , **hlohla, hlohla,(pour the soft feeds into the child's mouth) ,metsa metsa(force the child to swallow),*** no questions asked, **ga o emella mola(when the child gets up)***, you crying for what, coz you sorted, you ate, you see, that's pretty much how we did things like, in between thighs **[careworker would place the child in between her thighs to block the child from moving]** *phew phew, finished,* **o jele (the child would have eaten).**

The lack of knowledge and skill and lack of progress and change in the children were perceived as impacting motivationand careworkers'negative emotions (such as fear) influencing their feelings towards the children in their SCCs.

Participant 10: Lack of motivation

O mongwe aka nna a nna le ngwana, a ska fele aba isa toilet aba trainer, o hwetse ga o tsena ko claseng go sa nkhe monate, ka lebaka la gore, o mongwe o tlo berekela for chelate, eseneg gore o rata mmereko,

Some caregivers will just sit with the children and not even bother to do potty training, as you enter her class, you are welcomed by an unpleasant odour, because she came to work for money not because she has passion for the job.

Despite these limitations, the careworkers did the best they could within their means, with caring hands being their main tools.

Careworkers' perceptions of disability were shaped by the very communities they came from: the careworkers, were exposed to the same cultural beliefs and

misconceptions about disability that the children in their care face every day. Only when becoming a careworker,and interacting with disabled children did their perceptions change. They, in turn, want to impart the information to the public and help change their attitudes. Paget (2016) shares the same sentiments, that careworkers and parents should be empowered and equipped with knowledge to stand against stigmatising attitudes of the community. However, there may be careworkers who become demotivated by the prognosis children receive, and slow pace of progress, to the extent that they see no reason to work towards goals that may yield changes in the children, as they do not see a possibility of improvement. Ludici et al. (2019) found that the perception of disability as permanent and incurable leaves parents and careworkers disheartened and despondent to carry out any intervention. This is like what the careworkers shared, that there are some who do not implement intervention strategies as trained by the teams, and that there are parents who do not carry out the home program as requested by the SCCs.

Gladstone et al. (2017) pointed out that the basics include positive attitudes, food security and shelter, will directly affect the quality of care offered to a child with disabilities and should not be overlooked. Kuper et al. (2018) share the same opinion, emphasising the importance of attending to primary issues such as community exclusion, poverty effects and psychological distress above training on skill-set and behavioural change.

The careworkers opened the SCCs without formal knowledge of medical implications of childhood disabilities and no skill of offering stimulation and education to children with severe and profound intellectual disabilities who often presented with severe physical disabilities together with their intellectual disabilities (Geiger,2012).

Participant 2: resources

> *Ya e be e le journey, e reg, but now is better, because ditoys di teng, ne re sena ditoys, ene ge re bolela ba no re aowa rekang distimulation tse di so, ro di reka ka eng, wa e bona?*

It was quite a journey to get here, indeed, but now it is better, we have tools of trade, when we asked for help, people would just say you should get this and that kind of stimulation tools, but with what money… you see.

The careworkers expressed that their lack of knowledge and skill as they had no formal training in childhood disabilities was getting in their way and affecting their jobs. This was especially true with the children whose medical conditions have a potential risk of complications.

There are passionate careworkers, who delighted in contributing to society and creating a positive impact in the lives of children with disabilities. However, there are also those who work just to make a living due to the low socio-economic status of the communities in which they live and high unemployment rates. Some careworkers indicated that teamwork could be negatively affected by colleagues who do not really love what they do as they may subsequently neglect the children, absent themselves from work more frequently, fail to handover duty with detail and always make excuses of not giving in their best. Even though the careworkers perceive themselves as heroines that were bold enough to take the stance for the disabled children in their communities, they also shared their frustrations over lack of knowledge and skill of handling disabilities

Subcategory 1.2.2 Community and end-user challenges

This subcategory covers the challenges that the careworkers encountered with the children, their parents, and the community as end users of the service provided by the SCCs. The stigma that these children are faced with is instigated by their parents and the community who out of their lack of knowledge.

<u>Participant 11: Stigma</u>

> *Parents are the same because we fight parents with the so-called normal children, they don't have that love or attention for their own children, so what about a child that is actually disabled and then your family cannot accept your child, the community, and then you find yourself in your own island*

Below are the quotes that indicate that children are hidden in their homes due to stigma.

<u>Participant 6: Stigma</u>

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Ga go tle ngwana o nang le 3 years, go tla ngwana o o nang le 15 years, ngwana oo, let's say o profound or it's an autism child wa bona, ga o motsebe ngwana o, o mo thoma from the scratch, ntse a mmelie ko gae.

They won't bring the child to us at around the age of 3 but will bring him when he is 15 years old, let's say he has profound learning disability or autism you see, the careworker is unfamiliar with the child and has to start from scratch, the parent has been keeping (more like hiding) this child at home.

In terms of dealing with disability, the parents lack insight into the disability conditions and thus do not comply with the home program, end up dealing with disability in a way that clashes with the progress sought for by the SCCs.

Participant 9: Dealing with disabilities

O thoma ko mathomong, ka nako enngwe o kereya e le gore ngwana o ke mo rutilego ya toilet, and then ga fitlha kwa gae ba mo apesa pampers, and then, eba problem gore ge a fitlha mo nna ke tshwanetse ke boele morago, <u>even though we keep on communicating with parents</u>, it's not easy for us because rena re tshwanetse re always re ne re simolla ko tshimologong always.

we always have to start from scratch, we potty train a child at the centre, but their families put on diapers and not continue with the program, even though we keep on communicating with the parents, it's not easy for us, then the child and the careworkers experience setbacks as they always have to start afresh.

The delayed intervention affects the careworkers who must deal with children that at the most are dependent in all spheres.

Participant 3: Dealing with disabilities

O kgwetsa ngwana a sa tsebe toilet training, a tikakela, atithotela, and then re maker sure gore mo sentheng re ba le diaparo tsa spare, diaparo tse ngwana ge a fitlhile a kakile mola gating, re a mo hlapisha ka mo bafong ka disepe le di dettol, le di everything, and then ra tlhatswa diaparo ra di anega, a apara tsela, then ge di oma re a mmusetsa, maybe sometimes before eba after school transport e tla , o kakile gape, re a mmusetsa bafong re a mo hlapisha, ke gore ga re ba fe transport ba le makaka, and le transport re kgopetse gore e ska re fa bona ka makaka, and then number 2, nna ka gore ke tsamaya le bona ka transport, ge ke hwetsa ngwana a kakile mo gae, transport e a ema, ngwana ba

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nchenchetsa ena before ba mpha ena, so that is why le nna ke sa tsee bana ka makaka back to home.

We receive children who are not toilet trained, they mess themselves, we make sure to have spare clothes here at the centre, sometimes a child would mess himself to a point that we must clean him and wash his clothes, the child can even mess himself again just before the transport could take them home, I am the caregiver that collect and drops off the children at their homes, so I make sure that we don't load a child from home with a soiled diaper and neither do we drop a child off whose diaper needs to be changed.

Included in the community and user challenges, are issues of e.g., stigma, lack of knowledge (about disability) and not understanding how to deal with children with disability (Appendix G).

Due to community based harsh stigma, the children with disabilities are commonly hidden from the community and only get enrolled in the stimulation centres at a later age, this is usually after external intervention from the social workers or concerned community members (Paget et al. 2016). The late enrolment could be due to the social stigma, lack of insight on the parent site and poor support. Societal myths and misconceptions also contribute to parents concealing their children with disabilities (Chiu et al. 2013; Paget et al. 2016). Nyante and Carpenter (2019) have comparable findings and assert that children with disabilities are viewed as a punishment or curse and this perception coupled with societal stigma is the reason the parents abuse or neglect their children out of depression (Paget et al. 2016).

In addition, some children come from child-headed families and thus steps of taking a disabled child to the necessary platforms or institutions of help are often delayed or never done. The children who get admitted into the SCCs at a later age pose a few challenges to the careworkers. They present with negative health implications such as malnutrition, severe deformities, and poorly managed comorbidities. The careworkers expressed that they then experience difficulties in handling disability as they must work hard to unlearn children of the negative behaviours they shall have adopted prior to admission into the centres, the negative behavioural attributes include strong language, inappropriate sexual behaviour, aggressive or bullying behaviour as well as being used to everything being done for them and getting their way. On the other hand, the parents do not

have insight into their children's conditions because they lacked support and education into their child's condition from the time they gave birth. Their lack of insight brings forth distortions in communication and collaboration as they do not adhere to the recommendations made by careworkers and the education outreach team.

As a result of societal stigma, mothers delay accessing educational facilities for their children with disabilities despite advocacy efforts for early intervention (Van der Linde 2014 and Mohd Nordin et al 2019). Consequently children with disabilities experience further negative impact on their health and wellbeing (Johnson Boxall 2022).

The careworkers have also pointed out some level of stigmatisation instigated by the families who do not see potential in their disabled children for independence in occupational participation and therefore opt for excessively helping the children or carrying out the activities for them. Regrettably, as independence is not encouraged at the child's home, the child gets used to everything being done for him during the school holidays and that erodes the hard-earned progress made at the centre. Hasan et al. (2020) suggested that the children spend more time at the centres than at their homes, thus the parents shift their responsibilities to the careworkers with the ideology that the careworkers are trained and in better capacity to care for the children.

In their expressions of the dealing with disabilities, the careworkers expressed that they experience their job as psychologically and physically strenuous, considering the complete dependence of the SPID children and their need for full time monitoring. They must do transfers with overweight older children who are completely dependent, feed them, clean them, and withstand their behavioural issues. Similar findings were reported by Nyante and Carpenter (2019) that activities like bathing the children, changing diapers, washing soiled linen, and feeding the children were described as most demanding and tiring by the careworkers. Raina et al. (2005) concurs with these findings and emphasises that managing the child 's health demands may affect the careworker both physically and psychologically.

The careworkers shared how they perceive their role through alluding on what makes their job special, by putting an emphasis on the job not being easy and not for everyone by highlighting the difficulties that they must withstand.

Subcategory1.2.3: Challenges with resources

The third subcategory of category two of theme one, is challenges with resources that include limited infrastructure, challenges with transport, as well as learning materials wanting with respect to the SCCs being situated in rural under-resourced setting.

Participant 5: Challenges with resources

> *Chelete e e fitlhang ke yona fela, e fitlhang ko gae, ene e labella di everything ko gae, o bona le seemo gore se jwang, wa e bona, so mo disentheng tsa go sokola tsa go tshwana le rena, mona ge ba le 50, 30 ya bana ga ba patele, 20 e a patella, so you will never manage ka bana ba ififty mo eleng gore chelete go tsena ya bana ba i20, wa e bona.*

> **Some households run solely on the child's disability grant, you can even see through their living conditions, you see. Thus, in centres like ours that are already struggling, here when I have a total of 50 children, 30 do not pay (centre care fees), only 20 of them pay, so you will never manage 50 children with money from 20 children, you see.**

The careworkers reported to have been operating in overcrowded places of poor infrastructure. Thus, some SCCs were operating from garages, shacks, and old abandoned buildings.

Participant 2: Infrastructure

> *Ba over-crowded thata mo skolong, ene re na le two room fela le marobalo a rena, thata ke a bana ba bannyane, ba bagolo ba tshwanetse nka bo setse rena le marobalo a mangwe".*
> **The children are over-crowded, and we have only two rooms. Our sleeping dormitories are meant for small children, rightfully we should have sleeper rooms that are appropriate for our much older kids as well.**

The SCCs that are decent were built by missionaries and private sector donations. More than half of the participants expressed frustrations over infrastructure, lack of space to operate from and overcrowded sleeping dormitories for the boarding facilities. Only four of the twelve centres that took part

in the study were of decent quality infrastructure and that is because they were built by missionary projects. Other centres were hopeful of obtaining sponsors to help them build, even if it may be an extra one more room or be provisioned with corrugate mobile classroom.

Most of the households that the children come from depend on the child disability grant as the only income that takes care of all the financial needs of the family. The centres experience challenges with care fees and transport payments as the parents cannot afford to pay. At times, some children are withheld from attending the stimulation centre due to the financial strain that the centre fees and transport cost place on the non-affording parents.

The children often do not have the correct assisitice devices for positioning and seating which makes it difficult to care for them. Gains achieved in positioning are often not carried through at home as children must leave their sitting and mobility equipment at the SCCs as they cannot be boarded with them on their transport facilities.

Participant 12: Assistive devices

> **We caregivers actually tend to become assistive devices, instead of having assistive devices that help you help the child.**
> *I don't have the right chairs, I don't have the right wheelchairs, then I have to become that wheelchair for that particular child, if we have to feed that particular child, then I have to become the chair, hold the child in that particular position while my partner feeds the child, because that's the only right way to do it, to avoid choking, to avoid the child vomiting…*

This unfortunately leads to children spending more time on the floors at home or using compromised sitting equipment like old, dilapidated wheelchairs, or donated oversized wheelchairs, some children are even spending more time on mats and mattresses.

The children in the SCCs do not have access to free or subsidised transport like the children in mainstream and special schools. The parents must pay for centre fees and transport, which lead to some children denied the opportunity to be enrolled in the SCCs as they cannot afford the centre and transport fees.

Participant 10: Transport

> *Le ditransport ka gore transport ya rena go tshwana le go na byanong ke ya kgale, e re fa problem ya gore ga re sa e kgona, re ntsha chelete e ntsi for petrol, le bo service,*

> **we have transport challenges, our vehicle is old, we overspend on fuel and repairs/service.**

Another challenge that is common is poor transportation facilities, some SCCs have better sponsored or donated transport systems like a bus or a taxi that can load children and their wheelchairs safely. Some SCCs load children at the back of vans or trucks. The children often must leave their mobility aids at the centres to ease their travelling between the SCCs and their homes.

The SCCs lacked basic resources such as stationery and used primitive objects such as bottle caps, stones and sticks for counting. There was no formal program, and the children would recite rhymes, eat, and sleep without proper structured stimulation, in addition there were no teaching resources that stimulate cognitive and scholastic aspects.

Participant 3: Teaching materials

> *rena mo sentheng, ne re se na, nka re eng, di equipment tse di enough, for go teacher bana.*

> **We did not have enough teaching materials or equipment here at the centre.**

> *ne re ba fa di homework tsa gore batle le dipaniki tsa go bala, ba dire dikotana, dipampiri, dicardbokisi, and then ge ke ba ruta ka mo classing ne ke ba ruta go count abo 1,*

> *I would give them homework to collect bottle caps, sticks, paper and cardboard to be used as counters and stationery in the classroom.*

In Pakistan, parents of children with disabilities revealed that the main concern is the lack of government provisioned infrastructure, lack of disability friendly transportation and untrained personnel that lack the expertise to work with disabled children (Qayyum, Lasi and Rafique 2013). This is part of the reason that the learning program for LSPID was stated in South Africa, as a result of the gaps identified in the education system concerning children with SPID.

Hence Zuurmond (2019) emphasised that empowerment for careworkers cannot be accomplished outside of addressing the main challenges of stigma, social exclusion, poverty, illiteracy, and lack of resources. The centres were opened without having everything that they needed in place. The careworkers reported

challenges with resources such as infrastructure, transport, learning materials and assistive devices. Their facilities are overcrowded, they struggle with vehicle maintenance and transportation that accommodate the children that use mobility aids. Moreover, the children do not have correct sitting mobility assistive devices and they had to use primitive collectable objects to use as learning materials, which all affects the type of care and stimulation that can be offered at the SCCs.

4.3.2 Theme 2: Mollo yo o sa o orego, o ka se go ntshe dipale - If you do not face the fire, you will never know its heat

The second theme covers the expectations and experiences of the learning program forLSPID and the program limitations. The Pedi proverb, mollo yo o sa orego o ka se go ntshe dipale, translates to: 'the fire that you do not warm yourself with, cannot cause you fire-burn marks.' This proverb means that the situation is better understood by the one who "is in it" than an onlooker. I chose this fire theme because the program came through as what the careworkers needed, to provide light and warmth and be used to prepare food. However, there are always two sides to an aspect. The fire may be too much, too low, or just right. In this section I opened the platform for the careworkers and explored how it is for them to sit around this fire, and how they experience it.

The two broad categories that emerged are (2.1.) high expectations of the careworkers and the (2.2) perceived low value the learning program appeared to place on the services they offer.

4.3.2.1 Category 2. 1: High expectations of careworkers

In this category, a comprehensive overview of what a typical day looks like for the careworker is laid out, with what the careworkers have always been doing even before the introduction of the learning program to LSPID, and how they feel with the expanded line of duty from the program. The category is spread out into two subcategories that unpacks the duties of the careworkers in terms of what they have always been doing (old tasks revisited (2.2.1)) and the newly introduced job descriptions (newly added tasks (2.2.2.) that is suggestive of elevated expectations on the careworkers. Below are the quotes that express how the careworkers feel about the added-on duties, their actual and perceived roles as well as their feelings about their pre-existing knowledge.

To successfully run their service, there are administrative duties, reporting to the parents and government departments. The old tasks also include care routine, transport chaperoning, administration and taking the children to the hospital or clinic for their medical review and collection of medication. These are the duties that the careworkers carried out prior to the introduction of the learning program for LSPID and continue to execute.

The careworkers remarked that they do not only provide care to these children, but they also get up early to collect them from their houses and deliver them back with the transport driver, to chaperone in the transport and be on guard against any incidents such as epileptic seizures, bullying and fighting amongst the children.

Participant 7: Transporting

dicaregiver tsa rena pilapila ba thoma ka go, le bona ba thoma ka go collecta bana. Mo di combing, ba thuse driver, driver ntse a driver ena o tlhokomela bana ka mo morago ka mo taxing, if anything motlhomongwe o mongwe o ba le diseizure then a kgone go mo thusa.

Our caregivers actually start by collecting the children to help the driver, so that they can chaperone the children should anything like seizure attack occur, then the caregiver can be there to handle it.

The careworkers also take the children to the clinic and to the hospital for consultations and for collecting medical repeats. When at the centre, their care routine includes basic hygiene activities such as bathing the children and assisting with their oral care, feeding, administering medication, and changing nappies.

Participant 11: Medical review

Mmereko wa ka is to make sure bana they are ok, bana ba na le dijo, bana they get medication, bana they get the right treatment, and di treatment tsa bona re a di latela, re a lata medication, re ya ko di review tsa bona,

My job is to make sure that the children are ok, they have food, and that they take their medication, the rightful medical treatment. We fetch the medicine from the hospital/clinic, and we attend their review appointments.

They do physical exercises to facilitate mobility, and train the children towards independence in toilet use, self-feeding and constructive play.

Participant 5: Care routine

> Gopola I am a caregiver neh, lona, mmereko wa ka ke go tlhokomela ngwana empa ke be le dilo tse dingwe ke mo dirisang tsona, *Tshwanetse ba tsebe gore ba tlhokomela bana ka go ba rutisha, ba dire di training tsa go tshwana le bo toilet training, le yona feeding training le tsona diphysio.*

> **Bear in mind, I am a caregiver neh(right), my job is to provide care routines for a child, and then there are more activities that I must do with this child.**

> **They must know that we take care of the children, we teach them, train them for toilet use and self-feeding, as well as give them physio(exercises).**

On top of the care routines, careworkers also have administrative duties such as marking the daily register, compiling the report cards for children per term.

Participant 12: Administration

> *We compile the files and make sure that everything that they need is in the files, then we have time to fix our own paperwork so that if the therapists and parents come then they find that we have our documents in place.*

All these duties are still expected from careworkers and as a result they work long hours and have very busy days (McKenzie et al. 2017; Geiger 2019).

Kuluski et al. (2021) elaborated that careworkers experience high rates of fatigue, due to the demands of servicing their care dependent clients and facing the economic implications of being a careworker that include loss of time and other and possible loss of other opportunities.

Subcategory 2.1.2 New tasks added

Newly introduced to the role of the careworkers is teaching and running the learning program for LSPID learning program as mandated by the DBE. As these children have high needs, the careworkers must incorporate the intervention strategies into their already busy days as recommended by the Policy for the Provision of Quality Education and Support for the Children with Severe to Profound Intellectual Disability learning program on which they received training from the education outreach team.

Participant 1: Teaching

Ge re ba ruta, pila pila ka mokgwa o ba re rutileng, kwa sekolong, ngwana o tshwanetse a concentrate mo go wena, although ga a concentrate, mara o tshwanetse o mo cenge, o kile wa bona, monagano wa gae, o mo rapele, ka dilo tse ntshi vele o mo sale morago. O mo sale morago, o ka se nore ka gore ga a utlwisisi o mo lathlelle, tshwanetse be ntho e a e itse.

When we teach them, the way that we were **trained(at** school-LSPID**), is that the child must concentrate on the careworker, even though he doesn't have concentrate per se, but the caregiver must get his attention, you see, the caregiver should do all it takes to get the child focused on the task at hand, the careworker must persist and be patient with the child, and not just give up on the child saying the child does not understand, the child must attain that concept.**

Mckenzie et al (2017) reported that more focus was previously invested on the care routine than delivering education, particularly where the SCCs are understaffed. It is illustrated that children receive warmth, love and care from the SCCs, without formal education. The learning program for LSPID is thus introduced to the SCCs to ensure provision of formal education through implementation of a learning program that is a special formulated curriculum for children with SPID, and the careworkers are trained to teach or carry out this learning program through integration into the daily routines.

Kuluski et al.(2021) caution that there is an increased trend of expecting careworkers to offer their services free of charge. A practice that has over the previous decades (2002) been described as blatant inequality allowing some to participate in activities that are worthwhile, while others are expected to carry out undesirable and menial tasks with no financial reward to meet the demands of their community challenges (Townsend and Wilcock,2002). The careworkers are in this regard, dismayed that the new added tasks to their job descriptions in the learning program for LSPID. These additional duties do not elevate their working profile by expecting them to carry out these added tasks without added remuneration.

Participant 5: New tasks added

le tlile, le tlile ka mmereko, le re fa mmereko, actually le adder mmereko o ne re o dira, le re nou re o dira so.

You came, you came with duties for us, you are giving us duties, actually you are adding on top of what we were doing, and you say to us now how you are to carry out your duties.

Kaluski et al. (2021) postulated that policies concerned with improving the quality of care must critically heed the careworkers , especially their unmet expectations to ascertain that their needs are not disregarded over those of their clients.

The careworkers thus experience the expectations of the learning program of LSPID as extra work, and it appears to them that their old tasks (mainly care routine) are not taken into consideration, when they are expected to carry out the new tasks (teaching and stimulation) to implement the learning program that has intensive structured teaching and methods of evaluating for progress.

Participant 12: Teaching, stimulation

> *now they are coming in with things that I'm supposed to do but they don't pay me to do it, and if you actually look at it, it's like ohk, ohk wait, they giving me a job to do and me doing that particular job they need results at the end of the day,* **but now they are not paying me to do that,** *because DSD take for example I'm just making an example by DSD, DSD pays me to change nappies and give food, like that's all, now LSPID comes along*, **LSPID wants me to complete files, teach children about Covid 19, expects me to be drawing the whole map from the clouds and everything like that and then (shows empty hands), how fair is that?**

 The careworkers are also disheartened that their contributions are not valued as the DBE has given them mandates without reimbursing them. They highlighted that DSD pays them for the old tasks that they have been doing and continue to do.

4.3.2.2 Category 2.2 Perceived low value of careworkers

This category explores the careworkers' feelings about the low value placed on the services they offer and their perception of being invisible and not important to the governmental departments. These feelings are expressed in the subcategories: malalignment of perceived need and actual needs, poor recognition, and job insecurity.

Subcategory 2.2.1. Malalignment of perceived needs and actual needs

Careworkers feel that the services they offer are overlooked, that there is no recognition of the work they do on the ground. Moreover, they feel that what the DBE chooses to assist with in terms of resources are arbitrarily chosen without their input and thus is not what they need.

Participant 12: Resources (assistive devices)

> *I am still stuck with that CP child who can't stand on their own, but the toys are gone,* **an there are those toys they are worth so much money** *,* **that money can be invested in buying equipment** *that a child can actually use, I mean eating utensils, wheelchairs, buggies, sand pits I mean there are so many things that they can invest in that will benefit the children, in a positive way, toys do benefit but like I'm saying if its plastic, it's not gonna work, because we dealing with different children and a normal child would understand that this thing ke nto ya go bapala(it's for playing) so I need to play with it and not faka (shove) it into my mouth, but now with this one everything I must squish, I must crush.*

Participant 12: Resources(infrastructure)

> **Those structures firstly need to change, they need to be built. They need to be renovated and changed, to fit those children, uhmm ok fine you bring us a TV, but I'm in a shack right now, what if they just open this thing, take the TV what's the point?**

There is also considerable fear of losing their jobs, as they perceive their contribution as undervalued. They assume that they will be later replaced with professionals who will be respected and valued in this field on the one hand. On the other hand, they feel that they do not get time that is sufficient for skill acquisition due to the long turnaround time of the education outreach team visits.

Participant 5: Skills training

> ***so ge o tla after two months o tlo mpontsha something, ke tlo tswela pele, ke tswele pele, mara gona le mo ke tlo ipotsisang gore mara am I still doing the right thing, wa e bona.***
>
> *So, if you come 2 months after having trained me on something, I will carry on with it, but at some point, I will pause and wonder am I still doing the right thing, you see?*

Participant 2: Skills training

> ***Ahh, ba re visita ha i-one. At least ga e kaba after two weeks, maybe twice per month wa e bona, re re re sale busy, ahhh ba tsamaile, bo boa next month wa e bona, at least ga le tlile ga i-two, le re bontshe mo le mola, mo re sa utlwisising akere re kgona go botsisa gore mo, re ira byang wa e bona***.
>
> *Ahh, they visit us only once. At least if they could visit us after (every)two weeks, (or) maybe twice per month you see. In the course of implementation, ahh then they are gone, they will only come the following month, you see, at least if they could visit twice or so, to show us here and there, then where we do not understand we can ask for clarity and say here what do we do, you see.*

A comparable situation is reported in the Western Cape province where SCCs were set up and opened by parents of children with disabilities as there were no available facilities for them to take their children to.

Since the careworkers were mostly parents, it was evident that they were eager to be educated on their children's conditions and showed great desire to be capacitated in knowledge and handling skills in this respect. Unfortunately, the necessary quality of environments required to meet the needs of these children in a form of adequate staffing, class, playground, and equipment was often not available (Geiger 2012).

Du Toit et al. (2021), pointed out that care facilities in South Africa are partially subsidised by the government and that the users encounter high financial constraints given the prevalent poverty and inequality in the country. Chocarro et al. (2021) emphasised the importance of having a dedicated training site, with the correct equipment and offering training on equipment that are of high level of technology. The careworkers highlighted that there is a discrepancy in what they require help with and what the DBE offers.

For instance a priority for the centre could be infrastructure and assistive devices, instead they receive therapy apparatus and teaching materials which they do not have adequate storage for as they are already operating in cramped spaces. However, infrastructure and assistive devices are the responsibilities of public works and health department respectively. That means even if the DBE has funds available, it cannot assist the NGOs with their priority needs, a concept which does not make sense to the careworkers as government is one entity to them. Thus, thorough planning must be done, to indicate the clear financial responsibilities of each department to ensure continuity and sustainability of the program (Geiger 2012). It is clear that for the successful implementation of this of the learning program for LSPID, the different departments of government need to take hands and work together. The collaboration is according to McKenzie et al. (2017), important to clarify the role of different sectors and ensure uninterrupted service provision.

Given the workload of the careworkers, the outreach education teams in the Western Cape planned to run the program with the weighting of careworker to child ratio of 1-8 (McKenzie et al.2017). In Mpumalanga even though this weighting is desired, it is often far exceeded to 1-12 careworker to child which affects the quality of care and stimulation being provided.

Geiger (2012) reported that the intensive onsite hands-on training was successful and appropriate in poorly resourced setups with motivated hardworking staff. Geiger (2012) argued that the developed countries model of low child-to-professional intervention is far-fetched to being a reality in the South African context, however, mentoring on a long-term basis with as little as one visit a month to the centre, and offering valuable support and training to the careworkers, will empower, and capacitate them to offer a comprehensive service to the children.

Willis et al. (2018), emphasised that ample time is necessary to enhance the results of intervention for children with disabilities as time allows for repetition, shared learning and makes people feel safe within the setting. The careworkers made expressions that concur with the remarks of Willis et al. (2018), that they require time through frequent visits by the education outreach teams to recap and repeat the training in effort to be sure of what they learned and alleviate anxieties of implementing incorrectly. The high turnover of visits to the SCCs is thus detrimental to the program as it affects the confidence of the careworkers. The careworkers also raised that the turnaround times of the visit by the teams is insufficient for them to attain a skill, as they encounter uncertainties and anxieties of whether they are practising what they were trained on correctly, and unfortunately the teams are not available for them to ask for clarity or to ascertain that they are implementing correctly.

Veitch et al. (2012) reported the discrepancy between the intent of policy and execution is illustrated by the impact of lack of human resources on service provision. The SCCs in Mpumalanga would like to be exposed to the education outreach team more frequently, however their high turnaround time is due to lack of staff and the team must serve a wide demographic spread district. Analogous situation was reported by Veitch et al. (2012) of circumstances where clients could not receive rehabilitation services, not because they are not eligible, but consequently, owing to policy-inclined service practices, coupled with limited human resources, those clients were simply deprived of services. "Sometimes the policies are written with metro populations in mind, and they are not necessarily applicable to how we can deliver services in this region but in other ways I think we work really well to accommodate the policies and still provide services in a way that is doable" (Veitch et al. 2012, pg 6).

Similar challenges to South Africa were reported by Veitch et al. (2012) in Australia that community outreach services to rural and remote areas are reliant on the availability and skill of therapists.

The fragmented policy outputs, and lack of intersectoral collaborations impede on the success of program implementation, which is experienced as negative by the careworkers and implies that they are not valued enough to offer well-coordinated service.

Category 2.2.2 Poor recognition

This category discusses the careworkers feelings of being disregarded and not noticed. The careworkers also feel that most of their learning occurred on the job through experience and years of working with the children.

Participant 5: Pre-existing knowledge

> *mmereko e gara ya sekolong bare ro rutiwa, but le fitlhile for three years le kreile centre e entse ele teng e runner, ene ge le fitlha la kereya gore re dira tsona"*
>
> **years we may not be educated, but you (LSPID program) have only been here for three years, and you found this centre existing, running and you found us doing the right things.**

In this light tgt careworkers feel their pre-existing knowledge and skill is not being taken into consideration.

Participant 11: Poor recognition

> *We actually don't exist; we don't belong anywhere*

Participant 12: Recognition

> *I am a caregiver, and I work with this particular child but then if somebody who went to school for seven years is gonna ask me a question if I'm gonna answer it, then that answer comes in here (points at her left ear) and comes out here(points at her right ear) then what's the point.*
>
> *I mean as it is right now, no one at the high table just gonna call it the high the table, no one at the high table can be able to do what I do, on a daily basis, yet they've got so much recognition, yet they've got so much allowances.*

Furthermore, the careworkers feel that stakeholders who are more educated than them do not heed to their inputs.

Participant 12: Poor recognition

Being a caregiver with no platform or with no right to say anything anywhere is actually discouraging.

Participant 11: Pre-existing knowledge

*I have been in this field for a long time, and I have so many experience, eh of dealing of ka di situation tsa bana ba(**with the situations of these children**) and to get somebody else to tell you about something that you know , sometimes it's a bit boring because you actually know that and some of the things you learn them on your own, to make it easier for your situation to be able to cope, with the children or with a child.*

Galvaan and Rauch Van der Merwe (2021), as well as Gladstone, et al. (2017) sensitise service providers that their interactions over knowledge-sharing and information imparting should incorporate service users in decision making platforms, yet the careworkers in their expressions bemoaned: '*We actually do not exist, we don't belong anywhere (Participant 11).*' This is indicative of high perceived exclusion. Similar findings are reported by Conradie et al. (2017) where more than half of the participants expressed occupational stress due to lack of participation in decision making in relation to the learning program for LSPID. As a result careworkers actually feel dehumanised as described by Ndlovu-Gatsheni (2018) as their knowledge has been devalued by the service provider.

Careworkers feel left out in high order/ executive planning and decision making processes/ gatherings over matters that pertain to the SCC. According to WHO(2011), it is important to consider both the service provider and end-user's perspectives, while Paget (2013) emphasized that the sustainability of a program lies on active participation of the end users. Yet, it would appear that in the LPSID program in Mpumalanga, there is no collaboration between these two parties. Thus sustainability is compromised.

Townsend and Wilcock (2004) discussed occupational injustice as a situation where occupations are classed, reimbursed, and given the value that improves life for others and yet in the same breath having others misused, abused and under harsh exploitation as well as being disregarded. In their expressions, the careworkers are experience the learning program for LSPID as prejudicial, which gives the education outreach team including occupational therapist the stance to

pause and assess for occupational health and justice in this case and sought for client advocacy and practice rectification.

Bester (2020) alluded that, the carers of children with disabilities would like to be active participants in the planning of interventions. Bester (2020) also recommends that this collaboration should consider the information needs, learning styles of the parents and careworkers aligned with adult teaching principles which necessitates a careworker specific education and training program that is co-created by both the carers.

Willis et al. (2018), reiterate that understanding the collaborations between how a program yield results and under which settings is important to customise and carry out successful interventions. Contrary to what literature recommends, it is overtly clear that careworkers in SA, are not afforded the platform to make contributions as expressed by one of the participants*: 'Being a caregiver with no platform or with no right to say anything anywhere is actually discouraging* (Participant 12).'

The careworkers voiced that they feel like they do not belong anywhere, they are not seen as team players or stakeholders hence they are left out on matters that are central to their job. They expressed that even if they make inputs, they are ignored as the other stakeholders are better qualified than them (people at the high table, the government, somebody who went to school for seven years). The careworkers expressed frustrations over their work not being valued, being taken for granted and hence under paid. These utterances highlighted the careworkers' negative experience of the program.

Subcategory 2.2.3 Job insecurity

This subcategory speaks to the careworkers perceived threat to their job owing to their level of education and considering how they are being paid. The careworkers are of the notion that they may be replaced by professionals as they are not valued.

Participant 12: Qualifications

But because now, government has to take over or because now things have to be done in a professional manner, you being passionate is not gonna save you, they gonna want somebody who is actually going to provide papers that I went to school and did this, and I'm qualified to do this, **so most of us caregivers who are unqualified actually are at risk.**

Participant 12: Qualifications

> *The same parents that took the Department of Education to court will be the ones that get us out of our job, saying they want their children to be taught by professionals. O tlo re o mo ruta jwang 1+1 ngwanaka wena o sa e tsebe?*
>
> **How can you teach my child the basics if you yourself are not learned?**

These ideas come from the type of training they get that are not accredited.

Participant 5: Accredited training

> *Le ska mpha pampiri e e kgabisitsweng yet certificate sa teng se sa bolele selo*
>
> ***Do not give us papers that are decorated as certificates, yet they are not accredited***

Participant 12: Accredited training

> ***I can have fifty certificates in my file, but if they are not accredited, what's the use***

And why they are not paid for the new added on responsibilities

Participant 4: Remuneration

> *Chelete e ke e kereyang mo, sometimes ga e mphe energy ya go bereka"*
>
> **The money we get paid here does not motivate me to work.**

Participant 6: Remuneration

> *ka gore vele stipend sa rena ke se nyane le ge re bereka very hard, ga re be…, re ba happy re a bereka akere, mara ga re be happy enough, rena re complainer ka stipend gore se nnyane mara le ge re dira mmereko oo boima so and then ntho eo, chelate ke e nnyane.*
>
> ***Indeed, the money we earn is very little, yet we work so hard, we are happy we are working, but we are not satisfied with our earnings and that makes us complain as we work hard.***

The SCC are recently uprading from offering only care routine to addition of formal funded education as per the LSPID policy. Hassan et al (2020) and Du Toit et al (2021),emphasised that careworkers are usually inadequately trained and underpaid, hence their serices are often limited to provision of shelter and meals. The careworkers in this study do not have formal training that is aligned with their job, at most their highest level of education is grade 12, hence they have expressed a need for more accredited training. Similarly, they also receive minimal remuneration in the form of stipends from the DSD.

The careworkers stressed that they require accredited training as an indication that their work is being valued and taken 'seriously.' In a study conducted in western Cape Province of South, educational qualifications of more than half careworkers were grade 10 or just above, which is similar to what was found in this study. The careworkers have at most completed the home-based care course, basic training in first aid, seating and positioning as well as feeding, communication, stimulation, and play. Even though the careworkers receive ongoing training this is unfortunately not designed and accredited to improve and qualify their skills (McKenzie et al. 2017).

Some careworkers fear that the call for providing formal accessible funded education in the SCCs may lead to their exit from the institution. The careworkers have the insecurity that the DBE may require professions to work with the intellectually disabled children and this may leave them without jobs. This could be emanating from poor communication of the vision and objectives of the programs and not bringing the careworkers on board; hence they develop insecurities.

Salojee (2007) indicated that it was necessary to get qualified personnel to meet the basic needs of children with disabilities. Thus, capacitating the careworkers

could alleviate the burdens on the systems by allowing the careworkers to connect the families of disabled children with the public resources. Hence the learning program for LSPID invests time and resources in training and capacitating the careworkers to upgrade the services rendered in the SCCs. Contrary to this, the careworkers feel that their level of education makes the professionals underrate and undermine their contribution, considering that they only receive in-service trainings that are not accredited with the national qualification framework and do not receive any form of reimbursement from the DBE.

Careworkers of children with SPID are prone to burnout given the intensity of the job (Van der Linde,2014; Conradie, Erwee and Visser et al 2017). Consequently, there is a high turnover of staff due which is detrimental to the institutions and a setback on training programs in terms of cost as the change in staff necessitates continued training of inexperienced staff. Raina et al. (2005) concurs and further expands that the careworker job is not popular and seldom desirable, thus it is highly unlikely that careworking may be persuaded as a future job prospect but may be linked with occupational choice and occupational engagement, in other words, careworkers choose this job for the gratification of empathy and contributing to the wellbeing of the disabled children. In the present study, this is not always the case, since young people take on the careworker's job as they do not have funds to further their studies, or as there are no job opportunities, thus people take what is available for the sake of survival. Hence, they will leave this job for any better opportunity they get.

Raina et al. (2005) emphasise that the caregiver's stress is perpetuated by a few factors and not just the taking care of the children. Income was found to have more effect on the careworker than formal education. More than half (58.1%) of the staff caring for individuals with ID reported underpayment as an occupational stress factor (Conradie et al.2017). Townsend and Wilcock (2002) pounded that remuneration, recognition of effort, approval and celebration of achievements as well as creating opportunities for meaningful participation are all enablers of justice. In this study, the careworkers reiterated that they are underpaid and often demotivated to execute their duties, furthermore, they will not hesitate to leave their jobs for greener pastures. This means the learning program for LSPID will constantly train new, inexperienced staff.

The careworkers feel that the training offered by the learning program for LSPID is not good enough as it is not accredited to elevate or offer them any form of qualification. Even though they receive certificates of attendance, to them these certificates do not carry water or mean anything as there are no levels of formally recognized qualifications i.e., National Qualifications Framework (NQF) level, beginner, intermediary or advanced qualification) that come with these training. The careworkers expressed deep concern of having nothing to show that they have been trained to care for children with disabilities and to deliver a learning program. The careworkers wish for a formal accredited qualification system that can be recognized through-out the country and serve to open doors for them as careworkers interprovincially. With such accredited training, the careworkers hope that their work will be secured as they have a fear of losing their jobs to qualified professionals. Concisely, the careworkers feel that the learning program for LSPID is wasting their time with training that is not accredited and does not improve their personal academic profile. They view it as demeaning to receive certificates of attendance that do not serve as a NQF qualification.

All the careworkers, even with humility and some with passive aggression, expressed deep job dissatisfaction over the little stipend they receive from the DSD, and no remuneration received from the DBE for implementing all the activities of the learning program for LSPID, that include teaching the children and carrying out the programmes of the therapists as well as doing all the admin that is involved.

The careworkers expressed that it seems as if all the focus is on the children and making provision of learning materials for them, whilst on the other hand, neglecting the very human resources that must ensure the successful implementation of the program. On a more concerning note, the careworkers voiced that their reluctance to carry out the programs and use the learning materials as trained, is due to the lack of positive reinforcement that should come with remuneration but rather, feelings of despondency and not being valued.

4.3.3 Theme 3: Go ba komana madula a bapile- To be prepared for anything

Preparedness puts one in a position that they can take accountability for their actions, it allows one to make educated predictions and expectations, to calculate outcomes of their actions and most importantly to evaluate themselves so that they can better themselves and grow in their experiences. The proverb 'Go ba komana madula a bapile,' which translates 'to be prepared for anything,' and 'komana' in meaning a "trainee" is suggestive of being prepared as result of having been trained, coached, and capacitated resonates well with this theme as the careworkers previously used to be taken by surprise to be caught off guard and did not see it coming. This could be understood as they were working in a field that they did not necessarily have a background in, no exposure to and yet this is a delicate field with a potential of risks.

4.3.3.1 Category 3.1: Noticeable changes

This category covers careworker capacitation and benefits to the community and service users. Most careworkers conveyed feelings of appreciation for the learning program for LSPID, it was to them like sudden showers of rain during a dry despondent season. The careworkers emphasised that they had no formal program, had no activities to fill the day at the centre other than the care routine. In other words, there was no formal teaching and learning taking place in the centres. The careworkers indicate that they would teach any concept they deemed necessary, unguided on what content is suitable for the children with severe and profound disabilities and how they should be evaluated for progress.

Subcategory 3.1.1Careworker capacitation

This category illustrates how the careworkers enjoy their improved wellbeing and their work after being capacitated with knowledge.

Participant 10: Improved knowledge

> gona le bana ba ne re sa itse gore ge a tshwanetse a nne fatshe, a sa batle, tshwanetse o dire byang, so after that workshop e mputse matlho, gore tshwanetse ke dealer byang ka tsona dilo tse byao,

There are children whom we did not know how to handle if we wanted them to sit and they refused or were roaming, but after the workshop, it has opened my eyes, now I know how to deal with such instances.

They immediately identify some of the incorrect practices that they were executing due to lack of knowledge and instigate change with eagerness. This subcategory indicated the willingness to change practice.

Participant 12: Improved knowledge & practice change

but now after the knowledge, after exposure, I go like yah it brought us up, but yay things are different, these are different children we need to be careful on the things that we do.

Participant 8: Practice change

tse dingwe tse ne re di dira wrong, re a kgona gore re di lokise re di dire pila go ya ka tsela eo ba re thusang ka yona.

We can now see that some of the things we were doing were wrong, we can now correct our practices according to the knowledge they have given us.

The careworker wellbeing increased upon exposure to and training on the learning program for LSPID. The careworkers expressed that their view and perception of working with disabled children has completely changed, they described feelings of renewed strength and excitement of new possibilities that may arise as they are capacitated, fuelled, and better positioned for impact. Similar findings were reported by participants in the carer training conducted by Chocarro et al. (2021), that they emerged skilled, knowledgeable and capacitated to promote child development.

Participant 8: Practice change

tse dingwe tse ne re di dira wrong, re a kgona gore re di lokise re di dire pila go ya ka tsela eo ba re thusang ka yona.

We can now see that some of the things we were doing were wrong, we can now correct our practices according to the knowledge they have given us.

> *gona le lefasenyana le le mphsya le ba re kentshitseng mo go lona. re kgona go bona dilo ka tsela e nngwe…*
> *It's like a whole new world that they have been exposed to, now we can see life in a different light.*

The careworkers acknowledged that some of their practices were incorrect, and that was not out of negligence or deliberate but mainly because they lacked knowledge and did not know of the potential harm they could pose on the children. The careworkers commended the training for bringing them the light and steering them towards corrected practices.

Adams et al. (2011), obtained positive results of change in behaviour and practices upon conducting an education program to the primary carers addressing nutrition, adapting food consistency to be consumed orally with ease, using correct utensils, and positioning devices to align the child for being fed or self-feed in a sensitive yet highly responsive manner. These results resonate with careworker's expressions of changed practices.

Training needs are not limited to equipping careworkers with medical background knowledge, but also protect them from mental breakdowns arising from seeking unrealistic help the children with SPID. With the improved knowledge comes improved self-perception and work wellbeing thus after the training, the careworkers are empowered to do more than what they did before and became bold to undertake complex activities of which they had previously required approval of the professionals (Chocarro et al. 2021).

There is remarkable difference in careworkers work-wellbeing that is recorded under the challenges of doing this work before and after exposure to and training on the program for LSPID. The quotes above are suggestive of a positive impact and influence that the learning program for LSPID had on the wellbeing of the careworkers. The learning program is also experienced as effective as the

children are reported to enjoy the activities that they are engaged in through this new program, and careworkers now do not experience these children as difficult.

Subcategory 3.2 Community and service users

The careworkers expressed gratitude over the training received from the education outreach team of health professionals for the children who previously did not receive rehabilitation services.

<u>**Participant 1: Status of the centre**</u>

> *Before, ne go sena selo, mara gona byanong ke gona re bonang gore ke skolo, nako e la ne re sa bone, serious to be honest.*
>
> **Before, there was nothing going on, but now, this looks like an educational facility (school), initially it did not look like that, serious(ly), to be honest.**

Access to rehabilitation is limited since agents cannot afford transport to the hospitals as it is difficult to transport children on buggies and wheelchairs to the health facilities via public transport (minibus taxis). The presence of the educational outreach team brought forth a change in the status of the SCCs through provision of training on a formal program thus benefiting the service users.

<u>**Participant 3: Benefits**</u>

> *Role ya LSPID ea thusa because, akere le different, go na le physio, go na speech therapist what, at least oa kgona go ruta bana ba a communicate le bona, even le sign language le ena se oa topa, oa tseba gore ae, oa e bona, ma physio o kgona le go ba stimulate, wa e bona, a be are le botse motswadi wa gae a mo dire so, be se rea founa re re o mo ire 1,2,3.*
>
> **The role that LSPID plays is significant because you are a multidisciplinary team, a child gets speech therapy, physiotherapy and so forth, and it's great because you tell how to transfer the skill to the parent at home to ensure continuity.**

It is indisputable that the training programs are efficient in reducing the burden on rehabilitation services, and reducing untimely preventable death, as well as long term complications associated with disability such as contractures and deformities (Kuper, Smythe and Duttine 2018). The children with SPID in South Africa did not have access to education and rehabilitation services that include speech therapy, physiotherapy and occupational therapy were limited to tertiary hospitals and

inaccessible to this population (Geiger 2012). Moreover, trained health and rehabilitation workers are scarce in Africa, the situations are extreme in rural areas, where this challenge is usually exacerbated by lack of facilities and equipment for rehabilitation (Donald et al. 2014). Hence, outreach programmes are of high value to these underserved areas (Grut et al. 2012). This explains the appreciation the careworkers expressed over the multidisciplinary team intervention availed to their SCCs by the education outreach team.

Participant 9: Benefits

So, e re butse matlho and then se sengwe gape bana le bona ba di thabela dilo tse re ba dirisang tsona tse dimphya tseo re di kereileng ka yona program e.

It has opened our eyes, and even the children enjoy the activities we engage them in, and they are happy with this new program.

Mckenzie et al. (2017) emphasised that the education approach for children with SPID should deviate the focus from what the children cannot do and invest efforts on providing support for maximising participation.

The careworkers described how they struggle with rehabilitation services in Nkangala district of Mpumalanga which is one of the rural, low economic settings and underserved part of South Africa. They expressed gratitude and appreciation over the relief that the learning prograram for LSPID has brought to them, especially now that multidisciplinary intervention has been brought to the children who could in no way afford it. Thus, the careworkers experienced the program as effective with regards to broadening their horizon with knowledge and servicing the children with rehabilitation and education, even though children with SPID are likely to remain dependent in a number of areas and require high support, (Kuper 2018; Van der Linde; 2014). Thus the program does partially fulfil some of its aims to capacitate careworkers in offering improved care, stimulation and education (Spansberg et al. 2013; DBE 2016).

4.3.3.2 Subcategory 3.3 Careworker recommendations
This caregory extrapolates the recommendations shared by the careworkers. The careworkers expressed feelings of being undermined, that their inputs into the running of the of the program for LSPID were not sought. They feel that decisions

were made in their absence and yet they are expected to do the groundwork and ensure the deliverables.

Participant 10: Recommendations

> *And then, mo dijong ya**,** akere Education efa, ena le dijo, le rona at least, le ge ba ka se re fe dijo tse tsotlhe, go be le tse dingwe tse ba re ngathelang, a re cheke gore ko di sentheng thathathata ntho e e berekiswang ke e e feng, and then ba fele ba re fa, tsona, ga gona bothata moo.*

> **With regards to food, the Department of education provides food (to schools). May they please consider assisting the centres as well, even if they don't give us everything but perhaps give us only that which we mainly feed our kids, that too will help.**

A few of them questioned whether they were excluded from the planner processes due to their level of education. Furthermore, the careworkers voiced that how could they be helped when they are not asked about the help they require. Their perceptions are suggestive of the experienced exclusions and the careworkers pounded the famous disability slogan that states 'nothing about us without us'.

Participant 12: Nothing about us without us

> *I will recommend that when they prepare to go do something, for the centres, like they say nothing about us without us, don't take decisions without us, don't wanna buy something for me without consulting me, because I'm not gonna be same as the next person, you might have bought it*

> *someone else and it worked for them, but I'm not them, I am me and, I've got my own needs, so before you just decide for everything, ask for my opinion, on that particular thing, ask for my say on that particular thing, because now you just piling things on top of me, and for one, I have a question, how am I gonna use all these things coz they don't even benefit me, and then if you find those things just sitting there, I'm in the wrong obviously, so you can't take such vital decisions without involving the people who are on the ground all the time.*

The careworkers recommended that they would like to be capacitated to a level where they too can be involved in training as trainers, for other careworkers to learn from a careworker, or parent- to parent training owing to the shared experiences. According to Chocarro et al. (2021), careworkers' training follows a

psycho- educational approach which unfolds peer learning and shared experiences that boasts self-perception and realisation of their unique contribution. Zuurmond et. al (2019) also encourages active involvement of caregivers as co-facilitators of the training program, as they have shared lived experiences and suggest that this practice may heighten the outcomes of intervention. Paget et al. (2016) suggest that programs that train professionals and carers should be integrated to existing services to augment for inaccessibility to rehabilitation services in LMIC and put the emphasis on 'training the trainer'.

Literature has over decades been stressing the importance of affording the careworkers an opportunity to express their concerns and what they deem as priorities for intervention (King et al. 2004; Palisano et al. 2010). Yet to this very day, the careworkers in Nkangala expressed a desire to collaborate and co create in matters that involve the SCCs. The success of a program depends on the calibre of the facilitators to build a rapport with the careworkers. Furthermore, Zuurmond et al. (2019) emphasised that it is important to engage the careworkers and place them in leadership roles to achieve collective collaborations. Contrary to this, the careworkers in Nkangala are dismayed and disheartened that the learning program for LSPID is taking a top bottom approach and treats them as passive recipients who are denied the platform to make inputs and be made conversant with decisions and plans from high up. Zuurmond et al. (2019) argue that without such an approach the caregivers do not have the capacity to influence change in practices and societal behaviours as they are already poor, illiterate, stigmatised, discriminated, and excluded.

More than half of the participants were brave enough to express their dissatisfaction with not being active participants in forums that plan and inform the practices of the learning program for LSPID, that they do not have a platform to make inputs. They also raised that they would like to be involved in the process of determining what should be purchased for the SCCs. Overall, the careworkers would like to make inputs and contributions and not only be on the receiving end as implementers (Bester 2000; Zuurmond et al. 2019). The careworkers recommended that they too be capacitated to have slots in training/ workshops as trainers, as it will go a long way to have peer training - 'parent-to parent' or 'careworker to careworker.'

Participant 11: Recommendations

> *So, the people who are giving training I'm not saying they are not good at what they are doing, eh they are good but sometimes if somebody who is actually experienced that eh given the opportunity to do that eh it's good, parent to parent, or caregivers to caregivers, but these caregivers should be equipped, should be well trained.*

There was an emphasis on improving the education outreach team's turnaround time, to harness the onsite training. They also deliberated that stipend payment will improve their work output and reduce staff turnover as workers leave the field for better paying jobs. With regards to training, the careworkers reiterated that they should be trained on courses that are accredited and registered on the NQF to improve their qualification status.

Participant 5: Accredited training

> *ge le ntrainile mpheng something se se registered le ska no mpha a blank page mo e e leng gore e kgabisitswe mara something se se registered*

> **Upon training, please give me an accredited certificate, not a blank page that is decorated but not something that is registered.**

The careworkers indicated that the training program thus comes in handy to ameliorate the faced challenges through education and positioning the careworkers for community awareness campaigns. Hence the LSPID careworker training is being strategic and holistic in attending to illhealth, stigma, isolation, and poverty by skilling the careworkers on health promotion and facilitation of development through primary activities that include feeding, positioning, communication, play and early stimulation as well as child education towards social participation and community integration.

It is noteworthy that although the careworkers were afraid of the unknown over their job of caring for disabled children, they thought it would be more difficult for them to cope with disabled children and the work intensity. Their assumption of duty as through the training programme, helped them conquer their fears and gave them the exposure to childhood disabilities, particularly learning disabilities. In addition to their training, they would like for their support staff to be trained on

appropriate diet for children with disabilities, how food should be prepared and cleanliness, they would like for their support staff to be equipped as they are standby careworkers who replace the main careworkers when they are on leave or absent. They would also like for their centre managers to be trained in line with their office administrative duties to enhance the learning program for LSPID. As careworkers have their own problems and deal with problems that affect the children it was recommended that the education outreach team consider offering the careworkers a staff wellness program, to give them emotional support, give debriefing after adverse events and facilitate counselling for staff, to improve staff performance. Most importantly, what stood out was that those decisions and plans about the SCCs should not be done in isolation of the careworkers.

The careworkers put forth their expectations of the program herein, thus, consideration and application of the above recommendations will bring forth improvement in the careworker's experience of the training and learning program for LSPID as well as their contribution of their role and the program at large.

4.4 Conclusion

This chapter merged the findings and discussion in order to attempt to do justice to the nature of a qualitative study.

Three themes, with categories and subcategories, where relevant were put forward, and described in detail based on the data found and the researcher's in-depth experience working with these caretakers. The themes were supported by quotes after which triangulation of the findings were done, concluding how the findings elude the various objectives.

In the final chapter a synthesis of the study is provided, pointing to how the research question was answered. Implications and limitations of the study are described, and potential future recommendations posited.

CHAPTER 5- CONCLUSION

5.1 Introduction

This chapter presents conclusions on the research project: answers to the research question and the objectives. The researcher will also share recommendations to inform future practice, further research, and highlight the unique role of occupational therapy in this context. The researcher will elaborate on the limitations and value of study, and finally conclude with reflections on the study.

5.2 Findings according to the objectives

The objectives were addressed by the themes.

Objective 1: To explore the lived experiences of the careworkers in providing services for children with SPID in their communities

Table 5.1. Theme,category,subcategory and codes as addressed in objective 1

Theme	Category	Subcategory	Code	Objectives answered
Theme 1: Monatlala oa ema ema Hunger compels you to go out and hunt.	Unique Role in our communities.	n/a	Advocating for children's rights	**To explore the lived experiences of the careworkers in providing services for children with SPID in their communities.**
			Fighting stigma	
			Offering relief (to mothers)	
			Pushing community integration	
	Challenges	Careworker challenges	Knowledge	
			Skills	
			Motivation	
			Well-being	
		Community and service user challenges	Stigma	
			Lack of knowledge	
			Dealing with disability	
		Resource challenges	Infrastructure	
			Qualifications	

The careworkers are proud of what they do, they reinstate that their job is demanding and not everyone can do it. They realise the special contribution they make in the lives of the children with severe and profound intellectual disabilities, their parents and the community at large.

Objective 2: To explore the perceptions of the careworkers of the learning program for LSPID and the training on the program received from the education outreach team in the Nkangala District of Mpumalanga

Table 5.2. Theme,category,subcategory and codes addressed in objective 2

Theme	Category	Subcategory	Code	Objective
Theme 2: Mollo yo sa o orego o ka se go ntshe dipale. If you do not face the fire, you will not know it's heat	High expectations on careworkers	"Old tasks" revisited	Care routine	**To explore the perceptions of the careworkers on the introduction of the learning program for LSPID in the SCCs in the Nkangala District of Mpumalanga.**
			Transportation	
			Administration	
			Clinic/hospital f/u	
		"New task" added	Stimulation & teaching	
	Perceived low value of our work	Malalignment of perceived needs and actual needs	Resources	
			Teaching materials	
			Skills	
		Poor recognition of pre-existing knowledge		
		Job (in)security	Remuneration	

Careworkers expect more from the LSPID project, even the type of assistance that is outside the authority of the Department of Education. They expect to be assisted with their key issues such as infrastructure, transport, feeding scheme and assistive devices. They also expect to be remunerated for the added work from the Department of education such carrying out the learning programme, intensified stimulation and executing the related administrative duties.

It is a great milestone they have achieved to have the stimulation centres and their work recognized by the government of South Africa and the DBE. However, the careworkers are disheartened that they are not involved in the high order planning, organising of the events pertaining to the SCCs, but only expected to carry out mandates, moreover without remuneration. The careworkers also fear for their jobs, that they may ultimately be replaced by professionals as they feel undermined on the basis of not being qualified as professionals to do their job.

However, they are not pleased that the training provided by education outreach team is not accredited and registered in the National Qualification Framework and thus bears no qualifications. There are also perceptions of job threats that the careworkers have, that the department of education may replace them with better qualified officials to 'teach' the children with SPID.

Objective 3: To explore the perceptions of careworkers after six to twelve months about the effectiveness of the learning program for LSPID and the training on the program received from the education outreach team

Table 5.3. Theme,category,subcategory and codes addressed in objective 3

Theme	Category	Subcategory	Codes	Objective
Go ba Komana Madula a bapile (Be prepared for anything)	Noticeable changes	Careworker capacitation	Improved knowledge	**To explore the perceptions of careworkers after six to twelve months about the effectiveness of the learning program for LSPID and the training on the program received from the education outreach team.**
			Practice changes	
			Caregiver well-being	
		Learning programme Community and service users	Status of centre	
			Benefits	
	Careworker recommendations	Nothing about us without us	Planning platforms/stakeholder sittings Procurements for the centres	

The careworkers are of the impression that their training on the learning program for LSPID is not an accredited 'course' as they are an undermined population, hence they are not being included in decision making forums or in platforms where they can get first-hand information about policies and plans for the SCCs and also be afforded the opportunity to make inputs and contributions.

The careworkers perceive the training as fruitful and gap filling. There is an emphasis on the impact of the program as being eye opening and elevating the careworkers to a better profile i.e., from non-trained laypeople to intensively trained and skilled in using provisioned tools and equipment. The careworkers perceive the program as effective in providing multidisciplinary rehabilitation service and improved education to the children. They also perceive the program as effective in training the careworkers, provisioning tools of trade and the learner teacher materials. The careworkers have indicated that they have improved insight and knowledge into the leaner conditions, and improved knowledge into approach and strategies to stimulate and teach the children with severe and profound intellectual disabilities.

5.3 Main Findings

The aim of the study is to explore the experience of careworkers about the services they offer for the children with SPID and the effect of the learning program for LSPID and the training received from the education outreach team in the Nkangala District of Mpumalanga. The perceptions of the careworkers about the training they received and how this affects the intervention for learners with SPID is important as successful implantation of the program depends on them. Since the learning program for LSPID is quite recently introduced, exploratory data are required to provide a basis for further research to ensure sustainability of the program.

The participants described their experiences as both positive and negative, there are aspects of the program that they find satisfying such as being educated, capacitated, and equipped with working with children with severe to profound intellectual disabilities. However, they did not beat about the bush in venting their dissatisfaction with not being paid by the DBE for their expanded job demands as well as perceiving the discrepancy between their actual needs and the assistance received.

5.3.1 The contribution of Stimulation Care Centres

South Africa does not have any formal registered institution that offers formal education to the children with severe and profound intellectual disabilities, hence the Department of Education was taken to court. The high court of South Africa ruled in favour of the children and reiterated that the children deserve education for their dignity and development, and that education may be delivered in a form of self-care skills, emotional and social skills, fine and gross motor skills, as well as communication and cognitive development. The careworkers take pride in their initiatives of getting the children out of their homes and out of that harsh separation and isolation of belonging nowhere. Had it not been these SCCs, it was going to be difficult to even locate these children, establish their database, baseline functioning and their needs to establish intervention for them. Regardless of their challenges and demands, Petrenchik and King (2011) emphasise that all children have a need to participate in activities within environments that present them with

the just right challenge, social involvement, sense of belonging (to be accepted for who they are) and freedom of being (autonomy). Hence the establishment of SCCs answers for a greater course, although these establishments are still far from being conducive environments that can cater for the needs of learners with SPID in terms of resources.

5.3.2 Challenges encountered

The SCCs have been excluded from the government budget and thus could not afford staffing remuneration and basic resources required for provisioning quality services to the children. At most these SCCs were operating from a portion of the disability grants that the children receive and subsequently pay as fees. Geiger (2012) pounded that even with the provisioned subsidies, the remaining funds can barely cover the minimal careworkers' remunerations. The underpaid staff, albeit lacking in knowledge and skill, exhibit commendable motivation and drive to give care, love, and stimulation to the over-crowded children of mixed disabilities in these very poorly resourced facilities (Geiger 2012).

 Not bringing the careworkers on board (or excluding the careworkers in executive planning) affects the outcomes of the learning program for LSPID as the careworkers are the main role players who are expected to execute the strategies activities by LSPID. There may be reluctance to follow through since the careworkers are not active agents in the project and careworkers feel like they have not actively influenced the decision making and outcomes. The careworkers view the project as requiring their service yet undermining them (on the basis of their level of education) to make inputs and contribute on the vision and mission of the project as a whole.

5.4 Contribution of the study

Before the effectiveness of the training offered to careworkers in SCCs for LSPID in Mpumalanga can be established, it is important to determine if the training meets the needs of the careworkers in terms of their expectations and ability to use the newly introduced training practically. This study served to provide evidence for the learning programme for LSPID and training provided by the outreach team.

The study has contributed towards giving formal feedback on the training and on identified challenges so that issues can be identified and addressed to further support implementation of the learning program for LSPID in the Mpumalanga SCCs. The study served as beacon of hope to the careworkers as it offered them the opportunity to express themselves. Participating in formal research gave them the assurance that their views and contributions have a formal medium of being presented at affiliated gathering platforms including congresses and symposiums, as well as be in record in a form of thesis and journal articles.

This study hopes to contribute to a body of knowledge regarding the careworkers and aspects that affect the service provision and policy implementation for the children in the SCCs. The outcomes of the study hope to enable the DBE to get a review that may be utilised across the country to meet the expectations of the careworkers in the SCCs, thus improving their experience of the program and reciprocally increasing their output of the objectives.

5.5 Limitations of the study

The study was qualitative in nature and therefore conducted on a small sample. Though this qualitative data provided a necessary baseline for human experiences of these caretakers in providing peripheral but extremely necessary services.

The study setting is a small under-resourced rural area, these areas have obvious resource challenges such as infrastructure, transport, water, and sanitation as well as disabled children with poor health due to reduced access to health facilities and malnutrition related health adversities.

The interview scheme could have perhaps incorporated questions that ask about other programs, if any that the careworkers have experienced, other outreach services to establish what the expectations of the careworkers were.

5.6 Implications and recommendations for future research

The study also identified the potential gap in occupational justice as expressed. Careworkers are reported to be inadequately trained and without the skill that may enable them to provide education to the children with SPID. The training that the careworkers received were found to be poorly coordinated and fragmented. It is worth noting that the careworkers came to work to bridge a gap in times of dire need and not necessarily out of expertise (Geiger 2012; McKenzie et al. 2017).

McKenzie et al. (2017) postulated that in pursuit of accredited training for the careworkers, the role of the education outreach team and the informal onsite job training should not be underestimated.

Although the intent of this study is not to produce findings which are generalisable to other contexts, recommendations may be appropriate for application in settings other than the learning program for LSPID of Nkangala district of Mpumalanga Province where the study was conducted. The researcher, therefore, intends to make findings available through publishing in peer-reviewed journals and presenting the findings at both local and international platforms.

- **Careworkers' wellness program- for debriefing, counselling, and channelling to a healthy working life**

The careworkers voiced frustration of feeling neglected, that all the attention is directed at the children, and they are being disregarded. The careworkers recommended the worker's wellness program where they can receive support over their emotionally draining job and feedback on their performance to alleviate a sense of feeling unappreciated and undervalued as employees. Follow up on proposed recommendations by careworkers on what the learning program for LSPID can do differently to foster healthy, meaningful, occupational wellbeing. The study highlights how occupational therapy, and the entire education outreach team can advocate and represent the voiceless, marginalised populations to promote occupational health and healing from occupational injustices.

- **Improve collaboration with the stimulation care centres**

Collaboration can improve, in a manner that careworkers or centre managers are involved in sittings that concern planning and discussions of matters pertaining to the SCCs. That way, the careworkers can make inputs and get first-hand information about ideas that are proposed to be put into place so that they can feel a part of the program by co-creating and collaborating and not overlooked as passive on the ground implementers.

- **Department of Basic Education to have frequent sit-in with representatives from the SCCs**

The careworkers would appreciate to meet with officials from DBE, to be given the recognition of the work they do on the ground, and not only be evaluated for program output. The careworkers would also appreciate formal feedback upon evaluation to be presented to them and not only to the involved transversal multidisciplinary team.

- **Education Outreach teams to reduce their turnaround time and increase their visiting frequency**

At least more than one team should be deployed to cover districts that are large in total number of SCCs or where SCCs are located far apart from one another. The lowered turnaround time will reduce anxiety in careworkers as they can make enquiries, follow up questions and perfect the skills learned.

- **Provide the careworkers with accredited trainings**

Careworkers will be motivated to attend training and implement what they are trained on should there be levels of competency to achieve and should the training be accredited and registered on the NQF structure. The careworkers believe that qualifying in trainings will open doors for them. In respect of the above, it was recommended that careworkers should get training that is accredited on the National Qualification Framework to improve their career path. The DBE may consider paying the carerworkers for the added responsibilities. The DBE could also collaborate with other departments such as public works, transport, health and DSD to collate a practical policy for the services of the learning program for LSPID to prevent repercussions and loopholes to the program.

● **Provide the careworkers with stipend or renumeration from the Department of Basic Education**

To improve execution of the learning program and services at the centre carried out by the careworkers as mandated by the DBE. The careworkers experience it as exploitation to be overworked and underpaid, they have respect for the department of Social Development that reimburses them executing the care routine to the children and feel mistreated by the department of education that expands their work plan and job description without the equivalent remuneration.

● Learning program for LSPID to cater for the children above 18 years of age, as their chronological age does not correspond with their developmental age due to delayed/hampered development secondary to disability.

● **The role of the education outreach team to be realised, embraced, and capitalised on**

The education outreach team should take pride in not only training the careworkers but ensuring their work satisfaction and occupational wellbeing. The education outreach team could prioritise on the children's holistic intervention by integrating the contributions of all involved parties through advocacy for occupational justice and wellbeing, involvement, and participation in an improved repertoire of occupations that are meaningful to the children, their parents and careworkers. Perhaps, the education outreach team should embrace the challenge of uplifting the standard of services and intervention in the South African context to the level of the best practices across the globe in settings of similar economic state.

● **Involved Departments to collaborate services**

For the success of the learning program for LSPID, the involved departments will have to collaborate and take hands to ensure that the services that complement one another can be put into place. Otherwise, the services clash and affect one another negatively, i.e., the equipment and learner teacher support material (LTSM) get damaged as it is stored under inferior quality infrastructure with leaking roofs or get stolen as the buildings are not secured and can be easily broken into. On the other hand, children's education is limited by no access to

assistive devices regarded as the responsibility of the Department of Health, i.e., wheelchairs, standing frames, spectacles.

5.7 Implications and recommendations for future research

● The children in the centres could have also made an indication of their experiences and perceptions of the stimulation and life in the centre before and after the LSPID program.

● The study did not get the views of the transversal multidisciplinary team training the careworkers, it would have been comprehensive to collate their views and perceptions of the project and determine if there are similar or different views between them as the service providers and the careworkers as the service recipients.

● Procure better quality LTSM, adequate quantity and suited for the child conditions.

The participants recommended that the procurement takes into consideration the fact that the children at the centres have lower cognitive functioning and are tactile seeking. They highlighted that toys of better quality would have a longer shelf life as the children explore differently to children without neurological fall outs, i.e., sensory seeking children bang on the toys, chew on them, and seldom use them.

5.8 Conclusion

It is commendable what motivation, volition and drive can yield when there is hunger and a void to be filled in the community. How the parents of the children with disabilities stood up and took it upon themselves to create spaces for their children to come together and receive some form of community integration, stimulation and learning through establishing the SCCs is remarkable and will remain in. It surprises the community that the departments with jurisdictions and authority can neglect the core problems (infrastructure, transportation, assistive devices, Nutrition) and utilise funds on provisions that are not of priority (stimulation toys, learner teacher materials,) only because it is not the said department's (DoE in this instance) mandate and responsibility to meet the needs,

regardless of whether the involved department has the financial capacity to address the main needs.

It was touchy to observe the facial expressions, body language emphasis and strong emotions when careworkers drew courage to express their despondent feelings over being overworked, underpaid, and receiving training that is not accredited to a researcher they regard as a person with power. On the other hand, it was heart-warming and encouraging to hear the heartfelt appreciation of the careworkers over services and multidisciplinary team intervention that came to their shores, whilst access to rehabilitation services in these parts of the country is still regarded as a rarity. Even though they would rather choose assistance of infrastructure and transport over education program and teacher learner materials, they do acknowledge that their daily routines are now filled with a variety of activities, they enjoy stimulating the children, the children experience fulfilment while at the centre and the activities they age in make the time at the centre worthwhile for both the careworkers and the children. The experience was a reminder of what occupational therapy is all about, building rapport so well that all barriers of expression can be broken, and a mixture of feelings and experiences can be shared without reservations.

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APPENDIX A – ETHICS CLEARANCE CERTIFICATE

UNIVERSITY OF THE WITWATERSRAND, JOHANNESBURG	HUMAN RESEARCH ETHICS COMMITTEE (MEDICAL)

Office of the Deputy Vice-Chancellor (Research & Post Graduate Affairs)

TO: Ms GV Diale and Mr M Letsoala
School of Therapeutic Sciences
Department of Occupational Therapy
Medical School
University

E-mail: 0603981A@students.wits.ac.za

CC: Supervisor: Mlles L Koch & L Masego; Dr T van der Merwe
<Lyndsay.Koch@wits.ac.za>
and <HREC-Medical.ResearchOffice@wits.ac.za>

FROM: Iain Burns
Human Research Ethics Committee (Medical)
Tel: 011 717 1252

E-mail: Iain.Burns@wits.ac.za

DATE: 2020/11/17

REF: *R14/49*

PROTOCOL NO: M200983 *(This is your ethics application study reference number. Please quote this reference number in all correspondence relating to this study)*

PROJECT TITLE: *Careworker's perceptions of training provided by an educational outreach team for learners with severe to profound intellectual disabilities*

Please find attached the Clearance Certificate for the above project. I hope it goes well and that an article in a recognized publication comes out of it. This will reflect well on your professional standing and contribute to the Government funding of the University.

MSWorks2000/Iain0007/Clearscan.wps

UNIVERSITY OF THE
WITWATERSRAND,
JOHANNESBURG

HUMAN RESEARCH ETHICS COMMITTEE (MEDICAL)
CLEARANCE CERTIFICATE NO. M200983

NAME:
(Principal Investigator)

Ms GV Diale and Mr M Letsoala

DEPARTMENT:

School of Therapeutic Sciences
Department of Occupational Therapy
Medical School
University

PROJECT TITLE:

Careworker's perceptions of training provided by an
educational outreach team for learners with severe to
profound intellectual disabilities

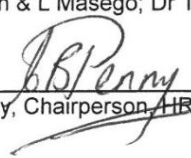**DATE CONSIDERED:**

2020/10/02

DECISION:

Approved unconditionally

CONDITIONS:

SUPERVISOR:

Miles L Koch & L Masego; Dr T van der Merwe

APPROVED BY:

Dr CB Penny, Chairperson, HREC (Medical)

DATE OF APPROVAL:

2020/11/17

This clearance certificate is valid for 5 years from the date of approval. Extension may be applied for.

DECLARATION OF INVESTIGATORS

To be completed in duplicate and **ONE COPY** returned to the Research Office Secretary on the 3rd
Floor, Phillip Tobias Building, Parktown, University of the Witwatersrand, Johannesburg.
I/we fully understand the conditions under which I am/we are authorized to carry out the above-
mentioned research and I/we undertake to ensure compliance with these conditions. Should any
departure be contemplated, from the research protocol as approved, I/we undertake to submit details to
the Committee. **I agree to submit a yearly progress report**. When a funder requires annual re-
certification, the application date will be one year after the date when the study was initially reviewed.
In this case, the study was initially reviewed in **September** and will therefore reports and re-certification
will be due early in the month of **September** each year. Unreported changes to the application may
invalidate the clearance given by the HREC (Medical).

Principal Investigator Signature   Date

APPENDIX B - AUTHORITY PERMISSION LETTER

social development
MPUMALANGA PROVINCE
REPUBLIC OF SOUTH AFRICA

Building 3, NO. 7 Government Boulevard, Riverside Park, Mbombela, 1200
Mpumalanga Province, Private Bag X 11213, Mbombela, 1200
Tel: +27 (13) 766 3428, Fax: +27 (13) 766 3456/57

| Litiko Letekutfutfukisa Tenhlalakahle | UmNyango WezokuThuthukiswa KwezokuHlalokuhle | Departement van Maatskaplike Ontwikkeling |

Enq: Ms. Elize Botha
Tel: 013 766 3053
Ref No.: 12/5/R

MS. G.V. DIALE
CELL: 072 6904649
valitheg@gmail.com

RE: PERMISSION TO CONDUCT A RESEARCH STUDY ON THE CARE WORKERS WORKING IN THE STIMULATION CENTRES OF NKANGALA DISTRICT

Dear Ms Diale,
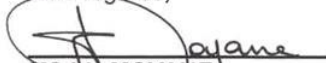(Galetshetse Vallery Diale. PERSAL no: 91164634)

Your e-mail communique dated 1 October 2020 has reference.

The Department gladly supports your research on "Caseworkers' perceptions of training provided by an education outreach team for the learners with severe to profound intellectual disabilities" that you will undertake as part of your post graduate studies. In principle the department has no objection against you accessing Disability Care Centres to conduct your research, however:

- Even though the Department of Social Development supports and works closely with these Centres, they remain autonomous and you will have to obtain consent from them as well as from individual participants.
- Ethical oversight by obtaining ethics approval from the Human Research Ethics Committee (HREC) of the University of Witwatersrand is commended since It is critical that the principles of ethical research be maintained. Particularly where it concerns vulnerable groups such as persons with disabilities.

The Department wishes you the best with your endeavours and look forward to the outcomes of your study.

Kind regards,

MS LH MOYANE
ACTING HEAD: SOCIAL DEVELOPMENT
DATE: 07 | 10 | 2020

APPENDIX C1

AUTHORITY PERMISSION LETTER

education
MPUMALANGA PROVINCE
REPUBLIC OF SOUTH AFRICA

Ikhamanga Building, Government Boulevard, Riverside Park, Mpumalanga Province
Private Bag X11341, Mbombela, 1200.
Tel: 013 766 5552/5115, Toll Free Line: 0800 203 116

Litiko le Temfundvo, Umnyango we Funda   Departement van Onderwys   Ndzawulo ya Dyondzo

Enq: G.V. Diale

Cell: 072 6904649
valitheg@gmail.com

To: THE HEAD OF DEPARTMENT
DEPARTMENT OF SOCIAL DEVELOPMENT
MPUMALANGA PROVINCE

From: Ms. G.V. DIALE
CHIEF EDUCATION OCCUPATIONAL THERAPIST
INCLUSIVE EDUCATION- LSPID PGROGRAM
NKANGALA DISTRICT

Date: 26-08-2020

Re: Permission to Conduct a research study on the care workers working in the stimulation centres of Nkangala District.

BACKGROUND
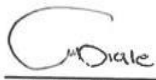
Before the effectiveness of the training offered to care workers in stimulation care centres for LSPID in Mpumalanga can be established, it is important to determine whether the training meets the needs of the care workers in terms of their expectations as well as their ability to use the newly introduced content practically.

PURPOSE

The purpose of the study is to explore the perceptions of these care workers on the learning programme. The aim is to ultimately improve the training, curriculum implementation and therapeutic services rendered by the LSPID team.

I, Galetshetse Vallery Diale (Full names), identified by number: 91164634 (Persal number), employed as: Chief Education Occupational Therapist, (designation) at: Kwamhlanga district (Location).

Hereby wish to request for permission to conduct a research study in the care centres titled: "**Careworkers' perceptions of training provided by an education outreach team for the learners with severe to profound intellectual disabilities**" for master's degree dissertation through the University of Witwatersrand. The study entails interviewing the careworkers to explore their experience of the service rendered by the outreach team.

G.V DIALE

Date

CET OT Nkangala district

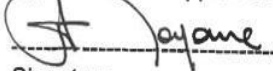I, LUCY H MOYANE (full names) in capacity as a (A) HEAD OF DEPT (designation)

at DSD (location))grant Ms G.V Diale (the researcher) permission to conduct a research

project in the Mpumalanga Nkangala district care centres.

Remarks

It will be appreciated if the research report can be shared with the Department

Approved/ Not Approved

Signature

07 | 10 | 2020

Date

UNIVERSITY OF THE
WITWATERSRAND,
JOHANNESBURG

FACULTY OF
HEALTH SCIENCES

09/09/2020

TO: THE HEAD OF DEPARTMENT, Department of Social Development. Mpumalanga Province.

RE: STUDENT 0603981A-GV DIALE PROTOCOL: M.SC OCCUPATIONAL THERAPY BY DISSERTATION

I herewith declare that the GV Diale (student no: 0603981A) is a registered MSc student in the Occupational Therapy Department of the University of the Witwatersrand. The student is already a qualified occupational therapist working in the stimulation centres of Nkangala district Department Inclusive Education and the sub-directorate of Leaners with Severe to Profound Intellectual Disabilities and is completing a postgraduate degreee.

In order to complete her postgraduate studies, Ms Diale is required to conduct research within her field of choice. Ms Diale's research protocol has been passed by the Wits Faculty of Health Sciences: School of Therapeutic Sciences Research Assessment Committee and has been submitted to the Human Research Ethics Committee (HREC) of the University of Witwatersrand for ethical clearance.

The student is already a qualified occupational therapist working in the stimulation centres of Nkangala district Department Inclusive Education and the sub-directorate of Leaners with Severe to Profound Intellectual Disabilities.

The Occupational Therapy Department of the University of the Witwatersrand would like to ask you to grant the student permission to conduct the research in the Nkangala stimulation centers where she works.

The research report will be made available to your department upon completion.

Sincerely

Lyndsay Koch

Research Supervisor
Department of Occupational Therapy, School of Therapeutic Sciences
Tel no.:   011 717 3701
E-email: Lyndsay.Koch@wits.ac.za

APPENDIX C - INFORMATION SHEET

PARTICIPANT INFORMATION SHEET

Dear Prospective participant

The Department of Basic Education has recently introduced a program for children with severe to profound intellectual disabilities in the stimulation centres across the country.

This program's main objective is to ensure that the children in the centres receive quality funded education, and that the careworkers are trained to provide to implement the learning program.

Since the program is relatively new, it is worthwhile to conduct formal research to obtain both objective and subjective data that can help inform the program for evaluation and analytical criticism towards its review and improvement.

I have thus applied for clearance from the human ethics department of Wits University and permission from the Mpumalanga Department of social development to conduct formal research on how you the careworkers perceive and experience the LSPID program occupational therapy's point of view.

You have been identified as a potential participant based on criterion set up based on the need described above.

 The following will be required of you if you choose to participate in the research:

 • You will be asked to fill in a form to give some background information about yourself

 • A private interview lasting no more than 90 minutes each will be conducted at the shelter or the district office or any place convenient for you. In these interviews

111

you will tell me about your work as a caregiver, and how do you experience the LSPID program since its inception in your centre. These interviews will be recorded and typed out. Some of what you say may be quoted in the presentation and publication of this research.

In order to protect you I will ensure the following:

• All your information will be treated as highly confidential. This means that I will mark all your documents with a code instead of your name. I will use this code when referring to you. I will also make sure that all documents are kept safe and in private.

• You may withdraw from the research at any time with no penalty.

Please also take note that you will not receive any remuneration (payment) for participating in the study. If you want to participate in the research, please fill in and sign the informed consent form on the next page. You are also welcome to contact me or my supervisor if you have any questions about the research.

 Kind Regards

-------------------------------   -------------------------

Ms. Galetshetse Diale   Ms. Lyndsay Koch

0726904649   0117173701

OT -LSPID NKANNGALA   Research   Supervisor   (Wits University)

APPENDIX D - CONSENT TO TAKE PART IN RESEARCH

I---, voluntarily agree to take part in this study.

Nna ---, ke ithaopa go tsea karolo mo boithutong bjo

I understand that even if I agree to participate now, I can withdraw at any time, refuse to answer any question without any consequence of any kind.

Ke kwishisha gore le ge dumela go tsea karolo gona bjale, nka nna ka ikgogela morago nako ennge le enngwe, ka se dumele go fetola dipotsiso kwa ntle ga ditlamorago tsa mofuta ofe goba ofe.

I understand that I can withdraw permission to use data from my interview within two weeks after the interview, in which case material will be deleted.

Ke kwishisha gore nka latola ka tumelelo ya go shumisha dikarabo tse ke neelaneng ka tsona mo lebakeng la dibeke tse pedi morago ga go botsisiwa dipotsiso

I have had the purpose and nature of the study explained to me in writing and I have had the opportunity to ask questions about the study.

Ke hlaloseditswe ka morero le mabaka a boithuto bjo mo setlankaneng se se ngwadilwego fase, ebile ke filwe monyetla le sebaka sa go bitsisa dipotsiso.

I understand that participation involves audio recording and interpretation of information gathered in themes.

Ke kwishisha gore tea karolo go akaretsa go gatisiwa ga dikarabo le go tlhathololwa go ya ka motlhoditero

I understand that I will not benefit directly from participating in this research.
I agree to my interview being audio recorded.

Ke kwishisha gore nka se name ke gweditse go golega ka baka la go tsea karolo.

I understand that all information I provide in this study will be treated confidentially.

Ke kwishisha gore dikarabo ka moka tseo ke fanago ka tsona di tlo swarwa ka tlhompho esego go phatlalatswa boshaedi.

I understand that in any report on the results of this research my identity will remain anonymous.

Ke kwishisha gore mo gotlhe moo dipoelo tsa boithutelo bjo di tlo go gatisiwa gona, dikarabo tsaka di tlo hlahiswa jwale ka tsa tlhokaina.

This will be done by changing my name and disguising any details of my interview which may reveal my identity or the identity of people I speak about.

Seno se tlo dirwa ka go fetola lebitso laka, le karolo tsa dikarabo tsaka tseo di ka lemoshang batho ka botsebegi goba boitshupo bjaka..

I understand that disguised extracts from my interview may be quoted in dissertation, conference presentation and published papers.

Ke kwishisha gore dintlha tse dingwe tsa dikarabo tsa ka di ka nopolwa kwa borutishing, kwa dipegong goba go gatisiwa mo dipampiring tsa go phatlalatswa

I understand that signed consent forms and original audio recordings will be retained by the researcher, only the researcher and her supervisors will have access to the data.

Ke kwishisha gore mangwalo a tumelelo ya botsea karolo ao a saenetswego, le direcord/dikgatiso tsa ka di tlo ba mo matsogong a moithuti le bahlahli ba gagwe fela.

I understand that a transcript of my interview in which all identifying information has been removed will be retained for 2 years.

Ke kwishisha gore, kwalo fase ya dikarabo tseo ke fanego ka tsona ge ke botsiwsa dipotsiso, gomme e sa bee lebitso goba botsebebgi baka molaleng,e tlo swarwa tekano ya mengwaga e meraro

I understand that under freedom of information legislation I am entitled to access the information I have provided at any time whilst it is in storage as specified above.

Ke kwishisha gore ke na le tumelelo ya go kgopela dikgatiso tsa dikarabo tsa thuto e, nako enngwe le enngwe

I understand that I am free to contact any people involved in the research to seek further clarification and information

Kea kwishisha gore ke dumeletswe le go lokololwa go amana le batho bao ba amegago mo borutelong bo.

------------------------------------   ------------------------
Signature of participant   Date

I believe the participant is granting informed consent to participate in this study

--   ----------------------------
Signature of researcher   Date

APPENDIX E - DEMOGRAPHIC DATA

Full names/Mabitso le Sefane:

Age/Mengwaga:

Gender/Bong:

Work address/Aterese ya Moshomo

Highest level of education/O feletse kae ka dithuto

Formal training/Dithuto tsa mangwalo:

How long have you been a careworker for children with disabilities?

Ke sebaka se se kaa kaang o shoma jwale ka motlhokomedi wa bana bao ba sa itekanelago?

How long have you been exposed to LSPID outreach team training and intervention?

Ke sebaka se se kaakang o shomishana le ba lefapha la LSPID?

APPENDIX F - INTERVIEW SCHEDULE

1. **Describe your role and duties as a careworker in the stimulation centre**
Tlhalosa moshomo wa gago le karolo eo o e tseang mo sentheng

2. **What do you find challenging about your work and the children with severe and profound intellectual disabilities?**
Ke eng se o se khumanang sele boimanyana ka moshomo wa gao le bana ba ba golofetseng monagano kudu?

3. ***Can you tell me about the training that the LSPID outreach team has provided? What did you learn from these training?***

O ka ntlhalosetsa ka borutishi("training") ba go dirwa ke setlhopha sa LSPID. O ithutile eng go tswa go borutishi bjo?

4. **Has your role and duties changed since your exposure to LSPID learning program, can you tell me about it?**
Ekaba moshomo le karalo ya gao mo sentheng di fetogile ge o sale o thomile go shomishana le go hlahlana le ba LSPID? O ka ntlhalosetsa ka ga seo?

5. **What impact does the learning program from the LSPID outreach team have on the children in the stimulation centre?**
Setlhopha se sa LSPID sena le seabe se se fe mo baneng ba ba leng mo sentheng?

6. **How does the learning program fit in the child's activities of daily living?**
Lenaneo thuto (Learning program) le amana joang le ditiro tsa ka metlha?

7. **What makes you satisfied about the LSPID outreach team learning program?**
ke eng se se go kgotsofatsang ka setlhopha sa ba bashomi ba LSPID?

8. **What is it about the LSPID team learning program that does not make you satisfied?**
ke eng se se sa go kgatlheng ka se tlhopha sa LSPID?

9. **What recommendations would you make for the LSPID outreach team to improve the learning program?** *O ka eletsana joang le setlhopha sa LSPID go kaonofatsa moshomo wa bona?*

APPENDIX G - CODEBOOK EXCERPTS

	F	G	H	I	J	K	L	M	N	O	
							Caregiver recommendations				
	er material	stipend/remunerations		turn around time		Train on LTSM		Support Staff		Feeding sch	
	especially mechine e ya go pressiwa e , ya go bolele e, wae bona yes	stipend	Just only if maybe ge nkebe gona le something nyana maybe on **top, nkile wa bona,akere wa itse gore mathata a dichelete** ge bana ba gola, le ona a gola.Up to so far, nna ke right,	Improve turn around time	Uhm, what I can say ke gore like, **why le sa dire like di program tsa lena di tsamae ka kotara?** Like the way like dikolo ga di bulwa re bane le program, ge di, di a tswallla akere ka March and then di re from then April	Train on LTSM usage	So if you gave us maybe an example of how we can use that's when we will know when to use our own minds gore ok, trampolin e re ka e user so, maybe bana ba ba sa itseng go tsamaya maybe we just put	main the support staff	le organize le tse dingwe di training rena le **bomme ba apeyang, organizing** gore ba ye **skolong** ba ye go rutelwa le re keng cleanness, ba up the standard.	Feeding scheme, office equipment	V b n k b l b r g b t e e t g t l g r b v b r

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Top of image (partial): "...you gave us maybe an example of how we can use t..."

	A	B	C	D	E	F
1			caregiver highlights from the program			
2	caregiver capacitated		children benefiting		learner teacher material	
	improved understanding, increased knowledge, better capacitated	but throug h their educati on, re nna equipp ed, and then re kgona go underst ander most of the things,	Assited children who could not afford/access rehabilitation serivices. *improved service delivery	Uhm, what I can say ke gore, ba kgonne go thusa bana ba ba ntsi ba e leng gore they could not afford some of the things, more especially lets come to the equipmen	Appreciates learner teacher material- electronic speech assitive devices	especially mechine e ya go pressiwa e , ya go bolele e, wae bona yes

Formula bar: especially ba eleng gore ba difficult ga o tsebe gore o ka dealer jwang le bona,

	C	D	E	F	G	H	I
	CHALLENGES WITH CAREGIVERS		CHALLENGES WITH CHILDREN		CHALLENGES WITH THE TEAM		ORGANIZATIONAL CHALL
	There are passionate workers, no passion- working for salary. *Challenge with the caregivers.1	gona le batho ba e leng gore re tlile mmerekong, gona le batho ba e eleng gore they have been sent, wa ntlhaloganya gore ke raya byang, go na le batho ba e leng gore re tlile cheleteng, go na le batho eleng gore re tlile thusong,	late intervention, late enrollment of children into the centres. Children with fixed behaviours and patterns , children with fixed complications. *challenge with the children.1	ga go tle ngwana o nang le 3 years, go tla ngwana o o nang le 15 years, ngwana oo, lets say o profound or its an autism child wa bona , ga o motsebe ngwana o, o mo thoma from the scratch,	communication, involvement of caregivers upon receipt of leaner teacher material. * challenge with the outreach team.1	most of the time ga le tlisa dilo, le a di tlisa, le di isa ko go principal, re tlisitse dilo ke tse, but you don't call us then le re bolelle gore you can use this ko go so, le so, le so, because as I'm saying not all of us are here being called, but, some of us we just come to work, and then ra di tsea ra di beya, even though princinal a	Work demands.Challenges with work intensity, organizational challenge.1

Sheet1 Sheet2 Sheet3 (+)

ready

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