A psychoeducational programme for caregivers of people with intellectual disability within the Western Cape

by

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DEDICATION

Dedicated to everyone who has ever been told, treated as, or made to feel that they are worthless.

May reading about these inspiring caregivers of people with intellectual disability be a restorative self-worth experience for you, as it was for me when engaging with them.

~ Bonita Gordon

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ABSTRACT

In the Western Cape, 98% of people living with intellectual disability are being taken care of by caregivers. These caregivers often sacrifice their own aspirations in their devotion to the person living with intellectual disability - with little, to no, monetary remuneration and recognition. Often, they neglect themselves emotionally, as well as physically, and this could lead to burnout and depression. In this study, the researcher seeks to understand the issues that could lead to caregiver distress and to develop a solution in the form of a targeted psychoeducational programme for caregivers.

A mixed-methods research approach was used in the study - a combination of quantitative research and qualitative research approaches. More specifically, applied intervention research was utilised since the concern of the study is to induce a practical change in a troublesome situation. The two theoretical frameworks that guide this study are the biopsychosocial model and the strength-based approach.

The research approach to this study was rooted in the mixed-methods research approach, as the researcher collected both numeric and text information. The researcher applied the *embedded* mixed-methods design, which is a variant of the mixed-methods research approach. Twenty-five (25) participants in the qualitative phase and one hundred respondents for the quantitative phase were selected.

During the qualitative phase, the researcher employed exploratory research to obtain basic information and new insights regarding caregiver distress. During the quantitative phase, the researcher used the pre-experimental design, namely the ‘one-group pre-test post-test design’ that contributed to making valuable interpretations and comparisons regarding the impact and value of the psychoeducational programme. Cognitive behaviour therapy guided by a strength-based approach was used as a practice framework for the development of the psychoeducational programme. The manual was developed out of an in-depth literature review, as well as interviews with the *informal* caregivers. The psychoeducational programme was conducted with the *formal* caregivers. The researcher collected data whilst the respondents attended a one-day training programme.

The statistical findings showed that there was an increased level of knowledge after the intervention programme. Furthermore, according to these findings, 99% of respondents indicated that the psychoeducational programme would have a positive impact in alleviating caregiver distress. The research results further suggest that 85% of respondents felt much better equipped to take care of a person with intellectual disability after the training. The results also support the academic literature which found that caregivers of people with intellectual disability are predominantly female.

Based on the results of this research, it can be concluded that the tools presented in the psychoeducational programme empower caregivers in their caregiving capacity. Moreover, the programme is shown to be effective in imparting knowledge on caregiving of people with intellectual disabilities. However, further refinement of the programme is still required.

This knowledge yields important insights for social workers and other health professionals to render relevant intervention programmes, support and resources - not only to the person with intellectual disability but also to his or her caregiver. The study calls for policies and procedures to be put in place to address the plight of caregivers. Additionally, findings from this study reinforce the need to further develop collaboration between social and healthcare service providers and caregivers to enhance the caregiving ability of the latter.

Key concepts:
Intellectual disability
Formal paid caregivers
Informal unpaid caregivers
Psychoeducational programme
Caregiver distress

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ACRONYMS

ACT: Acceptance and commitment therapy

ASD: Autism spectrum disorder

CBT: Cognitive Behavioural Therapy

CP: Cerebral Palsy

DSM-5: Diagnostic and Statistical Manual of Mental Disorders - Fifth edition

DD: Developmental disability

FAS: Fetal alcohol syndrome

GCS: Grover-Counter Scale

IASSIDD: International Association for the Scientific Study of Intellectual and Developmental Disabilities

ICD-11: The eleventh revision of the International Classification of Diseases

ID: Intellectual disability

LRC: Legal Resources Centre

LMIC: Low- and middle-income country

LSEN: Learners with special educational needs

MHCA: Mental Health Care Act

MR: Mental retardation

NCCMH: National Collaborating Centre for Mental Health
PCP: Participant

SASSA: South African Social Security Agency

SIRG: Special Interest Research Group

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

WCFID: Western Cape Forum of Intellectual Disability

WISC-V: Wechsler Intelligence Scale in Children-V

WHO: World Health Organization

CHAPTER 1
GENERAL INTRODUCTION TO THE STUDY

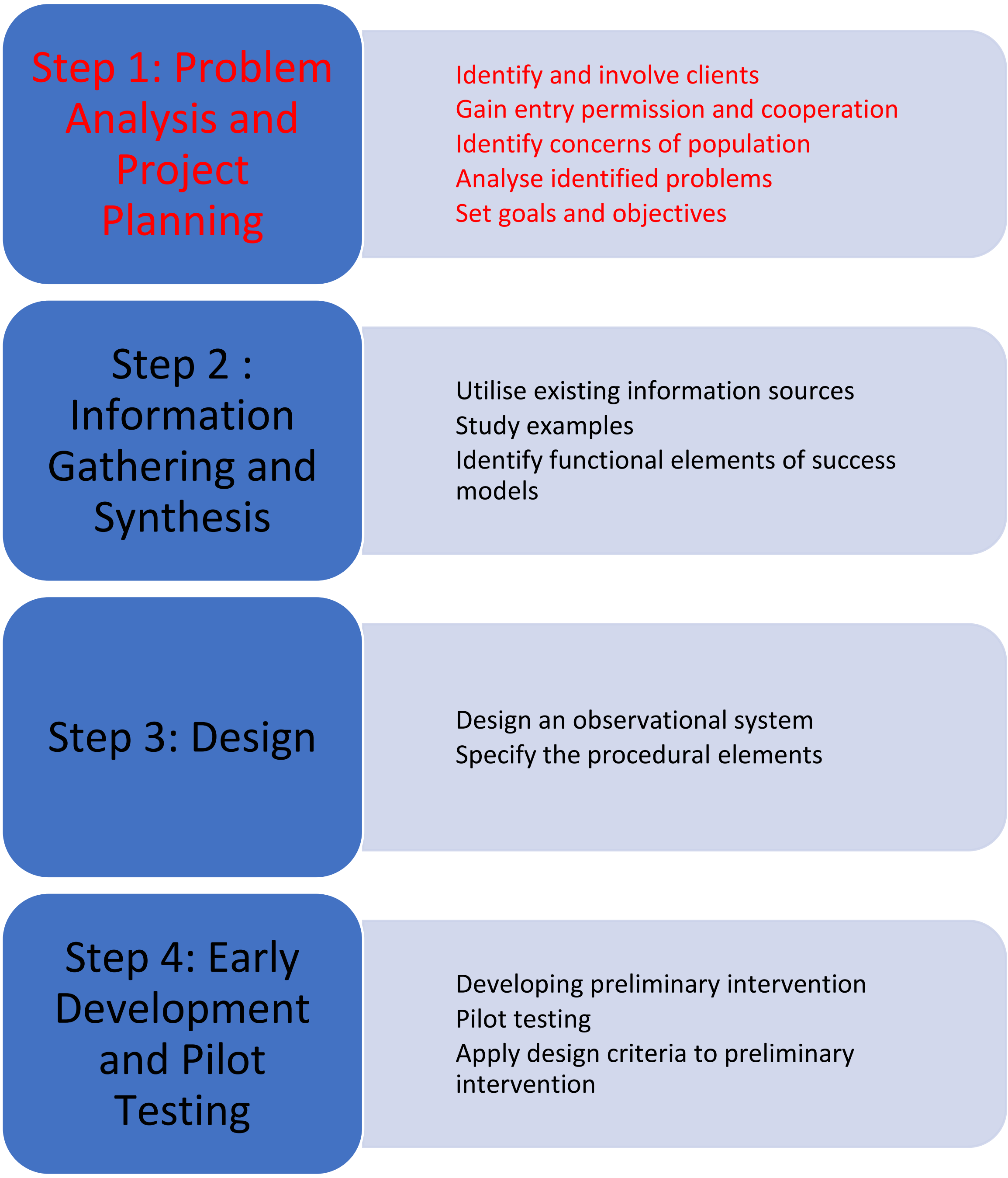


Figure 1: Graphic representation of the phases of intervention research. Adapted from Rothman and Thomas (1994:28); Fraser and Galinsky (2010:459-466).

1.1 Introduction

With 98% of people living with intellectual disability in the Western Cape and being the responsibility of their caregivers, these caregivers are often the unacknowledged heroes of the intellectual disability community (Mckenzie, McConkey & Adnams, 2016:45-54; Kench, 2016:163). Caregivers often sacrifice their aspirations in their devotion to the person living with intellectual disability - with little, to no, monetary remuneration and recognition (Kench, 2016:163; Coetzee, 2016:157; Perkins, 2009:11). Often, they neglect themselves emotionally, as well as physically, and this could lead to burnout and depression (Coetzee, 2016:157).

In the present study, the researcher sought to understand the issues that could lead to caregiver burnout and endeavoured to develop a solution through a targeted psychoeducational programme for caregivers. Chapter 1 outlines the background of the study, its rationale and problem statement, goals and objectives, an overview of the research methodology and the content of the chapters.

1.2 Background

People living with intellectual disability have a significantly reduced ability to understand new or complex information and to learn and apply new skills (World Health Organisation (WHO) [s.a.]; Salvador-Carulla & Bertelli, 2008:10; Adnams & Johns, 2016:8; Purugganan, 2018:299). This results in a reduced ability to cope independently (impaired social functioning) and begins before adulthood, with a lasting effect on development (WHO [s.a.]; Salvador-Carulla & Bertelli, 2008:10; Adnams & Johns, 2016:8; Purugganan, 2018:299).

It is estimated that approximately 1%-2% of the world’s population are living with intellectual disability (Maulik, Mascarenhas, Mathers, Dua & Saxena, 2011:419-436; Weise, Pollack, Britt & Trollor, 2016:1119-1127). In terms of the global context, Capri, Abrahams, McKenzie, Coetzee, Mkabile, Saptouw, Hooper, Smith (2018:1-17) state that intellectual disability is the most prevalent disability worldwide.

Within a national context, South Africa - as a lower-middle-income country - has a greater prevalence of intellectual disability than high-income countries (Capri et al., 2018:1-17). Additionally, within the Western Cape, a large population-based study conducted in 2002 and 2003 reported that about 3% of the population of the Western Cape live with intellectual disability (Kleintjes, Flisher, Fick, Railoun, Lund, Molteno & Robertson, 2006:157-160). Based on more recent statistics regarding the population of the Western Cape, Coetzee, Swartz, Capri and Adnams (2019:3) estimate that 195 000 individuals live with intellectual disability. Mckenzie et al. (2016:45-54) have deduced that approximately 98% of people with ID are living with their families and caregivers in their communities - with an informal and unpaid arrangement. The latter authors further state that the remaining 2%, predominantly from the Coloured and White culture rather than the Black culture, are living in residential group-home facilities being taken care of by formal paid caregivers.

The burden of caregiving can leave the caregivers of people with ID emotionally depleted as there are currently few evidence-based programmes available to support them (Smith Da Walt, Greenberg & Mailick, 2018:251-263). A targeted psychoeducational programme has been shown to reduce caregiver stress and improve outcomes for both the caregiver and the person with intellectual disability (Smith Da Walt et al., 2018:251-263).

Intervention research guided the present study which intends to address the research gaps in psychoeducational programmes for this particular group of caregivers. Such a programme, aiming to educate parents and/or caregivers about intellectual disabilities, related mental illnesses and how to manage challenging behaviour, was designed by the researcher.

The research was conducted in the Western Cape Province, South Africa. Data collection took place from May 2021 to June 2022. Both paid and unpaid caregivers of people with intellectual disability were the main concern of this study. The theories that underpin the study are discussed in Chapter 2, namely the biopsychosocial theoretical framework and the strength-based approach. Chapters 3, 4 and 5 present the literature review. Chapter 6 offers a detailed discussion of the research methodology that was followed. The first phase of the research involved the collection of qualitative data from informal (unpaid) caregivers, the analysis and interpretation of these data, including the findings, are discussed in Chapter 7. Next, Chapter 8 outlines the development of the psychoeducational programme for this particular group. The second phase of the research entailed collecting quantitative data from formal (paid) caregivers. Chapter 9 provides an analysis, interpretation and a discussion of these empirical findings. Chapter 10 contains a discussion of the key findings of the study, followed by conclusions based on these findings. Moreover, the researcher provides recommendations for practice and further research.

The following key concepts are relevant to the study:

Intellectual Disability: Intellectual disability means intellectual and adaptive difficulties in three domain skills, namely conceptual skills (thinking and reasoning), social skills (interpersonal communication), as well as practical skills (ability to care for self) (Adnams & Johns, 2016:8). In the present study, intellectual disability is characterised by significant limitations in reasoning, learning, problem-solving and adaptive functioning. A person living with intellectual disability needs assistance in making informed decisions and may need help with activities of daily living, such as brushing their teeth and getting dressed.

Formal Paid Caregivers: In the context of the present study, a formal, paid caregiver is a person who is employed to support the needs of a person, or people, with intellectual disability. However, caregivers may or may not have formal qualifications in caregiving (Coetzee, 2016:157-158). Examples of formal, paid caregivers are care assistants and housemothers in residential homes for people with intellectual disability, supervisors in protective workshops for people with ID, and nurses caring for people in small or large institutions, such as hospitals (Coetzee, 2016:157-158; Kench, 2016:163). However, in the present study, formal caregivers will include all examples of caregivers mentioned above but will exclude nurses in large institutions, such as hospitals.

Informal Unpaid Caregivers: Mtshali (2017:1) explains that the term ‘informal caregivers’ came into existence in South Africa when people with intellectual disability were re-integrating into their community from institutional living as previously ordained by the apartheid era. The term usually refers to the parents, siblings, grandparents or other relatives who would take care of such a person without formal remuneration for their services in caregiving. This type of caregiving has a higher prevalence in South Africa than in other countries due to the lack of residential placement and vocational opportunities for people living with intellectual disability (Coetzee, 2016:157). In the present research, unpaid caregivers included biological mothers, fathers, siblings, grandparents and other relatives. Informal unpaid caregivers also include community members who have taken on the direct role of full-time caregiving without being formally paid or being biologically related to the person living with ID, such as foster-care parents and community neighbours.

Psychoeducational Programme: A psychoeducational programme refers to a highly structured evidence-based programme that often follows a manual or a pre-planned curriculum. The goal of a psychoeducational programme is to provide education regarding the disability, provide practice guidelines in problem-solving and render opportunities for social support with others who have similar experiences. Having this in place will, in turn, alleviate caregiver distress (Smith Da Walt et al., 2018:251-263).

In the present study, the definition of a psychoeducational programme is an evidence-based therapeutic intervention that follows a pre-planned set of topics within a manual for caregivers of people with intellectual disability in order to provide information and support to better understand and cope with the impairment.

Caregiver Distress: Caregiver distress is a condition that manifests as exhaustion, depression, anger and/or guilt due to unmitigated caregiver responsibilities for someone with a disability (Lipsky & Burk, 2009:303-319; Blouin, Smith-Miller, Harden & Li, 2016:329-335; Catalano, Holloway & Mpofu, 2018:2). High caregiver distress correlates with negative caregiver and care-receiver interaction, which can exacerbate problem behaviour displayed by the person with ID (McConnell & Savage, 2015:101). The concept ‘caregiver distress’ is discussed throughout the thesis, particularly in greater detail in Section 4.3.

1.3 Problem Statement and Rationale of the Study

Based on the literature review, numerous studies have been conducted in the field of caregiving and persons with ID (Yoong & Koritsas, 2012:609-619; McKenzie et al., 2016:45-54; Adnams & Johns, 2016:8; Lauderdale-Littin & Blacher, 2017:230-239; Smith Da Walt, Greenberg & Mailick, 2018:251-263). Research has also been done on the prevalence of intellectual disability in the Western Cape (Kleintjes et al., 2006:157-160; Mckenzie et al., 2016:45-54). Furthermore, studies on the intellectual disability caused by fetal alcohol syndrome and its prevalence in the high-risk area of the Western Cape have been undertaken (May, Brooke, Gossage, Croxford, Adnams, Jones, Robinson & Viljoen, 2000:1905-1912; May, Blankenship, Marais, Gossage, Kalberg, Barnard, De Vries, Robinson et al., 2013:818-830). However, the literature does not indicate a targeted psychoeducational programme for caregivers of people with intellectual disability within the Western Cape.

The challenges of educational and support needs of this population group are unique, and the focus of the study is to address this research lacuna. The researcher, as a social worker, worked in the field of intellectual disability within the Western Cape for over a decade and found the lack of adequate resources and insufficient support to the caregivers to be an impediment to social work service delivery. These inadequacies prompted the researcher to conduct the present study and, therefore, contribute to the research field to benefit caregivers of people with intellectual disability.

The study allows the researcher to address the scientific gap identified in the literature, and the contribution which it aims to make is that it would particularly benefit people living with intellectual disability, as the opportunity has been created to enhance the insight, knowledge and skills of their parents, siblings and neighbours upon whom they depend as their caregivers. An additional benefit of the study is to organisations that provide residential care to people with intellectual disability. The management of these authority structures would be able to develop a greater awareness of the inner workings of their employed caregivers to whom they entrust the care of the persons with intellectual disability. The information would provide management with (a) the opportunity to re-evaluate the support structures in place regarding whether they adequately address the needs of the formal caregiver employees and (b) the tools to enhance the skills of their caregivers.

1.3.1 Research Question

The research question should be clear and relate to the goal of the study (Maree & van der Westhuizen, 2011:30).

The following research question guided the study:
What constitutes a psychoeducational programme for caregivers of people living with intellectual disability?

The following research **sub-questions** inform the research question:

- What is the nature, extent, cause and impact of caregiver distress amongst caregivers of people with intellectual disability?
- What core elements should be included in a psychoeducational programme that would alleviate caregiver distress?

1.4 Goal and Objectives

The study aimed to develop, implement and evaluate a psychoeducational programme for caregivers of people with intellectual disability, who were the unit of analysis of the study within the Western Cape.

The specific objectives of the study are described in the following two categories:

1.4.1 Objectives for the Qualitative Phase (first phase with informal caregivers):

- To contextualise caregiving of people with intellectual disability using the biopsychosocial model and strength-based approaches.

- To explore the experiences of caregivers of people living with intellectual disabilities.
- To gather information regarding the care needs of people living with intellectual disabilities and the impact thereof on caregivers.
- To ascertain the specific knowledge and skills required by caregivers of people living with intellectual disabilities.

1.4.2 Objectives for the Quantitative Phase (second phase with formal caregivers):

- To design a psychoeducational programme for caregivers of people with intellectual disabilities based on the needs identified in the first phase and aimed at improving their knowledge of ID and its challenges.
- To conduct a pre-test measurement with caregivers regarding their knowledge of caregiving of people with intellectual disabilities.
- To implement the psychoeducational programme through training of caregivers during a one-day session.
- To conduct a post-test measurement with caregivers regarding their knowledge of caregiving of people with intellectual disabilities after completion of the training.
- To analyse the effectiveness of the programme by comparing pre- and post-test results.
- To draw conclusions and make recommendations based on the research findings for further refinement and implementation of the proposed psychoeducational programme.

1.5 Research Hypothesis

A hypothesis is a belief or an idea of the nature of certain study variables in the population, is derived from a theory and is a statement of something that should be observed in the real world to establish whether the theory is correct (Babbie & Mouton, 2001:643; Pietersen & Maree, 2011a:203).

1.5.1 Hypothesis

If caregivers participate in a psychoeducational programme developed during this study, this will alleviate caregivers' distress and their level of care-related knowledge and resilience skills will improve as they render caregiving services to people with intellectual disabilities in the Western Cape.

1.5.2 Sub-hypothesis

A psychoeducational programme for caregivers of people in the Western Cape who live with ID will improve the former's care-related knowledge and skills, as well as alleviate their work-induced distress.

1.6 Research Methodology

The study is rooted in the mixed-methods research approach, as the researcher intended to collect both numeric and text data. Intervention research is applied action undertaken by the researcher to maintain or enhance the functioning and well-being of an individual, family, group, community or population (De Vos & Strydom, 2011:473-475). Thus, the type of research undertaken is applied intervention research, as the researcher identified the problem, sought assistance in ascertaining the extent of the problem, and then applied solutions to the problem (Abbott & McKinney, 2013:50).

The researcher applied the embedded mixed-methods design, which is a variant of the mixed-methods research approach (Ivankova, Creswell & Plano Clark, 2011:269-270). In this design, one data set plays a supportive, secondary role in a study based primarily on the other data set. For the first phase, the qualitative approach, a case study design, more specifically a collective case study design, was utilised, so that comparisons could be made between cases (Fouchè & Schurink, 2011:322). For the second phase, the quantitative approach, the researcher used the pre-experimental design, namely the 'one-group pre-test post-test design', which contributed to making valuable interpretations and comparisons regarding the impact and value of the psychoeducational programme (Fouché, Delport & de Vos., 2011:147-148). The qualitative phase informed and supported the quantitative phase.

During the qualitative phase, the researcher used the purposive sampling method, as her judgement informed the sampling of 25 participants who would partake in the study. The researcher developed a semi-structured interview schedule for data collection during the qualitative phase. These data were analysed using a thematic analysis. During the quantitative phase, the researcher made use of probability sampling as the researcher had a list of names and the selection was completely random (Strydom, 2011b:228; Maree & Pietersen, 2011a:172). Using the training programme, a pilot test was done with nine respondents. Thereafter, a one-day training event (split over two days), in which 100 participants took part, was arranged for the research purpose. The researcher utilised pre- and post-test questionnaires as data collection instruments. An independent coder was used to ensure the trustworthiness of the data. The research methodology is discussed in greater detail in Chapter 6.

1.7 Chapter outline

This research report consists of the following chapters.

Table 1: Chapter outline

CHAPTER	DESCRIPTION
Chapter 1 General introduction to the study	Chapter 1 contains the general overview of the research topic, followed by the rationale and problem statement, the goal and objectives of the study, as well as a summary of the research methodology.
Chapter 2 Theoretical framework	In Chapter 2, an in-depth discussion of the theoretical framework underlying the study, namely the strength-based approach and the biopsychosocial model, is provided.

Chapter 3 Literature review: Conceptualising intellectual disability	In Chapter 3, intellectual disability is defined and conceptualised.
Chapter 4 Literature review: The care needs of people with ID and the impact on the caregiver	This chapter presents a literature overview of the care needs of people with intellectual disability and the impact this has on the caregiver. The role of the social worker and applicable legislation are discussed.
Chapter 5 Literature review: Psychoeducational programme for caregivers of people with ID	A literature overview is given on the significance of a psychoeducational programme for caregivers of the persons with intellectual disability and the core elements that should be included to enhance caregiving skills and alleviate caregiver distress.
Chapter 6 Research methodology	This chapter contains a detailed discussion of the research methodology that was followed in the study.
Chapter 7 Research Findings: Qualitative phase	This chapter provides an analysis and interpretation of the mixed-methods research approach: qualitative data analysis.
Chapter 8 Psychoeducational programme for caregivers of people with ID	An outline of the psychoeducational programme for caregivers of people with intellectual disability is provided in this chapter.
Chapter 9 Research Findings: Quantitative phase	This chapter provides an analysis and interpretation of mixed methods research approach: quantitative data analysis. This includes a discussion of the empirical findings.

Chapter 10 Summary, conclusions, and recommendations	The key findings of the study are discussed, followed by conclusions based on these findings. The researcher also provides recommendations for practice and research.

1.8 LIMITATIONS OF THE STUDY

Although this research was carefully prepared, the researcher is still aware of its limitations and shortcomings. Limitations and strengths of the study are also discussed in Section 10.5. The following have been found to be the main limitations to the study:

1.8.1 Duration of the training

The programme was developed as a one-day training. However, due to the complexity of intellectual disability the researcher concedes that caregivers may need more training than what was offered.

1.8.2 The views of persons with ID were excluded

Persons with intellectual disability did not participate in the research. It should be respected that people with intellectual disabilities have their own opinions and insights into their care needs and how they wish to be supported by their caregivers. Their views would have added rich value to the psychoeducational programme. There were however ethical and practical challenges associated with conducting empirical research with people with intellectual disabilities such as informed consent.

1.8.3 Different lived experiences between formal and informal caregivers

The manual was developed based on the interviews with informal caregivers. However, the preliminary intervention was conducted with formal caregivers. The reason for this was in the difficulty of recruitment of the adequate number of informal caregivers needed for the second phase of the research study due to impracticalities such as finding alternative care for an entire day to participate in the psychoeducational programme and the lack of transportation. However, the formal caregivers may not have the same lived experience as the informal caregivers, and this could impact their responses in the questionnaires.

1.9 SUMMARY

Despite the notable role played by caregivers in caring for people with intellectual disabilities, a psychoeducational programme that could address caregiver distress is yet to be investigated. Previous research has not assessed the prevalence of care-related distress experienced by this particular group of caregivers in the Western Cape to propose a solution to the problem.

The hypothesis of the study is that, if caregivers were to participate in the psychoeducational programme developed during this study, this would help alleviate caregiver distress and their level of care-related knowledge and resiliency skills would improve.

An overview of the research methodology in the present study was provided.
An overview of the contents of the research report was provided. The next chapter discusses the theoretical framework that guided the study.

CHAPTER 2
THEORETICAL FRAMEWORK FOR THE STUDY

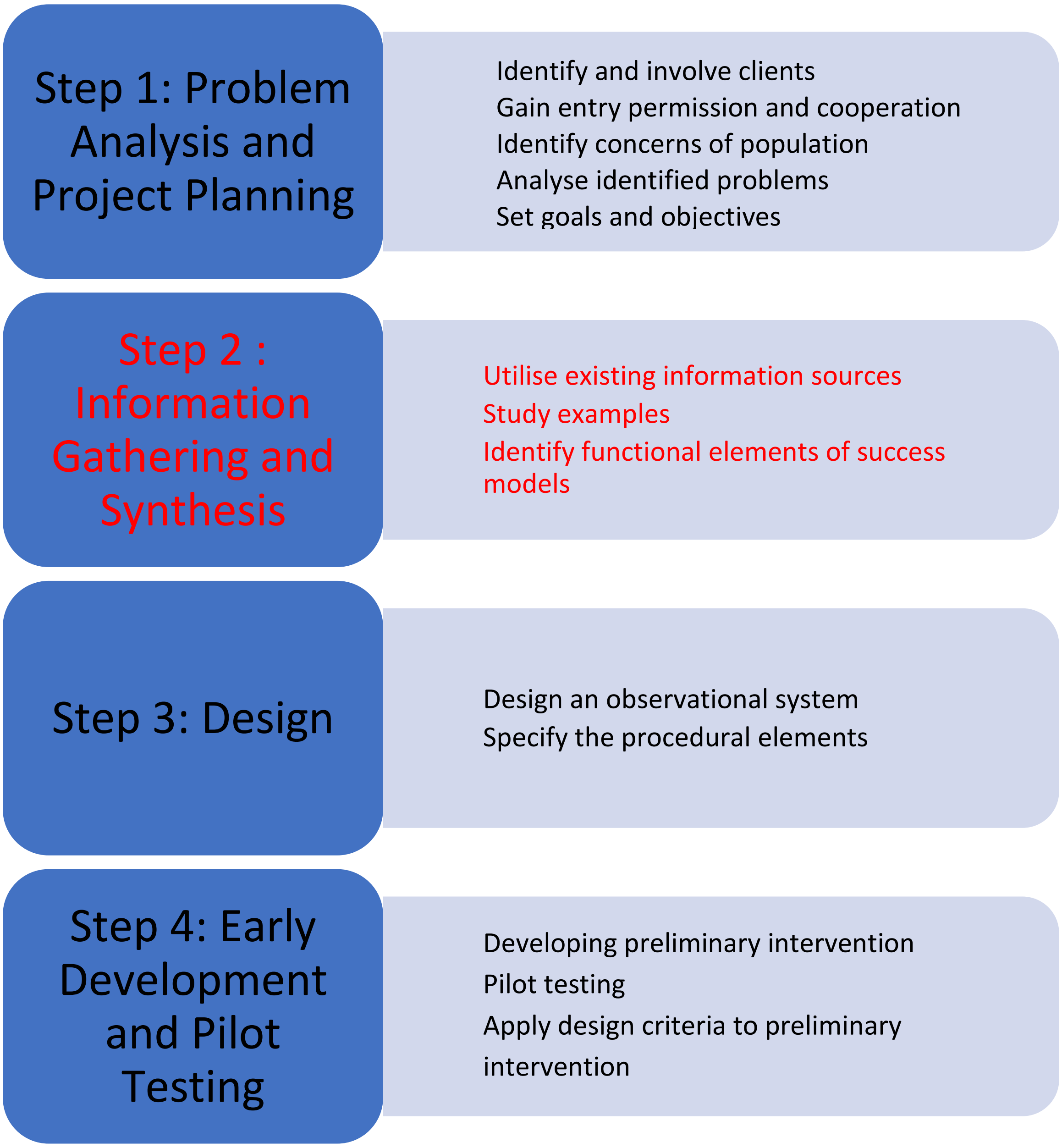


Figure 2: Graphic representation of the phases of intervention research. Adapted from Rothman and Thomas (1994:28); Fraser and Galinsky (2010:459-466)

2.1 Introduction

The researcher aims to develop a positive biopsychosocial capacity and capability in caregivers through a strength-based approach (Black & Hoeft, 2015:13-20). Therefore, the most applicable theoretical frameworks to guide the proposed study are the biopsychosocial model and the strength-based approach. The researcher observed a shared mission and a compatibility that distinguish these two theoretical approaches. Both aim to shift the help professions from a problem-based paradigm to embracing a collaborative approach. This should be accomplished by elevating caregivers to an expert level status at which they can identify ways of building their own resilience and protecting their health (Engel, 2003:2; Pulla, 2017:102).

2.2 Biopsychosocial Model (BPS Model)

The biopsychosocial model will be discussed next. After an introduction to the model, its evolution, three of its broad aspects, as well as its relevance to this study, will be elaborated upon.

2.2.1 Introduction to the BPS Model

The biopsychosocial model systematically considers the biological, psychological and social aspects of the life and circumstances of people with intellectual disability, as well as their complex interactions, in order to understand health, illness and service delivery (Black & Hoeft, 2015:13-20; Wade & Halligan, 2017:995-1004). This model incorporates understanding and assisting the individual, whilst considering all relevant factors and their interactive roles as they pertain to the individual’s health (Black & Hoeft, 2015:13-20; Wade & Halligan, 2017:995-1004).

Regarding the biological factors, emphasis is placed on biological processes, such as physical health and disability (Black & Hoeft, 2015:13-20; Wade & Halligan, 2017:995-1004). The psychological factors encompass experiences with respect to self-concept, coping skills and social skills (Black & Hoeft, 2015:13-20; Wade & Halligan, 2017:995-1004). Lastly, the social factors include environmental, cultural and social contexts, such as interpersonal peer relationships, employment and family dynamics (Black & Hoeft, 2015:13-20; Wade & Halligan, 2017:995-1004).

Suchman, Decoste, Rosenberger and McMahon (2012:360-371) state that these three components of the biopsychosocial model can be translated into practice through the design of psychosocial interventions and programmes to reduce stress through building the caregivers' capacity for sensitive and competent caregiving.

By utilising the biopsychosocial model to guide this research study, the prospect of developing a manual that is ecologically grounded and meaningful to people living with intellectual disability and their caregivers, would be significantly improved as it would allow for a greater understanding of how biological (stress response and brain development), psychological (emotion regulation and cognition) and social (behaviour regulation and functioning in families) development unfolds in a systems context (Black & Hoeft, 2015:13-20).

2.2.2 Evolution of the Biopsychosocial Model

Various models attempt at providing a conceptual framework and description of what disability is and how people experience the disability (Petasis, 2019:49; Retief & Letšosa, 2018:1-8). The most prevailing and commonly applied models are the medical, the social and the biopsychosocial model of disability (Petasis, 2019:49).

2.2.2.1 The religious model for disability

The oldest model of disability is the religious one which interprets disability as a punishment from God for sins committed by parents or ancestors (Retief & Letšosa, 2018:2). This model has a detrimental effect on families as the understanding is that, should the person not heal from his or her disability, it reflects on the family's lack of faith in God (Retief & Letšosa, 2018:2).

Most recently, it is the religious coping style, encompassing religious beliefs and faith values, which caregivers use more commonly to manage the disability (Gona, Mung'ala-Odera, Newton & Hartley, 2011:175-181; Panicker & Ramesh, 2019:1-14). When caregivers find themselves in a state of helplessness to meet life's challenges, they turn to their spiritual beliefs for hope (Gona et al., 2011:181; Ezeonu, Obu, Daniyan, Asiegbu, Oyim-Elechi, Edafioghor & Okoro, 2021). Particularly in low resource countries, a caregiver's religious belief that there is a reason for the disability, as well as his or her trust in their personal faith, provides endurance and alleviates caregiver distress (Ezeonu et al., 2021).

2.2.2.2 The medical model for disability

In the mid-1800s, the medical model gradually began to replace the religious model (Retief & Letšosa, 2018:2). According to this model, disability is regarded as a medical problem that resides within the person with the disability (Retief & Letšosa, 2018:3). Therefore, the medical model considers disability an illness and sets about developing a treatment plan which includes identifying the 'malfunction' and attempting to 'repair' it (Retief & Letšosa, 2018:3; Petasis, 2019:42).

In South Africa, the predominantly followed model is the medical model which reinforces stereotyping and isolation of people with ID (Petasis, 2019:49). Because of its interpretation of intellectual disability, people with disabilities are excluded from society (e.g., employment opportunities) and this leads to a lack of financial resources (Petasis, 2019:49). Often the adult with intellectual disability will sit at home with nothing to do (McKenzie & McConkey, 2016:536).

Disability was treated and understood within the context of the medical model before the development of the social model (Retief & Letšosa, 2018:3; Petasis, 2019:42).

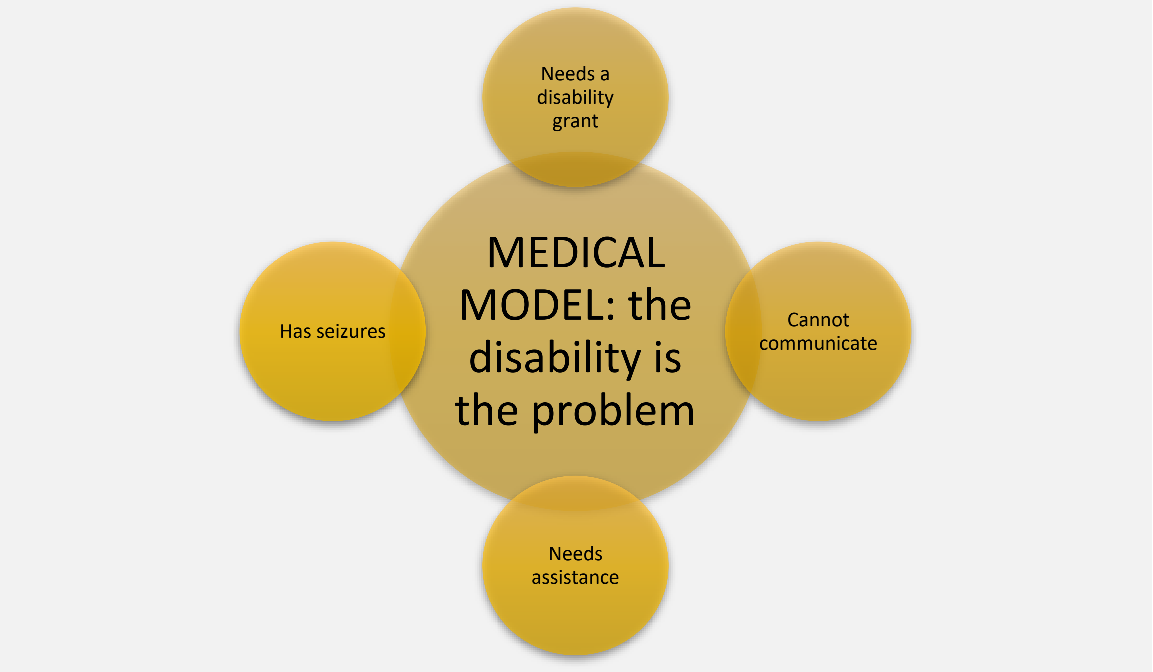


Figure 3: Depiction of the medical model of disability (Adapted from Shabodien 2016:4)

2.2.2.3 The social model for disability

Regarding disability, one of the neglected areas of the medical model is the social component of disability (Petasis, 2019:42). The social model was developed in the 1960s as a reaction to the limitations of the medical model (Retief & Letšosa, 2018:3).

Mike Oliver, who was a lecturer with a disability and an activist, coined the phrase "social model for disability" in 1983. He believed that disability is a situation caused by social conditions (Morgan, 2012:215-226; Retief & Letšosa, 2018:3; Petasis, 2019:44).

The social model of disability assumes that disability is affected by systemic obstacles relative to social and political paradigms (Petasis, 2019:42; Retief & Letšosa, 2018:4). Thus, the social model asserts that there are external social factors that are imposed on the person with the disability, which leads to isolation and exclusion from society (McKenzie, 2016:67-78; Petasis, 2019:42).

The social model is particularly concerned with addressing the "barriers to participation" as people with disabilities continue to live marginalized and excluded from society (Morgan, 2012:215-226; McKenzie, 2016:67-78; Retief & Letšosa, 2018:4). One of the criticisms against the social model is that it completely separates the social impairments from the disability which remains central to the person with disability's lived experience (Petasis, 2019:48). However, social model supporters uphold the notion that the impairments are not part of the disability and, therefore, the individual is not disabled; it is the environment that is disabling (Doyle, 2020:108; Petasis, 2019:48).

Figure 4: Depiction of the social model of disability (Adapted from Shabodien 2016:5)

2.2.2.4 The biopsychosocial model for disability

The biopsychosocial model for disability evolved in the 1970s out of the medical model for disability and aimed to address the neglected areas of the medical model (Engel,1977:129-136; Petasis, 2019:48; Engel, 2003:19). The biopsychosocial model follows a philosophy that incorporates both the medical and social models of disability (Petasis, 2019:48).

The biopsychosocial (BPS) model was originally described by Engel - a Professor of Psychiatry at the University of Rochester - in his paper 'The Need for a New Medical Model: A Challenge for Biomedicine' (Engel,1977:129-136). Engel attended a conference at which divergent opinions were put forward, some physicians preferring the ‘clear cut’ world of biomedicine versus those who felt that medical practice, at that time, was outdated as it ignored behavioural and psychological problems. Engel believed the latter and argued that a new model was needed to address the totality of illness, such as stress and its effects on behaviour (Engel,1977:129-136).

Engel (1977:129-136; 2003:2) highlighted the limitations of the medical model that would provide medication for an illness; that did, however, fall short at understanding and treating the social, psychological and behavioural dimensions of an illness, such as stress.

The way in which a physician approaches individuals is influenced by the conceptual models to which he/she subscribes (Engel, 2003:1). Physicians are unaware of the power of these models on their thinking and treatment plans (Engel, 2003:1). The biopsychosocial model is an alternative to the flawed and limited medical model. According to the medical model, the physician is the expert in the interaction, capable of providing relief from stress. This cripples the desired outcomes as it does not include the attributes of the individual as a human being (Engel, 2003:3). However, the biopsychosocial model encourages patient participation in the treatment plan (Engel, 1977:129-136; Engel, 2003:2).

The hallmark of a scientific model is that it provides a framework within which it may be applied (Engel, 2003:19). Both the medical and biopsychosocial models are scientific models. However, the biopsychosocial model addresses the neglected areas of the medical model (Engel, 1977:132; Engel, 2003:19).

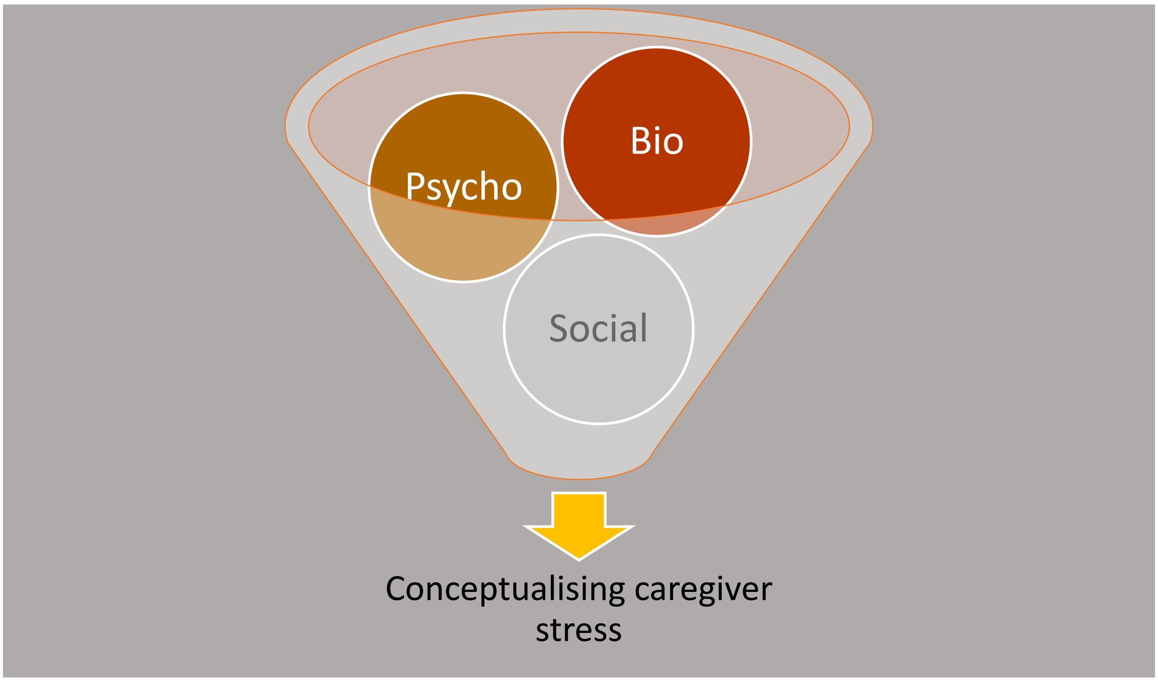


Figure 5: Conceptualising caregiver stress through the filter of the BPS Model (Adapted from Shabodien 2016:6)

2.2.3. The three Aspects of the Biopsychosocial Model

The biopsychosocial model examines how three important aspects (the biological, psychological and social) play a role in well-being, and emphasises the interconnectedness of these aspects.

2.2.3.1 Biological

Caregivers of people with intellectual and developmental disabilities tend to neglect their own physical health (Lafferty, O'Sullivan, O'Mahoney, Taggart & Van Bavel, 2016:19; Dawson et al., 2016:553-563). Mothers of adult children with ID have been found to be at an increased risk of physical health conditions associated with chronic stress, such as obesity, cardio-vascular diseases, auto-immune diseases and gastrointestinal disorders (McConnell & Savage, 2015:101). Parents of children with intellectual disability often presents with hypersomnia, poor concentration, weight-loss or weight-gain (Ugwuanyi, Ede, Agbigwe, Onuorah, Amaeze, Edeh, Aye, Ezeh, 2022:2). Poor physical health can have a disruptive effect on the caregiver's daily life.

2.2.3.2. Psychological

Parents of children with intellectual disability tend to be more anxious and obsessive (Ugwuanyi et al., 2022:2). Symptoms of depression, anxiety and even PTSD could emerge from the onset of being informed that their child has an intellectual disability (Mkabile, Garrun, Shelton & Swartz, 2021:1).

These parents also lack initiative and tend to be pessimistic due to the psychological strain of having a child with ID (Ugwuanyi et al., 2022:2). Caregivers who experience poor psychological well-being are more likely to have lower levels of resilience (Lafferty et al., 2016:15).

The psychological stress of paid caregivers of people with ID can be very costly to themselves, their work organisations, as well as the wider society (Leoni, Corti, Cavagnola, Healy & Noone, 2016:59-73). Their psychological stress is the result of their emotional and psychological reactions when they are unable to cope with caregiver demands (Singh, Lancioni, Medvedev, Myers, Chan, McPherson, Jackman & Kim, 2020:99-111; Ugwuanyi et al., 2022:3). In addition, the behaviour of the person with intellectual disability also has an impact on the psychological well-being of the caregiver (Adams, Rose, Jackson, Karakatsani & Oliver, 2018:257-275).

Interventions that include mindfulness and positive behaviour support have been found to have a positive psychological impact on both the person with intellectual disability as well as his or her caregiver (Singh et.al., 2020:99-111).

2.2.3.3 Social

Literature lacks information on social support for caregivers of people with ID in middle-income countries (Dada, Bastable & Halder, 2020:6644). The caregiver's capacity to support the person with ID in his or her effort to participate in social interactions may be linked to the amount of social support that they, as caregivers, receive. The responsibilities of these caregivers may cause them to withdraw from social relations due to the stigma attached to the phenomenon of intellectual disability (Mak & Cheung, 2008:532-533). Social factors associated with low resilience in these caregivers include low levels of family support and lower levels of social connectedness (Mak & Cheung, 2008:541; Lafferty et al., 2016:15). Having strong familial relationships is considered a key protective factor in maintaining caregiver resilience, particularly as families can pool their resources, maintain good communication, stay connected and share caregiving responsibilities (Mak & Cheung, 2008:541; Lafferty et al., 2016:15).

Social support can be sought from partners, family, extended family, friends, neighbours in the community, faith-based services, as well as networks developed through volunteering (Lafferty et al., 2016:16). Social support for the caregivers may also increase participation, as well as educational, psychological, medical and financial opportunities, for the person living with ID (Dada et al., 2020: 6644). Consequently, support and intervention should be directed both at the person with intellectual disability as well as his/her caregiver.

Furthermore, society needs to find ways to include people with ID and their caregivers in social, economic and political spheres.

2.2.4 Relevance of the Biopsychosocial Model to the Study

From a clinical perspective - whether a physician, a social worker, or any health professional - we need to gain an understanding of the daily experiences of caregivers of people with ID, considering multiple factors (e.g., income, education, community) that influence who they are (Bennett, Rohleder & Sturmberg, 2018:1339-1346).

To have a comprehensive understanding of a caregiver's lived experiences, it is important to consider all aspects of the phenomenon. The social model of disability proposes that the disability is caused by social exclusion of and discrimination against people with ID. On the other hand, the medical model emphasises that the impairment is within the individual, and this distinguishes him or her from non-impaired individuals (Petasis, 2019:48). The biopsychosocial model, however, encompasses both the medical and social modalities by presenting a more comprehensive and integrated understanding of impairment (Petasis, 2019:48).

What distinguishes the biopsychosocial model is that it allows the person with ID and his/her caregiver to become a member of the 'experts' who suggest solutions to the problem (Engel, 1977:129-136; Engel, 2003:2). The biopsychosocial model is based on the philosophy that disability is an interaction between three factors: namely, physical (bio), psychological (behaviour) and social (cultural environment) (Petasis, 2019:48). The biopsychosocial model provides a comprehensive framework from which to understand the needs, desires and interactions of the person with intellectual disability and the caregiver family (McDaniel & Pisani, 2012:12).

Intervention researchers attempt to enhance their understanding of community conditions and, in particular, the effectiveness of interventions designed to improve them. In so doing, these researchers blend their roles of scientist and change agent as they intend to understand and improve communities (Fawcett et al., 1994:49-51). By involving the caregivers as collaborators in the present study, its design and development efforts build on the knowledge of those who are affected.

Bennett et al. (2018:1339-1346) argue that, if an intervention can improve a caregiver’s ability to acclimatise to acute stress, then it may assist caregivers in managing their own daily stress, so that it does not negatively impact their physical health and may further improve their physical and mental wellness. Fouché, Delport and De Vos, (2011:148) concur with Bennett et al. (2018:1339-1346), and believe that, should a positive change occur, the researcher may conclude that the intervention was the cause of this improvement.

A critique against the biopsychosocial model is that it does not provide the simplest answer to a question to the degree that the medical model does (Philip & Cherian, 2020:219). However, by utilising the biopsychosocial model to comprehend caregiver challenges and resilience, the researcher comes to understand stress habituation and when to intervene.

Only once the researcher has this holistic understanding, will he/she have the clarity to recognise which intervention to use to address caregiver needs and motivate caregivers to engage in health protecting behaviours (Bennett et al., 2018:1339-1346).

2.3 Strength-based Approach

2.3.1. Introduction to the Strength-based Approach

Integrated with the biopsychosocial model, the researcher has also utilised the strengths-based approach to premise the study.

Fundamental to social work interventions is the practice of empowerment of the clients they serve, and the strength-based approach allows clients to play a role in their own empowerment and discover their own strengths (Pulla, 2017:98). The strength-based approach guides clinicians to veer away from a problem-focused lens that categorises clients as hopeless (Pulla, 2017:98; Ginsburg & Jablow, 2020:353; Moorkath, Ragesh & Hamza, 2019:175).

The strength-based approach is a deliberately planned and sustained use of strengths that promotes resilience as opposed to deficits (Pulla, 2017:99-100; Moorkath, Ragesh & Hamza, 2019:175).

The goal of the strength-based approach is to build and develop the individual's natural abilities and strengths to the point that this will diminish their need to engage in maladaptive behaviours (Ginsburg & Jablow, 2020:354).

The strength-based approach is based on the premise that people who face adversity and crises become resilient and resourceful. They learn skills to overcome adversities and view challenges as opportunities to practise their resourcefulness and respond in culturally meaningful ways (Moorkath et al., 2019:175).

2.3.2 Evolution of the Strength-based Approach

The strength-based approach emerged in the late 1980's as an alternative to previous dominant models (Pulla, 2017:102). The strength-based approach in social work emerged during a period when the helping professions were saturated with psychosocial approaches based on individual, family and community pathology (Saleebey, 1996:296-305).

Victimhood became ‘big business’ driven by a variety of therapists, gurus and ministers on the hunt for ‘wounded inner’ children and toxic family backgrounds (Saleebey, 1996:296-305). The strength-based approach does not allow social workers to ignore real problems. However, it does deny that individuals who face trauma and adversity are incapacitated or fail to evolve into the person they might have been (Saleebey, 1996:296-305). The strength-based approach demands a different way to look at individuals, families and communities (Saleebey, 1996:296-305).

The strength-based approach is based on the premise that an individual possesses a range of capabilities and inherent wisdom. It also highlights that the individual has lived through a range of experience, has developed characteristics and played roles that contribute to who he or she is and how he or she copes with a situation. Furthermore, the strength-based approach highlights the power of resilience in managing a challenging situation and helps persons to move towards hope (Moorkath et al., 2019:175).

2.3.3 Principles of the Strength-based Approach

Social workers who work in the mental health field, which is still predominantly influenced by the medical model, often continue to work with deficiencies. The strength-based approach does not ignore problems or deficiencies, but instead focuses on inherent strengths, mobilising resources and respecting the inherent wisdom of the client. This leads to these resources being discovered in the community in which they reside (Pulla, 2017:101; Moorkath et al., 2019:175).

Social problems within a developing country, such as a lack of resources or poverty, cannot be escaped. However, the strength-based approach compels the researcher towards the upper limits of human capacity and persuades him or her to work collaboratively with caregivers to perceive all possibilities that could build their hope, aspirations and visions (Pulla, 2017:101-102; Saleebey, 1996:296-305).

Figure 6: Depiction of the core strength principles adapted from Pulla (2017:110) and Hammond (2010:6)

2.3.3.1 Social Justice

Caregivers of people with ID daily face numerous social injustices from stereotyping to stigma and discrimination (Mak & Cheung, 2008:532). People with ID are often labelled, and oppression is a daily experience generated by social structures and social norms. However, oppression is not only external; it can be internal as well, leading to self-hate or shame (Pulla, 2017:108-109; Mak & Cheung, 2008:532).

With respect to the caregiver, just to be associated with the stigmatised individual may cause him/her to internalise the stigma and feel unhappy and helpless about his or her affiliation with the person with ID (Mak & Cheung, 2008:532). The strength-based approach allows the facilitator to assist the caregiver in understanding that vulnerabilities and power dynamics exist, but that there are many points of choice and resistance.

The strength-based approach helps the caregiver recognise the power within themselves (Pulla, 2017:109).

2.3.3.2 Transparency

Collaboration between the facilitator and the caregiver must be authentic for positive change to occur (Hammond, 2010:5). The caregiver must believe that the facilitator cares about him or her and is supporting change and capacity building - not trying to fix them (Hammond, 2010:5). The success of the strength-based approach is underpinned by the premise that restorative powers are intrinsic to all human beings and their bodies, and their emotions have a profound impact on their overall health and well-being (Pulla, 2017:109).

2.3.3.3 Empowerment

When an individual recognises and develops new strengths, this acts as a stimulus for further growth. This approach will allow caregivers to feel empowered to make their own choices and, in turn, this will contribute to their own growth, as well as that of the person they care for, their family and community The strength-based approach involves minimising the power imbalances between the caregiver and the facilitator whilst also creating a relationship in which the caregiver can grow (Pulla, 2017:109-111).

2.3.3.4 Collaborative partnership

Employing a strength-based approach involves a collaboration that will transform the caregiver, as well as the facilitator (Pulla, 2017:110). Building an empowering partnership involves participants bringing their own strengths into play to pursue their visions and dreams.

The caregiver may feel powerless at first. However, as the process unfolds, they begin to recognise that the facilitator is assisting them to become increasingly empowered to make healthy choices for themselves.

A collaborative process takes courage, commitment and generosity (Pulla, 2017:110). It is also important that the facilitator believes the caregiver’s related experiences.

2.3.3.5 Resilience

Caregivers will be more confident to start the journey of change when they begin with what they already know (Hammond, 2010:5). They must be cognisant of the danger that the language they use will create their own reality, as well as that of their families (Hammond, 2010:5). The strength-based approach moves away from stigmatising labels and views challenges as opportunities for growth and development of innate strengths (Hammond, 2010:5). It is important that the facilitator believes that everyone can bounce back from adversity, and that positive change is possible, in order to be able to support caregivers in their resilience-building journey (Pulla, 2017:111).

2.3.3.6 Strength building

The strength-based approach firmly embraces the belief that everyone possesses innate strengths that can be developed, and that no one is defined by his or her limitations (Hammond, 2010:5). Furthermore, the strength-based approach believes that everyone has the urge to succeed, is convinced that change is inevitable, and wants to make a positive contribution to his or her own life, as well as to the community (Hammond, 2010:5).

2.3.4 Cognitive behavioural therapy within the strength-based approach

Strength-based psychoeducational programmes which included cognitive behavioural therapeutic strategies for the caregiver, have indicated improvement in caregiver well-being (Steiner, 2011:178-179; McConnell & Savage, 2015:100-109; Duan & Bu, 2019:82-92). Cognitive behavioural therapy (CBT) has been established as the first line, evidence-based treatment for anxiety and depression (Clark, 2022:1-3).

Research (Steiner, 2011:178; McConnell & Savage, 2015:100-109; Panicker & Ramesh, 2019:1-14) indicates that parents of children with intellectual disability endure higher levels of stress and depression compared to parents of typically developing children.

Steiner (2011:178) argues that caregiver well-being - that is, the absence of stress, symptoms of depression and negative affect - appears to be strongly related to the behaviour of the person with ID. However, McConnell and Savage (2015:100-109) contend that caregiver distress may be the antecedent rather than the outcome of the behavioural problems displayed by the person living with intellectual disability. High caregiver distress is associated with less optimal caregiving and, in turn, predicts the emergence of behavioural problems in the person with ID. McConnell and Savage (2015:100-109) do concede, however, that the relationship between such behavioural problems and a caregiver's distress is generally considered transactional.

Psychoeducational programmes that have been documented to have led to improvements in caregiver well-being, included educating caregivers regarding cognitive behavioural therapeutic strategies to manage the challenging behaviour of the person with intellectual disability in their care (Steiner, 2011:178-179; McConnell & Savage, 2015:100-109).

Furthermore, beyond teaching caregivers' specific therapeutic strategies to manage the person with intellectual disability's cognitions, or their own cognitions, their ability to perceive the positive characteristics of the person they are taking care of is crucial in determining positive outcomes for the caregiver (Steiner, 2011:179; McConnell & Savage, 2015:100-109).

Identifying such positive characteristics in individual with a disability, as well as their relationship, may be particularly beneficial because the stressors associated with the disability are chronic. Thus, the strength-based cognitive intervention allows caregivers to conceptualise the behaviour of the person with intellectual disabilities in a more positive fashion (Steiner, 2011:179; Duan & Bu, 2019: 82-92).

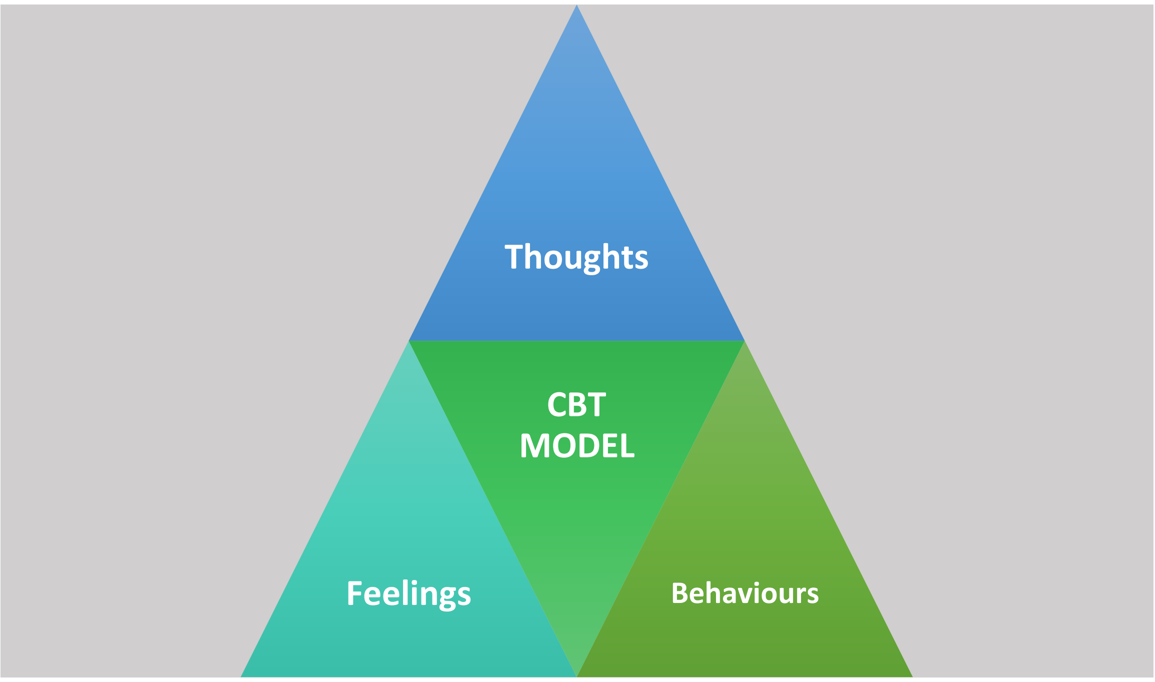


Figure 7: CBT Model Adapted from Field et al. (2015:206-220)

2.3.4.1 Cognitive behavioural therapy as a practice framework for the development of a psychoeducational programme

Cognitive behavioural therapy (CBT) is utilised as a treatment programme due to its success with significant numbers of patients with mental health problems (Hayes, Villatte, Levin & Hildebrandt, 2011:141-168; Field, Beeson & Jones, 2015:206-220; Leoni et al., 2016:59-73). Cognitive behavioural therapy emphasises that it is not a situation, nor circumstance, that causes caregiver distress; rather, it is the manner in which the caregiver interprets or views a particular event that will cause internal distress (Field et al., 2015:206-220; Hayes et al., 2011:141–68; Leoni et al., 2016:59-73).

Cognitive behavioural therapy states that thoughts, emotions and behaviour are intertwined and affect one another (Field et al., 2015:206-220; Kazantzis, Luong, Usatoff, Impala, Yew, & Hofmann, 2018: 349-357). CBT is based on the premise that how we think (cognition), how we feel (emotion) and how we act (behaviour) all interact with each other. Our thoughts determine our feelings, as well as the behaviour we choose (Field et al., 2015:206-220). Therefore, consistent maladaptive thoughts or behaviours can present problems for the caregiver.

Furthermore, cognitive behavioural therapy is based on the notion that thought distortions and maladaptive behaviours play a role in the development and maintenance of many psychological disorders, such as stress, depression and anxiety (Field et al., 2015:206-220; Kazantzis et al., 2018:349-357). Moreover, symptoms of stress, depression and anxiety are thought to be reduced by psycho-educating new information-processing skills and coping mechanisms (Wright, Basco & Thase, 2006:80; Field et al., 2015:206-220; Kazantzis et al., 2018:349-357). Cognitive behavioural therapy has been shown to be the most effective in treating symptoms of depression and anger (Surley & Dagnan, 2019:219-237).

Thus, cognitive behavioural therapy, as a practice framework for the development of a psychoeducational programme, would help challenge the negative thoughts of caregivers, as well as teach them how to change any damaging behaviours within themselves (Field et al., 2015:206-220; Wright et al., 2006:80).

By involving caregivers as co-therapists at times, cognitive behavioural therapy can be adapted in such a way that the person with intellectual disability can also benefit from it (Surley & Dagnan, 2019:219-237).

2.3.5 Relevance of the Strength-based Approach to the Study

The strength-based approach is appropriate for this study as it promotes resilience and empowerment versus focusing on disabilities (Pulla, 2017:100; Moorkath et al, 2019:175). This approach suggests that individuals should be viewed in the light of their values, strengths, hopes, aspirations and capacities, regardless of the stressful or burdensome nature of the situation around them (Peacock, Forbes, Markle-Reid, Hawranik, Morgan, Jansen, Leipert & Henderson, 2010:640-659). The ethics of caring and caretaking, nurturing and ensuring that individuals become resilient lies within the scope of the strength-based approach (Pulla, 2017:100).

Bowen, Walker and Holdsworth (2019:500-517) identify a core criticism of the strength-based approach, namely that problems do arise at times, due to some underlying inadequacy within the individual, for example, a caregiver’s negative attitude. Urbanowicz, Nicolaidis, den Houting, Shore, Gaudion, Girdler and Saverese

(2019:82-89) warn that, even though the strength-based approach aims to highlight strengths, the researcher should not apply it in such a way as to disregard the challenges involved.

However, Peacock et al. (2010:640–659) argue that, from a strength-based perspective, negative experiences and challenges are not ignored or disregarded, but rather, the burden of the challenge of caregiving is acknowledged as one part of an individual's personal and sociocultural experience. Pulla (2017:99) concurs that challenges and deficits are not denied, but that such deficiencies are often presented as needing specialist attention while, at the same time, disregarding the strength of the client.

The reality of the caregiver's experience is utilised to focus on the individual's strengths. The strength-based approach moves away from a preoccupation with problems and towards seeking, acknowledging, as well as fostering, the strengths in each situation, and thus providing a more balanced view of an individual's reality (Peacock et al., 2010:640–659). Blundo (2012:152) concurs that, by focusing on the caregiver's strength, resilience, social support and self-determination, the strength-based approach is a powerful approach to assisting caregivers with coming to terms with the stress and burdens that they may experience daily.

Moreover, this approach guides the researcher to work collaboratively with the caregiver, promoting the latter to a level of expertise regarding what has worked, what does not work and what might work in their lives (Pulla, 2017:102). In the utilisation of the strength-based approach to analysing findings in the present study, the researcher focuses on the possibilities of empowerment and opportunities for resilience-building that are revealed in the family caregiving journey.

2.4 SUMMARY

In this chapter, the in-depth discussion has focused on contextualising caregiving of people with intellectual disabilities by employing the theoretical frameworks of the biopsychosocial model and strength-based approach.

In the context of caregiving of people of intellectual disabilities three aspects (biological, psychological and social) have been individually covered. The biopsychosocial model emphasises that these three aspects play a role in the well-being of both the caregiver and the person with ID and, furthermore, highlights the interconnectedness of these factors.

The evolution of the biopsychosocial model of disability has been discussed, including the religious model, the medical model and the social model of disability. The relevance of the biopsychosocial model to the present study has also been provided.

Integrated with the biopsychosocial model, the researcher has also utilised the strength-based approach to premise the study. The evolution of this approach in social work has also been discussed.

The strength-based approach has been elaborated upon by contextualising caregiving of people with intellectual disabilities within the core strength principles, namely social justice, transparency, empowerment, collaborative partnership, resilience and strength building.

Cognitive behavioural therapy is utilised as a first-line treatment for people with depression and anxiety, and, within the strength-based perspective, was utilised as a practice framework for the development of a psychoeducational programme for caregivers of people with intellectual disabilities. The relevance of the strength-based approach to the present study has also been covered.

The next chapter conceptualises intellectual disability.

Figure 8: Graphic representation of the phases of intervention research. Adapted from Rothman and Thomas (1994:28); Fraser and Galinsky (2010:459-466).

3.1 Introduction

The focus of the present study is on caregivers of people with ID – to gain an understanding of caregiver distress and investigate a solution to alleviate it. However, to place the research question in context, it is important that the body of the literature review includes a brief conceptualising of intellectual disability.

In Chapter 3, intellectual disability is defined and conceptualised. Classification types of intellectual disability are provided. Differentiation has been made between intellectual disability and developmental disability, as well as the criteria for diagnosis. Furthermore, aetiology, epidemiology and prevalence of ID are discussed in a global and African context, as well as the challenges within the South African context. Challenges experienced by people with ID are explored, as well as intervention services to people with ID.

3.2 Conceptualising Intellectual Disability

The term 'intellectual disability' is internationally the most commonly adopted term; however, formerly referred to as mental retardation or MR (Salvador-Carulla & Bertelli, 2008:10; Tassé, Luckasson & Nygren, 2013:128-129; Harris, 2013:260-262; Adnams & Johns, 2016:8). However, over time, the term 'mental retardation' used in this context came to be understood as an insult - a derogatory term (Harris, 2013:260; Adnams & Johns, 2016:8). 'Intellectual disability' is the new term proposed for the DSM-5 which correlates with the ICD-11 diagnosis of intellectual disability in that both categorise it as a health condition or disorder (Harris, 2013:260).

Intellectual disability is characterised by deficits in conceptual functioning which refers to the ability to think and reason, social functioning which refers to communication and interpersonal skills, and adaptation skills which refer to self-care, such as grooming or the ability to manage money (Salvador-Carulla & Bertelli, 2008:10; Adnams & Johns, 2016:8; Purugganan, 2018:299).

People with intellectual disability often experience communication barriers. They have difficulties informing others of their needs and struggle with self-care (Linn, Chuaqui, Wilson & Arredondo, 2019:14). A child with intellectual disability will progress more slowly than his or her normally developing peers and may take more time to learn to crawl, stand and walk. It will experience difficulties with speaking, grooming without assistance and may not understand social norms. It will also display difficulties with problem-solving (Purugganan, 2018:300; Linn et al., 2019:14-15).

A third of all persons with ID present with comorbid psychiatric disorders, such as schizophrenia, bipolar mood disorders, depression or obsessive-compulsive disorders, and another 10%-20% exhibit challenging behaviours, such as aggression, which are not due to a psychiatric condition (Salvador-Carulla & Bertelli, 2008:10)

Furthermore, people with ID require support and care, as well as social and healthcare resources, throughout their entire lifespan and this imposes a considerable burden on families and caregivers (Salvador-Carulla & Bertelli, 2008:10; McKenzie et al., 2013:1750). Their ability to make informed decisions and judgements is impaired and their caregivers often become the central point of their lives. The daily care and responsibilities undertaken by caregivers are considerable (Perkins, 2009:7-10). The sacrifices which caregivers make often affects them financially, as well as socially.

3.2.1 Classifications of Intellectual Disability

The severity of the intellectual disability is classified as mild, moderate, severe or profound intellectual disability (Adnams, 2016a:10; Purugganan, 2018:300-301; Van Ool, Snoeijen-Schouwenaars, Tan, Schelhaas, Aldenkamp & Hendriksen, 2019:41). However, Tassé et al. (2013:130) express concerns with these classifications. The authors assert that the classification of ‘mild’ ID connotes that the condition is less severe than it is and, therefore, propose a name change to ‘marked’, ‘extensive’ and ‘pervasive’, and, furthermore, propose the classification of ‘other’ when a clinical subtype cannot be made.

Adnams (2016b:17) and Purugganan (2018:300-301) differentiate between the classifications of ID and ascertain to what degree IQ measures of intelligence correlate with a person’s adaptive functioning:

Table 2: Classifications of ID (Adapted from Adnams, 2016b:17 & Purugganan, 2018:300-301)

Mild ID	Majority (about 80%) of people with ID, fall into this category. Their IQ is generally between 50 and 69. Impairment in intellectual ability may be detected only during early school years. Their ability to read is on par with learners 9 to 11 years

	old. They may be able to reach Grade 6 level of academic functioning.
Moderate ID	About 10% of people with ID fall into this category. Their IQ is between 35 and 49. With teaching and support time, they may be able to perform basic tasks, such as dressing independently. They need varying degrees of support and supervision to reside and function within the community. They may be able to reach Grade 2 level of academic functioning.
Severe ID	This category accounts for about 4% of people with ID. Their IQ is between 20 and 34. Their development is distinctly delayed. They have a restricted vocabulary and difficulty with speech. They need considerable time and practice to gain some basic self-help skills. Extensive support from caregivers is required. They may be able to reach a pre-school level of academic functioning.
Profound ID	This category accounts for about 2% of people with ID. Their IQ is below 20. They have significantly reduced or no verbal speech. A reduced life expectancy, seizures and physical impairments are common. They need all-encompassing support from caregivers and are dependent on every aspect of personal care and daily living. Abilities comprise, at best, manipulation of objects.

3.2.2 Diagnosing of Intellectual Disability

The diagnosis of intellectual disability is necessary for mobilising appropriate support services and care. However, the process of labelling can result in stigma and exclusion. Diagnosis is justified if it will improve the quality of life of the individual being diagnosed (Adnams & Johns, 2016:9).

Such a diagnosis is, however, not a straightforward process and may require several assessments of adaptive and intellectual functioning (Purugganan, 2018:300). Certified psychologists utilise standardised questionnaires, such as the Vineland Adaptive Scales to assess adaptive functioning, while intellectual functioning is measured using standardised instruments, such as the Wechsler Intelligence Scale for Children-V (WISC-V) (Purugganan, 2018:300). The Grover-Counter Scale (GCS) is a psychometric test that was developed for people with intellectual disability by Professor Vera Grover, who served as the head of the Department of Psychology at the University of Cape Town from 1957 to 1967 (Saptouw, 2016:19-20). The GCS is used to test a person's cognitive functioning, especially in people with impaired language ability. The GCS serves as a supplement and not a replacement for standardized assessments (Saptouw, 2016:19-20).

Three internationally accepted criteria are needed for a reliable diagnosis of ID (Salvador-Carulla & Bertelli, 2008:14; Platt et al., 2019:952-961), and these are discussed next.

3.2.2.1 Criterion A: IQ below 70

When diagnosing intellectual disability there should be a presence of limitations to intellectual functioning (Tassé, Luckasson & Nygren, 2013:129). Profiles of cognitive impairments should be considered when measuring intelligence (Salvador-Carulla & Bertelli, 2008:15; Platt et al., 2019:952-961). Assessment of an individual's intellectual capacity is controversial as factors, such as the cultural component, should be accommodated, and international standardisation of instruments is limited (Salvador-Carulla & Bertelli, 2008:14).

3.2.2.2 Criterion B: Impairment of adaptive skills

The diagnosis of intellectual disability is partly based on the level of the person's adaptive skills, which refers to how the individual functions (Salvador-Carulla & Bertelli, 2008:15; Tassé, Luckasson & Nygren, 2013:129; Platt et al., 2019:952-961).

The Diagnostic and Statistical Manual of Mental Disorders-Fifth edition (DSM-5) includes three domains for adaptive deficits, namely the social, practical and conceptual domains (Adnams & Johns, 2016:8; Van Ool et al., 2019:40). The social domain includes interpersonal communication skills, social judgement, emotional regulation and the ability to make and retain friendships. The practical domain includes personal care, organising school or work, domestic tasks and the ability to manage money. The conceptual domain refers to executive functioning, memory, reading, writing and mathematics (Maulik, Mascarenhas, Mathers, Dua & Saxena, 2011:420; Van Ool, et al., 2019:40).

3.2.2.3. Criterion C: Age of onset before 18

Tassé et al. (2013:129) and Platt et al. (2019:952-961) state that, to diagnose intellectual disability, the onset thereof should be within the developmental years. Salvador-Carulla and Bertelli (2008:14-15) acknowledge that this is a diagnosing criterion but assert that the degree to which this criterion contributes to the diagnosis of ID is questionable and may also be confusing. There are numerous cognitive impairments that may appear before the age of 18 years, for example, adolescent schizophrenia or brain damage due to a physical injury. Thus, Salvador-Carulla and Bertelli (2008:14-15) assert that this criterion should be deleted as a diagnostic criterion.

3.3. Aetiology of Intellectual Disability

Linn et al. (2019:14) and Purugganan, (2018:301-302) state that for many people with ID the cause of the disability will never be known. Salvador-Carulla and Bertelli, (2008:10) concur but state that, more specifically, the cause of intellectual disability is not known in 60% of individuals with ID.

The known causes of intellectual disability can be ascribed to genetic, prenatal and environmental factors (Purugganan, 2018:301; Linn et al., 2019:15). The most known causes occur before birth, namely birth defects, Down Syndrome, Fetal Alcohol Syndrome and Fragile X Syndrome. Other causes of intellectual disability occur during the birthing process of the individual, such as oxygen deprivation (Linn et al., 2019:15).

In lower- to middle-income countries the excess rate of ID is due to aetiology that is fully preventable, such as diet deficiencies, pregnancy-and birth-related conditions (Salvador-Carulla & Bertelli, 2008:10; Adnams, 2016a:11-12). There is a higher prevalence of mild intellectual disability in lower- to middle-income countries as mild ID is associated more with environmental risk factors that increase the prevalence of ID (Adnams, 2016a:11). Genetic risk factors are linked more often to the severe degree of intellectual disability, and a poor environment may further compromise the development of these individuals (Adnams, 2016a:11). There are preventable conditions that may result in intellectual disability, such as Fetal Alcohol Syndrome, trauma and violence (e.g., head injuries), HIV and AIDS, and nutritional deficiencies (Adnams, 2016a:11).

3.4 Differences between Intellectual Disability and a Developmental Disability

Developmental disability encompasses intellectual disability in that it is a life-long disability that appears during the developmental stage in youth (Shukla, Gupta, Saini, Singh & Balasubramanian, 2017:705-714; Schalock, Luckasson & Tassé, 2019:225). Intellectual disability is a developmental disability; however, not all people with developmental disability would necessarily present with a co-occurring intellectual disability (Schalock et al., 2019:224). Developmental disabilities are a group of conditions that could include intellectual, physical and/or behavioural impairments (Shukla et al., 2017:705-714; Schalock et al., 2019:224).

Other examples of a developmental disability include autism spectrum disorder (ASD) which would not necessarily impact the intellectual ability of the individual. People with ASD have trouble regarding how they relate to and communicate with others (Seris & de Vries, 2016:38). Some of the early signs of autism spectrum disorder in infants include avoiding eye contact and becoming upset by a minor change of routine (Seris & de Vries, 2016:41). About half of all persons diagnosed with autism spectrum disorder have a co-occurring intellectual disability (Seris & de Vries, 2016:38).

A preventable developmental disability is Fetal Alcohol Syndrome (FAS) which is triggered by prenatal exposure to alcohol and has a lifelong impact on the intellectual capacity of the individual (Adnams, 2016c:33; Shukla et al., 2017:705-714; Purugganan, 2018:303). Therefore, FAS is the cause of intellectual disability and most people with FAS function within the mild intellectual disability range (Adnams, 2016c:31).

Cerebral palsy (CP) is a developmental disorder that impacts voluntary movement and coordination due to injury or poor development of the growing brain (Koopman, 2016:35; Shukla et al., 2017:705-714). In comparison to autism spectrum disorder, intellectual impairment is not necessarily found in all people with cerebral palsy. For instance, a speech impediment in a person with cerebral palsy may be incorrectly interpreted as an intellectual disability. One in two people with cerebral palsy has a co-occurring intellectual disability (Koopman, 2016:35).

Down Syndrome is a developmental disability that includes a genetic component, and intelligence is usually within the mild to moderate range of intellectual disability (Purugganan, 2018:302).

Therefore, the researcher reiterates that intellectual disability is part of a group of developmental disabilities and, furthermore, developmental disabilities include physical impairments and are not limited to intellectual impairments.

3.5 Epidemiology and Prevalence of Intellectual Disability

In the next section the researcher will discuss epidemiology and the prevalence of ID in a global and African context. She will also highlight some of the challenges in a South African context.

3.5.1. Global context

The Families Special Interest Research Group (Families SIRG) of the International Association for the Scientific Study of Intellectual and Developmental Disabilities (IASSIDD) conducted a review on the current state of knowledge regarding families who support a child with intellectual and developmental disability (Families SIRG, 2014:420-430). The review indicated that between 1 in 50 and 1 in 20 families worldwide include a child with ID (Families SIRG, 2014:421).

Internationally, the prevalence of intellectual disability is around 1,5 % in Western countries (Salvador-Carulla & Bertelli, 2008:10). According to Salvador-Carulla and Bertelli (2008:10), the highest rate of ID (4%) is found in low- to middle-income countries due to several preventable causes, such as poor diet (Maulik et al., 2011:419).

Linn et al. (2019:16) investigated the global impact of intellectual disability and found that the group of higher-income countries can more adequately address the needs of its people with intellectual disabilities versus the lower- to middle-income countries. Furthermore, the treatment gap in the latter group of countries is greater than 75% (Linn et al., 2019:16). This is supported by the review conducted by Families SIRG (2014:423) which states that a considerable amount of support is provided to families supporting a child with ID in higher-income countries.

Worldwide, intellectual disability is more complex than being just a health or social concern: it is also a human rights concern (Linn et al., 2019:14). It is a stigmatising condition that requires public health resources; however, most available data on its social and health implications are based on studies conducted in developed countries (Maulik et al., 2011:419).

Early diagnosis of a child with intellectual disability and prompt intervention are pivotal (Adnams, 2016a:13; Linn et al., 2019:15;). The earliest experiences of play in a child's development are critical, and early detection and intervention of intellectual disability will have lifelong advantages (Adnams, 2016a:13). However, early intervention centres for children with ID (below the age of 3 years) are predominately available only in higher- income countries (Linn et al., 2019:15).

3.5.2. Africa

McKenzie, McConkey and Adnams (2013:1750), as well as Samboma (2021:265), state that intellectual disability is probably the largest impairment grouping on the African continent. Mkabile et al. (2021:1) concur that the prevalence of intellectual disability is high in Africa.

Historically, people with ID and their families were viewed as cursed by God for immorality committed in the past. Consequently, they would be cast out by society (Mung'omba, 2008:143; Gona et al., 2011:176). Some of these traditional beliefs cause caregivers of children with ID to hide their children from the broader society for fear of segregation, isolation and discrimination (Gona et al., 2011:176). As a consequence, this lack of exposure of people with ID to the wider society is a further contributing factor to the ongoing stigma and discrimination (McKenzie et al., 2013:1751).

In Africa, there exists a lack of specialised intellectual disability services, such as education, health and social work services (Mkabile et al., 2021:7). Intervention programmes for caregivers of people with ID, such as support groups for them or for the people with ID to engage with the community, are often not practical in African societies due to barriers, such as stigma and cultural perceptions (Gona et al., 2011:176-177). People with ID are the most vulnerable and most ignored in African societies (Samboma, 2021:265).

The experience of social exclusion is intensified by the poverty in Africa (McKenzie et al., 2013:1750). In some African countries, such as Zambia, social disability grants are not payable to families taking care of people with ID (Mung'omba, 2008:144). Furthermore, barriers to education further exacerbate the experience of exclusion. Education of children with ID is imperative for them to reach their full potential and realise hopes of greater independence and community participation (McKenzie et al., 2013:1751). However, African societies are lagging behind as there is a shortage of special education teachers for people with ID (Samboma, 2021:267). Additionally, the specialised education systems that are available in some African countries are private and expensive (Mkabile et al., 2021:7).

There is the general assumption that healthcare professionals underestimate the distress of caregivers of people with ID, show a lack of empathy for their situation, and provide insufficient information to the degree that some caregivers prefer engaging the services of a traditional healer rather than a hospital clinician (Gona et al., 2011:181). Moreover, there also appears to be a lack of concern for ageing people with ID in

Africa and, thus, there is a need for programmes for people with ID across their lifespan (McKenzie et al., 2013:1754).

Social workers play a role in monitoring the care of people with ID. During the COVID-19 pandemic, many people with ID residing in group-homes were abused due to the lack of monitoring by social workers whose movements were restricted by the lockdown regulations (Samboma, 2021:266). Social workers are overworked, and funding to remunerate social workers is not always available (Samboma, 2021:267).

Although there may be a lack of resources and services, as well as persistent barriers to social inclusion, such as cultural perceptions, lack of education and stigma, studies indicate that some caregivers of people with ID have relied on their spiritual beliefs to cope (Gona et al., 2011:181; Mkabile et al., 2021:8). These caregivers have found that spiritual beliefs, such as that God has a purpose for their child with ID, are quite helpful and a strengthening factor in their ability to cope with life's challenges (Gona et al., 2011:180-181).

There are priority issues in Africa, such as increased public awareness of and investment in specialised intellectual disability services, that need to be identified and addressed (McKenzie et al., 2013:1754). Mkabile et al. (2021:9) state that too few studies have been conducted on intellectual disability in Africa and the patterns of care for African people as a collective.

3.5.3. South Africa

Exact statistics of the prevalence of intellectual disability in South Africa are unclear due to the lack of specific epidemiological data and the fact that overall studies of disability use different methods of research and different definitions of intellectual disability (McKenzie et al., 2016:45-54). This is also due to the way disability is categorised in the record-keeping of South African service providers (Christians, 2019).

The researcher consulted Theodore Christians (2019/05/10) of the South African Social Security Agency (SASSA) for information and statistics on caregivers of people with intellectual disability in South Africa. Christians (2019) related that, with regard to intellectual disabilities, no differentiation is made between it and other disabilities, such as physical or neuro-cognitive disability. Christians (2019), therefore, states that all disabilities are classified into one category, and SASSA does not keep specific statistics on intellectual disability. However, the researcher discovered in the findings of a large population-based study conducted in the Western Cape in 2002 and 2003, that about 3% of the population were living with intellectual disability (Kleintjes et al., 2006:157-160).

Furthermore, compared to high-income countries, little research has been done on caregiver experiences in low- to middle-income countries, such as South Africa (McKenzie & McConkey, 2016:531). Challenges in a South African context will be discussed in the next section.

3.6. Challenges in a South African Context

In the following section, the researcher will provide the challenges within a South African context by discussing Deinstitutionalisation and the Life Esidimeni tragedy.

3.6.1 Deinstitutionalisation

The term 'deinstitutionalisation' belongs to a shift in mental health practice that began in Europe and the USA in the 1950s and refers to the change in care-setting from specialised institutions to NGOs, community-based facilities and family members (Perkins, 2009:11; Robertson, Janse van Rensburg, Talatala, Chambers, Sunkel, Patel & Stevenson, 2018:262-263).

With the shift in political dispensation in New South Africa in 1994, primary health care became central as a result of the transformation of the health care system as indicated in the White Paper for Transformation of the Health System in South Africa and the National Health Act No. 61 of 2003. Therefore, in South Africa, deinstitutionalisation of people with intellectual disability meant that the bulk of the responsibility fell on the Primary Health Care System which constitutes community-based services (Petersen, Bhana, Campbell-Hall, Mjadu, Lund, Kleintjies, Hosegood, Flisher et al., 2009:140).

The pace of deinstitutionalisation escalated following the promulgation of the Mental Health Care Act No. 17 of 2002. Lund, Petersen, Kleintjes and Bhana (2012:402-405) investigated primary-, secondary - and tertiary levels of mental health services in South Africa and found that primary-level caregiving is not well equipped for the purpose of keeping up with the policy of deinstitutionalisation. The authors state that, in most instances, staff and facilities of primary-care level health clinics are not equipped to manage the mental health needs of the community.

Perkins (2009:11) and (Mtshali, 2017:1) state that, where institutionalised living was previously encouraged and the norm for people with ID, the shift currently is for people with ID to live within their family home and be included in the broader community.
Petersen et al. (2009:140-141) concur that, under the apartheid government, individuals with ID were treated in institutions, and with the change to a democratic political dispensation in 1994, the focus shifted to community integration of people with ID.

This information is relevant to the present study as the modern shift in psychiatric treatment led to the deinstitutionalisation of people with ID, and this places the burden of care on their caregivers who must adjust their lives accordingly (Perkins, 2009:11; Mtshali, 2017:1). Families, entrusted with the task of caring for their relatives with intellectual disability in an informal manner - something that was not previously their expected responsibility - were ill-equipped. Furthermore, the community mental health care resources were lacking and ill-prepared (Petersen et al., 2009:140-141).

The National Mental Health Policy Framework and Strategic Plan 2013-2020 (Department of Health, 2013:16) concurs in that it recognises the imbalance created by the rapid progression of deinstitutionalisation in South Africa, without the necessary development of community-based services.

The view of deinstitutionalisation and community involvement is affirmed by the United Nations Convention on the Rights of Persons with Disabilities (2007:4-31), that persons with ID have the same rights as all other human beings. They have the right to education, have the right of financial security and access to meaningful employment, and should live with their own families and participate in community life.

These principles were guided by the notion that if persons with intellectual disability were segregated from mainstream community, they would be perpetually stigmatized.

Therefore, it is the researcher's assertion that for the person with intellectual disabilities to exercise their rights as set out by the UN Convention (2006:4-31), the lack of community resources and the caretaking burden thrusted on caretakers, mental health and the caretaking skills of their caregiver becomes crucial.

3.6.2. Life Esidimeni Tragedy

The Life Esidimeni tragedy, that took place in the Gauteng province, is a humiliation to the South African Government's Health Department, and this also affected service delivery in other provinces, such as the Western Cape, by demanding greater accountability (Robertson, Janse van Rensburg, Talatala, Chambers, Sunkel, Patel & Stevenson, 2018:262-263). The incident was referred to as a medical maladministration scandal in South Africa (Capri, Watermeyer, McKenzie & Coetzee, 2018:153-154).

The Life Esidimeni tragedy involved over 2000 people living with mental and intellectual disabilities being hurriedly moved to ill-equipped and under-resourced non-governmental organisations (NGOs) causing the death of over 140 patients due to starvation and neglect (Ferlito & Dhai, 2018:157; Capri et al., 2018:153-154). The NGOs were unable to care for them adequately. The Gauteng Department of Health terminated an outsourced care contract with Life Esidimeni in 2015 with the purpose of cutting costs and bringing into effect the Mental Health Care Act No 17 of 2002 policy of deinstitutionalising psychiatric patients. At least half of the deceased lived with severe or profound intellectual disability (Capri et al., 2018:153-154).

The Health Ombud, Professor Makgoba, states in his report on the Life Esidimeni Disaster, that the NGOs where most patients had died had neither the basic competence and experience nor managerial capacity to take on the responsibility for these patients and, furthermore, were inadequately resourced. The Life Esidimeni tragedy reiterates the systematic flaws in mental health service planning and implementation in South Africa (Stein, Sordsdahl & Lund, 2018:147-148).

The lessons learned from the Life Esidimeni tragedy are relevant to this study as they demonstrate the burden of care placed on families and NGOs due to the Mental Health Care Act No 17 of 2002 policy of deinstitutionalisation. This policy does not consider the capacity – or lack thereof - of families and facilities that are to care for people with intellectual and other developmental disabilities.

This is relevant to this study as the researcher, by developing a psychoeducational programme, aims to contribute to the resources and skill set needed by caregivers to care for people with intellectual disabilities.

3.7. Challenges experienced by People with Intellectual Disability

People with intellectual disabilities face challenges with regard to relationships, education and employment which will be discussed next.

3.7.1. Relationships

There exists a general apprehension amongst informal and formal caregivers, as well as professionals, such as social workers and teachers, with regard to topics pertaining to relationships, sexuality education and intimacy where people with intellectual disability are concerned (Lafferty, McConkey & Simpson, 2012:29-43; Walker-Hirsch, 2014:3). A contributing factor to this apprehension amongst caregivers is the element of cultural and religious beliefs; for example, that masturbation is sinful. A further attitudinal barrier is the inability of caregivers to perceive the person with ID as an adult and the assumption that the intellectual disability precludes them from sexual desire (Lafferty et al., 2012:29-43). Nevertheless, people with ID depend on their informal or formal caregivers, as well as professionals for guidance and support in making decisions involving sexual expression and relationships (Walker-Hirsch, 2014:27).

A study conducted by Lafferty et al. (2012:29-43) found that the opportunities for people with intellectual disabilities to participate in relationships and sex education are often prohibited or constrained by their informal or formal caregivers, as well as professionals, such as social workers. The findings of the study indicated that informal caregivers were concerned with the vulnerability and safety of the person with ID.

Formal caregivers of residential placements were concerned about upholding the rules and regulations of their organisations. Professionals, such as social workers, were concerned about the relevant legislations in relation to sexuality of people with ID (Lafferty et al. 2012:29-43).

The study also found that there was a lack of training (or educational resources) to guide caregivers with regard to relationships and sexuality of people with ID. The primary concern for caregivers is the vulnerability of people with ID to abuse. Therefore, to mitigate the risk of abuse it was suggested that empowerment programmes be developed to educate persons with ID to know the difference between inappropriate and appropriate sexual behaviour and to acquire the vocabulary to express unwanted touch. Thus, the promotion of self-protection was highlighted (Lafferty et al. 2012:29-43). Allen (2014:161-174) agrees with the empowerment of people with ID when it comes to their sexuality but adds that those who are diverse in sexual relationships (gay, lesbian, bisexual or transgender) are also entitled to the whole-life experience of discovering and enjoying their sexuality - therefore also deserving of support and education.

3.7.2 Education

Globally, an estimated 50% of children with intellectual disabilities do not attend school (Linn et al., 2019:16). In South Africa, up to 70% of children with disabilities are not attending school (Donohue & Bornman, 2014:2). This is due to prejudice, stigma, inaccessible learning, insufficient qualified teachers and the perception that children with intellectual disability are ineducable (Donohue & Bornman, 2014:2; Linn et al., 2019:16).

In 2007, according to the ‘Right to Education’ task team (2016:64-70) of the Western Cape Forum for Intellectual Disability (WCFID), parents and employees of special-care centres rallied to challenge the State on the grounds of an exclusion from the right to basic education of children with severe and profound intellectual disability, as set out in the South African Constitution. They did so under the umbrella of the WCFID with support from the Legal Resources Centre (LRC). On 11 November 2010, they obtained a legal victory as the High Court ruled in their favour. As a result of the judgement, there was an increased subsidisation of Western Cape special-care centres and the provision of therapeutic teams which included occupational therapists, educators, physiotherapists, psychologists and speech therapists who conduct assessments and develop individualised learning programmes.

The judgement was applicable on provincial level and, therefore, implementation of the improvement of and accessibility to education for children with severe to profound intellectual disability began in the Western Cape. However, the ‘Right to Education’ task team (2016:70) asserts that, on a *national* level, all children with ID have the right to benefit and receive an education. This is supported by a study conducted by Elphick, De SasKropiwnicki and Elphick (2015:101-116) in a township in the Gauteng Province where caregivers successfully lobbied for new education services for their children with disabilities as they, too, believed that their children had the right to basic education.

Inclusive education and the developmental needs of people with intellectual disability, as well as the impact thereof on their caregivers, are further discussed in Section 4.4.1.

3.7.3 Employment

People with ID often face serious employment issues particularly in lower- to middle-income countries (Petasis, 2019:49; Ebuenyi et al., 2020:536). The difficulty which persons with ID experience when attempting to find employment is a cause of great concern for caregivers (Mkabile et al., 2021:5). Negative beliefs and attitudes about intellectual disability have brought about a culture of exclusion in which people with ID are not being sent to school or receiving employment (Petasis, 2019:49; Ebuenyi et al., 2020:541). Finance, therefore, poses a serious problem due to the person with intellectual disabilities being unable to work and the caregiver’s caregiving obligations (McKenzie & McConkey, 2016:536; Marsack-Topolewski & Church, 2019:145-156; Marsack-Topolewski, 2021:299-319).

In South Africa, people with ID receive a disability grant, discussed in more detail in Section 4.4.6, which for many caregiver families is a much-needed contribution (McKenzie et al., 2013:1753; Christians, 2019). This contrasts with certain countries in Africa, such as Zambia, where they receive little to no financial assistance from the government (Mung'omba, 2008:144).

McKenzie et al. (2013:1753) encourage income generation initiatives for people with ID. This is supported by a USA study conducted by Conroy, Ferris and Irvine (2010:269-277) which offered an alternative to the limited protective employment in workshops and adult daycentres by suggesting income generating initiatives through micro-enterprises for people with ID. With the support of their caregivers, people with intellectual disability would develop small businesses, for instance, selling colourful cones. The result of the study showed an enhanced quality of life for both the person with ID and his/her caregiver, and it also addressed the limited employment opportunities for people with ID (Conroy et al., 2010:269-277).

The recommended income generation initiative by McKenzie et al. (2013:1753) coincided with the findings of the study by Conroy et al. (2010:269-277) and is particularly relevant to the present research, as a section of the developing psychoeducational programme focuses on resourcefulness in a resource-constrained situation.

The intervention services for people with ID will be discussed next.

3.8 Intervention Services for People with Intellectual Disability

In South Africa, there are multidisciplinary intervention services gaps with regard to people living with ID (Adnams, 2010:439).

3.8.1. Early intervention services

Early intervention services for children with intellectual disability are critical to the well-being and optimal development of the child (Lipkin, Macias, Norwood, Brei, Davidson, Davis, Ellerbeck & Houtrow et al., 2020:1). A child with intellectually disability can develop optimally with an early intervention plan that includes the co-management of health, education and social services in conjunction with the caregiver family (Lipkin et al, 2020:1-21). Early intervention services include diagnosing and treating the condition, home surveillance visits and education of the caregivers (Lipkin et al, 2020:1-21). Participation of children with ID in early intervention programmes offer long-term benefits and, at the very least, minimise the decline of intellectual functioning that occurs in these children (Lipkin et al, 2020:1-21). However, early intervention centres for children with intellectual disability (below the age of 3) are predominately available only in higher-income countries (Linn et al., 2019:15).

Schoeman, Swanepoel and Van der Linde (2017:57) expressed a concern over the lack of early intervention services to people with ID in South Africa, as well as that the early intervention programmes that are available, are at tertiary and private healthcare level and not at primary healthcare level - which is the first point of access for most of the South Africa's population. Consequently, caregivers are ill-informed regarding their child's development.

3.8.2. Community Services

It is difficult for people to meet their own needs when they are excluded from the socio-economic life of the country and the community in which they reside (Booyens, Van Pletzen & Lorenzo, 2015:1). Essential community services and resources, such as housing, income, food, clothing and transportation, can be very difficult for people with ID to access (Ellem, O'Connor, Wilson & Williams, 2013:63).

Communities face challenges - for instance, stigma - which impede their readiness to foster social inclusion of people with intellectual disabilities. According to Simplican, Leader, Kosciulek and Leahy (2015:18-29), there are two domains of social inclusion for people with ID, namely interpersonal relationships and community participation. The authors add that improvement in these two domains would improve the quality of their life. Furthermore, it is important for service providers, such as social workers, to develop and promote interventions that would enhance the social inclusion of people with intellectual disabilities.

This is supported by a study conducted by Booyens et al. (2015:1-9) in 2011 and 2012 with community disability workers in three southern African countries, namely Botswana, Malawi and South Africa. One of the outcomes of the study was that there were inadequate and insufficient resources available for people with disabilities and their families in rural communities. Difficulties in accessing community resources, such as transportation, education and health services, contributed to their social exclusion.

People with ID are often viewed as passive recipients of community services without the acknowledgement of their strengths and own contributions. Social work support to people with ID should include helping them discover their innate gifts and talents, as well as connecting them with community services and resources that would add meaning to their lives (Ellem et al, 2013:63). However, often their talents and rights are overlooked, thus excluding them from actively participating in community life (Booyens et al., 2015:1).

3.8.3. Transition Initiatives and Services

Purugganan (2018:307) asserts that, when a person with intellectual disability reaches the age of 16, an initiated individualised transition plan would ensure continued support beyond special-needs education into areas, such as employment, adult living and recreation. However, as mentioned, children with intellectual disability generally experience difficulties in accessing education (Linn et al., 2019:16; Donohue & Bornman, 2014:2). Nevertheless, in South Africa, even if this education has been accessed, those who complete their special-needs education are limited in numbers (Capri, 2016:60).

To address this gap in services, Nel, van der Westhuyzen and Uys, (2007:13-18) developed a piloted transition model in South Africa for youth with intellectual disabilities. The model has three phases, namely the pre-vocational preparation which includes prevocational skills training by an occupational therapist, the second phase is followed by vocational onsite-training, and the third phase is placement and follow-up. The authors recommend that transition models, such as this one, should be government-driven, as the current schooling system would find it difficult to sustain such a transition service (Nel et al., 2007:18).

Currently, social workers remain an invaluable resource to people with intellectual disability as they support and direct them to the appropriate after-school programmes and access to community services (Purugganan, 2018:307).

3.8.4. Health and Mental Health Services

Mental health services in South Africa are seriously under-resourced (Coetzee et al., 2019:4), and intellectual disability is a secluded field with little access to other healthcare sectors (Salvador-Carulla & Bertelli, 2008:11). This is due to the opinion of many health professionals that intellectual disability is a social and educational concern and not a health concern (Salvador-Carulla & Bertelli, 2008:11).

Intellectual disability is referred to as a ‘hidden’ mental health priority area and an ‘unseen agenda’ for the health policy decision-makers (Salvador-Carulla & Bertelli, 2008:10-11). Health and mental health services for people with ID are few, and there is inadequate provision for multidisciplinary health services for these persons (Adnams, 2010:439). Additionally, in South Africa, there is a shortage of appropriately trained healthcare professionals to care adequately for people with ID (Coetzee et al., 2019:7).

This gap in services for people with ID extends to published research on intellectual disability (Adnams, 2010:439), which is confirmed by Salvador-Carulla and Bertelli, (2008:11) who state that research funding for intellectual disability studies is very limited as it is not a key topic in health programmes. Furthermore, one of the consequences of the lack of research funding is that the development of good practice guidelines and other tools to facilitate adequate caregiving of people with ID is hindered (Salvador-Carulla & Bertelli, 2008:11). Purugganan (2018:306) states that there should be a collaborative approach between the health services and the social work services, as well as the involvement of the caregiver-families, to address the services which people with ID require. This is significant to the current study as the researcher aims to contribute to the tools of caregiving of people with ID by means of the development of a psychoeducational manual.

3.9. Summary

Intellectual disability is a public health and human rights issue because of its impact on individuals living with ID, their caregivers, their families, as well as the community. Many of the causes of intellectual disability are unknown, and the known causes are attributed to genetic, prenatal and environmental factors.

Early intervention services for children with intellectual disability are available predominantly in higher-income countries, even though the prevalence of intellectual disability is higher in lower- to middle-income countries. Despite the demand for greater social inclusion of people with intellectual disability there remains a discrepancy of resources in lower- to middle- income countries (LMICs) versus higher-income countries. The challenges to enhancing the quality of life for children and adults with intellectual disability remain.

The next chapter discusses the care needs of people with intellectual disability and investigates the impact on the caregiver.

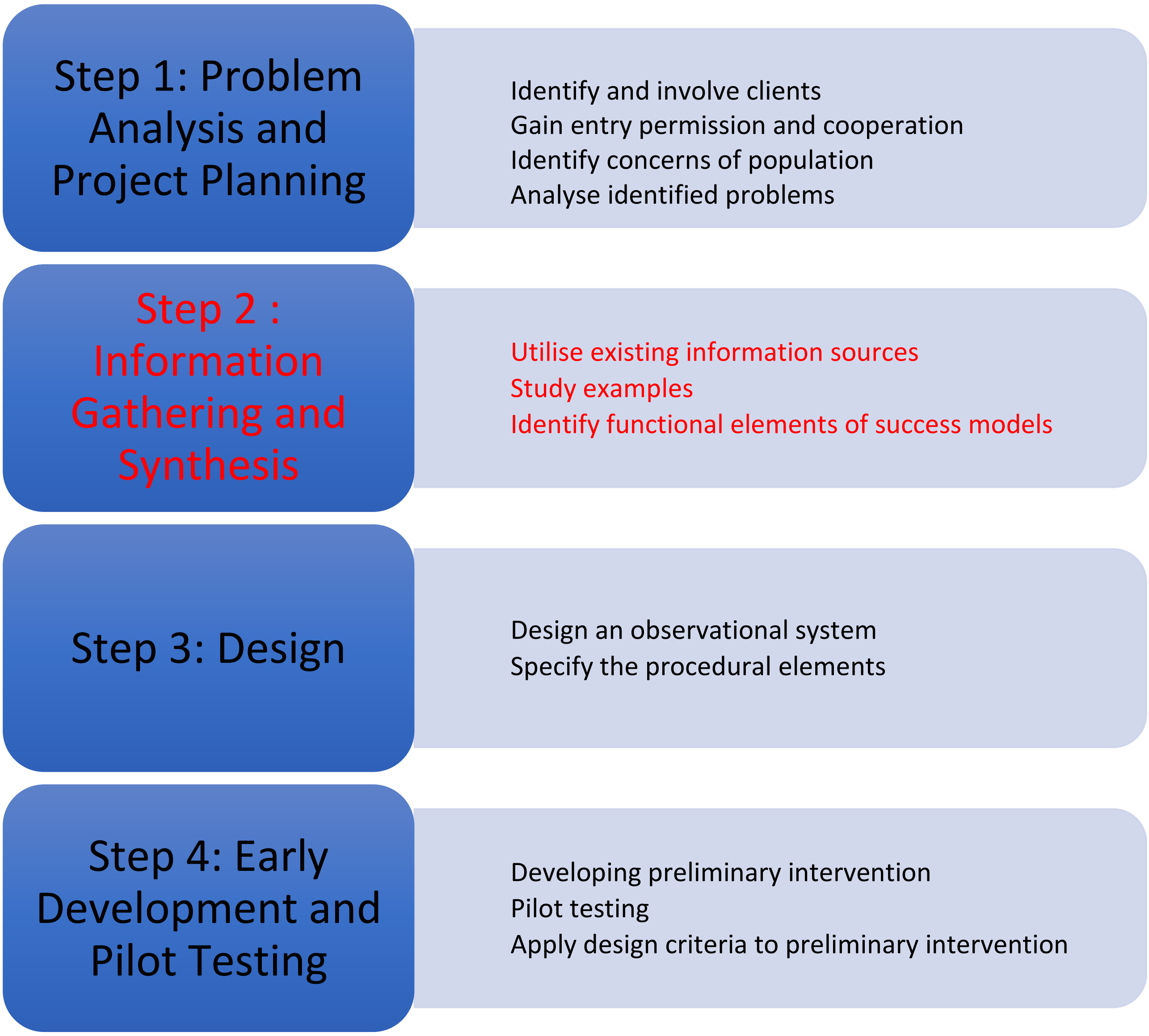


Figure 9: Graphic representation of the phases of intervention research. Adapted from Rothman and Thomas (1994:28); Fraser and Galinsky (2010:459-466)

4.1 Introduction

Research shows that caring for a person with intellectual disability can be burdensome and demanding (Steiner, 2011:178; McConnell & Savage, 2015:100-109; Panicker & Ramesh, 2019:1-14; Ezeonu et al., 2021; Ugwuanyi et al., 2022:2). In comparison to people with physical disabilities, people with intellectual disabilities have a different set of care needs that would allow them to function optimally in the community in which they reside and cope satisfactorily with their activities of daily living. People with a physical disability may need nursing assistance, but they are able to make informed decisions with clear judgement (Vecchio, Cybinski & Stevens, 2009:782-796). However, the person with ID relies on his or her caregiver's judgement who then makes decisions on his or her behalf. This means that the burden of care rests on the caregiver, and the latter's duties often include managing challenging behaviour, liaising with the health, legal and social systems, as well as devoting time to activities of daily living, such a grooming (Vecchio, Cybinski & Stevens, 2009:782-796)

In this chapter a literature overview of the care needs of people with intellectual disability and the impact on the caregiver is offered. Applicable legislation is provided.

4.2 Caring for People with Intellectual Disabilities

In low- to middle-income countries, such as South Africa, people with intellectual disabilities are predominantly cared for by their families (Coetzee, 2016:157; McKenzie & McConkey, 2016:531). These families are committed to their caregiver roles despite the burden thereof and the lack of adequate resources (McKenzie & McConkey, 2016:531-541).

In higher-income countries, targeted support services are developed for these caregivers to assist them in their caregiver role (Families SIRG, 2014:423). However, in LMIC, the need for support is much greater than in their higher-income counterparts, as the prevalence of intellectual disability is much higher (McKenzie & McConkey, 2016:531; Capri et al., 2018:1-17).

Caregivers can be categorised into two groups, namely informal unpaid or family caregivers and formally paid or employed caregivers (Perkins, 2009:11; Coetzee, 2016:157).

The two categories of caregivers will be discussed in Section 4.2.2 and Section 4.2.3.

4.2.2 Informal Unpaid or Family Caregivers

Informal caregivers are usually the parents, but often it is the mother of the person with intellectual disability who takes up the caregiving responsibility. Mak and Cheung, (2008:543), McKenzie (2016:67-78), as well as Ezeonu et al. (2021), indicate that most caregivers are predominantly female. Lafferty et al. (2016:13) concur but add that the majority of caregivers are lone (single, divorced, widowed) females. However, informal caregivers may also be the fathers, siblings, grandparents, or family friends and neighbours. Should the person with intellectual disability have high care support needs, caregivers could spend a considerable part of their day fulfilling various caregiver tasks and responsibilities.

The role of informal caregiving is usually unanticipated and thrust upon ill-prepared parents who had high aspirations for their children. Thus, when the anomalies of their child are discovered, they experience a range of emotions, such as feelings of guilt, sorrow and despair (Gona et al., 2011:179; Panicker & Ramesh, 2019:1-14; Muller-Kluits & Slabbert, 2020:137).

Informal and family caregivers receive no financial remuneration for their services. The South African Social Security Agency (SASSA) Act No. 9 of 2004 states that the South African Government provides a disability grant to adults and children with intellectual disability. However, often caregivers are unable to be employed themselves due to their caregiver obligations. Having a child with a disability, therefore, often leads to poverty (Gona et al., 2011:175-183). Be that as it may, informal caregiving is generally perceived as the most cost-effective way of caregiving (Muller-Kluits & Slabbert, 2020:137). This is due to the lack of affordable workshop and residential placements, particularly in LMICs (Coetzee, 2016:157; McKenzie & McConkey, 2016:531-532).

Informal caregivers in LMICs also reside in impoverished and disadvantaged settings, are prone to greater ill-health and are often socially more isolated (McKenzie & McConkey, 2016:531).

Perkins (2009:11) highlights the important benefits of informal caregiving: it helps maintain family structures and enables persons with intellectual disability to remain in their home environment and enjoy the benefits of receiving individualised attention. However, at the De Le Salle University Research Congress (2015) it was presented that one of the major stressors in informal unpaid family caregiving is that it takes an emotional toll on the parents who are concerned about the future.

Informal caregivers are often very concerned regarding the future care of their child, once they, the parents, pass away (Mkabile et al., 2021:5.) In African societies the expectation is that a child would take care of its parents in their old age; therefore, the parents are also concerned about their own future need for care (Gona et al., 2011:175-183).

Despite these concerns and challenges, informal caregivers are found to be very committed to their child. In a study conducted by McKenzie and McConkey (2016:531-541) with informal caregivers of people with ID in South Africa, the researchers found that informal caregivers have a strong commitment to their caregiver responsibilities despite the burden that they carry. Furthermore, the study found that improved family support and appropriate resources are needed, especially when the primary caregiver is no longer able to care for the person with ID. This is relevant to this study as the researcher aims to provide a training manual for caregivers which could contribute to the very scanty resources to informal caregivers of people with ID. Psychoeducation of the informal caregiver is discussed in more detail in Section 5.2.2.

4.2.3 Formally Paid or Employed Caregivers

Formally paid or employed caregivers include care assistants in residential homes, work supervisors in protective workshops, housemothers in group-homes and nurses caring for persons with intellectual disability in small or larger institutions. The researcher could not establish what the average monthly salary of formal caregivers of people with ID is in South Africa. However, Gould (2021:1240-1260) found that, in the United States, the monthly remuneration of formal caregivers is generally very low. The reason could be that formal caregiving is often perceived by society as a charitable occupation instead of a duty of justice that permeates from the human rights of people with ID.

Kench (2016:163) and Blouin et al. (2016:329-335) emphasise that the most important task of the formal caregiver is to help make the residential facility a place where people with intellectual disability can grow and learn, and where new skills can be acquired.

However, persons with ID may display challenging behaviours, such as being unpredictable, unresponsive or resistant to the caregiver's efforts (Meintjies, 2004:595; Coetzee, 2016:157). This can cause the formal caregiver to avoid interaction with the individual (Chancey, Weihl, Root, Rehfeldt, McCauley, Takeguchi & Pritchard, 2019:160-169) and/or increase his or her work-related stress levels (Meintjies, 2004:595; Coetzee, 2016:157). In this case work demands seem overwhelming (Meintjies, 2004:595; Coetzee, 2016:157). Moreover, this work stress can be further aggravated by staff shortages, a heavy workload, limited resources and extended working hours (Blouin, Smith-Miller, Harden & Li, 2016:329-335; Coetzee, 2016:157).

As far as challenging behaviour is concerned, formal caregivers do not necessarily have the training to manage such behaviour (Tilley, Ledger & Bardsley, 2015:6). Coetzee (2016:157-158) concurs and adds that formal caregivers may or may not have training in caregiving at all. A study conducted by Simpson, Adams, Manokara and Malone (2022:1-11) highlighted the great desire of formal caregivers for knowledge and training in order to feel more equipped for taking care of people with intellectual disability. Their research results further indicated that training priorities pointed out by formal caregivers were management of problematic behaviour, knowledge and understanding of intellectual disability and practical interventions, including positive support in caregiving (Simpson et al., 2022:5-9). The outcome of a study conducted by Chancey et al. (2019:160-169) suggests that the practical intervention of Acceptance and Commitment Therapy (ACT) has shown to improve formal caregiver interactions with people with ID. (ACT is described in more detail in Section 5.3.2.5.)

Kench (2016:163) and Blouin et al. (2016:329-335) agree that training is necessary and add that formal caregivers should receive ongoing psychoeducation with regard to the benefits of self-care; for example, the importance of sleep hygiene and understanding people with intellectual disability. Negative caregiver attitudes, which could be rooted in fears or mistaken beliefs, should be explored. Kench (2016:163) goes on to state that a well-trained and competent caregiver will be respected by other employees of the organisation, as well as by the parents of the person living with intellectual disability. The author reiterates that a trained caregiver will also contribute greatly to the well-being and development of the child or adult with ID. The management of work stress is further discussed in Section 5.2.1.

The above information is relevant to the present study as the developed psychoeducational programme includes the management of challenging behaviour, Acceptance and Commitment Therapy (ACT), and selfcare. Furthermore, the psychoeducational programme provides guidance regarding what is expected of formal caregivers and deepens their awareness of the support needs of people with intellectual disability - which is important for formal caregivers to know (Kench, 2016:163).

4.3 The Impact of caring for People with ID

In the following section, the impact of caring for people with ID will be covered by discussing the nature and extent, causes and impact of caregiving, the socio-economic impact and, lastly, the domains of caregiving.

4.3.1. Nature and Extent, Causes and Impact of Caregiving

Caregiver distress is a condition that manifests as exhaustion, depression, anger and/or guilt due to unmitigated caregiver responsibilities for someone with a disability (Blouin et al., 2016:329-335; Catalano, Holloway & Mpofu, 2018:2; Lipsky & Burk, 2009, 303-319;). Caregiver distress can lead to emotional outbursts, heightened irritability and decreased tolerance to stress, all of which may negatively impact not only the caregiver, but also the person with ID (Blouin et al., 2016:329-335). Disability is seen as a burden and a source of social stigma that impacts the person with ID, as well as his or her caregiver (Ezeonu et al., 2021).

The causes of caregiver distress are multifactorial and include managing the challenging behaviour of the person with ID, caregiver lack of quality sleep, extreme caregiver obligations, perceived caregiver burden, social isolation, financial concerns, decline in physical health and disruption in family cohesion (Gillespie-Smith et al., 2021:1-15; Bedewy, 2021:1911094).

Understanding caregiver burden is fundamental to determining the mechanism which may effectively support caregivers of people with ID (Marsack-Topolewski & Church, 2019:145-156). Four types of caregiver burden have been identified: time dependence, developmental, emotional and financial burdens (Marsack-Topolewski & Church, 2019:145-156; Marsack-Topolewski, 2021:299-319). Taking care of a person with intellectual disability can impact each of these four domains of the caregiver.

4.3.2. Socio-economic Impact

In South Africa, one of the most serious challenges that stem from redirecting the care of a person with intellectual disability from institutions to the community is the dire socio-economic state of most families (Mtshali, 2017:6). In the Safer Western Cape Conference Report, the Western Cape Minister of Community Safety, Alan Winde, highlights some of the extensive evidence regarding social inequities, such as substance abuse, crime and violence which are rife in the Western Cape (2018:5-32). These social injustices could lead to an increased number of persons living with intellectual disability in the form of Fetal Alcohol Syndrome (FAS) and head injuries, causing cognitive impairment (Adnams, 2016c:30; Mtshali, 2017:6).

As the number of people living with intellectual disability is increasing due to the negative impact of the dire socio-economic climate of the Western Cape, it makes sense that the consequences thereof are that the burden of care on caregivers is also increasing. This information is important in terms of the proposed study as increasingly more caregivers need training to be equipped in the management of people with intellectual disability.

The City of Cape Town's Socio-Economic Profile Report (2017:12-13) reveals that there has been an increase in poverty and, therefore, an economic decline in the Western Cape. The weight of economic pressures, specifically between 2011 and 2015, has increased poverty levels among households and residents of the Western Cape. These findings are verified by the Poverty Trends in South Africa Report (2017:19-111) released by Statistics South Africa, which cites that the rising unemployment levels, low commodity prices, higher consumer prices, lower investment levels, household dependency on credit and policy uncertainty are the key contributors to the economic decline in recent times.

The rise of poverty in the Western Cape is important to this study as this negatively impacts caregivers of people with intellectual disability. Informal caregivers fall into the category of 'unemployed' as caregiver duties are thrust upon them without remuneration. The report on the Poverty Trends in South Africa (2017:19-111), categorises people vulnerable to poverty. The most predominant categories of vulnerable adults are females (more specifically African females), children aged 17 years and younger, people from rural areas and those with no education. Coetzee (2016:158) states that a caregiver who experiences poverty and hardship often struggles to allocate enough resources to the care of the person with ID. This information is important to the proposed study, as the impact of poverty on the caregiver's ability to render adequate caregiving will be assessed.

4.3.3 Domains of caregiving

There are four domains of caregiver burden (Marsack-Topolewski & Church, 2019:145-156; Marsack-Topolewski, 2021:299-319).

- *Time dependence caregiver burden:* Many caregivers report that their caregiver duties are of an ongoing nature. The around-the-clock nature of caregiving is particularly stressful.

- *Developmental caregiver burden*: This refers to caregivers feeling out of step with life events or normative events of their peers. They feel that they cannot relate to their peers and feel excluded from enjoying normal developmental milestones.
- *Emotional caregiver burden*: This refers to feelings of sadness, stress and concern for the well-being of their child.
- *Financial caregiver burden*: Many caregivers forgo employment opportunities due to their caregiver obligations. Caregiving also involves certain expenses; for example, paying for transportation or services.

Should the caregiver of a person with intellectual disability remain unsupported, there is a risk that the burden of care could lead to caregiver stress and caregiver fatigue (Blouin et al., 2016:329-335; Coetzee, 2016:159). The caregiver will feel stressed only if he/she believes that he/she is unable to cope with the burden of meeting the caregiving obligations. Coetzee (2016:159) also points out that, should the caregiver feel that he or she cannot effectively deal with the challenge of caregiving, this can then lead to added stress. Considering these stressors drives home the importance of the present study undertaken with the aim of developing a psychoeducational programme for caregivers to equip them better for the challenge of caregiving.

4.4 Care needs of People with ID and the Challenges of their Caregivers

Caregivers of people with intellectual disabilities face daily challenges that can lead to mental health problems within themselves and difficulties with the task of caregiving (Ó Donnchadha, 2018:181; Provenzi, Grumi, Rinaldi & Giusti, 2021)**.** The following section further explores the cause, nature and extent of caregiver distress amongst caregivers of people with intellectual disability.

4.4.1 Developmental Needs

Ebuenyi, Rottenburg, Bunders-Aelen and Regeer (2020:536) assert that people with intellectual disability have a developmental need and a right to education. However, they are often excluded from training and vocational programmes. Donohue and

Bornman (2014:2) concur and report that, in South Africa, up to 70% of children with intellectual disability of school-going age are not attending school. These children are often thought of as not needing to attend a special school as they are unable to keep up with their classmates (Ebuenyi et al., 2020:539).

This perception could be ascribed to the ambiguity of the implementation of the Education White Paper 6 policy (Department of Education, 2001) that emphasises inclusive education. The Education White Paper 6 on special needs education states that learners with disabilities are to join mainstream class with their developing peers and that barriers to learning are to be addressed before they should be considered to enter a special-needs school.

To meet the developmental needs of people with intellectual disabilities they need to be granted access to scholastic and behavioural intervention services, such as life skills training and healthcare services which include occupational therapy, speech and language therapy and physiotherapy (Jeste, Hyde, Distefano, Halladay, Ray, Porath, Wilson & Thurm 2020:825-833; Dhiman, Sahu, Reed, Ganesh, Goyal & Jain, 2020:825-833).

Teachers in South African classrooms are struggling to meet the increasing influx of learners who are experiencing diverse barriers to learning and development, as they do not have the necessary skills to provide support and to adapt classroom teaching (Engelbrecht, Nel, Nel & Tlale, 2015:1-10). Affirmative action policies and national and international human rights legislators should address the barriers to the enrolment in training programmes for people with ID (Ebuenyi et al., 2020:536). This impacts caregivers as they often report a lack of treatment by special-needs educational services for their children (Mkabile et al., 2021:5). An additional factor is that many caregivers do not believe that their child is educable and, therefore, will not apply for their child to attend school (Ezeonu et al., 2021). Furthermore, those who are enrolled in schools have caregivers who can afford the cost of schooling (Ezeonu et al., 2021). The result often is that the caregivers of children with intellectual disabilities are not informed regarding further support for the learning needs of their child – which increases caregiver distress (Dhiman et al., 2020:825-833).

4.4.2. Pharmacological Needs

With regard to medical treatment, there can be considerable confusion and uncertainty for the medical professional, as well as the caregivers of people with intellectual disability (Deutsch & Burket, 2021:110017). Medical practitioners often have difficulty in diagnosing and prescribing the correct treatment plan due to communication difficulties with people with intellectual disability (Ziviani, Lennox, Allison, Lyons & Del Mar, 2004:211-225; Deutsch & Burket, 2021:110017).

Psychotropic medication is generally prescribed to people with intellectual disability and who exhibit challenging behaviour patterns (Deutsch & Burket, 2021:110017). Such behaviour includes aggression to self, their caregiver and objects; self-injurious behaviours, such as head-banging; repetitive stereotypical behaviours, as well as hyperactivity (Newcomb & Hagopian, 2018:96-109; Deutsch & Burket, 2021:110017).

However, medical practitioners could have difficulty prescribing the correct treatment dose (Ziviani et al., 2004:211-225; Deutsch & Burket, 2021:110017). The result is that challenging behaviour could also be due to the medication. The regular monitoring of medication is important as behaviour could improve should the dose of the medication be reduced or discontinued (Deutsch & Burket, 2021:110017). On a practical level, this entails supervision of medication adherence and the cost of travelling for outpatient and pharmacological appointments for the caregiver and the person they care for. The lack of traveling fees as well as the high cost of travelling are major causes of caregiver distress (Coomer, 2013:271-276; Mkabile & Swartz, 2020:7). Moreover, many caregivers report a lack of adequate medical treatment by health care professionals (Mkabile et al., 2021:5).

Depending on the level of functioning of the person with intellectual disability, it is best that they take personal responsibility for adhering to their prescribed medication regime to encourage independence (Slaggert & Jongsma, 2015:118). However, it is also important that caregivers monitor – and also involve the rest of the household in this responsibility - that the person with ID ingests the medication as prescribed to manage medical conditions, such as a physical pain, as he or she may not be able to fully articulate the discomfort experienced (Slaggert & Jongsma, 2015:118).

In the case of a person with ID resisting medication, the following should be considered: The caregiver should ask the pharmacist to provide information to the person with intellectual disability regarding the importance of taking the medication as prescribed (Slaggert & Jongsma, 2015:118). Furthermore, joining a peer support group where they can discuss their physical or mental concerns would be beneficial (Slaggert & Jongsma, 2015:118). In addition, a psychological assessment could identify the reason or barriers which underlie the resistance to taking the medication as prescribed (Slaggert & Jongsma, 2015:118).

4.4.3. The Emotional Need for Belonging

The emotional need for belonging is a core need for people with intellectual disabilities (Mahar, Cobigo & Stuart, 2013:1031). They are often viewed as dependent objects of care rather than people worthy of respect and deserving of a full enjoyment of human rights (Mahar et al., 2013:1031; McKenzie, 2016:67-78).

Mahar, Cobigo and Stuart, (2013:1031) explain that a sense of belonging is a personal feeling of value and respect developed in a mutual relationship that is built on a shared experience, on beliefs or communal attributes. The authors add that future research should focus on developing indicators of the various aspects of social inclusion for people with intellectual disabilities.

The sense of belonging pertains to social inclusion within the broader society but also within the family unit. Parents of people with intellectual disability report having higher than average rates of stress, depression and anxiety (McConnell & Savage, 2015:100; Panicker, & Ramesh, 2019:1-14). The reasons for this are that having a child with an intellectual disability impacts the caregiver's relationship with other members of the family (Yoong & Koritsas, 2012:609-619; Lauderdale-Littin & Blacher, 2017:230-239). Chronic caregiver distress places the caregiver at increased risk of marital problems and family dysfunction (McConnell & Savage, 2015:100).

Everyone within the family, including the siblings of the person living with ID, must adjust to the implications of having such a family member in the household (Yoong &

Koritsas, 2012:609-619; Lauderdale-Littin & Blacher, 2017:230-239; Ezeonu et al., 2021). Any negative impact in general on a developing sibling will vary based on the caregiver's stress level (Yoong & Koritsas, 2012:609-619; Lauderdale-Littin & Blacher, 2017:230-239). A caregiver, who feels negative about caring for the child with intellectual disability, would adversely influence the attitude of their other children towards their sibling with intellectual disability. This could impact the sense of belonging of the person with ID (Mahar et al., 2013:1031).

Another cause of family dysfunction that is very pertinent to the Western Cape is substance abuse within the home (Safer Western Cape Conference Report, 2018:5-32). A caregiver's abuse of substances, such as alcohol and drugs, is a maladaptive coping response to caregiver distress (Gillespie-Smith, McConachie, Ballantyne, Auyeung & Goodall, 2021:1-15). Disengagement occurs when the caregiver is not emotionally involved anymore in the reality of their experience (Harris, 2019:35). Furthermore, a disengaged caregiver does not believe that he or she has much influence over the situation anyway (Ginsburg & Jablow, 2020:316).

Alcohol-drug-social disengagement is an emotional avoidance coping strategy of the caregiver who believes that not thinking about their child's disability would assist with adapting to it (Ezeonu et al., 2021). However, these researchers assert that the use of alcohol to disengage could lead to additional stress and abandoning their caregiver duties. This assertion correlates with the findings of Gillespie-Smith et al. (2021:1-15) who state that caregiver disengagement can lead to further psychological distress and an increase in challenging behaviour by the person with ID.

Mkabile et al. (2021:1-2) argue that, for black African families, experiences and outcomes of caring for their children with intellectual disabilities are expected to be worse due to the legacies of colonialism, such as apartheid, poverty and poor living conditions. In African societies, the expectation is that the child would take care of the parents in their old age and having a child with disability renders the future uncertain (Gona et al., 2011:175-183). Under Apartheid, black people received the least services followed by the Coloured and Indian groups (McKenzie & McConkey, 2016: 532). Whilst these racial divisions have no place in South Africa currently, at the time, the focus of provision for the White population was the focus of the government (McKenzie

& McConkey, 2016: 532). According to the researcher's observations, many South Africans are still living the legacy of Apartheid.

The displacement of family members during the South African political struggle significantly impacted black African families (Carton, 2014:365-384; Mkabile et al., 2021:2). The system of migrant labour, in which young black men would leave their families and move across the country to seek employment in order to pay ukuthela (the government taxes) and take care of their wives and children, contributed to the current functioning and structure of African families (Mkabile et al., 2021:2; Carton, 2014:365-384).

The legacy of apartheid impacted the African family unit of a person with intellectual disability. With systemic barriers, such as historical discrimination, current social roles and norms, as well as community stigmatisation, the caregiver may feel powerless and have a sense that he or she does not 'qualify' to belong, which negatively impacts their perceived caregiver burden and distress (Mak & Cheung, 2008:532-533; Mahar et al., 2013:1031). Improving service delivery, such as skills development and appropriate coping tools for the caregivers, would address many of the negative effects experienced by family members (Yoong & Koritsas, 2012:609-619; Lauderdale-Littin & Blacher, 2017:230-239; Ezeonu et al., 2021). This is relevant to the present research as caregiver training could simultaneously improve family relationships.

4.4.4. Environmental needs

Caregivers' distress stems from a need for protection - a supportive, safe environment and community - for persons with ID (Courtenay & Perera, 2020:231-236). However, such persons are often viewed as incompetent, burdensome and an economic drain and, consequently, they are not treated with much respect making them vulnerable to community crime, bullying, gang violence, as well as sexual assaults and abuse (McKenzie, 2016:67-78). They are vulnerable to manipulation to perform sexual acts with the promise of payment which, in turn, places them at risk of sexually transmitted diseases, such as HIV/AIDS (McKenzie, 2016:67-78). The impact on caregivers is that many try to alleviate their safety concerns by taking the person with ID wherever they go and not letting them out of their sight. Many view their community as indifferent and hostile towards people with ID (McKenzie, 2016:67-78).

Scior, Hamid, Hastings, Werner, Belton, Laniyan, Patel and Kett (2020:165-175) conducted a study to gauge the extent to which intellectual disability continues to be stigmatised and to ascertain what kind of initiatives are in place to increase such persons' inclusion and address stigma around the globe. The findings of the study were that the public in many parts of the world generally support the fundamental principle of inclusion of children and adults with intellectual disability. Nonetheless, negative attitudes persist. High levels of stigma remain a reality in many places (Pulla, 2017:108-109).

Furthermore, the findings of the study coincide with a longitudinal study conducted by Song, Mailick and Greenberg (2018:152-158) which indicated that the effects of the experience of stigmatisation in the form of daily discrimination, embarrassment and shame places caregivers of people with developmental disorders, such as intellectual disability, at higher risk of poorer physical health with a greater number of chronic health conditions. Current interventions to address stigmatisation are inadequate and more needs to be done globally to reduce the stigma associated with ID. In many parts of the world, the life expectancy of people with ID still appears to be very low, and support and advocacy is almost entirely their families' responsibility (Scior et al., 2020:165-175).

4.4.5. Assistance with Daily Living

The concept of 'daily living' includes the ability associated with meeting daily needs, such as self-care tasks like grooming and dressing – for instance, brushing of teeth, bathing, feeding (Marsack-Topolewski, 2021:299-319). Assistance with daily living involves support with the above tasks, but also includes activities necessary to maintain a normal life, such as cooking a simple meal or utilising public transport (Marsack-Topolewski, 2021:299-319). The support that people with intellectual disabilities need can range from minor assistance to total dependence on their caregiver. Consequently, the degree of assistance necessary can contribute to a caregiver's burden (Marsack-Topolewski, 2021:299-319).

It is important for support services to encourage caregivers to socialise with other adults, make use of respite care and access disability support services for families, as this would have a positive impact on their mental well-being. Furthermore, it is important for the person with the disability to develop independent skills from the caregiver to the greatest possible extent to enhance the caregiver's quality of life and lessen his or her distress (Marsack-Topolewski & Church, 2019:145-156; Ezeonu et al., 2021).

4.4.6. Financial Needs

In this section, two aspects of financial needs will be discussed, namely daily financial needs and future financial needs.

4.4.6.1. Daily financial needs

The Social Assistance Act (SAA) No. 13 of 2004 does not recognise the financial needs of caregivers of people with ID. The SAA, in Chapter 2 (12), stipulates that an individual is eligible for a Grant in Aid should their mental and physical condition require them to need regular assistance by another individual. Therefore, the person with intellectual disability is the recipient of an additional Grant in Aid and not the caregiver (Christians, 2019). This equates to a total of R2200 per month to a person with intellectual disability who receives an additional Grant in Aid to that of the disability grant (Christians, 2019). The fact that informal caregivers receive no remuneration for their caregiving correlates with McKenzie's (2016:67-78) assertion that the need of the caregiver becomes invisible when it comes to distribution of goods and services.

Often, caregivers are unable to be employed themselves – or need to resign from formal employment - due to their caregiver obligations (Gona et al., 2011:175-183). It can, therefore, be concluded that, in practical terms, this amount of R2200 per month is to cover the expenses of both the person with ID and his or her caregiver. Although, as Christians (2019) states, this amount of money is only for the care of the person with ID it is less than the minimum wage in South Africa which, at R22,99 per hour in 2022, equates to R3678.40 per month (Steyn, 2022:62-62).

Capri et al. (2018:1-17) explain that due to the lack of educational programmes for people with intellectual disability in South Africa, the burden of caregiving and lack of support, hinders informal caregivers' pursuit of employment. Nevertheless, informal caregiving remains the only feasible option for numerous people with ID in the Western Cape (McKenzie, 2016:67-78).

4.4.6.2. Future financial needs

Caregivers are concerned about the future financial needs of the person with intellectual disability should they pass away (Mkabile et al., 2021:1-2). They are also concerned about their own caregiving needs, particularly in African societies where the expectations are that the child will take care of its elderly parents (Gona et al., 2011:175-183). Moreover, people with intellectual disability are now living longer with some families becoming two-generation elderly families, and, in some cases, the person with ID may outlive his or her parents. Under these circumstances there appears to be a growing number of siblings who assume the role of caregiver for the person with ID when a parent passes away (Lafferty et al., 2016:10).

The higher prevalence of intellectual disabilities in low-income countries, such as South Africa, allied with an increased life expectancy of people with intellectual disability worldwide, means that more children are surviving into adulthood and many will continue to need lifelong support (McKenzie et al., 2013:1750; McKenzie & McConkey, 2016:531). A research study conducted in Cape Town in 2015 found that caregivers of people with intellectual disability have an intense commitment to caregiving, and the unclear future options of care for the person with the intellectual disability makes them extremely anxious (McKenzie & McConkey, 2016:535).

Though the future options may be unclear, it remains important for social work support services to caregivers, to include proactive future planning in terms of arrangements to be made for persons with ID when the primary caregiver dies. This includes financial security, as well as procuring an advocate to protect the legal rights of the person with

ID in the Final Will of the caregiver (Hole, Stainton, & Wilson 2013:571-589). As the child grows into an adult, legal guardianship should also be addressed (Purugganan, 2018:307). The researcher is of the opinion that, although securing a procurator is very necessary, this might not be financially feasible for caregivers of lower-income communities.

The role of the social worker in assisting caregivers of people with ID will be discussed next.

4.5. The Role of Social Work in assisting Caregivers of People with ID

Muller-Kluits and Slabbert (2020:138) assert that social workers play a key role in assisting caregivers of people with ID by addressing the caregiver burden they may experience. Furthermore, that social workers do this by mobilising the access to much needed resources through interventions, such as advise, referral and advocacy. This is supported by a South African study conducted by Maphosa and Chiwanza, (2021:155-163) that found that caregivers perceived social workers as pivotal in relieving their burden of care, navigating the tasks of caregiving and helping with the provision of adequate support.

Social work practice consists of the professional application of social work techniques, values and principles (Olckers, 2013:47). The role of the social worker in assisting caregivers of people with ID includes (but is not limited to) psychoeducation, participation in legislative processes and the facilitation of the caregiver’s improvement of psychosocial functioning (Olckers, 2013:47; Muller-Kluits & Slabbert, 2020:139). These social work professional applications will be discussed next.

4.5.1. Social Workers’ Psychoeducation of Caregivers on caring for a Person with ID

Caregivers have an array of unfulfilled training needs (Maphosa & Chiwanza, 2021:155). The social worker plays the pivotal role of educator, not only in the community as to how to prevent certain disabilities, but also to the caregiver once he or she takes on the role of caregiver (Muller-Kluits & Slabbert, 2020:139). The role of educator is critical as many caregivers feel overwhelmed by their caregiver obligations (Muller-Kluits & Slabbert, 2020:139; Maphosa & Chiwanza, 2021:156;). Social work psychoeducation would include knowledge that could assist in their caregiving duties (Muller-Kluits, & Slabbert, 2020:139).

4.5.2. Social workers assist caregivers to maintain, improve and restore psychosocial functioning

One of the important roles that social workers play with regard to caregivers of people with ID is to provide psychosocial support (Samboma, 2021:267). According to Simplican et al. (2015:18-29), social exclusion from community resources can have a negative impact on the psychosocial functioning of the caregiver. Social workers have a mandate to provide adequate services, support and resources to people with disabilities (Maphosa & Chiwanza, 2021:156). Furthermore, it is the social worker's role to enable the independent interaction between the caregiver and the resources within the community (Muller-Kluits & Slabbert, 2020:139).

The mobilisation of resources, such as the Government's disability grant, can improve the psychosocial functioning of the caregiver. Some families in South Africa simply do not know about and how to access the Government's disability grant (Booyens et al., 2015:5). However, fundamental to social work interventions is the practice of empowerment of caregivers (Pulla, 2017:98-102), and this is pertinent to the current study as the manual being developed incorporates the important aspect of access to caregiver resources.

4.5.3. Social Workers participate in legislative processes

Social workers should understand people with intellectual disabilities within the context in which they reside, as well as the experiences of their caregivers, as this would allow social work interventions to be aligned with the legislative and policy frameworks. This is important as social workers should be prepared to participate in legislative processes in which they may be required to make recommendations regarding the legal capacity of a person with an intellectual disability (Holler & Werner, 2022:826-833).

Furthermore, this would allow social workers to take up their role as advocate and mediator on behalf of the caregiver family. Often social workers must act as mediator between the caregiver and the person with ID, as well as between the caregiver and other health professionals, to ensure that the needs of the family are adequately understood, acknowledged and addressed (Muller-Kluits & Slabbert, 2020:139).

As discussed, social work interventions to caregivers of people with ID should be aligned with the legislative policies and frameworks which will be discussed next.

4.6. Legislative and Policy Framework

The following legislative and policy documents underpin the study and reinforce the legitimacy of the development and implementation of a psychoeducational programme for caregivers.

4.6.1. The United Nations Convention on the Rights of Persons with Disabilities (UNCRPD)

The UNCRPD is the first international legally binding mechanism providing governments with minimum standards regarding the rights of people with disabilities. In 2007, South Africa ratified the UNCRPD, thus indicating the Government’s commitment to protecting the rights of people with disabilities. Article 3 of the UNCRP states the general principles of the Convention which include, but are not limited to, the tenet that people with disabilities have the right to respect of their inherent dignity, non-discrimination, full participation in society, equality of opportunities and accessibility.

4.6.2. The Constitution of the Republic of South Africa, 1996

The Constitution of the Republic of South Africa emphasises the rights of people with disabilities to service delivery. The Constitution states that “[t]he State may not unfairly discriminate directly or indirectly against anyone on one or more grounds, including race, gender and disability.” The Constitution is relevant to the study as it is the primary legislative framework that relates to the unfair discrimination of people with intellectual disabilities.

4.6.3. The Mental Health Care Act No. 17 of 2002 (MHCA)

The MHCA protects the rights and dignity of people with intellectual disabilities, including those with psychiatric conditions, such as schizophrenia or bipolar mood disorder. The Act focuses on interventions and regulations, including the rights and duties relating to voluntary care treatment, rehabilitation and treatment of those whose cognitive ability and judgement is too impaired to make an informed decision.

This is relevant to the study as it would, therefore, be their caregivers' responsibility to decide on treatment on their behalf by completing Form 4 of the MHCA. The MHCA makes provisions which allow that, for those with diminished decision-making ability, their caregivers act in their best interest and make decisions on their behalf. For instance, this legislation provides for the situation in which a person with ID does not agree to admission to a mental health facility. In this case, the caregiver can assist in the relevant decision to be made, along with the mental health treatment team, namely that involuntary admission is in the person with intellectual disability's best interest.

4.6.4. White Paper on the Rights of Persons with Disabilities (2015)

The White Paper advocates for the socio-economic inclusion of persons with disabilities and requests Government, civil society and the private sector to work together in realising this.

This is applicable to the present study, as the White Paper, amongst others, promotes the aspect of human dignity for people with disabilities and their families. Human dignity "refers to an individual or group's sense of self-respect and self-worth, physical and psychological integrity and empowerment" (White Paper, 2015:8).

4.6.5. Policy on Vulnerable Groups (2013)

The Policy on Vulnerable Groups reiterates the challenges people with disabilities face as it relates to meaningful participation in community activities and access to services, employment opportunities and appropriate skills training. This is relevant to the study as one of the policy directives is the creation of awareness and training programmes as part of a holistic service to vulnerable groups, such as persons with disabilities.

4.6.6. Section 54 of the Criminal Law (Sexual and Related Matters) Amendment Act, 2007 (Act 32 of 2007)

Section 54 of the Criminal Law Amendment Act states that the reporting of abuse applies to all persons. In terms of Section 54 every person has a duty to report sexual abuse/offences and may be liable for penalties should they not report these - unless the report is done in “good faith” The Act obligates all persons to report such abuse - including if it is the caregiver him-/herself abusing the person in his or her care. This is relevant to the study as people with intellectual disability are often the victims of abuse.

4.6.7. Observed Legislation Gap regarding Adults with Intellectual Disabilities

The researcher could not find in the legislation reference to a situation in which an adult (person older than 18 years) with intellectual disability could be statutorily removed from his or her caregiver’s care should he/she be abused by the former. The research into protective legislation for people with intellectual disability has, thus, observed a legislative gap. The following could be established: -

- ➢ The South African Children’s Act No. 38 of 2005 and the Children’s Amendment Act No. 42 of 2007 recognise children with disabilities and their right not to be subjected to medical, social, cultural or religious practices that are detrimental to their health and well-being. However, adults with intellectual disabilities are not recognised under this legislation.

- To the best of the researcher's knowledge, after extensive investigation, the MHCA also does not refer to statutory protection of adults with intellectual disabilities who are being abused by a caregiver.
- The South African Law Reform Commission (SALRC) has undertaken an investigation (Project 122) that is to lead to legislation being established for the protection of the rights of those with declining decision-making ability from abuse. This is due to the inappropriate and outdated ways in which the South African Law deals with people with declining decision-making ability. However, the role and function of the SALRC is limited to the investigation and only the suggestion of this law to the Government.
- The Domestic Violence Act makes provision for a protection order, but this would entail the person with the intellectual disability applying for a protection order themselves. However, when the caregiver is the abuser, it would be very challenging, due to their impaired cognitive ability, for the person with ID to recognise the abuse and advocate for themselves.
- The Department of Social Development advocates the rights of people with disabilities, as well as providing social welfare services. However, the researcher could not find an indication that the Department of Social Development has statutory structures in place to protect adults with intellectual disabilities who are being abused.

Therefore, the researcher's contention is that there is no specific law that statutorily protects abused adult persons with ID, meaning that they cannot legally be removed from an abusive caregiver through a court enquiry, and that this is a serious legislative gap. Capri et al. (2018:153-154) propose a Vulnerable Adults Act that would legally oblige the State to protect adults with ID, as the MHCA is inadequate to do so.

It is, therefore, imperative that those who are duty-bound to report with regard to a violation of the Children's Act should also take cognizance of their duty to report cases in which adults with intellectual disabilities are at risk of abuse, neglect or in need of protection from other kinds of harm.

4.7. SUMMARY

Caregivers can be categorised into two groups, namely informal unpaid (or family) caregivers and formally paid (or employed) caregivers. Persons with ID will need lifelong support and this responsibility falls on their caregiver. The causes of caregiver distress are multifactorial and include management of the challenging behaviour of the person with ID, caregiver lack of quality sleep, extreme caregiver obligations, perceived caregiver burden, social isolation, financial concerns, decline in physical health and disruption in family cohesion. Caregiver fatigue can lead to emotional outbursts, heightened irritability and decreased tolerance of stress, all of which may negatively impact the caregiver, as well as the person with intellectual disability. Caregivers will feel stressed only if they believe that they are unable to cope with the burden of meeting their caregiving obligations.

There are four domains of caregiver burden, namely the time dependence caregiver burden, developmental caregiver burden, emotional caregiver burden and financial caregiver burden.

The researcher identified several factors associated with caregiver distress that can be alleviated to help safeguard caregivers. Meeting the developmental needs of the person with ID is not always accessible to him or her, and this includes scholastic skills, occupational therapy and life skills. Pharmacological needs can cause confusion, and the cost implications are also a burden to the caregiver. The emotional needs of persons with ID are expected to be met by their caregivers who themselves have emotional unmet needs – often with other children to take care of as well. The person with ID must overcome many barriers, such as community stigmatisation and safety concerns, in order to practise their human right to societal participation. The caregiver is expected to assist the person with ID with his or her daily activities, but also attempts to make them as independent as possible. Caregivers are often unable to work due to their caregiver duties and receive no remuneration from the Government.

The role of the social worker in assisting caregivers includes psychoeducation, maintaining, improving and restoring psychosocial functioning, as well as participation in legislative processes.

Legislation and policy frameworks for the present study have been discussed. However, a legislative gap was also identified.

The next chapter provides a literature overview regarding the significance of a psychoeducational programme for caregivers of people with intellectual disability and the core elements that should be included.

CHAPTER 5

PSYCHOEDUCATIONAL PROGRAMME FOR CAREGIVERS OF PEOPLE WITH INTELLECTUAL DISABILITY

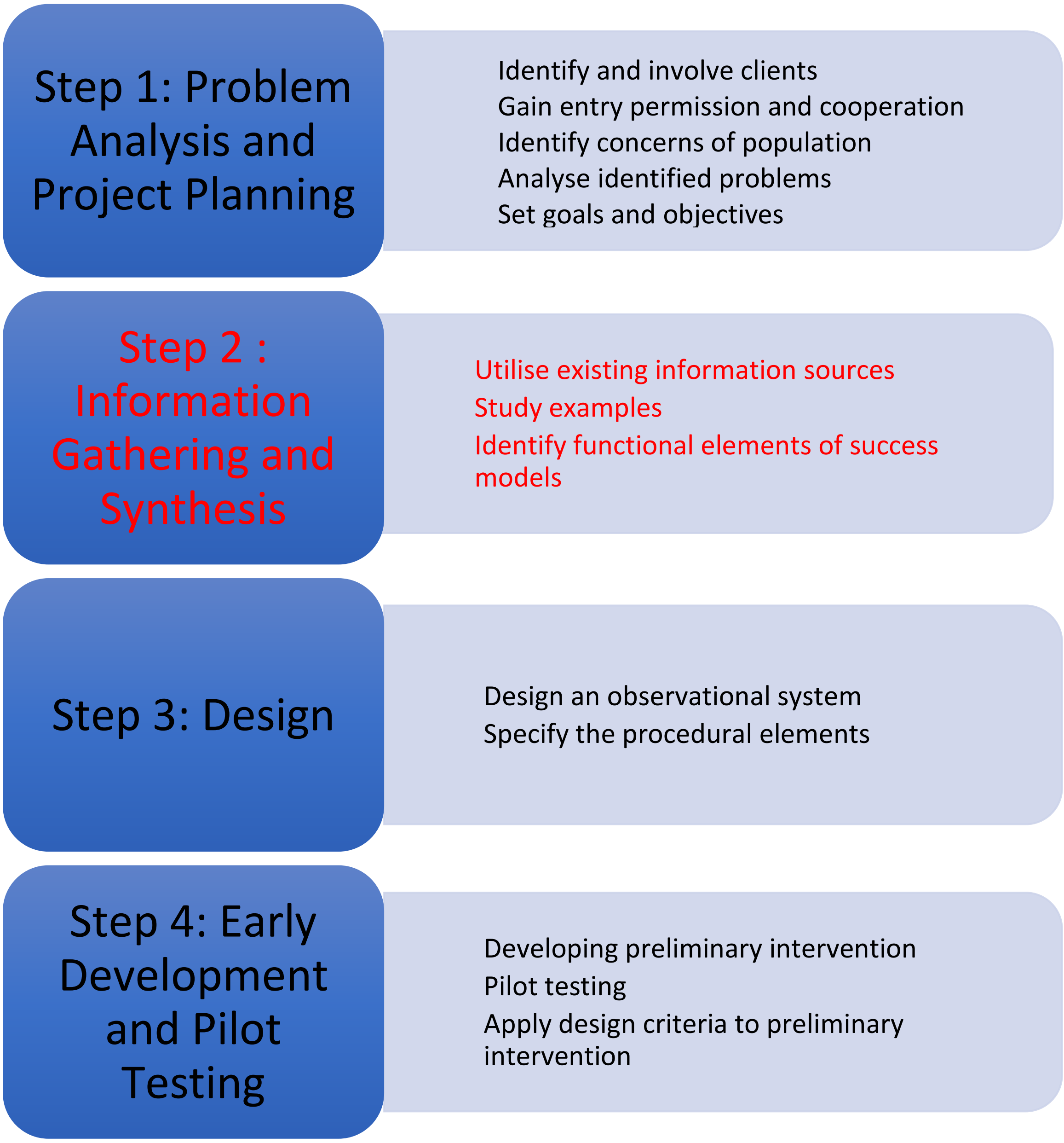


Figure 10: Graphic representation of the phases of intervention research. Adapted from Rothman and Thomas (1994:28); Fraser and Galinsky (2010:459-466).

5.1 Introduction

There are currently few evidence-based programmes available to caregivers of people with intellectual disability (Smith Da Walt et al., 2018:251-263; Kleintjes et al., 2020:31). However, a targeted psychoeducational programme has been shown to reduce caregiver stress and improve outcomes for both the caregiver and the person with intellectual disability (Smith Da Walt et al., 2018:251-263).

A psychoeducational programme refers to a highly structured evidence-based programme that often follows a manual or a pre-planned curriculum (Smith Da Walt, et al., 2018:251-263). The goal of such a programme is to provide education regarding the disability, as well as practice guidelines in problem-solving, and to render opportunities for social support through interaction with others who have similar experiences. Having this in place will, in turn, alleviate caregiver distress (Smith Da Walt et al., 2018:251-263). Bedewy, (2021:1911094) asserts that, should service professionals fail to focus interventions on addressing the needs of caregivers, their role with respect to the person with the intellectual disability could be negatively impacted.

In this chapter a literature overview regarding the significance of a psychoeducational programme for caregivers of people with intellectual disability, the core elements that should be included to enhance their caregiving skills, as well as methods of alleviating caregiver distress, is presented.

5.2 The Significance of a Psychoeducational Programme

Petersen and Lund (2011:754) point out that there are several gaps in community-based psychoeducational rehabilitation programmes in South Africa. According to them, community care is inadequate, and this is evidenced by the revolving-door phenomenon in which there is a high frequency of admissions to hospitals and use of police and prison services. Coetzee et al. (2019:4) concur that, in South Africa, limited training opportunities are available to caregivers of people with ID.

The researcher could not locate existing psychoeducational programmes targeted at caregivers of people with intellectual disability in the Western Cape or in the South African context. This is supported by literature (Smith Da Walt et al., 2018:251-263;

Kleintjes, McKenzie, Abrahams & Adnams, 2020:31) which has found that, in South Africa, there is insufficient integration of practice-based programmes regarding intellectual disability into academic and in-service training programmes for practitioners. The lack of such practice-based programmes limits competence in service delivery in health, social care and education (Kleintjes et.al, 2020:31).

In his chapter in the book *Understanding Intellectual Disability* - written specifically for South African readers - Kench (2016:163) recommends that a psychoeducational programme for caregivers should include basic knowledge of intellectual disability, orientation regarding attitudes towards intellectual disability and guidance on managing a person with intellectual disability.

There is an overlapping need for psychoeducation for both informal and formal caregivers of people with ID. In the next section psychoeducation for both formal and informal caregivers will be discussed.

5.2.1 Psychoeducation for the Formal Caregiver: The Management of Work Stress

The uniqueness of psychoeducation for formal caregivers of people with ID is the issue of work stress that affects a substantial portion of their daily lives (Ó Donnchadha, 2018:181). Work stress is a change in the employee’s physical and mental state in response to the workplace which poses a considered challenge or threat to that employee (Thomas, Colligan & Higgans, 2005:89).

In this research, as previously stated, a formal and paid caregiver is a person who is employed to support the needs of a person or people with ID and who does not necessarily have training in this respect. In South Africa, there is a shortage of appropriately trained healthcare professionals to care adequately for people with ID (Coetzee et al., 2019:7). Work stress occurs when formal caregivers experience that their work demands are beyond their capacity to cope with (Coetzee, 2016:157; Meintjies, 2004:595).

Chronic work stress can be detrimental to the caregiver’s health and can lead to depression, anxiety and burnout (Favrod, Jan du Chêne, Martin Soelch, Garthus-Niegel, Tolsa, Legault, Briet & Horsch, 2018:1-12).

Numerous researchers (Coetzee, 2016:157; Leoni et al., 2016:59-73; Singh et al., 2020:99-111; Ugwuanyi et al., 2022:3) have repeatedly indicated that it is strenuous to take care of a person with ID.

However, contrary to this, a study done in the USA by Hastings and Horne (2004:53-62) discovered that formally employed caregivers found it rewarding to take care of persons with ID. The study indicates that some contributing elements to formal caregiver work satisfaction include the support they receive from work colleagues, learning about the needs of people with ID, and learning to adjust to issues they cannot change.

Work-life integration is a phenomenon in which what happens at work can influence the employee's private life and vice versa (Arnold & Randall, 2010:48). For instance, an employee experiences trauma in his/her work, such as managing a violent outburst of a person with ID, and the ripple-effect of this extends to family and friends in their personal life (Meintjies, 2004:665).

The cause of work stress on formal caregivers includes incidents of challenging behaviour (Koritsas, Iacono, Carling-Jenkins & Chan, 2010:6-7; Leoni et al., 2016:59-73). The display of such behaviour could result in the person with ID losing his or her very scarce and much needed residential placement (Courtenay & Perera, 2020:231-236). As will be discussed in Section 5.3.3.3, several factors could lead to a person with intellectual disability having a violent outburst. When caregivers intervene to protect other persons with ID or other caregivers, they themselves often become the target of the violence (Uys, 2004:595).

However, the Occupational Health and Safety (OHS) Act No. 181 of 1993, 17(4), states that every employee has the right to be safe in the workplace. Dickman (2003:152) corroborates this and insists that safety is necessary in any organisation. Thus, it is important that a psychoeducational plan for caregivers should include mechanisms for managing challenging behaviour (Leoni et al., 2016:59-73). Formally paid caregivers of people with ID habitually experience challenging situations in the workplace, as facing distressing experiences is a daily routine in ID facilities (Koritsas et al., 2010:6-7; Leoni et al., 2016:59-73). Consequently, support from management by monitoring the situation is vitally important. Management of aggression in the workplace includes adequate training, response protocols and debriefing of the caregivers (Koritsas et al., 2010:6-7). Otherwise, repeated exposure to these challenges can lead to caregivers utilising maladaptive coping tools, such as unhealthy life choices, mental health and psychological problems, higher absenteeism and low productivity (Leoni et al., 2016:59-73). Therefore, the psychological distress of caregivers can be very costly to their organisation (Leoni et al., 2016:59-73).

Rich, DiGregorio and Strassle (2021:603-618) maintain that people with ID are disproportionately impacted by trauma. The general perception of formally employed caregivers is that they do not intentionally cause trauma to people with intellectual disabilities, but that there are system barriers that prevent trauma-informed care from being available (Rich, DiGregorio, & Strassle, 2021:603-618). The perception with respect to paid caregivers is that high staff-turnover, lack of accessible mental healthcare professionals, lack of training, as well as stigmatisation, are contributing factors to their unwittingly creating a trauma-filled environment for people with intellectual disability (Rich, DiGregorio & Strassle, 2021:603-618).

Teo, Kennedy-Behr and Lowe (2018:1503-1504) suggest that formal caregivers may experience ambiguity in their role and responsibilities when working with a person with ID. They further argue that there is a need for training of these caregivers, as well as a need for clear and well-defined communication and collaboration between service providers, such as social workers, and caregivers.

Arnold and Randall (2010:458) reiterate the importance of training so that, even if the employee becomes involved in an emergency workplace incident, the incident will not distress them. They add that employees who face physical danger, such as police, mineworkers or firemen, often appear to have reduced stress levels. Employees who are adequately trained to manage a crisis, often use these incidents as a source of motivation and satisfaction. This re-emphasises the importance of psychoeducational training for caregivers.

The following should be included in the training of caregivers in order to improve their well-being, improve the care rendered to the recipient, as well as decrease sick-leave (Favrod et al., 2018:1-12):

- reframing the traumatic workplace incident
- allowing the caregiver, a break to recover in between the frequently occurring work-related stress incidents will

Furthermore:

- Interventions should also include emotional acceptance and commitment therapy as they have shown to reduce occupational stress even if there has been no change in the challenges of the workplace (Leoni et al., 2016:59-73).
- Elements, such as resilience building, social support and appropriate coping strategies are helpful protective factors against work stress (Favrod et al., 2018:10).
- Interventions that have a cognitive behavioural approach and include psychoeducation to reduce work-related stress have been proven to be effective (Eddy, 2021:26-27).

These elements discussed above relate to the present study, as the researcher is piloting a psychoeducational programme that incorporates the elements of resilience-building, social support and coping strategies, as well as implementing a cognitive behaviour approach as a practice framework with the aim of alleviating caregiver distress.

5.2.2 Psychoeducation for the Informal Caregiver

Kench (2016:163) recommends that a psychoeducational programme to caregivers of people with ID should include basic knowledge of intellectual disability. Purugganan (2018:306) agrees and argues that medical practitioners play a key role in the psychoeducational process of caregivers, from the identification of the intellectual disability and providing information, to being an important advocate for people with ID and their families to receive intervention services and resources.

However, in a study by Ziviani et al. (2004:211-225) it was found that general medical practitioners identify themselves as ill-equipped to provide primary health care to people with intellectual disability. The findings suggested that doctors were concerned with the aspects of communication difficulties which influenced their ability to diagnose adequately, manage and inform the person with intellectual disability, as well as his or her caregivers. Deutsch and Burket (2021:110017) concur and add that, due to these communication difficulties, the medical treatment of people with ID can be a challenge for the medical practitioners. The problem lies not only in treating persons with ID but also in educating their caregivers. Moreover, Salvador-Carulla and Bertelli (2008:11) assert that training with respect to ID is not included in the psychiatric curriculum of many countries and, therefore, most psychiatrists are not prepared to manage the health needs or requirements of people with ID.

The lack of information provided to informal caregivers is confirmed by Mkabile and Swarts's study (2020:1026-1037) conducted with caregivers of people with ID in the Khayelitsha (Cape Town) district. These authors found that some caregivers were not informed by medical practitioners as to what their children's condition was. The findings of the study further highlighted a need for collaboration between the biomedical and alternative healthcare systems in educating caregivers regarding intellectual disability. Furthermore, Gona et al. (2011:175-183) agree that medical staff are underestimating caregivers' need for information, and that the information provided was scanty or not provided at all. Moreover, the attitude of hospital staff drove some caregivers to prefer engaging the services of a traditional healer rather than a hospital clinician (Gona et al., 2011:181).

However, a study conducted by Schoeman et al. (2017:52-61) contradicts Gona et al.'s conclusion by stating that the reason why caregivers are ill-informed regarding their child's development is due to their non-adherence to follow-up appointments. The study's findings were that 87% of participants were unconcerned about their child's development. Further reasons for defaulting on follow-up appointments included employment obligations and other responsibilities. Whether it is the mental health professionals who do not provide information, or the caregivers who do not adhere to follow-up appointments, Schoeman et al. (2017:52-61) agree that caregivers lack information on intellectual disability.

Bourke-Taylor, Lee, Tirlea, Joyce, Morgan and Haines (2021:3690-3706) conducted a study on interventions to improve the mental health of mothers of children with a disability and found that interventions that adopt psychoeducational and cognitive behavioural approaches are shown to be the most effective. Furthermore, they explain that the cognitive behavioural approach operates on the principle that thoughts, emotions and behaviours are interconnected, and cognitive strategies can be used to influence change. Additionally, the psychoeducational approach includes providing programmes that facilitate the caregiver’s knowledge and understanding of health, thought patterns and coping strategies (Bourke-Taylor et al.,2021:3693)

The aim of the psychoeducational programme is to empower caregivers with the knowledge and understanding of various core elements of the disability and, in this way, be effective in enhancing caregiver well-being (Sarkhel, Singh & Arora, 2020:319; Bedewy, 2021:1911094). This is relevant to the present study as the researcher aims to develop a psychoeducational programme that utilises cognitive behavioural therapy within a strength-based approach as a practice framework with the goal of empowering caregivers and enhancing their well-being.

The various core elements of a psychoeducation programme for both formal and informal caregivers will be discussed in the next section.

5.3 Core Elements included in a Psychoeducational Programme to alleviate Caregiver Distress

It is important that multidisciplinary professionals, including social workers who work with people with ID, should support the capacity-building of caregivers to include the management of the complex needs of those with ID whom they care for (Kleintjes et.al, 2020:31). The literature review indicates the following core elements for a psychoeducational programme for caregivers of people with ID.

5.3.1. Knowledge on Intellectual Disability

People living with intellectual disability have a significantly reduced ability to understand new or complex information and to learn and apply new skills (World Health Organisation (WHO) [s.a.]). This results in a reduced ability to cope independently (impaired social functioning) and begins before adulthood - with a lasting effect on development (WHO, [s.a.]). There are three criteria for the current definition of intellectual disability: formal designation of low intelligence through artificial problem-solving tasks, impairment in one's ability to function in one’s social environment, and early-age onset (Platt et al., 2019:952-961; Gillespie-Smith et al., 2021:1-15).

Caregivers have attributed various reasons to intellectual disability: some believe that disability is a punishment from God, others believe in the superstition of bewitchment, while yet others interpret ID as a spiritual attack or demon possession (Mkabile et al., 2021:5; Ezeonu et al., 2021). Many caregivers do not have any idea what the cause of their child's intellectual disability is (Ezeonu et al., 2021).

Understanding intellectual disability will assist the caregiver to cope better with caring for the person with ID (Ezeonu et al., 2021). Moreover, the caregiver should also understand the care needs of a person with intellectual disability as discussed in Chapter 3.

5.3.2 The Resilient Caregiver

Resilience has been found to be the key factor in successful adaptation of caregivers of people with ID (McConnell & Savage, 2015:100; Lafferty et al., 2016:15). Resilience is defined as the ability to recover from adversity and return to the original form or position (Ginsburg & Jablow, 2020:41). Therefore, resilience is not a skill or trait that the individual needs to acquire; rather, it is already within them and just needs to be nurtured (Ginsburg & Jablow, 2020:41).

Usually, a caregiver's first response to the news that their child has an intellectual disability is an emotional one of shame, grief, denial and resentment (Bedewy, 2021:1911094). Caregivers who experience poor psychological well-being are more likely to have lower levels of resilience (Lafferty et al., 2016:15), and those who are unable to adapt to the revelation that their child has an intellectual disability may fall into despair, depression and low self-esteem (Bedewy, 2021:1911094).

Resilience is a critical human characteristic that can be nurtured through multiple processes, such as meaning making, benefit finding, mindfulness meditation, physical exercise, cognitive behavioural therapy, emotional acceptance and commitment therapy, social-emotional training and expressive journaling (Bennett et al., 2018:1339-1346).

Ginsburg and Jablow (2020:39-48) maintain that, when it comes to resilience, it is vital for the caregiver to model resilience strategies for the person in their care. Furthermore, caregivers must nurture themselves in the same way that they care for the person they are committed to.

5.3.2.1 The mindset of a resilient caregiver

Hammond (2010:6) emphasises that the desired outcome of the strength-based approach is resilience. Moreover, the author describes the mindset of a resilient person in the following manner.

Resilient individuals: -

- Have a strong sense of hope and optimism
- View life as a dynamic journey based on how they perceive themselves and with whom they surround themselves
- Have learned to set realistic goals for themselves
- Rely on productive and growth-fostering coping tools
- View obstacles as challenges to confront - not avoid
- Intentionally build on their strength whilst being cognisant of their vulnerabilities
- Have a strong sense of self and believe in their own competencies
- Possess effective interactional skills and seek out assistance when needed
- Understand what they can and cannot control in their lives
- Embrace the need to support and give back to others

5.3.2.2. The 7-C Model of resilience

Ginsburg and Jablow (2020:39-48) describe the 7-C Model of resilience as follows.

(a) Competence

Competence refers to handling a situation or task effectively, having specific skills and being passionate about a topic, such as intellectual disability.

Basic questions which the caregiver should ask him- or herself (Ginsburg & Jablow, 2020:42):

- Do I help my child to focus on his/her strengths? Do I focus on my strengths and continuously build on them?

- Do I communicate in such a way that it empowers my child?
- Do I allow my child to make safe mistakes so that he/she can learn from it versus being overprotective?

(b) Confidence

A caregiver needs to believe in his or her own abilities. It is about perceiving challenging situations as opportunities for growth and learning.

Basic questions the caregiver should consider (Ginsburg & Jablow, 2020:43):

- Do I see the best in my child so that he can see the best in him- or herself?
- Do I praise him/her when he/she does well? Do I praise myself enough?
- Do I acknowledge him or her when he or she is being helpful and kind?

(c) Connection

This is about the caregiver knowing that he or she is not alone in challenging situations, and this creates a sense of security. Having close ties with family and/or a social group, as well as a sense of community, are foundations for developing creative solutions.

Some examples of basic questions which caregivers should ask themselves include (Ginsburg & Jablow, 2020:39-44): -

- Does my child feel safe to come to me for emotional support in times of difficulty?
- Do I allow my child to express all types of emotions, or do I suppress unpleasant feelings?
- Do I encourage my child to feel pride in various ethnic, religious or cultural groups to which they belong?

(d) Character

Character is based on a solid set of personal morals and values and nurturing a caring attitude towards others.

Caregivers should ask themselves (Ginsburg & Jablow, 2020:39-44): -

- Do I value my child so clearly that I model the importance of caring for others?
- Do I help my child understand how his or her behaviour may affect other people positively or negatively?

- Am I careful to avoid racist statements or stereotyping about any other groups?

(e) Contribution

This refers to caregivers, insight into the importance of their personal contribution to their world. The experience of helping others makes it easier to request assistance when they are in need themselves.

Thus, a caregiver should ask him- or herself (Ginsburg & Jablow, 2020:39-45): -

- Do I model the importance of serving others within my community?
- Do I create opportunities for my child to serve others?
- Do I create a culture of serving others within my household?

(f) Coping

Coping is dependent on skills and self-confidence in dealing with stressful situations. It involves the caregiver's developed ability to overcome the adversities in life.

Some examples of basic questions which the caregiver should ask him- or herself include (Ginsburg & Jablow, 2020:39-46): -

- Do I model problem-solving, or do I react emotionally when I am overwhelmed?
- Do I model the importance of caring for my body through nutrition, exercise and adequate sleep?
- Do I create a family environment in which talking and listening to each other are safe, comfortable and productive?

(g) Control

Caregivers need to know that they have some control over their life and environment. Their decisions and actions may have an influence on the outcome. Control also refers to taking personal responsibility for actions and decisions made.

Caregivers should, therefore, ask themselves (Ginsburg & Jablow, 2020:39-47): -

- Do I think about the future one step at a time?
- Do I help my child understand that no one can control all circumstances but that we can shift the odds by choosing positive behaviours?
- Do I reward demonstrated responsibility?

5.3.2.3 Caregiver coping strategies

It is important to understand the caregiver coping strategies for effective caregiver obligations (Panicker & Ramesh, 2019:1-14; Ezeonu et al., 2021). Caring for a person living with intellectual disability can be very strenuous, and if caregivers neglect to take care of themselves, they could become prone to depression and anxiety (Coetzee, 2016:157).

Coping styles can differ from one individual to another (Ginsburg & Jablow, 2020:262). The most common coping style used by caregivers of people with ID is religious coping which encompasses religious beliefs and faith values (Gona et al., 2011:181; Panicker & Ramesh, 2019:1-14). A caregiver's mental health plays an important role in the quality of care he/she provides to the person with an intellectual disability and having an appropriate coping style will diminish the symptoms of depression and stress (Panicker & Ramesh, 2019:1-14).

Lazarus and Folkman's (in Marsack-Topolewski and Church, 2019:145-156) stress and coping theory, provides a framework that can be used to determine caregiver burden and furthermore that coping has two major functions.

The two major functions of coping can be distinguished between management of the problem, known as problem-focused coping and regulation of emotion, known as emotion-focused coping as explained next (Panicker, & Ramesh, 2019:1-14; Auriemma, Ding, Zhang, Rabinowitz, Shen & Lantier-Galatas, 2022:51-63; Gona et al., 2011:179-181; Ginsburg & Jablow, 2020:262).

(a) Problem-focused coping

This entails using everyday problem-solving skills to engage the problem actively. It involves identifying the problem, considering possible solutions and taking action to address the problem. Examples of problem-focused coping is writing a to-do list, asking for support and setting healthy boundaries (Gona et al., 2011:179-181; Panicker & Ramesh, 2019:1-14; Ginsburg & Jablow, 2020:262; Auriemma, Ding, Zhang, Rabinowitz, Shen & Lantier-Galatas, 2022:51-63).

(b) Emotion-focused coping

This involves making efforts to change or reduce the negative emotions associated with stress by, for instance, engaging the difficult emotions in a way that is healthy, such as cognitive reappraisal. This entails superimposing constructive meaning on a situation that is challenging. Examples of emotion-focused coping are meditating, exercising, crying, journaling and self-pampering (Gona et al., 2011:179-181; Panicker & Ramesh, 2019:1-14; Ginsburg & Jablow, 2020:262; Auriemma, Ding, Zhang, Rabinowitz, Shen & Lantier-Galatas, 2022:51-63)

Not all emotion-focused coping styles are positive as some people choose to avoid the problem through denial or withdrawal. Some examples of maladaptive emotion-focused coping styles are substance abuse to cloud their awareness of the problem or bullying others to make themselves feel in control and better in the short term (Gona et al., 2011:179-181; Ginsburg & Jablow, 2020:262).

5.3.2.4 Caregiver Cognitive distortions

A cognitive distortion is an exaggerated or irrational thought pattern that can lead to the onset or perpetuation of psychopathological states, such as stress, depression and anxiety (Helmond, Petra, Overbeek, Geertjan, Brugman, Daniel, Gibbs & John, 2015:245-262; Surley & Dagnan, 2019:219-237). The caregiver may believe that it is external circumstances that cause his/her negative emotions when, in fact, these emotions could be the result of his or her interpretation of the situation (Wright et al., 2006:89-99).

Ugwuanyi et al. (2022:3) mention some examples of irrational thoughts which such caregivers may entertain. For instance, they may prevent social interactions between their child and others due to the possibility of bullying by other children, and they may believe that they are unable to endure the emotional trauma of seeing their child being bullied because of his or her intellectual disability. They may also believe that they cannot cope with the discomfort of the sight of their child with the disability, or that it is unbearable to see their child amongst neurotypical children with no disability.

Hayes et al. (2011:141–68), as well as Surley and Dagnan (2019:219-237) explain that cognitive behavioural therapy will help diminish the impact of cognitive distortions. Repeated distorted thought patterns become habitual to the caregiver and will, therefore, take on the semblance of truth (Wright et al., 2006:89-99). Caregivers are not aware that these thought patterns are distorted as they have succumbed to such thinking over a period of time. Once the caregiver can identify these cognitive distortions, he or she is able to gain authority over them and change the way he/she feels (Wright et al., 2006:89-99).

(a) Common cognitive distortions

Willner (2009:416-419), as well as Yurica and DiTomasso (2005:117-122), explain some common cognitive distortions with which caregivers of people with intellectual disability may present:

- **Mind reading**

  Caregivers assume that they know what the person with the intellectual disability is thinking; for example, that he or she does not like the caregiver, or that people are judging them. This type of thinking may make the caregiver feel insecure or fearful (Yurica & DiTomasso, 2005:117-122; Willner, 2009:416-419).

- **Catastrophising**

  Caregivers may believe that anything that can or will happen is going to be so appalling that they will not be able to cope with or survive it. This type of thinking convinces the caregiver that the worst-case scenarios may be the most likely outcome; for example, “My life is always a failure.” The caregiver presumes that his or her prediction is correct, and such a frame of mind prevents helpful action (Yurica & DiTomasso, 2005:117-122; Willner, 2009:416-419).

- **Labelling**

  Caregivers may see blanket negative traits both within themselves and possibly within the person living with intellectual disability. For example, if the person with

ID makes a bad choice the caregiver may label him/her as a bad person. The label becomes their identity (Yurica & DiTomasso, 2005:117-122; Willner, 2009:416-419).

- **Negative filter**

They may fixate on the negatives and rarely notice the positives or strengths of a situation. They minimize the good they do and focus on the mistakes they made. This type of thinking can lead to depression (Yurica & DiTomasso, 2005:117-122; Willner, 2009:416-419).

- **All-or-nothing thinking**

Caregivers may view events, or people, in all-or-nothing terms. They may think that they should either perform a task perfectly or else they are failing. This type of thinking is common especially with regard to performance. This thinking pattern may convince the caregiver that he or she is justified to feel hopeless (Yurica & DiTomasso, 2005:117-122; Willner, 2009:416-419).

- **Personalising**

Caregivers may blame themselves to a disproportionate degree for negative events and fail to see that the person with the intellectual disability may hold some responsibility as well. Caregivers may also assume that they are intentionally excluded or targeted. Taking things personally may make the caregiver feel guilty, helpless, overwhelmed and burdened (Yurica & DiTomasso, 2005:117-122; Willner, 2009:416-419).

- **Emotional reasoning**

Caregivers may let their feelings guide their interpretation of reality by assuming that their feelings reflect reality. They may feel anxious in social situations and assume that they are an awkward person. Or, when they struggle with a task, they assume that they are dumb. Emotional reasoning intensifies negative emotions (Yurica & DiTomasso, 2005:117-122; Willner, 2009:416-419).

(b) Developing rational thought techniques

Distorted thinking accelerates the development of caregiver stress, which, in turn, increases the likelihood that the parent or caregiver will engage in maladaptive parenting behaviours (Kennedy, 2012:20-21).

Cognitive behavioural therapy ultimately aims to teach caregivers with less complex symptoms to be their own therapist by helping them recognise and understand their current patterns of thought and behaviour, and by equipping them with the tools to change these maladaptive cognitive and behavioural patterns (Abramowitz, Blakey, Reuman, & Buchholz, 2018:311-322). Caregivers can then also apply these tools to assist those they are caring for (Abramowitz et.al., 2018:311-322). It is important that caregivers adopt rational thought patterns as they often need to make decisions on behalf of the person with the intellectual disability.

Developing rational thinking through cognitive restructuring, cognitive reappraisal and cognitive diffusion will be discussed next.

- **Cognitive restructuring**

Cognitive restructuring has been used as one of the treatment measures to assist parents of children with intellectual disability who present with symptoms of depression (Ugwuanyi et al., 2022:3). Cognitive restructuring is a psychotherapeutic treatment strategy conducted by licensed mental health practitioners of cognitive behavioural therapy (CBT) within a therapeutic setting (Clark, 2022:1-3). It is a goal-directed, structured and collaborative intervention strategy that focuses on exploring and substituting maladaptive thoughts that generate emotional distress (Clark, 2022:2).

However, cognitive restructuring is not needed to achieve cognitive reappraisal in CBT (Clark, 2022:3).

- **Cognitive reappraisal**

Cognitive reappraisal is one of several thinking processes accountable for effective CBT (Clark, 2022:3). Cognitive reappraisal happens when an emotional change occurs brought about by a new perspective on the meaning of a situation and, therefore, reframing the thought pattern (Clark, 2022:2). The use of positive reappraisal has been shown to lower depression and stress symptoms (Panicker, & Ramesh, 2019:1-14). Furthermore, cognitive reappraisal can also assist the caregiver in managing challenging behaviours as the stressful situation is reappraised in positive terms (Gillespie-Smith et al., 2021:1-15). Individuals with higher emotional intelligence find greater use in cognitive reappraisal than individuals with lower emotional intelligence who tend to suppress their emotions (Megías-Robles, Gutiérrez-Cobo, Gómez-Leal, Cabello, Gross & Fernández- Berrocal, 2019:1-8). Greater use of cognitive reappraisal and lesser use of expressive suppression is associated with better psychological health, social functioning and life satisfaction (Megías-Robles et al., 2019:1-8).

Caregivers can examine whether their thoughts are rational in the following ways (Wright et al., 2006:173 -197; Harris, 2019:310-313): -

- Write down thoughts to bring distance between them and self, and foster objectivity. Read them out loud.
- Look for another perspective on the thought.
- Look for exceptions to the thought: Is it partially wrong?
- Assess both sides of the situation. All situations have advantages and disadvantages.
- Examine evidence for your thought: Is the thought truthful?
- Develop and adopt a thought list based on personal values.

- **Cognitive diffusion**

Fusion with our thoughts happens when there is no separation between ourselves and our thoughts (Harris, 2019:20). The differences between cognitive fusion and diffusion are tabled below (Harris, (2019:22): -

Table 3: Differences between cognitive fusion and diffusion adapted from Harris, (2019:22).

COGNITIVE FUSION	COGNITIVE DIFFUSION
The thought is something we must obey, give in to or act upon.	The thought is not something we must obey, give in to or act upon.

The thought is a threat, we need to avoid or discard it.	We recognise that the thoughts and feelings cannot harm us and are no threat.
The thoughts are very important and need all our attention.	They may or may not be important; we choose the amount of attention we give them.

Cognitive diffusion is one of the core therapeutic processes of Acceptance and Commitment Therapy (ACT). There has been a recent third wave of CBT and ACT is the most dominant of the new developments (Leoni et al., 2016:59-73; Harris, 2019:3; Philip & Cherian, 2022:78-82).

5.3.2.5 Acceptance and commitment therapy (ACT)

Emotional acceptance and commitment therapy is an evidence-based intervention shown to reduce stress and burnout, as well as increase the well-being of caregivers of people with intellectual disability (Leoni et al., 2016:59-73).

Upon receiving the diagnosis that their child has an intellectual disability, many caregivers struggle to process and accept this fact (Gona et al., 2011:179; Panicker & Ramesh, 2019:1-14; Muller-Kluits & Slabbert, 2020:137). Some caregivers undergo pain and devastation when they realise that their future dreams and expectations will not be met due to their child's disability (Gona et al., 2011:179). The coping style of acceptance (namely, learning to accept the disability) was found to be effective in reducing the disappointment related to the situation and the possible challenging behaviours of the person with ID (Panicker, & Ramesh, 2019:1-14, Ezeonu et al., 2021).

Emotional acceptance and commitment therapy utilises a cognitive behavioural approach to contextualise thoughts and bring about the acknowledgement of difficult feelings and emotions. Instead of avoiding difficult emotions, accepting them brings about a willingness to experience and accept the trying circumstances (Leoni et al., 2016:59-73; Harris, 2019:284). The attention shifts to defusing the difficult thoughts by noticing them and making space for them by allowing them to be there without having to obey them (Harris, 2019:121).

It is a mistaken belief that we can control and resist our thoughts when fighting unwanted thoughts exacerbates them (Philip & Cherian, 2022:79).

Emotional acceptance and commitment therapy focuses on six core processes, namely cognitive diffusion, acceptance, contact with the present moment, observing the self, values and committed action (Leoni et al., 2016:59-73; Harris, 2019:5-8; Philip & Cherian, 2022:78-82).

Harris (2019:252) explains the language of ACT: -

- Be willing to make space for your thoughts and feelings.
- Drop the struggle and stop the fight with your emotions.
- Soften up around the circumstances and just let it be.
- Breath into it and lean into it.

The application of emotional acceptance and commitment therapy has a positive impact not only on caregivers but also on the person with ID whom they are taking care of (Leoni et al., 2016:59-73).

5.3.2.6 The Good Enough Caregiver

Caregivers of people with ID often strive to be perfect in their caregiver obligations, and it is best practice for professional support persons to encourage them to strive for ‘good enough’ caregiving (Young, 2012:11). Many caregivers have the tendency and desire to want to do everything for the person with ID (Young, 2012:11). Coetzee, Adnams and Swartz (2018:341) applied the concept of ‘good enough’ parenting, coined in 2001 by D. W. Winnicott, to a mother of a person with ID who was experiencing emotional difficulties with her child becoming progressively independent from her as the child grew older.

Flood (2019:3) comments on the ‘good enough parent’ concept of Winnicott, saying that, in a healthy environment, it is normal for a child to move progressively towards independence. The ‘good enough’ caregiver stands in contrast to the ‘perfect’ caregiver and acknowledges that it is not possible to be perfect in caregiving. The role of the caregiver is to provide a safe, responsive environment, but he or she needs to acknowledge that in their human nature they will be unreliable at times (Flood, 2019:3).

Young (2012:11-12) describes the attributes of the ‘good enough’ caregiver in the following manner: -

- The ‘good enough’ caregiver loves the person with ID.
- The ‘good enough’ caregiver tries to make the best decisions for him-/herself and the person with ID.
- The ‘good enough’ caregiver does the best with the resources available.
- The ‘good enough’ caregiver makes mistakes but tries to learn from them.

5.3.2.7. Developing an internal locus of control

Understanding the dichotomy of control is what distinguishes a resilient and empowered individual (Hammond, 2010:6; Rajan, Srikrishna & Romate, 2018:297-306; Harris, 2019:102). It is part of acceptance and commitment therapy to train caregivers to focus on what they can control (Harris, 2019:102).

Mental health professionals, such as social workers and those in the help professions, need to help parents develop an internal locus to improve their resilience. The more resilient caregivers are, the more they will play an active part in their children’s rehabilitation (Rajan et al., 2018:297-306). An internal locus of control serves as a protective mechanism against their stress associated with raising a child with disability (Rajan et al., 2018:297-306). Caregiver distress has been associated with an external locus of control (Lloyd & Hastings, 2009:111; Rajan et al., 2018:297-306).

When caregivers focus their efforts on something they cannot control, the impact on their anxiety can be paralysing (Ginsburg & Jablow, 2020:353). It is, therefore, important for them to understand that they might be able to influence others but cannot control them (Harris, 2019:329).

Caregivers with an external locus-of-control orientation may believe that the child has control over child-caregiver situations and that they themselves have no control over their child. The external locus of control can contribute to increased anger, frustration, depression and anxiety in the caregiver (Kennedy, 2012:18; Rajan et al., 2018: 297-306).

Caregivers with an internal locus of control make efforts - within their control - to improve the situation they are in and are less prone to stress-related health concerns, such as anxiety or depression (Rajan et al., 2018: 297-306). A caregiver with an internal orientation to control has a higher level of resilience; therefore, interventions for caregivers should include the development of an internal locus of control (Rajan et al., 2018:302-303).

Thus, caregivers should focus their efforts on issues they can control and influence. Understanding the dichotomy of control is identifying and clarifying the difference between what is in caregivers' control and what is not (Harris 2019:102-103; Ginsburg & Jablow, 2020:345-347).

Table 4: Understanding the Dichotomy of Control adapted from Harris (2019:102-103); Ginsburg & Jablow (2020:345-347).

Outside my control	**Within my control**
Most of my thoughts	How I respond to my thoughts
Whether or not I achieve the outcomes I want	What I say and do may increase my chances to achieve what I want but I cannot control the outcome.
What other people say and do	What I say might influence other people.
How others judge and perceive me and my child	Whether I act like the sort of person I would like to be
Most of life's difficult events, e.g., the economic crisis	Whether I live a value-based life

5.3.3 The Resilient Family

Parents of people with ID report to experience higher-than-average levels of stress, depression and anxiety (McConnell & Savage, 2015:100; Panicker & Ramesh, 2019:1-14). Chronic distress places the caregiver at increased risk of marital problems, family dysfunction and several physical and mental ailments (McConnell & Savage, 2015:100). Having a child with a disability makes caregivers vulnerable to divorce due to their caregiver obligations and an increase in caregiver distress, making them less receptive to the needs of their spouse (Ezeonu et al., 2021). When the child with ID displays behavioural problems, this may aggravate caregiver stress which can negatively impact on the family and cause further dysfunction (McConnell & Savage, 2015:101).

Having a child with an intellectual disability impacts the caregiver's relationship with others (Yoong & Koritsas, 2012:609-619; Lauderdale-Littin & Blacher, 2017:230-239). Everyone in the family, including the siblings of the person with ID, must adjust (Yoong & Koritsas, 2012:609-619; Lauderdale-Littin & Blacher, 2017:230-239). Any negative impact, typically on a developing sibling, will vary based on the caregiver's stress level (Yoong & Koritsas, 2012:609-619; Lauderdale-Littin & Blacher, 2017: 230-239). A caregiver, who feels negative about caring for a child with intellectual disability would negatively impact the feelings of the other children towards this particular sibling. Therefore, conversely, improving service delivery, such as respite care and skills development of caregivers, would address many of the negative impacts experienced by family members (Yoong & Koritsas, 2012:609-619; Lauderdale-Littin & Blacher, 2017:230-239; Ezeonu et al., 2021).

Cognitive behavioural therapy has been shown to be the most effective in treating symptoms of depression and anger (Surley & Dagnan, 2019:219-237). By involving caregivers in such therapy, it can be adapted in a way that would also benefit the person with intellectual disability (Surley, & Dagnan, 2019:219-237).

5.3.3.1 Family Resilience Model

Bedewy (2021:1911094) notes that it is unclear why some families struggle with the caregiving of a person with ID while other families thrive and adapt well. This is confirmed by the findings of Lafferty et al. (2016:9) who suggest that the family that copes well may be considered 'resilient' as they are able to overcome, reset or adapt to the physical and psychological demands that come with taking care of a person with intellectual disability. The findings of Lafferty et al. (2016:9) correlate with the concept of the 'family resilience model', which refers to a family's capacity to overcome life's challenges together (Caldwell, Jones, Gallus & Henry, 2018:374-388).

Families are usually the primary caregivers of people with ID (Panicker & Ramesh, 2019:1-14). This is particularly the case in South Africa where nearly all adult persons with intellectual disabilities live in the care of their families (McKenzie et al., 2013:1750; McKenzie, 2016:67). Perhaps the most important aspect of family caregiving is that it helps maintain family structures and enables persons with intellectual disability to remain in their home environment and enjoy the benefits of receiving individualised attention (Perkins, 2009:11).

However, caregiver obligations prohibit the primary caregiver from finding employment. This leads to neglecting the basic needs of the siblings and places additional strain on the caregiver (Gona et al., 2011:181). Thus, for some families, disability leads to poverty (Gona et al., 2011:181; Ezeonu et al., 2021). Another major stressor in family caregiving is that parents are often very concerned regarding the future care of their child, once they, the parents, pass away (Mkabile et al., 2021:5). Should the siblings move away, the ongoing responsibility of caregiving remains with the aging parents (McKenzie & McConkey, 2016:549). People with intellectual disability are now living longer with some families becoming two-elderly-generation families. In some cases, the person with intellectual disability may outlive his or her parents. Under these circumstances there appears to be a growing number of siblings who assume the role of caregiver for the person with intellectual disability when a parent passes away (Lafferty et al., 2016:10).

Caldwell et al. (2018:374-388) propose the family resilience model as a foundation for creating and developing empowerment and resilience in families of people with intellectual disabilities. Family empowerment protects families during challenging times (Caldwell et al., 2018:374-388). Furthermore, the model advocates a strength-based approach which not only promotes coping mechanisms for current difficulties but also grows the family's strength capacity to navigate through future life challenges (Caldwell et al., 2018:374-388). Building family resilience is an ongoing process and requires that all family members participate. A factor that protects the family as they move through various challenges is family empowerment (Caldwell et. al., 2018:374-388)

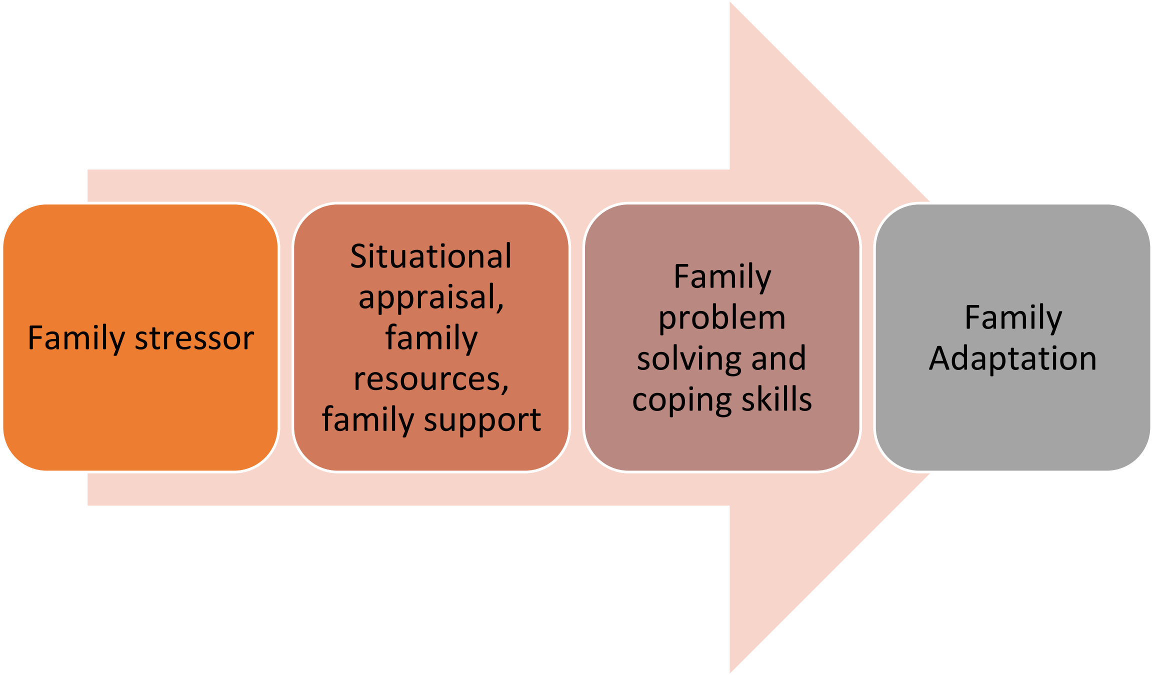


Figure 11: Family Resilience Model adapted from Caldwell et al. (2018:374-388)

Social factors associated with low resilience in caregivers of people with ID include low levels of family support and lower levels of social connectedness (Lafferty et al., 2016:15). Family cohesion and cooperation has been found to be a pivotal factor in helping the primary caregiver cope (Ezeonu et al., 2021). Enjoying strong familial relationships is considered a key protective factor in maintaining caregiver resilience, particularly as families can pool their resources, maintain good communication, stay connected and share caregiving responsibilities (Lafferty et al., 2016:15).

5.3.3.2 Managing behaviour that challenges

Mothers of persons with ID have a higher prevalence of mental health difficulties which is exacerbated by their child's challenging behaviour (Adams et al., 2018:257-275). Newcomb and Hagopian (2018:96-109) established that children with intellectual disability display challenging behaviour at disproportionately higher rates than their typically developing peers. This behaviour includes self-injuring behaviour (e.g., head banging), aggression, pica, disruption and wandering behaviour resulting in a diminished quality of life for both the individual and his or her families (Newcomb &

Hagopian, 2018:96-109; Deutsch & Burket, 2021:110017). High levels of challenging behaviour exhibited by the person with intellectual disability correlates with poor caregiver resilience (Lafferty et al., 2016:19), and high caregiver distress correlates with negative caregiver-child interaction, which can exacerbate the problematic behaviour that the child displays (McConnell & Savage, 2015:101).

Even though increased emphasis is placed on the importance of providing good standards of care for people with ID, in South Africa, there is a lack of evidence-based interventions regarding problematic behaviour in persons with ID (Coetzee et al., 2019:1). The National Institute for Health and Care Excellence (NICE) developed a guideline to advise on the management and support of people with learning disabilities and behavioural problems (NCCMH, 2015). Coetzee et al. (2019:2-10) argue that these guidelines are often contextually inappropriate for resource-constrained middle- and lower-income countries, such as South Africa.

Steiner (2011:178) argues that caregiver well-being - that is, the absence of stress, symptoms of depression and negative affect - appears to be strongly related to the behaviour of the person with ID. However, McConnell and Savage (2015:100-109) contend that caregiver distress may be the antecedent rather than the outcome of the afore-mentioned behavioural problems. High caregiver distress is associated with less optimal caregiving and, in turn, predicts that the person with ID may develop behavioural problems. McConnell and Savage (2015:100-109) do concede, however, that the relationship between the behavioural pattern of the person with intellectual disability and caregiver distress is generally considered transactional.

Psychoeducational programmes that have been documented to lead to improvements in caregiver well-being, include educating caregivers regarding cognitive behavioural therapeutic strategies to manage the challenging behaviour of the person living with intellectual disability (Steiner, 2011:178-179; McConnell & Savage, 2015:100-109).

5.3.3.3 Causes of Challenging Behaviour

People with ID usually establish a daily routine for themselves and, therefore, need to be prepared when there is an emerging change to their routine (Courtenay & Perera, 2020:231-236). Should the caregiver fail to prepare the person with ID in advance an immediate change could raise levels of anxiety and stress within the person with ID, resulting in a behavioural outburst (Courtenay & Perera, 2020:231-236). Gillespie-Smith et al. (2021:1-15) concur and advise that planning is an effective coping strategy as the caregiver has time to evaluate how to handle a stressor with action strategies.

Intellectual disability is characterised by social, cognitive and adaptive skill deficits (Platt et al., 2019:952-961; Gillespie-Smith et al., 2021:1-15). These deficits cause the person with ID to experience trouble with cognitively understanding and adjusting to any changes to his/her day-to-day routine, to disruptions or restrictions on activities he or she enjoys. This can then lead to challenging behaviour (Courtenay & Perera, 2020:231-236; Gillespie-Smith et al., 2021:1-15). The display of challenging behaviour is a stress response in persons with ID and the result could be that they lose their group home placement or that the psychotropic medication is increased (Courtenay & Perera, 2020:231-236).

Caregiver disengagement through alcohol or avoidance can lead to further psychological distress and an increase in challenging behaviour by the person with intellectual disability (Gillespie-Smith et al., 2021:1-15).

To manage the discussed problematic behaviour, caregivers must be equipped to regulate their own interpretation and emotional responses to the challenging behaviour (Gillespie-Smith et al., 2021:1-15). Reappraisal is a coping strategy as it can assist the caregiver in reframing a stressful situation in positive terms (Gillespie-Smith et al., 2021:1-15).

Koritsas and Iacono (2012:236-248) agree that the causes of challenging behaviour are complex and propose the biopsychosocial model as the best-fit framework for understanding these causes as it requires consideration of biological, psychological and social factors as determinants for problematic behaviour.

Determinants of behaviour that challenges, using the biopsychosocial framework of Koritsas and Iacono (2012:243).

Table 5: Biopsychosocial framework of causes of behaviour that challenges in people with ID, adapted from Koritsas & Iacono (2012:243).

Biological factors	Possible psychiatric disorder and physical health or ill-health; possibility of a physical pain, (e.g., toothache) -

	and the person with ID is unable to cognitively comprehend or communicate the pain
Psychological factors	Distress response; unable to understand and learn, poor coping skills; unable to cope with changes in their routine
Social factors	Change in environment or relationships, wanting attention (possibly from a disengaged caregiver)

5.3.3.4. Positive Behavioural Support

In the field of intellectual disability, there has been a growing interest in positive behavioural support as an intervention framework to address behaviour that challenges (Kincaid, Dunlap, Kern, Lane, Bambara, Brown, Fox & Knoster, 2016:69; Singh, Lancioni, Karazsia, Chan & Winton, 2016:1-13; Bowring, Totsika, Hastings & Toogood, 2020:193).

Positive behavioural support is an approach to behaviour that includes ongoing evidence-based intervention and decisions that are focused on building competences and creating supportive environments that prevent the occurrence of behaviour that challenges (Kincaid et al., 2016:71). Moreover, it is primarily focused on enhancing the quality of life of the person with ID, as well as his or her caregiver, and on reducing incidents of challenging behaviour (Carr, Dunlap, Horner, Koegel, Turnbull, Sailor, Anderson, Albin et al., 2002:6; Kincaid et al., 2016:69). Positive behavioural support allows caregivers to respond in a calm manner and has been shown to improve the psychological well-being of the caregiver, as well as the person with intellectual disability (Singh et al., 2016:1-13). Consequently, restrictive procedures, such as physical restraints and emergency medications, are reduced. Finally, positive behavioural support encourages the caregiver to change the nature of his or her care to reduce the aggression in the person with ID (Singh et al., 2016:1-13).

5.3.3.4.1 Basic caregiver strategies for applying positive behavioural support

Positive behavioural support is the most preferred intervention in managing behaviour that challenges in people with intellectual disability. The following are basic strategies for applying positive behavioural support (Carr et al., 2002:1-13; Singh, et al., 2016:1-13; Kincaid et al., 2016:69-73; Bowring et al., 2020:193-203):

- The caregiver is to set expectations of desired behaviour. If the person with ID is unsure of what is expected from him/her, the caregiver could use pictures, posters or role-playing to eliminate confusion regarding what desired behaviour looks like.
- The caregiver needs to be consistent with positive behavioural support through daily interactions, as this intervention is about the general way of engaging with the person with ID and creating a safe, positive environment.
- The caregiver is to praise positive behaviour. This will acknowledge the good behaviour of the person with ID and reinforce it.
- The caregiver continuously evaluates the needs of the person with ID. This includes assessing support structures, such as workshop placement and community engagement.
- The caregiver does not overly control the person with ID and respects his/her right to personal choice and independence.

Positive behavioural support, as an intervention framework, means that the caregiver must proactively rearrange the environment to enhance the quality of life of the person with ID instead on solely focusing on reducing behaviour that challenges (Carr et al., 2002:7; Kincaid et al., 2016:69-73).

5.3.4 The Resilient Community

The resilient community will be discussed under community respite care, household safety skills and identifying community resources.

5.3.4.1 Community Respite Care Services

There has been an increased demand from caregivers for respite care services (Lafferty et al., 2016:14). Respite care has been used to assist parents to alleviate symptoms of depression (Ugwuanyi et al., 2022:3). Respite care services can vary in location, duration and timing of the care, as well as who provides the care (Teo, Kennedy-Behr & Lowe, 2018:1505).

The NICE Guideline 11 of 2015 (Section 14.3.2) supports and recommends the rendering of respite care services to caregivers of people with ID (NCCMH, 2015). However, Teo et al. (2018:1505) contradict this and argue that there has been little evidence that respite care services contribute to enduring and consistent beneficial effects on the well-being of caregivers. The authors further argue that respite care services have not always been a positive experience for caregivers.

Until recently, the Western Cape Department of Health allocated 20 placements in two ID hospitals for brief admissions with the rationale of providing a break to caregivers (Coetzee et al., 2019:7). However, Coetzee et al. (2019:7) add that this service has been discontinued in one of the two hospitals, leaving less than 10 places available. Lafferty et al. (2016:14), as well as McKenzie and McConkey (2016:537), agree that there has been a decline in the availability of respite care services to caregivers of people with ID.

Home-based community support has been found to be very valuable to caregivers of people with ID and this highlights the importance of caregivers mobilising internal community resources to build resilience (McKenzie & McConkey, 2016:549).

South Africa is a resource-constrained country in relation to respite care services to families with individuals with ID (Coetzee et al., 2019:4-9). Where respite care is needed the caregiver should mobilise support from within his or her family, so that siblings or other relatives can be incorporated as substitute caregivers and provide respite care to the full-time caregiver (Coetzee et al., 2019:4-9).

5.3.4.2 House Safety Skills

Household safety skills include an understanding of safe handling of poisons and household chemicals, as well as the safe use of matches and electrical appliances or natural gas (Slaggert & Jongsma, 2015:100). These skills are essential to protecting the person with ID, as well as his or her caregiver from accidental injury within the home. The former can lack household safety skills when the latter is overprotective. The caregiver should model the safe handling of independent skills, such as boiling the kettle for a hot beverage (Slaggert & Jongsma, 2015:100).

Slaggert and Jongsma (2015:100) suggest the following to promote household safety skills for the person with ID: -

- Have reinforcements or awards on hand for progress made in learning.
- Keep matches in a safe place.
- Instruct the person with ID on the need to avoid hot water and hot objects.
- Model safe handling of hot objects, such as a kettle, iron and heaters.

5.3.4.3 Identifying existing community resources

A vast majority of people in South Africa have experienced historical trauma which involves poverty and marginalisation, creating a dire need for mental health resources at community level (Petersen et al., 2009:149). Taking care of a child with intellectual disability in an already resource-constrained country, such as South Africa, can thrust a caregiver-family into poverty.

Lafferty et al. (2016:14) argue that caregivers of people with ID have many unmet service needs, such as psychological and counselling services, dietitian services and home-based respite care services, and that low levels of resource support are associated with low levels of resilience in caregivers. Primarily, the current health care level is focused on emergency management and for the human rights agenda to be achieved. However, greater equity and efficient resources are required as well (Petersen et al., 2009:149).

The strength-based approach does not ignore the resource-constraints, but instead respects caregivers' innate wisdom which identifies resources in their community and focuses on their inherent strengths to mobilise these resources (Pulla, 2017:101). This approach concurs with Youngs' position (2012:21) who maintains that caregivers of people with ID should take inventory and proactively assess the resources they do have.

Caregivers should also draw up a list of people they can count on when they need them. The list can include mental health professionals, trusted family members, community members, community services and the home repair specialist (Young, 2012:23). There is currently an inefficient use of existing resources, such as traditional healers who could be engaged more effectively to identify patients with mental health problems (Petersen et al., 2009:148).

Once caregivers have identified and mobilised their support network, they are to educate their team on the person with ID (triggers, hobbies), as well as what themselves need (respite care, transportation). Social support can be sought from partners, family, extended family, friends, neighbours in the community, faith-based services, as well as networks developed through volunteering (Lafferty et al., 2016:16). Furthermore, caregivers should advocate for themselves and make appropriate use of social media to lobby for services (Young, 2012:37).

Record-keeping is important and it is advisable for the caregiver to have a ring binder that contains the following information (Young, 2012:34): -

- Picture of the person with intellectual disability
- Height, weight, birthmarks
- Likes and dislikes
- Emergency contact numbers
- School and workshop information
- Name of medical professionals
- List of medication and hospital care plan
- Environmental triggers
- Positive reinforcements to use
- A guideline on how to manage challenging behaviour
- Preferred activities

It is also important for the caregiver to, at least annually, update the information in the ring binder (Young, 2012:34).

5.4 SUMMARY

There are currently few evidence-based intervention programmes available to caregivers of people with intellectual disability. However, a targeted psychoeducational programme has been shown to reduce caregiver stress and improve outcomes for both the caregiver and the person with ID. The significance of a psychoeducational programme for both the formal and informal caregiver was discussed.

The core elements of a psychoeducational programme were identified from the literature review, including knowledge on intellectual disability, the resilient caregiver, resilient family and resilient community.

Regarding the resilient caregiver, the mindset of a resilient caregiver was discussed, as well as the various building blocks to resilience in the 7-C Model of resilience. The two types of coping strategies, namely problem-focused coping and emotion-focused coping were reviewed. The cognitive processes of caregivers were also explored with respect to common cognitive distortions, as well as how to ensure rational thinking.

The new research on acceptance and commitment therapy (ACT) was examined, as well as the concept of the ‘good enough’ caregiver. The importance of an internal locus of control was discussed and clarification was offered concerning what is within versus what is outside our control.

The topic of the resilient family explored the impact of challenging behaviour on the caregiver’s family, as well as the causes and management thereof. The family-resilience model suggests that family empowerment through skills development can assist a family, as a unit, to successfully endure a family crisis. The concept of the positive behavioural support intervention was proposed to manage behaviour that challenges and basic positive behavioural support strategies were provided.

The resilient community covered community respite care services, household safety skills and the identification of existing resources.

The next chapter discusses the research methodology for the present study.

CHAPTER 6
RESEARCH METHODOLOGY

Step 1: Problem Analysis and Project Planning

Identify and involve clients
Gaining entry permission and cooperation
Identify concerns of population
Analysing identified problems
Setting goals and objectives

Step 2 : Information Gathering and Synthesis

Utilising Existing information sources
Studying examples
Identifying functional elements of success models

Step 3: Design

Design an observational system
Specify the procedural elements

Step 4: Early Development and Pilot Testing

Developing preliminary intervention
Pilot testing
Apply design criteria to preliminary intervention

Figure 12: Graphic representation of the phases of intervention research. Adapted from Rothman and Thomas (1994:28); Fraser and Galinsky (2010:459-466).

6.1 Introduction

The previous chapters explored the prevalence and challenges of intellectual disability in South Africa, as well as the care needs of people with ID, the resource constraints and the impact thereof on their caregivers. It is evident that far more resources that would alleviate caregiver distress are needed.

The purpose of this chapter is to describe the research methodology followed in conducting the study. This scientific research included selection of sampling, data collection and data analysis. Ethical approval for the study was given by the Human Research Ethics Committee of the University of Pretoria (HREC reference number: HUM034/0720).

6.2 Research Goal

Research can be categorised as either *basic* or *applied* (Fouchè & De Vos, 2011:94). Basic research is not concerned with solving the immediate problem but rather with expanding on existing knowledge. The researcher in the present study utilised applied research as it is the scientific planning of inducing solutions to a troublesome situation (Thyer, 2010a:18-19; Fouchè & De Vos, 2011:94)

The applied research goal for the present study was to develop, implement and evaluate a psychoeducational programme for caregivers of people with intellectual disability in the Western Cape. The caregivers were the unit of analysis of the study,

6.3 Research Approach

The study is rooted in the mixed-methods research approach, as the researcher collected both numeric and text information with the purpose of forming a holistic picture of the problem (Delport & Fouchè, 2011:435; Uprichard & Dawney, 2019:19-32). The data were, therefore, integrated and related. Academia has consensus in terms of the mixed-methods research approach, namely that whichever methods are used, whether they be qualitative or quantitative, integrating the mixed data results is the desirable outcome. The mixed-methods research approach combines quantitative and qualitative methods to explore social phenomena (Uprichard & Dawney, 2019:19-32).

In the context of the present study, the mixed-methods research approach was utilised to investigate the nature, causes and impact of caregiver distress, as well as to study how these are currently addressed in practice. This approach enabled the researcher to obtain quantitative, as well as qualitative, data from caregivers of people with intellectual disability to understand the phenomenon of caregiver distress and ascertain their requirements from an educational perspective. The researcher believes that, by using the mixed-methods research approach, the psychoeducational programme developed from the data will augment resources for caregivers and will, simultaneously, reduce caregiver distress.

Applied intervention research is undertaken by a researcher to enhance or maintain the functioning and well-being of an individual, family, group, community, or population (De Vos & Strydom, 2011:473-475). The researcher identifies the problem, seeks assistance in ascertaining the extent of the problem and then applies solutions to the problem (Abbott & Mckinney, 2013:50). Fawcett, Suarez-Balcazar, Balcazar, Paine, Blanchard and Embree (1994:25) explain that intervention research is a form of applied action research as it creates means for improving community life, health and well-being. Intervention researchers attempt to adhere to the dual purpose of applied research, which is, firstly, to promote an understanding of the individual and community conditions and, secondly, to contribute to their improvement (Fawcett et al., 1994:25; Fouché & De Vos, 2011:94).

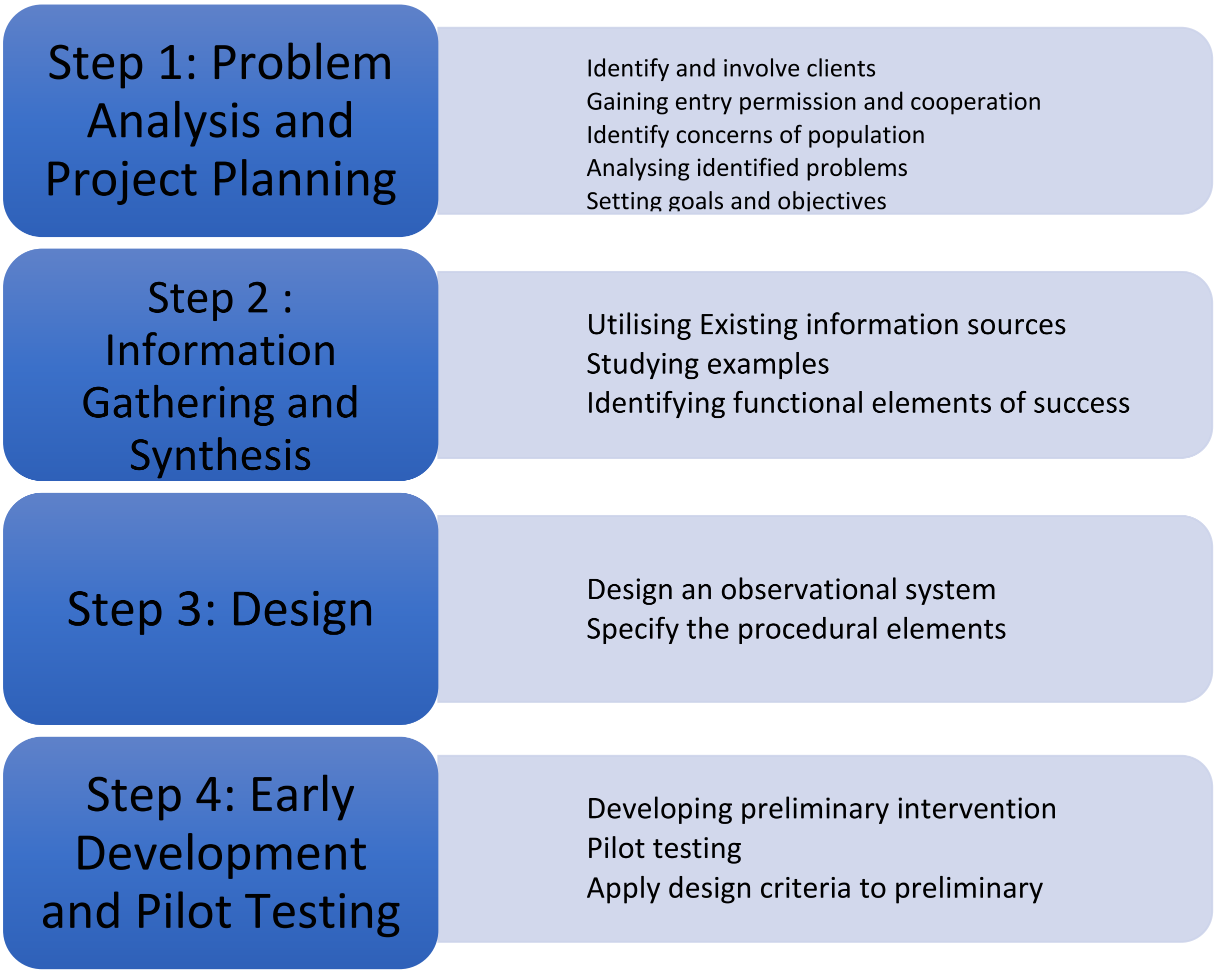


Figure 13: Steps in the intervention research. Adapted from Rothman and Thomas (1994:28); Fraser and Galinsky (2010:459-466).

6.3.1 Steps in Intervention Research

At the beginning of each chapter the researcher provides a graphic depiction of the steps of intervention research and highlights in red the step on which the chapter will report. The intervention research model consists of the following steps (Rothman & Thomas, 1994:28; Fraser & Galinsky, 2010:459-466).

Step 1: Problem analysis and project planning

The researcher endeavoured to define the problem by consulting the academic sphere for a collection of scholarly writings and literature on the research topic (Fraser &

Galinsky, 2010:459-466). The researcher identified that the literature does not indicate a targeted psychoeducational programme for caregivers of people with intellectual disability in the Western Cape, and thus an intervention needs to be devised (Fraser & Galinsky, 2010:459-466). The researcher obtained permission and support from the Western Cape Forum for Intellectual Disability to conduct the research (see Appendix 2).

Step 2: Information gathering and synthesis

To plan the intervention research programme, the researcher needed to establish what others had done to understand and address the problem (De Vos & Strydom, 2011:480) and, therefore, conducted an extensive review of the literature. Amongst other issues, the review focused on caregiver burnout and the impact thereof on the person living with intellectual disability. The researcher also conducted interviews with full-time caregivers of people with intellectual disability.

Step 3: Design

Within this phase, a manual on caregiving for people with intellectual disability was designed, as informed by the data (Fraser & Galinsky, 2010:459-466). The manual comprised session-by-session content: the goals of each session, the essential content of each session, including activities that reinforce the content (Fraser & Galinsky, 2010:459-466). Once the first draft had been developed, experts within the field of intellectual disability in the Western Cape reviewed it - some of them attached to the Division of Intellectual Disability in the Department of Psychiatry at the University of Cape Town. The researcher reworked the manual until all the comments and recommendations of the reviewers had been addressed (Fraser & Galinsky, 2010:459-466; De Vos & Strydom, 2011:482-483). Thereafter, pilot testing for feasibility could commence.

Step 4: Early development and pilot-testing

During this phase, the preliminary intervention programme, with a basic manual, was developed and evaluated under field conditions (De Vos & Strydom, 2011:483-484).

The purpose of the pilot-testing was to determine whether the intervention programme would work and which of the elements of the prototype needed revision. Once amended, the presentation of the preliminary programme took place. Guidelines and values continually informed the design process of the intervention research (De Vos & Strydom, 2011:483-484). Next, a process evaluation took place in which the researcher evaluated, amongst other aspects, whether the programme was easy and practical to use, as well as compatible with the Western Cape's customs and values (De Vos & Strydom, 2011:485). The researcher considered the caregivers' feedback for future and further development of the intervention programme.

Step 5: Evaluation and advanced development of the programme

This step involved an evaluation and advanced development of the intervention programme.

Step 6: Dissemination of the programme

Dissemination of the programme would have been the final element of the entire design process (Rothman & Thomas, 1994:10-11). However, Steps 5 and 6 are beyond the scope of this research study and did not form part of the research process.

Intervention researchers attempt to enhance their understanding of community conditions and the effectiveness of interventions designed to improve them. They thus blend their roles of scientist and change agent (Fawcett et al., 1994:49-51).

By involving the caregivers as collaborators in the present study, design and development efforts built on the knowledge of those who are affected.

6.4 Type of Research

The research type was applied *in nature.* The study sought to immediately provide data that would scientifically describe and explain the phenomena (Fouché & De Vos, 2011:94; Abbott & Mckinney, 2013:50). Applied research was appropriate for the present study as it focuses on the actual real-world problems as they relate to a specific study (Abbott & Mckinney, 2013:50). In this case, caregivers can plan and induce change should the findings of the study provide empirical data that prove the situation to be troublesome. The study was applied *in nature* as it sought to bring about practical solutions to the problem of caregiver distress with the eventual aim of sustained change for caregivers of people living with intellectual disability (Marlow, 2011:34; Leedy & Ormrod, 2013:27). In summary, the study sought to understand the phenomenon, as well as propose a solution.

6.5 Research Design

The research design provided the plan and structure of how the researcher would conduct the study. She applied the embedded mixed-methods design, which is a variant of the mixed-methods research approach (Ivankova, Creswell & Clark, 2011:269-270). In this design, one data set provides a supportive, secondary role in a study based primarily on the other data set. The two data sets were collated concurrently (Delport & Fouchè, 2011:443; Creswell & Clark, 2011:90). The reason for choosing the embedded mixed-methods design was that several groups were researched at one point in time using predominantly the quantitative data collection method. It was also appropriate utilise the embedded mixed-methods design, as authors Fetters, Curry and Creswell (2013:2134–2156), as well as Creswell and Clark (2011:90-91), contend that with this design, data collection and analysis link at multiple points.

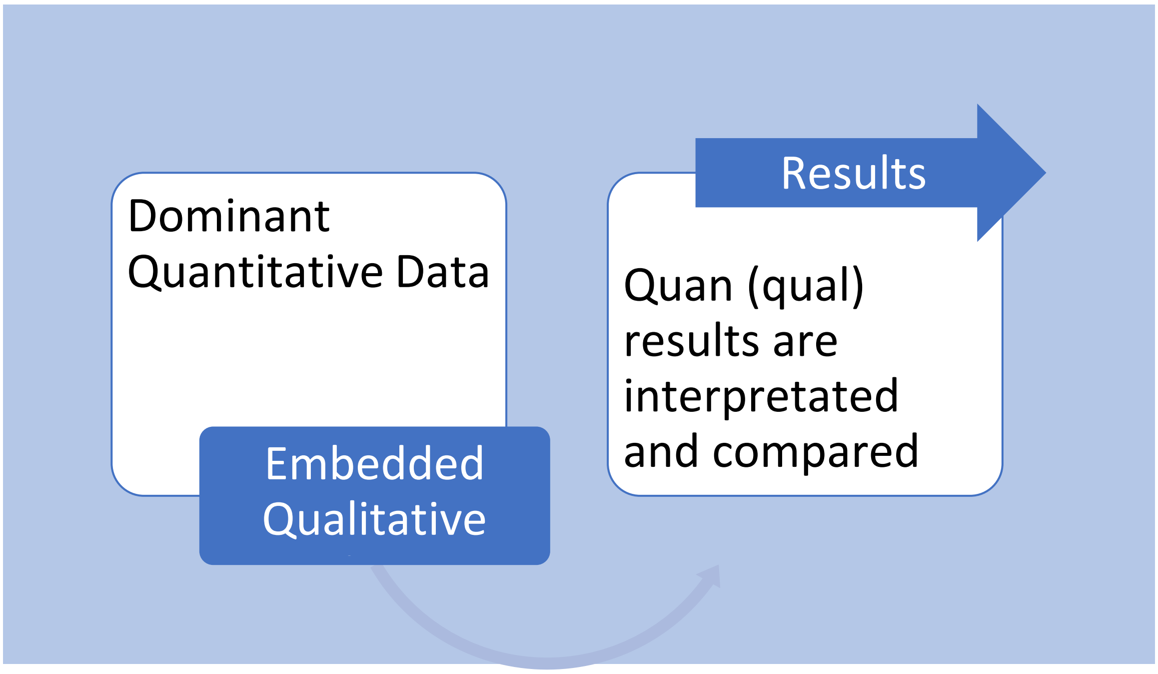


Figure 14: Embedded mixed-method design (Adapted from Ivankova, Creswell & Clark, 2011:270).

6.5.1 Qualitative Research Design

Using qualitative research, the researcher attempts to collect rich descriptive data in respect of a phenomenon to develop an understanding of it through observation and study. In this case the phenomenon was caregiver distress, (Nieuwenhuis, 2011a:50) During the qualitative phase, the researcher employed exploratory research to obtain basic information and new insights regarding caregiver distress (Fouchè, & De Vos, 2011:95).

A case study design, more specifically a collective case study design, was utilised, so that comparisons could be made between cases (Fouchè, & Schurink, 2011:322). Relevant theories, therefore, could be extended and validated. Furthermore, this research method was useful in answering the "how" and "why" questions (Nieuwenhuis, 2011b:75). Additionally, being a 'collective' case study, it offered a multi-perspective analysis in which the researcher could assess the views of several participants - in other words, caregivers in a similar situation.

A case study research design opens the possibility of giving voice to the powerless and voiceless, and this is essential for the researcher's endeavour to gain a deeper understanding of the dynamics of the situation questions (Nieuwenhuis, 2011b:75).

6.5.2 Quantitative Research Design

Logan and Royse (2010:221-234), Thyer (2010b:183-204), as well as Fouché, Delport and De Vos (2011:142-158) explain that quantitative research designs can be classified in two categories, namely *experimental* designs and *non-experimental* designs. Experimental designs are categorised into three types: the pre-experimental, quasi-experimental and the true experimental design. Non-experimental designs, on the other hand, comprise two categories: randomised cross-sectional survey design and replicated cross-sectional survey design.

The researcher specifically used the pre-experimental design, namely the 'one-group pre-test post-test design' which contributed to formulating valuable interpretations and comparisons regarding the impact and value of the psychoeducational programme (Fouché, Delport & De Vos, 2011:147-148).

The design is written in the following symbols:

Table 6: Pre-test Post-test Design (Fouché, Delport & De Vos, 2011:147-148)

$$\mathbf{O_1 \;\; X \;\; O_2}$$

Symbols	Interpretation
O_1	Pre-test with Formal Caregivers
X	Intervention (Psychoeducational programme)
O_2	Post-test with Formal Caregivers

While the respondents, who were the formal caregivers, attended the training on the psychoeducational programme, data collection was conducted. The researcher aimed to assess whether the psychoeducational programme (independent variable) had a positive impact on their understanding of intellectual disability (dependent variable). Therefore, before the commencement of the training, the respondents completed a pre-test questionnaire for the researcher to measure and assess their understanding of intellectual disability. The researcher then conducted the psychoeducational training programme. After the completion of the programme, the respondents completed a post-test questionnaire which enabled the researcher to measure and assess whether their understanding of intellectual disability had improved. Fouché, Delport & De Vos, (2011:148) explain that, should a positive change occur, the researcher may conclude that the intervention was the cause of this improvement.

A quantitative research design was utilised to ensure that a systematic and objective process was followed. With the quantitative research approach, the researcher used numerical data from only a selected subgroup of the population, namely the caregivers of people with intellectual disability in the Western Cape, to be able to generalise the findings to all caregivers of people with intellectual disability in South Africa (Logan & Royse, 2010:229; Maree & Pietersen, 2011b:145).

6.6 Research Methods

In the next section, the research methods, namely the research population and sampling, mixed-methods data collection, the pilot study and data analysis, will be discussed.

6.6.1 Research Population and Sampling

The research population and research sampling will be discussed next.

6.6.1.1 Research population

The research population consists of the informal and formal caregivers of people with intellectual disability in the regions of the Western Cape, namely West Coast, City of Cape Town, Cape Winelands, Overberg, Garden Route and Central Karoo. The study was conducted with informal unpaid caregivers, namely biological mothers, fathers, siblings, grandparents, as well as other relatives, foster parents, and community members who took on the direct responsibility of caregiving. The formal caregivers included care assistants, nurses and housemothers of residential homes, group-homes and education centres for people with intellectual disability, as well as supervisors in protective workshops for people with intellectual disability. However, the study excluded nurses caring for people with ID in large institutions, such as hospitals.

The reason for excluding nurses from large institutions such as hospitals is that they are professionally trained and generally surrounded by a multidisciplinary team of health professionals such as doctors, occupational therapists, social workers etc. which could also contribute to their skillset. The researcher aimed to narrow the scope of the study to those caregivers within the community that are generally not exposed to training on intellectual disability.

6.6.1.2 Research sampling

Maree and Pietersen (2011a:172) explain that, due to the restrictions on time and cost, it is usually impossible to include the entire population in the research. Consequently, the researcher made use of sampling. Mixed-methods sampling strategies were employed that allowed the researcher to draw clear inferences from both the qualitative and quantitative data (Delport & Fouchè, 2011:446; Creswell & Clark, 2011:171).

(a) Qualitative phase

Sampling in the qualitative phase will be discussed next.

- **Sampling Method**

For the qualitative approach, it was important that qualitative sampling methods were employed, so that qualitative sampling could be conducted once the circumstances of the study were clear (Strydom & Delport, 2011:391). Non-probability sampling was used as the researcher did not know the exact size of the population of informal caregivers in the Western Cape and, therefore, the informal caregivers did not have an equal chance of selection (Strydom, 2011b:231; Creswell & Clark, 2011:174-175; Maree & Pietersen, 2011a:176-177). Utilising the purposive sampling method, the researcher's judgement informed the selection of participants for the study. The sample group was composed of caregivers who embodied the most characteristics based on the selection criteria for the population (Strydom, 2011b:232; Maree & Pietersen, 2011a:178).

- **Sample Size**

Sampling in qualitative research is flexible, less structured than quantitative research and often continues until saturation point is achieved, also known as data saturation, meaning that no new themes are emerging from the data collection process (Strydom & Delport, 2011:390-391; Nieuwenhuis 2011b:79). A sample size of 25 informal caregivers was used to meet the objectives of the qualitative phase of the study.

- **Recruitment of participants**

The researcher approached Cape Mental Health, as this is a predominantly social work organisation (they employ psychologists as well). Cape Mental Health's services include rendering services to unpaid informal caregivers of people with intellectual disabilities. However, due to COVID 19 this organisation decided to focus its research assistance on COVID 19-related studies only.

The researcher then enlisted the assistance of a network of social workers who is familiar with the field of disability within the Western Cape as well as requested on social media until an adequate number of informal caregivers that met the selection criteria volunteered to participate in the research study.

- **Non-proportional purposive sampling selection criteria**

In the qualitative phase, the selection criteria for unpaid informal caregivers were that they should be caring for a person with intellectual disability on a full-time basis and that they should reside in the Western Cape.

(b) Quantitative phase

Sampling in the quantitative context will be discussed next.

- **Sampling method**

Probability sampling includes techniques in which samples are selected in such a way that each element in the population has an equal chance of being selected (Maree & Pietersen, 2011a:172; Strydom, 2011b:228). The researcher made use of probability sampling as she had a list of names, and the selection was completely random (Strydom, 2011b:228; Maree & Pietersen, 2011a:172). It was important for her to utilize the study population (the caregivers with whom the research problem is concerned) so that the objectives of the study would be met.

- **Sample size**

In terms of the sample size, the researcher attempted to obtain the largest sample possible (Strydom, 2011b:225). A sample size of 100 formal caregivers was utilised which was enough to meet the objectives of the quantitative phase of this study. It is important in quantitative sampling methods, that the sample is representative of characteristics, such as socio-economic class and gender of the study population, and thus appropriate for the research question. The method ensured that the study was feasible, and the findings could be adequately generalised to the entire population (Strydom, 2011b:226).

- **Recruitment of respondents**

The researcher liaised with the Western Cape Forum for Intellectual Disability (WCFID) as this forum networks with various organisations, such as residential group-homes, workshops and facilities which employ caregivers. The researcher met and liaised with the Director of the WCFID. The team of the WCFID suggested organisations which employ caregivers, the researcher made contact and they further referred other organisations within the Western Cape. Furthermore, the researcher placed the invitation on social media that was shared by many including the research supervisor. An invitation, where the stipulation criteria was stipulated, was sent out to those who volunteered to take part in the research study. Many managers of group-homes, workshops and day-centres responded to the invitation by completing the registration form provided via email. The researcher thus had a list of formal caregivers who had completed the registration form and could do a random selection from that list (Strydom, 2011b:228; Maree & Pietersen, 2011a:172).

- **Simple random sampling selection criteria**

In the quantitative phase, the selection criteria for employed caregivers was that they be formally employed by an organisation, such as a residential group-home or protective workshop, and that the conditions of their employment primarily entailed taking care of a person with intellectual disability. They were also to reside in the Western Cape. As stated, the researcher had a list of names of formal caregivers who completed the registration forms. The researcher had a predetermined, equal number of one hundred (100) respondents who would be selected as the sample size to attend the training (Maree & Pietersen, 2011a:172-173). The researcher placed the names in a box and randomly drew names until she reached the sample size total of 100 names.

6.6.2 Mixed-Methods Data Collection

A mixed-methods data collection approach was considered the appropriate tool for this research, as it draws upon the strengths of both quantitative and qualitative data collection and analysis. It provides an innovative approach to investigating complex processes and systems in health and healthcare, as well as contemporary issues in health services (Fetters et al., 2013:2134–2156).

In the next sections, the researcher elaborates on mixed-methods data collection within both the quantitative and qualitative phases.

6.6.2.1 Qualitative research phase

In terms of the qualitative research phase, the researcher developed a semi-structured interview schedule (attached as Appendix 5) to gain a detailed picture of the experiences and needs of unpaid caregivers of persons living with intellectual disability (Greeff, 2011:351). Semi-structured interviews require the participant to answer a set of predetermined questions, but it does allow for probing and clarification of the questions (Nieuwenhuis, 2011b:86). The researcher was attentive to the responses of the participants, so that emerging lines of inquiry directly related to the phenomena studied, were identified. An interview schedule is a data collection tool that is specifically useful in cases where participants have a low literacy level (Delport & Roestenburg, 2011:186).

The advantage gained from integrating the two forms of data in this study was that the researcher could use the qualitative data to assess the validity of quantitative findings - and use the quantitative data to explain findings derived from the qualitative data (Fetters et al., 2013:2134–2156; O'Cathain, Murphy & Nicholl, 2010:4587). Therefore, the researcher used the data collected from the questionnaires completed by the formal caregivers to help explain the information obtained from the informal caregivers who had been interviewed. The training based on the developed programme was conducted with the employed caregivers.

6.6.2.2 Quantitative research phase

In terms of the quantitative research phase, the researcher used the Likert Scale questionnaire. The survey questions for the Likert Scale questionnaire were developed by conducting an in-depth literature study on the issues that caregivers face (Browne

& Greene, 2005:103). Once the issues had been identified, survey questions/statements could be formulated. The format of the four-level Likert Scale questionnaire was: strongly disagree – disagree - agree - strongly agree. Thus, the questionnaire presented the caregivers with statements followed by response choices on a symmetric agree-disagree scale - a continuum of expressed attitudes - so that they were able to indicate their degree of agreement or disagreement with each statement by merely ticking the most appropriate attitude (Delport & Roestenburg, 2011:211-212; Maree & Pietersen, 2011b:149; Rubin & Babbie, 2014:166). In this way, the range captured the intensity of their feelings for a given question.

The format of the items in the questionnaire was primarily closed-ended (e.g., multiple choice or ranking), but also included very basic open-ended items (short answer questions). However, the focus was mainly on closed-ended questions. This allowed the researcher to undertake a more refined examination of the influences of multiple variables and to acknowledge the importance of the complexity of social situations in a caregiver's life (Mertens, 2009:268-305).

Even though the structure of the Likert Scale questionnaire was straightforward and easy to understand, the researcher was present for questions that arose. (The Likert Scale questionnaire is attached within Appendix 8 and Appendix 9.)

6.6.3 Pilot study

Intervention researchers design a pilot study to determine whether an intervention will work, as well as to examine how and why a programme works or not (Fawcett et al., 1994:36-37). It was important to do a pilot-test during both the qualitative and quantitative phases of the study.

6.6.3.1 Qualitative phase

In the qualitative phase, pilot-testing was more informal to identify certain trends (Strydom & Delport, 2011:394). The purpose was to ascertain whether relevant data would be obtainable from the participants. The pilot-test assisted in pre-empting problems that could have arisen during the actual qualitative interviews of the main investigation (Strydom & Delport, 2011:394-395).

Pilot-testing commenced by reviewing and discussing the interview schedule with the experts who were selected based on their professional experience within the field of intellectual disability.

Table 7: Experts in the field: Interviews with Professionals

Field of expertise	***Key Comments***	***Date***
Specialist Psychiatrist: Intellectual Disability	"This work addresses family distress by providing a resource that will strengthen and enhance family resilience."	21 April 2021 & 6 May 2022
Clinical Psychologist Specialist: Intellectual Disability	"Behaviour that challenges in people with intellectual disability cannot be divorced from societal resources."	21 April 2021 & 6 May 2022
Director of the Western Cape Forum for Intellectual Disability	"The court case won by WCFID held government a lot more accountable for the needs of people with intellectual disability. However, funding does not go to caregiver salaries."	20 April 2021
Vera Grover Professor of Intellectual Disability at	"This is a research gap…Caregivers of people with intellectual disability with high support needs are an important target group."	19 April 2021

University of Cape Town.		
President of IASSIDD (International Association for the Scientific Study of Intellectual and Developmental Disabilities)	“The manual should be developed out of the needs of the caregiver. When identifying the resources both internal and external resources of the caregiver should be explored. “	20 April 2021
Educational Psychologist, Western Cape Education Department	“To take care of children with intellectual disability starts with selfcare. It is important that selfcare of the caregiver be included in the manual.”	17 March 2022

According to De Vos and Strydom (2011:483-484), during the fourth phase of intervention research, namely the ‘early development and pilot-testing phase’, the preliminary intervention programme, with a basic manual, is developed and evaluated under field conditions. The purpose of the pilot-testing is to determine whether the intervention programme would work and which of the elements of the prototype need revision (De Vos & Strydom, 2011:484). During this phase, the researcher consulted with some of the experts in the field regarding the content of the programme and questionnaires which the latter was also sent to a qualified statistician for review. These professionals were in the expert position of indicating to the researcher ahead of time any challenges or omissions that could hinder the objectives of the study.

6.6.3.2 Quantitative phase

It was important that the researcher pre-tested the research procedure with a group of respondents who would not be part of the one-day preliminary research but were potential clients of the programme. The pilot-test would identify problems in the programme which included the manual and questionnaires. This enabled the researcher to make the necessary amendments or adjustments accordingly. A total of nine caregivers formed the pilot study and collaborated with the researcher to determine whether the intended programme would indeed address the needs of the population in the appropriate manner (De Vos & Strydom, 2011:480).

The researcher interviewed the respondents of the pilot study after they had completed the pre-test questionnaire, the training, and the post-test questionnaire. The nine caregivers had the opportunity to describe to the researcher their experience of the training programme, as well as the completion of the questionnaires, i.e., whether it was clear, difficult, or insensitive. The researcher was able to determine whether they understood the questions the way they were intended. Browne and Greene (2005:114) emphasise that there must be no chance of ambiguity in the final questionnaire.

Guidelines and values continually inform the design process of intervention research (De Vos & Strydom, 2011:483-484). During this phase, a process evaluation took place in which the researcher evaluated, amongst other aspects, whether the programme was easy to understand and practical to use, as well as whether it was compatible with the Western Cape’s customs and values (De Vos & Strydom, 2011:485). The researcher considered the feedback of the nine caregiver-respondents of the pilot study. Further development towards the improvement of the intervention programme was undertaken to the complete satisfaction of the researcher and, therefore, the presentation of the preliminary programme could take place (De Vos & Strydom, 2011:480).

6.6.4 Data analysis

Data analysis was conducted in both the qualitative and the quantitative phases. Mouton (2014:108) explains that data analysis, whether in the qualitative or quantitative phase, involves reducing the data into manageable themes, patterns, trends and relationships.

There are similar steps to be followed in both qualitative and quantitative data analysis, namely preparing for data analysis, exploring the data, analysing the data, representing the analysis, interpreting the analysis and validation of the data (Creswell & Clark, 2011:204).

For this present mixed methods intervention study, Table 8 shows the procedure followed for each step differed for qualitative and quantitative research (Creswell & Clark, 2011:204-205):

Table 8: Mixed-Methods Data Analysis adapted from Creswell & Clark, 2011:204-205)

Rigorous quantitative data analysis procedures	Procedures for data analysis	Persuasive qualitative data analysis procedures
The researcher coded the data by assigning numeric values. She prepared the data for analysis using the Microsoft Excel Program. The researcher recoded/computed new variables for computer analysis. The researcher established a codebook.	**Preparing the data for analysis**	The researcher organised the data. The data were transcribed to text from the audio-recordings of interviews with the unpaid caregivers.
The researcher visually inspected the data, conducted descriptive analyses and checked for trends and distributions.	**Exploring the data**	The researcher read through the transcripts and wrote memos of themes that emerged.

The researcher chose an appropriate statistical software program for the statistical test and analysed the data to answer the research question.	**Analysing the data**	The researcher coded the data, grouped the main themes and assigned labels to them. The researcher interrelated themes to a smaller set of themes.
The researcher represented results in statements of results and provided the results in tables and figures.	**Representing the data analysis**	The researcher represented findings in a discussion of themes or categories. She presented visual models, figures and/or tables.
The researcher explained how the results address the research question and hypothesis and compared the results with academic literature.	**Interpreting the results**	The researcher assessed how the research questions were answered and compared the findings with literature. The researcher reflected on the personal meaning of the findings.
The researcher established the validity and reliability of the current data. The researcher tested the internal and external validity of the results.	**Validating the results**	The researcher used validation strategies, such as triangulation of finding and disconfirming evidence.

6.6.4.1 Qualitative Data Analysis

In qualitative data analysis, there is no single correct method of analysing the data, but rather multiple data analysis strategies and frameworks (Leedy & Ormrod, 2013: 158). The researcher enhances the credibility of the analysis by analysing the data collected thoroughly and critically. For instance, the researcher would account for deviant cases by indicating when a participant does not report what the other participants are reporting. This would be good practice in data analysis which, in turn, makes the interpretation of the data reliable (Browne & Greene, 2005:87).

The researcher used manual thematic analysis to interpret the data with the assistance of an independent reviewer. Alhojailan (2012:39) indicates that, in some instances, manual thematic analysis is preferred by researchers. Software, such as NVivo, can be useful for analysing qualitative data and grouping and organising them into similar themes or ideas. However, software does not reflect the researcher’s impressions of the data (Alhojailan, 2012:39).

The following analytical steps were implemented, adapted from Creswell and Clark (2011:204-205): -

(a) Preparing the data for analysis

> The volume of data was collected during interviews conducted with 25 informal caregivers of people with ID. The researcher continuously journaled all analytical thoughts and critical reflections throughout the research process by compiling field notes in a research diary (Schurink, Fouché & De Vos, 2011:402). The next critical task was to employ the services of a typist who transcribed the audio- recordings of the interviews. (It is important to note that the typist signed a confidentiality agreement.) The researcher briefed the typist on how to transcribe the audio-recordings. Words, such as “uhm, well, I suppose”, are important elements of the discussion and should not be omitted (Nieuwenhuis, 2011c:104). The typist listened to all the recordings and transcribed them verbatim. The researcher translated the interviews that were conducted in Afrikaans into English. The data were saved in an electronic folder to enable the researcher to access the files when

required for data reduction, representation, and interpretation (Nieuwenhuis, 2011c:105).

(b) Exploring the data

The researcher compared the transcripts with the audio-recordings to ensure trustworthiness of the data. The audio-recordings were played and replayed to gain a better understanding of the non-textual data (Schurink et al., 2011:402). Emerging themes and patterns, with their meaning, were reflected upon and critically assessed. Memos and code notes were written of emerging themes by means of line-by-line analysis of each interview transcription (Schurink et al., 2011:402). The researcher continued to search for themes that confirmed or contradicted, or provided alternative explanations to the initially formulated themes, as this is a crucial step in ensuring credibility of the data.

(c) Analysing the data

Coding was done manually as the researcher analysed patterns and their meaning. The researcher used open coding as it is a part of data analysis that pertains to categorising the data after close examination (Schurink et al., 2011:412). During open coding the data were reduced and organised into categorising data whilst continuously and closely examining and comparing similarities and differences. The researcher reflected on the ‘discrete parts’ relevance to the research question (Nieuwenhuis, 2011c:100.; Schurink et al., 2011:412-413). Four categories with themes emerged. Moreover, to ensure credibility, the researcher tested emergent understanding and evaluated how details that were not in the data could be important for analysis (Browne & Greene, 2005:87).

No new themes emerged, which was an indication that the point of data saturation had been reached. The main themes were grouped, and labels were assigned to them. The main themes were interrelated to a smaller set of subthemes.

(d) Representing the data analysis

In Chapter 7, the researcher will present the findings in a discussion of the identified categories, themes and subthemes captured. The researcher, furthermore, provides the verbatim quotations from the interviews that support the themes presented. The thematic analysis led to the emergence of the following main categories of themes:

- The lack of psychoeducation for the caregiver
- Socio-economic impact
- Caregiver resource constraints
- Psychosocial impact on the caregiver

The researcher also used a tabular form to represent the data (Schurink et al., 2011:418).

(e) Interpreting the results

The researcher interpreted the results by relating the findings to existing literature and analysing whether the literature is supported or disproved by the new findings (Mouton, 2014:109). The researcher also reflected on the meaning of the findings based on the insights and personal views of the participants.

The different phenomena were linked according to their commonalities. The researcher was able to draw conclusions based on substantiated evidence from the data in correlation to what is already known, to reveal new insights or corroborate existing knowledge (Nieuwenhuis, 2011c:113). The conclusions were applicable to the participants of the present study within their own context.

(f) Validating the results

Assessing the trustworthiness of the data is of paramount importance in research, as trustworthiness is the decisive test of the data analysis, findings and conclusions (Nieuwenhuis, 2011c:113). In qualitative research, the issue of validating the results can be addressed by paying attention to credibility, transferability, dependability and confirmability (Maree & Van der Westhuizen, 2011:38; Schurink et al., 2011:419-421; Anney, 2014:272-281).

- **Credibility**

Taking the advice of Creswell and Clark (2011:212), Schurink et al. (2011:419-421) and Anney (2014:272-281), the researcher enhanced the credibility of the study by an in-depth description of the complexities of the variables and interactions that were embedded in the data derived from the research setting. The researcher assessed whether there was a match between the participants' views and the researcher's depiction and representation of them. She also ensured credibility through member-checking, as she took a summary of the findings back to the participants to assess whether the information obtained was an accurate reflection of their experiences. (The verbatim responses of the participants had been transcribed and were verified against the literature and theoretical framework, namely the biopsychosocial model and the strength-based approach.

- **Transferability**

Transferability refers to the degree to which the results of the qualitative research can be transferred to other contexts (Schurink et al., 2011:420). Data from different sources were used to corroborate and illuminate the research question. The researcher interviewed experts, as well as informal caregivers, as utilising multiple informants for data collection enhances transferability (Schurink et al., 2011:420; Anney, 2014:272-281).

Designing a study that incorporates multiple informants or the use of more than one data collection method can greatly enhance the study's usefulness in other settings (Schurink et al., 2011:420).

- **Dependability**

Dependability refers to the stability of the research findings and the researcher's attempt to be transparent (Kalu & Bwalya, 2017:51). To ensure dependability, the researcher should provide enough information for the reader to determine how dependable the study is (Kalu & Bwalya, 2017:51). By ensuring that the research process is logical, well documented and audited, the dependability of the study is ensured (Schurink et al., 2011:420; Anney, 2014:272-281). Nieuwenhuis, (2011c:115) adds that the dependability of the research study is enhanced when the researcher discloses upfront the limitations of the study. Often researchers will encounter difficulties in collecting and analysing data and, by stating these limitations upfront, a better understanding is provided to the reader as to how the researcher arrived at the conclusion (Nieuwenhuis, 2011c:115) The researcher acknowledged the limitations to the study upfront. The services of an independent coder were utilised; this facilitated sound analysis and interpretation of data. Cross-checking the coding determines the level of consistency in the coding process (Creswell & Clark, 2011:212). No inconsistencies were found. Therefore, the use of the independent coder validated the dependability of the research findings.

- **Conformability**

Conformability refers to the steps taken by the researcher to ensure that the findings that emerged were not influenced by their own predisposition or bias (Kalu & Bwalya, 2017:51). The researcher controlled the risk for bias by digitally recording the interviews, and the data were transcribed verbatim. An audit trail was established by documenting and saving the data.

The researcher also provided evidence that corroborates the findings and interpretation of the study. In doing so, the conformability of the study was ensured (Schurink et al., 2011:421; Anney, 2014: 272-281).

6.6.4.2 Quantitative Data Analysis

Quantitative data analysis and interpretation is the culmination of the research fieldwork regarding sets of data, such as quantitative survey data (Mouton, 2014:108). The purpose of quantitative data analysis is to reduce the data into an interpretable numerical form so that the relations of the research problems can be assessed, tested and conclusions can be drawn (Fouchè & Bartley, 2011:249).

The following analytical steps were implemented, adapted from Creswell and Clark (2011:204-205): -

(a) Preparing the data for analysis

The collected data must be prepared for data entry (Fouchè & Bartley, 2011:252). In the present study, the data analysis was done with the help of the statistician and research consultant from the Centre of Post Graduate Studies of the Cape Peninsula University of Technology.

The researcher established a codebook and memorandum on how to score the responses (Fouchè & Bartley, 2011:252). The data were coded by assigning numeric values to the responses provided by the respondents who had completed the pre- and post-test questionnaires. All responses were coded by assigning a numeric value to them - including non-responses. This is to ensure that all responses to every question can be accounted for (Fouchè & Bartley, 2011:252).

Each respondent’s score was computed by summing the number of responses the participant gives; that was allocating attitudes 1 to 4 (with 1 being ‘strongly agree’, followed on a continuum with 4 being ‘strongly disagree’) to the categories and adding each respondent’s attitudes or values based on their responses (Maree & Pietersen, 2011c:167; Delport & Roestenburg, 2011:207).

The researcher prepared the data for analysis by computing the responses, using Microsoft Excel 365 (Fouchè & Bartley, 2011:249).

(b) Exploring the data

The researcher visually inspected the data, conducted descriptive analyses and checked for trends and distributions. The utilisation of descriptive statistics meant that the researcher applied several statistical methods to organise and summarise the data in a meaningful way to enhance the understanding of the data characteristics (Pietersen & Maree, 2011b:183-195).

(c) Analysing the data

In quantitative research, the numeric structure provides useful information about the world. It is, therefore, important that the researcher analysed the data to answer the research question of the present study (Onwuegbuzie & Leech, 2006:487). The analysis of the data was guided by the study research question (Creswell & Clark, 2011:207). The pre- and post-test scored data were merged for easy comparison and analysis. The scoring made it possible to examine whether the level of knowledge had decreased or increased in the post-test section of the implementation of the preliminary intervention programme. Therefore, this process allowed the researcher to evaluate the respondents' prior knowledge to the intervention, as well as the knowledge gained after the intervention.

(d) Presenting the data analysis

The data analysis is presented in Chapter 9 which contains descriptive and inferential statistics (Creswell & Clark, 2011:209). Each table of results is well organised with a clear title and with the rows and columns labelled. Furthermore, the researcher also used charts to represent the descriptive results visually. These figures are easy to read and understand (Creswell & Clark, 2011:209).

In this study the means and standard deviations of the responses to each question are shown in a table to reflect the direct comparison between the pre-test and post-test questionnaire data.

Furthermore, the strength of this comparison for each question was tested by using a paired t-test. This test is done by finding the numerical difference between the responses per person per question (post-response minus pre-response). These averaged differences follow a t-distribution, and thus a t-test is used to test whether the difference is significantly greater than zero. Since we are comparing two responses per respondent, the test is called a “paired t-test.”

(e) Interpreting the results

After having represented the results in a statistical format, a researcher needs to provide an interpretation of the meaning of the results (Creswell & Clark, 2011:209). The researcher used univariate descriptive statistics to aggregate the responses to the various questions. She analysed one variable at a time with the view of describing that variable (Fouchè & Bartley, 2011:254).

Descriptive statistics describe numerical data by means of finding the means (average) and standard deviations, and by representing the frequencies of each variable in charts (Fouchè & Bartley, 2011:251). The results of the paired t-tests were also interpreted to see whether there was a significant change in the opinion/perception of the respondents after the training. The researcher explained how the statistical results address the research question and compared the results with academic literature, which provided explanations for what the researcher had found (Creswell & Clark, 2011:210).

All analyses were done using Microsoft Excel 365.

(f) Validating the results

The researcher ensured the reliability and validity of the questionnaire - as the instrument, by developing it based on a series of indicators identified in the literature (Browne & Greene, 2005:103). Internal validity refers to the extent to which fundamental conclusions can be drawn and external validity refers to the generalisability of the findings or research results to the wider environment (Maree & Van der Westhuizen, 2011:39; Mouton, 2014:100-102). The researcher ensured the internal validity of the research data by having the questionnaire reviewed by experts, as well as a qualified statistician. The researcher ensured external validity and therefore generalisability of the data by making certain that the sample selected for the research study was an adequate representation of the population being studied (Maree & Van der Westhuizen, 2011:37-39; Mouton, 2014:100-102).

The researcher further verified the validity of the data by utilising the paired *t*-test to test for significant differences between the pre-test and the post-test results. This was done with the assistance of an independent statistician. The paired *t*-test is a popular statistical technique widely used for its suitability in many practical applications. The paired *t*-test was appropriate as the researcher aimed to compare the average scores regarding the same quantitative variables (topics) within a single sample (caregiver respondents) at two different times (pre- and post-test) (Pietersen & Maree, 2011c:225).

The lack of standardisation of research instruments in South Africa could be a major limitation to the study (Maree & Van der Westhuizen, 2011:39). However, the researcher ensured that the measuring instrument (questionnaire) was reliable in the South African context by translating and standardising it, using a sample of South African caregivers.

- **Triangulation of the findings**

Maree and Van der Westhuizen (2011:39) define triangulation as the process of utilising multiple perceptions to clarify meaning, thus verifying the repeatability of the interpretation of the findings. The triangulation of findings in this study refers to the interpretation of the findings by mixing qualitative and quantitative research methods and data.

The researcher triangulated the findings from the pre- and post-test questionnaires (quantitative components) and the face-to-face interviews (qualitative component) to facilitate the verification and validity of the findings.

6.7 The Impact of the COVID-19 Pandemic

The COVID-19 pandemic had a significant impact on the study. Due to it, the Cape Mental Health Society diverted all its assistance to research into COVID-19-related studies only. The Society was, therefore, unable to assist the researcher with the recruitment of subjects. However, the researcher was able to use social media as well as liaise with a network of social workers who works in the field of disability to assist.

Securing a venue for the training sessions proved to be very difficult. The researcher had to be cognisant of and adhere to the then current COVID-19 regulations in terms of the number of people who could be accommodated in any one venue. The management Alexandra Hospital, which is a hospital that specialises in services to people with ID, limited the use of their training venues to their own employees only.

The Western Cape Forum for Intellectual Disability did avail their training venue for this research study. However, due to the regulations, only 20 people could be accommodated in the venue per day. The Dorothea Special School had a large hall that could accommodate more caregivers. To allow, however, for social distancing, the one-day training was done over two days to reach 100 respondents. In one instance, the psychoeducational training session had to be postponed on the very day that it was scheduled to take place, due to a COVID-19 outbreak at the scheduled venue, and an alternative venue had to be found.

Finally, some caregivers could not attend the training due to being ill with COVID-19.

6.8. Ethical Considerations

The ethics of science considers what is wrong and what is right in the performance of research. The researcher has the right to search for truth but not at the expense of the rights of other individuals in society (Mouton, 2014:238-239).

The researcher considered the following ethical considerations.

6.7.1 Avoidance of Harm

A research process must not expose the subjects to significant risk of personal harm (Mouton, 2014:245). The researcher ensured that the questions were posed in such a manner as to avoid traumatising the subjects. Though emotional harm could be more difficult to predict than physical discomfort, it often has far-reaching consequences for the subjects. During the research process, the researcher avoided any possible harm from befalling the subjects by thoroughly informing them beforehand of the potential impact of the research. This allowed the respondents or participants to withdraw from the research if they so wished (Strydom, 2011:115; Reamer, 2010:574).

6.7.2 Informed consent

Informed consent must be acquired when the risk of research is greater than the risk of daily life (Mouton, 2014:245). For consent to be informed, the subjects must be knowledgeable and competent (Otto & Petrilla, 2003:198). The researcher ensured that they were fully knowledgeable regarding the goal and procedures of the study, as well as the risk and benefits involved in participating in the study. This was done in a letter of informed consent and verbally repeated on the day of the training.

The anonymity of the respondents and participants was ensured, and they provided written consent (Reamer, 2010:568; Strydom, 2011:117-118). It was imperative that the caregivers understood that they were not forced to participate and that their participation was entirely voluntary (Strydom, 2011:116).

6.7.3 Deception of Subjects and/or Participants

It is unethical to offer or withhold incorrect information from the respondents regarding the research that is being conducted. The researcher identified questions that might have been a concern for this target group. Deception happens when the researcher intentionally misleads the subjects through verbal or written instructions on any aspect of the research. The subjects were fully informed that they were participating in a research process, as well as of the risks and benefits of their participation (Reamer, 2010:572; Strydom, 2011:119).

6.7.4 Violation of Privacy /Anonymity/Confidentiality

Research participants have the right to remain anonymous (Mouton, 2014:243). The researcher respected the privacy of the caregivers by conducting the study in a confidential manner, which means that the researcher did not make use of any names. The numbering system allowed the researcher to protect the identity of the respondents (Reamer, 2010:572; Strydom, 2011:119). Moreover, the researcher guaranteed the confidentiality of the participants taking part in the semi-structured interviews by limiting the access of others to their personal information (Strydom, 2011a:119). Permission was also obtained from the participants before the use of a digital recorder (Nieuwenhuis, 2011b:89; Strydom, 2011a:117). Finally, the researcher informed the participants that the data would be stored at the Department of Social Work and Criminology, University of Pretoria, for 15 years.

6.7.5 Debriefing of Participants

This study required caregivers to discuss challenging experiences that had occurred to them in the past, and this could open emotional wounds that had not been dealt with. It may have been difficult for the researcher to avoid this risk entirely even though all was done to avoid it. With the permission of each caregiver, individual debriefing sessions would have been arranged on request. Should the researcher have identified harm to a respondent, she would have immediately referred him or her to a professional counsellor, as advised by Strydom (2011:122). The contact details of the professional counsellor were also provided to the participants in the letter of informed consent.

6.7.6 Actions and Competence of the Researcher

The researcher is a qualified social worker with 19 years' social work experience, 11 of which have been in the field of psychiatry. The researcher also has years of experience in ethical conduct as a professional and is trained in the necessary skills and competencies to conduct this study effectively (Reamer, 2010:564; Strydom, 2011:123).

Researchers should maintain objectivity and integrity when conducting research. This implies adherence to the highest possible technical standards in research (Mouton, 2014:240). The researcher utilised an independent coder to ensure the trustworthiness of the data. The research was also conducted under supervision of an experienced research supervisor.

6.7.7 Cooperation with Contributors and Sponsors

Research projects are often too expensive for a researcher to manage financially on their own (Strydom, 2011:125). The researcher wants to thank the Dorothea Special Education Centre for graciously making their hall available for the training. Furthermore, the researcher wishes to acknowledge the Dorothea School kitchen staff for preparing all the refreshments and the administrative staff for printing the training materials. All was done at no cost to the researcher. Additionally, the researcher wants to acknowledge and thank the various group homes and workshops that came from surrounding areas to Dorothea School and provided the transportation for their employees to the training hall.

6.7.8 Publication of Findings

The parties involved and who participated in the study were notified of the findings by making the research report available in such a manner that the confidentiality of the caregivers continued to be maintained (Reamer, 2010:574; Strydom, 2011:126).

The research report will be made available in the format of a thesis.

6.9 SUMMARY

This chapter focused on the research methodology. The study was rooted in the mixed-methods research approach which is a combination of both the qualitative and quantitative approaches. The researcher applied the embedded mixed-methods design - a variant of the mixed-methods research design - to allow the qualitative phase to inform and support the dominant quantitative phase.

Applied intervention research was appropriate as the aim of the research was to contribute a solution to a troublesome situation: creating a psychoeducational training programme targeted at caregivers of people with intellectual disabilities in order to enhance the formers' capacity and resilience and alleviate caregiver distress.

The respondents attended a one-day psychoeducational training programme. Prior to the commencement of the training the respondents completed a pre-test questionnaire to assess their knowledge of and attitude to aspects related to caregiving of people with intellectual disability. After completion of the training, they were required to complete a post-test questionnaire that would assess their possible new level of knowledge of and possibly revised attitude to aspects of caregiving of people with ID. Should the results indicate a positive change, it could be concluded that the intervention contributed to the positive change. The 'one-group pre-test post-test design' is a pre-experimental design which enabled significant interpretation and comparison regarding the impact and value of the training programme.

The first four phases of intervention research guided the research methodology. In the first phase, problem analysis and project planning, the research identified the research problem, namely the need for caregivers to receive psychoeducational training to alleviate caregiver distress. With regard to the project planning stage, the researcher identified the caregivers and asked for (and received) support, cooperation and permission from the Western Cape Forum for Intellectual Disability to conduct the research.

The second phase of intervention research, namely information gathering and synthesis, focuses on gathering information. The literature revealed that there was a lack of psychoeducational programmes for caregivers of people with intellectual disabilities. One of the experts whom the researcher approached for their expert input to guide the research, referred to this as a research gap. The researcher could not find existing psychoeducational programmes for caregivers in South Africa, especially in the Western Cape context.

In the third phase, namely the design phase, the researcher developed an observational system and specified the procedural elements. The psychoeducational programme was developed for caregivers of people with intellectual disability. It was pilot-tested with experts and nine caregivers who did not form part of the preliminary intervention study in the fourth phase, namely the early development and pilot-testing phase. The pilot-testing was done to ensure the programme's cultural appropriateness, quality, and feasibility. The phase concluded with the preliminary intervention programme - the one-day training session.

Steps 5 and 6 which include dissemination, publishing the programme materials and certification, are beyond the scope of this study and did not form part of the research process.

The practical implementation of the different facets of the research process was discussed in terms of the different methods applied and how it progressed and was achieved. Ethical considerations were also provided.

The next chapter discusses the empirical findings of the qualitative research which was the first phase.

CHAPTER 7
EMPIRICAL FINDINGS OF QUALITATIVE RESEARCH-FIRST PHASE

Figure 15: Graphic representation of the phases of the intervention research. Adapted from Rothman and Thomas (1994:28); Fraser and Galinsky (2010:459-466).

7. 1 Introduction

The researcher conducted the first phase of the mixed-methods approach, namely the qualitative phase, with participants using the purposive sampling method. In this chapter, the researcher will describe the findings of the qualitative phase. In the light of the theoretical frameworks biopsychosocial model and the strength-based approach, the researcher will describe the findings of this phase in the present chapter. She will focus on the goals and objectives of the first phase, as well as the research questions and empirical findings. The quotes of the participants will be grouped according to their content and will be confirmed by literature.

7.2. Pilot Testing: Qualitative Phase

The pilot test assisted in pre-empting problems that could have arisen during the actual qualitative interviews of the main investigation (Strydom & Delport, 2011:394-395). In this phase, pilot testing commenced by reviewing and discussing the interview schedule with the experts in the field. Pilot testing of the qualitative phase was comprehensively discussed in Section 6.6.3.1.

7.3 EMPIRICAL FINDINGS – FIRST PHASE (Qualitative)

The research findings derived from the qualitative phase of the study have been substantiated by literature and are discussed and presented as follows: -

- The biographical details of each caregiver participant, in both descriptive and graphic illustrations, are provided.
- The themes and subthemes, as they emerged from the data, are presented in table format and then discussed. The thematic analysis of the themes is presented using verbatim quotes from the interviews with the caregivers.

7.3.1 Section A: Findings derived from the Caregiver Participants

In the qualitative phase, 25 participants were interviewed. In four cases, the mother and father both participated in the same interview as caregivers of the same individual with ID. Two of the participants are caregivers of more than one person with ID.

7.3.1.1 Biographical profiles of caregivers

This section gives an overview of the caregiver participants and their biographical profiles, followed by the thematic analysis.

Table 9: Biographical profiles

Participant Identification	Age	Marital Status	Race	Highest Qualification	Relation to person with intellectual disability	Income	Age and Gender person with ID	Daily activity of person with ID
PCP01 **PCP02**	50 51	married	Coloured	matric	parents	Unemployed, grant of ID	17, female	LSEN School
PCP03	58	single	White	matric	legal foster mom	Unemployed, grant of ID	17, twins, males	LSEN School
PCP04 **PCP05**	52 52	married	Coloured	grade 10	parents	DG & grant of ID	21, male	at home
PCP06	42	single	Coloured	matric	mother	Employed, grant of ID	21, male	workshop

PCP07	52	separated	Coloured	Grade 8	mother	Unemployed, grant of ID	30, male	at home
PCP08	53	single	Coloured	grade 11	neighbour	Employed, grant of ID	13, male	LSEN School
PCP09	67	married	White	Grade 8	mother	Pensioner and grant of ID	40, male	at home
PCP10	34	single	Black	grade 11	mother	Unemployed, grant of ID	4, male	at home
PCP11	53	widowed	Coloured	grade 5	mother	Employed, grant of ID	25, male	at home
PCP12 **PCP13**	70 70	married	Coloured	grade 7	no relation, previous foster parents	Pensioner and grant of ID	28, female	workshop
PCP14	51	divorced	Coloured	matric	mother	Employed, grant of ID	31, male	at home
PCP15 **PCP16**	52 57	married	Coloured	Grade 8	parents	Employed, grant of ID	21, male	at home
PCP17	48	married	Black	honours in Policing	mother	Employed	29, female; 20, female; 18, male	protective workshops

PCP18	67	Married, husband has Alzheimer's	Indian	grade 10	mother	Pensioner and grant of ID	37, male	at home
PCP19	51	single	Coloured	grade 10	mother	Unemployed, grant of ID	17, female	at home
PCP20	39	married	Coloured	matric, bookkeeping certificate	mother	Employed	9, male	School
PCP21	63	widowed	Coloured	grade 7	no relation	Pensioner	15, male	LSEN School
PCP22	58	widowed	Coloured	matric	mother	Unemployed grant of ID	31, male	car wash
PCP23	42	married	Coloured	nursing certificate	mother	Unemployed, husband employed	12, male	LSEN School
PCP24	32	married	Coloured	matric	sister	Unemployed, grant of ID, husband employed	17, female	LSEN School
PCP25	50	married	Coloured	grade 8	legal foster mom	DG & grant of ID	18, male	car wash

An analysis of the data revealed that a large number of the participants indicated that they were single, separated, divorced or widowed. One participant was a *compound* caregiver taking care of her husband with Alzheimer's as well.

There was a total of 21 female and 4 male participants. Table 10 shows that the number of lone participants is higher than the number of supported participants who partook in the study. These findings are consistent with the literature that indicates that most caregivers of persons with intellectual disability are lone females (Lafferty et al., 2016:13).

Table 10: Lone versus Double participants

Participants	Total
Lone (single, divorced, widowed)	57%
Double (married, live-in partner)	43%

The data also revealed that significantly more participants indicated that their only income was their pensions grant, or a disability grant for themselves, or they solely relied on the grant of the person with ID. Table 11 shows that 66,7% of participants were unemployed, being a pensioner or receiving a DG for themselves or for the person with ID. Employed caregivers made up 33,3% of the group.

Table 11: Unemployed versus Employed

Participants	Total
Unemployed	66,7%
Employed	33,3%

Many stated that their caregiver obligations prohibited them from finding employment. These findings are consistent with the literature which indicates that many caregivers of persons with intellectual disability forgo employment opportunities due to their caregiver obligations (Marsack-Topolewski & Church, 2019:145-156; Marsack-Topolewski, 2021:299-319). Consequently, for some families, disability leads to poverty (Gona et al., 2011:181; Ezeonu et al., 2021). The following table provides a description of the participants.

Table 12: Description of participants

Participant	Description
PCP01 (Wife) and **PCP02 (Husband)**	These participants are a married couple with four children of which the youngest is a 17-year-old daughter living with intellectual disability. Participant 01 has, since the birth of their daughter, been unable to work due to taking care of their child. Participant 02 has experience as a carpenter. He often has no work, and they rely on their other daughter for provision. They live in the poverty-stricken area of Bonteheuwel and have a stable marriage.
PCP03	Participant 03 is a white single woman who has been fostering black twin boys with intellectual disabilities since they were babies. The three of them live in one of the houses of their local church. The boys' disability grant is their only income.
PCP04 (Wife) and PCP05 (Husband)	These participants are a married couple, and PCP 04 (the wife) has been diagnosed with Diabetes Type 1. Due to her diabetes, she is now legally blind. Her mobility is also impaired and, consequently, she must rely on her husband and her only child, who is a person with ID, for her own care. Assisting his mother has at times led frustration and anger outbursts from the person with ID. He has become physically violent with her. PCP 05 is unemployed and is the primary caregiver of both his wife and son.

PCP06	Participant 06 was abandoned by the father of her son (living with ID) and daughter. He ended the relationship with this participant when the boy was six years old, married and started a new family. He gives her R1000/month maintenance for both children. He does not invite the children to his home to interact with his other children and wife and has seldom visited them over the years. When he does call, he would speak only to his daughter and not his son due to communication challenges. Nonetheless, according to his mother, the son yearns for a relationship with his father, and this leads to anger outburst towards his mother and sister. The mother must work and leaves him in the care of his maternal grandmother (they reside with her) during the day.
PCP07	This participant recently separated from her husband. Her youngest child is a 31-year-old person with ID, and he is completely non-verbal. She relies on her other adult children to assist financially with his care. She is unable to work due to his daily care needs.
PCP08	This participant started taking care of a 13-year-old boy with ID as she noticed that his biological (single) mother, who resides in the same neighbourhood and has six children, was overwhelmed by her care duties towards him. The caregiver took the child into her care having come to a private arrangement with the mom, when he was six years old. She is not his legal foster mother, but she administers his disability grant. She takes him for his hospital appointments and to the LSEN school. She is employed and her older biological children assist with his care when she is at work.

PCP09	This participant is intensely frustrated with trying to find placement for her son. This is an impoverished white family. Due to her aging condition and ill health, she is becoming increasingly unable to manage her 40-year-old son’s challenging behaviour. Her son is non-verbal. Their house is unkept with broken windows and doors, and broken furniture caused by her son’s outbursts.
PCP10	This is a single black participant who became increasingly isolated after the birth of her son. Her son has an intellectual, as well as physical disability. The relationship with her son’s father ended soon after he was born. She is unable to work due to her caregiving duties and has also lost contact with her friends. She comes across as very sad and depressed but very committed to the care of her child.
PCP11	This participant is a single working mother of three adult children all of whom are unemployed. There is much conflict among the children. The daughter refuses to assist with the care of her brother who lives with ID. Her other son uses cannabis (dagga) with the person with ID son who is prone to violent outbursts. This caregiver appears to have lost control of her household.

PCP12 (Wife) and **PCP 13 (Husband)**	This is an elderly couple who have been married for 48 years. They became the foster parents of the person with ID when she was formally placed with them as a baby. The baby was later diagnosed with severe FAS (fetal alcohol syndrome). Once the baby had been legally placed in their care by social workers, it was their experience that the social workers did not come back to monitor the child. According to the caregiver couple, they would be called into the social workers' office every two years for the renewal of the foster care documents. The couple were disappointed by the lack of support from social services. Currently the person with ID is 28 years old and has aged out of the foster care system. The caregivers are becoming progressively frailer. Financially, they take care of her with their pension grant and the disability grant of the person with ID. These participants hope that, when they pass on, their biological adult daughter would take over caregiver duties for the person with ID.
PCP14	She is a divorced mother of three adult children. She is in full-time employment and pays her domestic worker to take care of her son with ID. She receives no financial or emotional support from the biological father of her son. He does not have contact with his son. From time to time the two siblings assist by offering their mother respite care when they take out their brother with ID for the day.
PCP15 (Wife) and PCP16 (Husband)	These participants are a married couple who have three sons of whom the last-born has ID. They are very protective of their son. Their greatest concern is community stigma and how others might victimise their son. Both parents are employed. They reside with the father's family (with a separate entrance

	to the home), and the family assists with caring for their son when they are at work.
PCP17	This is a black employed (married) mother who receives great support from her husband. All three of their children has an intellectual disability and either in a workshop or at the LSEN school during the day.
PCP18	This participant's son has ID and is visually impaired as well. She is a 67-year-old person who also takes care of her husband who has Alzheimer's disease. There is much pressure on this caregiver as she drives everyone to their hospital appointments; thus, she neglects her own care. She is especially frustrated with the lack of resources that would address her son's needs.
PCP19	This is a single mother residing in the servant's quarters of her son's house with her daughter who has ID. She is unable to work due to the care of her daughter. Her daughter has violent outbursts and would undress herself and walk down the street. Due to her troublesome behaviour, the daughter was requested to leave the LSEN school. The mother is at home the entire day with her child, trying to manage her behaviour. This caregiver is very disappointed with the lack of support from social and healthcare services.

PCP20	This participant's child was diagnosed with ID by the education psychologist of the Western Cape Education Department and was told that he needed to be in an LSEN school. She is awaiting admission for her son to attend an LSEN school. In the meantime, she is paying an occupational therapist and speech therapist to offer him developmental sessions. She is hoping that early intervention would improve his abilities.
PCP21	This participant met the 15-year-old person with ID in a children's home when he was three years old. He was abandoned at the children's home by his biological mother when he was a baby. The caregiver kept visiting him and she would take him home occasionally for weekend visits. When he was 12 years old, about three years ago, he was sexually molested at the children's home. She was asked to take him home permanently for his safety. However, the boy was not legally placed with her. There have been many delays with social services regarding the legal placement of the child in her care. She is currently taking care of him with her pension and no other income from the government.
PCP22	Participant 22 is a widow, taking care of her 31-year-old son who lives with ID. He has had many violent outbursts against her. She called the police a few times and they did not know how to assist her. Due to his disability, he would be vulnerable in jail, but then he is a danger to his mother at home. They would assist her in taking him to hospital. By the time they arrive at the hospital he would be calm, and they would send him home where he starts fighting with his mother again. She

	is weary of the cycle and would like to have coping tools to better manage him at home.
PCP23	This participant left her employment as a nursing assistant to take care of her 12-year-old son with ID. Her greatest concern is community stigma and the way her son is being mistreated by the community. He also presents with challenging behaviour and is outgrowing her in stature which, according to her, is having a negative impact on her ability to manage his behaviour.
PCP24	The participant is a newly married lady taking care of her sister after their mother's passing. She is unable to work as the care of her sister is her highest priority. She wishes she could buy a pair of shoes for herself, but all her resources are absorbed by the care for her sister. She is hoping to find employment that would allow her to take care of her sister as well.
PCP25	Participant 25 is the legal foster mother of the person with ID formally placed in her care by social services. His biological mother died and left him in the care of his maternal grandfather who later married this caregiver. She has a great relationship with the person with ID even though his behaviour can be challenging at times. She explains that she remains very calm when he acts out and will address his outbursts when he has settled down.

7.3.2 Section B: Thematic Analysis of the informal Caregiver Interviews

A thematic analysis strives to identify patterns of themes in the interview data (Roberts, Dowell & Nie, 2019:1-8).

The following section focuses on themes, subthemes and categories in the research, with the table below indicating a synopsis of them, followed by a discussion of these themes, subthemes and categories. The verbatim quotes from the interviews will be substantiated by literature.

Table 13: Themes, Subthemes, Category

Themes	Subtheme	Category
Theme 1: Caregiver perception of intellectual disability	**Subtheme 1.1** Information at diagnosis **Subtheme 1.2** Beliefs, causes and denial of intellectual disability **Subtheme 1.3** Information on available services, resources and education plan for children with ID **Subtheme 1.4** Managing behaviours that challenge	**Category 1:** The lack of psychoeducation for the caregiver
Theme 2: Experiences of financial implications	**Subtheme 2.1** Financial constraints of the caregiver **Subtheme 2.2** Anxiety about future care and provision for the person with intellectual disability	**Category 2:** Socio-economic impact

Theme 3: Experiences of barriers in accessing resources	**Subtheme 3.1** Access to healthcare, police and social work services **Subtheme 3.2** Workshop and placements **Subtheme 3.3** The need for respite care **Subtheme 3.4** Transportation **Subtheme 3.5** Lack of household safety awareness	**Category 3:** Caregiver resource constraints
Theme 4: Personal impact of caregiving	**Subtheme 4.1** Social support, family conflict and caregiver isolation **Subtheme 4.2** Community stigma **Subtheme 4.3** Personal psychological and physical health **Subtheme 4.4** Resilience	**Category 4:** Psychosocial impact on the caregiver

7.3.2.1 Category 1: The lack of psychoeducation of the caregiver

The researcher found that the lack of psychoeducation of the caregiver is a contributing factor to caregiver distress. In this category the theme and subthemes that emerged entailed the caregivers' understanding of intellectual disability, as well as the information and support provided to the caregivers at diagnosis of the intellectual disability of their loved one. Further details on the themes and subthemes are provided next.

(a) Theme 1: Caregiver perception of intellectual disability

The participants shared their belief of the causes of intellectual disability. Some believed that they themselves were the cause of the intellectual disability or that their family had been cursed. Some admitted being in denial of the diagnosis. Many mentioned the limited information received from professionals in the field and they did their own research. Four subthemes emanated and will be discussed next.

- **Subtheme 1.1 Information at diagnosis**

Three (3) participants expressed a lack of information at the diagnosis of their child. One participant explained that she discovered her child had an abnormality when she read a note of the doctor. The other two participants expressed doing their own research.

The following verbatim statements supports their assertions (the reader to note that to protect confidentiality, the original names were changed to pseudonyms):

> *PCP05: "They never explained to me what Intellectual disability is. I did my own research – I got a laptop, and I did my own research."*
>
> *PCP07: "Toe Lesley 6 jaar oud was.. het ek die brief gelees wat die Doctor vir my gegee het wat ek geneem het na die Social Worker. Daar het ek gelees dat my kind nie normal is nie." (When Lesley was 6 years old, I read a letter which the doctor gave me to take to the social worker. In there I read that my child is not normal.)*
>
> *PCP14: "Look, I did not know much at the time. I had to figure things out for myself as life went on. Because I did not know what it (intellectual disability) was, I had to investigate it, read on it, go to workshops, go to Red Cross, and educate myself and, you know, all the mothers sit and talk to each other and give advice. I was not clued up."*

The experiences described by these participants correspond with the study conducted on caregivers of people with ID in Khayelitsha (Cape Town district) by Mkabile and Swartz (2020:1026-1037). These authors found that some caregivers were poorly informed by the medical practitioners with respect to their children's condition. Schoeman et al. (2017:57) expressed their concern over the lack of early intervention services to people with ID due to caregivers being ill-informed on their child's development.

A core component of the cognitive behavioural therapy model is psychoeducation (Wright et al., 2006:80; Leoni et al., 2016:59-73; Kazantzis et al., 2018:349-357). From these findings it is evident that caregivers are frustrated by the insufficient information and lack of psychoeducation provided to them by the health system. With the help of the framework of the cognitive behavioural therapy model the researcher aims to provide psychoeducation regarding the various facets of the disability and its treatment to empower caregivers, so that they can work alongside the mental health professionals for a better overall outcome (Sarkhel et al., 2020:319). This is of great importance as the lack of information will mean that caregivers may be left with traditional beliefs or personal assumptions on intellectual disability, as discussed in Subtheme 1.2.

- **Subtheme 1.2 Beliefs, causes and denial of intellectual disability**

Some participants shared their belief regarding the causes of intellectual disability. One parent believed that it had been caused by an injection given to her baby, while another believed it was due to antibiotics that she had taken during her pregnancy**.** Yet another participant was told that her family could be cursed. Some admitted that they had gone into denial of their loved one's diagnosis. Their responses are captured as follows:

> *PCP03: "I just got the kids with no information. I found out on my own what was going on with them and I found out through experience. I learnt the hard way with no training and no help."*
>
> *PCP04: "I was on antibiotics, and I did not know that it would interfere with my pregnancy. I always told my husband that I am the cause for my child being the way he is."*
>
> *PCP09: "He was born normal then he had an injection which led to convulsions. He got a high temperature and then his brain was damaged. He would never be the same."*
>
> *PCP011: "Die dokter het gese sy brein is nie lekker nie. Ek het my nie geworry nie want ek het gedink my kind sal weer reg kom. Hy moet terug gegaan het vir speech therapy maar toe gaan ek nie. Ek het gedink dat die Here vir him gesond sal maak." (The doctor said that his brain is not well. I did not worry about it because I thought my child will recover. He needed to attend speech therapy, but I did not take him. I thought to myself that God will heal him.)*
>
> *PCP15: "As a parent I didn't want to know the reality. I burst out in tears."*
>
> *PCP17: "People were telling me that it's witchcraft and that someone is jealous of me."*

Mckenzie et al. (2013:1750-1755) explained that, in South Africa, traditional beliefs about intellectual disability are most often rooted in negative assumptions, such as bewitchment and the fear of ancestors. Consequently, the caregiver would seek the services of a traditional healer to cure his or her child. Empowering caregivers of people with ID by providing information on the condition and awareness of coping mechanisms and resources, is a main research priority in intellectual disability research (Tomlinson, Yasamy, Emerson, Officer, Richler & Saxena, 2014:1121-1130).

Culture includes all societal norms, thoughts and values, and caregivers tend to attribute these to the person they are taking care of (Ebuenyi et al., 2020:537). Beliefs and practices relating to the disability can lead to discrimination and hinder access to training programmes (Ebuenyi et al., 2020:537). Having a strength-based approach may address cultural barriers and ensure better inclusion of people with disabilities (Ebuenyi et al., 2020:536).

- **Subtheme 1.3 Information on available services, resources and education plan for children with ID**

Many participants mentioned that, when their child was diagnosed with an intellectual disability, while enrolled at a mainstream school, the school had no care plan for the educational future of their child, nor advised them that they were eligible for the disability grant. Many did not know what kind of school would accommodate their child going forward, neither were they aware that they could receive a disability grant. One mother received forms from social workers and was expected to complete these forms without understanding them. Consequently, she had been taking care of him for the past three years without receiving a disability grant for him. The responses are as follows:

> *PCP05: "I never got the childcare grant until he was 18. How can you have a child that is disabled, and you can't get help?? The information gets lost between the different groups – so if the parents have the money and the education they get by, but there is not enough information in the communities – there is no road map."*
>
> *PCP06: "When I left Red Cross when he was about 6 or 7 years old he started school. I was on my own, so I had no professional help… to tell me how to help with these challenges and I would hear from people that you could get a disability for him." (the professionals did not inform her.)*

> *PCP09: "Only when he was 18 (did he receive a disability grant for the first time) and I didn't know about it. I should have had it when he was 2 years old, but I never knew about the disability grant."*
>
> *PCP14: "He only got a disability grant only from the age of 12 years old. I did not know that he could get one."*
>
> *PCP16: "When he was at creche, the teachers said that there was something not right. The school psychologist also picked up that he is in the wrong school. But they let him wait and he struggled at school. We were told that he is a special child, but nobody wanted him in their school… We were never told he has intellectual disability, until we took him to Alexandra Hospital. He was 15 or 16 years old."*
>
> *PCP17: "I wish social workers could be more professional and work with passion. And put themselves in our shoes. I felt like the school psychologist just said take your kids to another school. After they told me that my child must go to another school, they never followed up on me. I had to fumble and fall. And how many people fumble, fall, and die."*
>
> *PCP21: "Hulle (social workers) het toe die kind vir my gegee sonder papiere. Ek is nou 3 jare met niks geld vir hom. Ek moes vorms invul maar ek kon nie die vorms verstaan nie."* (*They gave the child to me without any documents. For the past three years I have been taking care of him and not receiving any money for it. I must complete forms, but I don't understand the forms).*

These findings are substantiated by Donohue and Bornman (2014:2) who report that, in South Africa, up to 70% of children of school-going age, and with disabilities, are not attending school. This could be due to the ambiguity in respect of the implementation of the Education White Paper 6 policy (Department of Education, 2001) that emphasises inclusive education. The policy prescribes that barriers to learning are to be addressed at school level and that learners with disabilities are to be taught in mainstream classes with their developing peers before they would be considered to enter a special needs school. The findings are further substantiated by a study conducted by Booyens et al. (2015:5) which found that some schools in South Africa failed to inform parents of children with ID that they could access a government disability grant - and how to go about this.

Teachers in South African classrooms are struggling to meet the increasing influx of learners who are experiencing diverse barriers to learning and development, as they (the teachers) do not have the necessary skills to provide support and to adapt classroom teaching (Engelbrecht et al., 2015:1-10). Often the result is that the caregivers of children with intellectual disabilities are not informed as to how to offer further support for the future learning needs of their child. Ebuenyi et al. (2020:541) suggest that a strength-based approach, a tailor-made programme, teacher training, as well as clearer policies, will provide for inclusive education of people with ID.

- **Subtheme 1.4 Managing behaviours that challenge**

Most caregivers described the struggle of coping with the challenging behaviour of the person with intellectual disability. They confess to resorting to desperate measures to manage such troublesome behaviour. One mother admitted to hitting her child to the point that he needed to be hospitalised and spoke of the regret she felt about the incident. Another mother uses cigarettes to calm her son down and further indicated that she would switch on the kettle if she needed to burn him should the violence escalate. One mother shared that she is suffering domestic violence with no one coming to help her. Yet another mother expressed the fear she has for her 12-year-old son. Their assertions are captured as follows:

> *PCP03: "We are suffering domestic violence here and all the help is given to the abused wives but if they would realise the abuse that we (as caregivers) have to face."*
>
> *PCP06: "The cigarettes calm him down a bit and I know that he needs them so I had to make a plan (during COVID) so that he could have a cigarette… he used to choke me and he used to break a lot of things. There were times I would switch on the kettle because I would think if this child did any harm, I would burn him. That is the desperation."*
>
> *PCP07: "Die ouer hy het geraak, die swaarder vir my en met die dinge wat hy wil he. Hy verstaan nie die word NEE nie. Hy is nou 30 jaar oud en hy is nog steeds die selfde. Maar wat kan ek maak? Ek kan net bid!!" (The older he became, the more difficult it was for me to get the things he wants. He does not understand the word NO. He is 30 years old now and it remains the same. What can I do? All I can do is pray!!)*
>
> *PCP011: "Hy het my hele huis opgebreek. Toe kon ek nie anders nie en toe slaan ek hom, en toe slaan ek hom hospital toe. Ek het myself verwyt dat ek hom geslaan het." (He damaged my home. I felt that I had no choice and so I hit him. I beat him to the point he had to go to hospital. I blamed myself for hitting him like that.)*
>
> *PCP12: "n Mens weet nie hoe om na n gestremde kind te kyk nie. Sy slaan my so dat ek sterretjies sien. Ek het nie geweet wat om te maak nie." (One does not know how to take care of someone with a disability. She hit me to the extent that I saw stars. I didn't know what to do.)*

> *PCP23: "Daar is altyd a fight, ons wil net peace kry. Wanneer hy klein was kon ons hom nog handle maar hy is nou te veel vir my. Hy gryp my want hy is nou lekker groot en ek is bang vir hom – hy het vir my op die grond gegooi ek het ge le in pain." (There is always a fight. We just want peace. When he was little, we could handle him but now it has become too much for me. He grabs me because now he is grown, and I am afraid of him. He threw me to the ground, and I was lying there in pain.)*

Mothers of people with ID have a higher prevalence of mental health difficulties which is exacerbated by their child's challenging behaviour (Adams et al., 2018:257-275). Newcomb and Hagopian (2018:96-109) explain that children with intellectual disability display challenging behaviour at disproportionately higher rates than their typically developing peers.

Behaviour that challenges, such as self-injuring behaviour (e.g., head banging), aggression, pica, disruption and wandering behaviour, result in a diminished quality of life for both the individual and his or her family (Newcomb & Hagopian, 2018:96-109). The biopsychosocial model provides a framework for understanding the biological, psychological and social factors that cause such behaviour (Koritsas & Iacono, 2012:243). The cognitive behavioural therapy model provides a framework for the training of skills which can be used effectively by caregivers of people with intellectual disability (Leoni et al., 2016:59-73; Surley & Dagnan, 2019:219-237).

7.3.2.2 Category 2: Socio-Economic impact

This category describes the socio-economic impact on the caregiver of a person living with intellectual disability.

Theme 2: Experiences of financial implications

Participants described how their role as a caregiver impeded their ability to work and provide for themselves and their families. The disability grant is often their only source of income, and this greatly impacts the concerns they have for their child's future care when they are no longer there.

Two subthemes emanated from this theme, namely the financial constraints experienced by the caregiver, as well as caregiver anxiety about the future provision for the person with intellectual disability.

- **Subtheme 2.1: Financial constraints of the caregiver**

Many caregivers explained that they were forced to resign from work to take care of the person with intellectual disability. One participant stated that being employed impacted her ability to collect his medication. Another participant explained that the demands of caregiving and being employed were too overwhelming, and so she decided to resign from her employment. One caregiver terminated her employment due to a lack of support she had as caregiver. Yet another said that due to repeated hospital appointments she was unable to work.

> *PCP07: "Ek het besluit om my werk te los omdat dit is too much om te werk en vir hom te sorg." (I decided to leave my job as it is too much to work and care for him at the same time.)*
>
> *PCP11: "Ek werk alleen en ek kan nie baie uit die werk uit bly nie. Dis moeilik om sy pille te gaan op tel." (I am the only employed person and I cannot stay away from work. It's difficult for me to collect his medication.)*
>
> *PCP14: "I took him at the age of 6 months to physio for a year every day at Red Cross Hospital. I could not work."*
>
> *PCP19: "I had to leave my work as I had no one to take care of her."*

Some participants described the financial constraints which caregiving had on their household and that the person with ID did not always comprehend these financial difficulties. Another participant sold her furniture to cope financially. Two participants mentioned that they receive no support from the father of the children.

> *PCP05: "The disability grant is R1800, and they cannot survive on that. I am not well off, but I want my child to be self-sufficient. R1800 won't pay your rent."*
>
> *PCP06: "It's been very tough for me - especially now with Covid we were on short-time, I don't always have money and he also has to hear from me all the time that I don't have money and he doesn't always understand that I don't have money. I have never ever been able to save. Everytime I think I can start saving, something happens."*
>
> *PCP06: "I don't know where his father is. His father was involved in the beginning, but he no longer lives in Cape Town. He does not pay maintenance."*
>
> *PCP14: "I never ever received any maintenance for my kids, but I did it on my own and I made it. He tells me that the Government looks after your child and R1800 is nothing and I tell him it's your son."*
>
> *PCP18: "We are in financial difficulty, but God takes care of us. I sold my furniture."*

> *PCP19: "Lisa is very expensive; she eats the whole day. Lisa's disability grant is my only income. I used to iron but I can't even go char because my sister refuses to watch her for me because of her behaviour. I must pay rent with her money."*

These results are correlated by literature that indicates that the daily care and responsibilities undertaken by caregivers are considerable and that the sacrifices caregivers make often affect them financially (Perkins, 2009:7-10; Marsack-Topolewski & Church, 2019:145-156; Marsack-Topolewski, 2021:299-319).

Furthermore, in South Africa, nearly all adult persons with intellectual disabilities live in the care of their families (McKenzie et al., 2013:1750; McKenzie, 2016:67). After completion of the LSEN school years there are limited pathways for a person with ID to find meaningful employment. Even protective workshops are referred to as schools and not considered employment (McKenzie & McConkey, 2016:537). Often the adult with ID will sit at home with nothing to do (McKenzie & McConkey, 2016:536). Finances, therefore, pose a serious problem due to the person with intellectual disabilities' inability to work and the caregiver's caregiving obligations (McKenzie & McConkey, 2016:536).

The medical model for disability, as explained within Chapter 2, suggests that persons with disabilities may be excluded from ordinary societal obligations, such as employment, and that eventually they suffer financial lack (Petasis, 2019:49). South Africa still follows predominately the medical model for disability, resulting in people with intellectual disabilities being isolated from the labour market (Petasis, 2019:49). The present study reveals that, in the case of many of the participants, caregiving of a person with ID has led them to be in a financially vulnerable position. However, the present study is guided by the strength-based approach which supports the notion that individuals who face crises learn skills, such as resourcefulness, to overcome adversities (Moorkath et al., 2019:175).

- **Subtheme 2.2 Anxiety about future care of and provision for the person with ID**

Many participants expressed anxiety about the future care of and provision for the person with ID. One mother explained that, if it was not for her caregiving, her two children with ID would be homeless; she perceived this as a worse crisis than COVID-

19. A single mother expected the child's father to take care of him as her own family wanted nothing to do with her child. Another mother admitted that the future care of her son was her most serious cause of concern. One mother had concerns that her child would be abused after her passing away. Another mother described how the future of her child led her to depression and anxiety, and yet another mother prayed to God that, when she died, her child would die with her. Their verbatim quotes are given next: -

> *PCP03: "If they were not living with me, they would have been on the streets. When I look at the homeless people and the hobbos at our soup kitchen, I see a mental health crisis. Our homeless people have mental problems and they amounted to street people through no fault of theirs. We have a crisis which is by far worse than Covid-19."*
>
> *PCP06: "If anything happens to me, then Kevin needs to go to his father. His father will have to look after him, because my family wants nothing to do with him. Kevin can't look after himself. I do worry a lot about him."*
>
> *PCP11: "Dis my grootste bekommernis. Waarheen gaan hy (wanneer ek sterf) want my dogter se reguit dat sy nie agter hom sal kyk nie.. Ek het altyd gebid. "Here hou my net terwille van my kind." (That's my biggest concern. Where will he go (when I die) because my daughter told me straight that she won't take care of him. I always prayed; Lord, please, spare me for the sake of my child.)*
>
> *PCP12: "Ek het gedink wat gaan van die kind word? Hulle abuse dan sulke mense. Ek kyk mos TV." (I thought: "What is going to happen to this child? They abuse people like her. I know because I see this on TV.)*
>
> *PCP15: "I always have this fear and anxiety – who will take care of him when we are not there anymore. No one understands him like we do."*
>
> *PCP17: "Yesterday I was thinking: What is next? The question "What next" will lead to depression and anxiety. Where to with my child?"*
>
> *PCP18: "I say 'God, if you have to take me then please take Adrian with me so that I can go in peace."*

These results correlate with literature that indicates that parents of people with ID report to have higher than average rates of stress, depression and anxiety (McConnell & Savage, 2015:100; Panicker & Ramesh, 2019:1-14). This is often due to the lifelong support that people with ID need, and most often this responsibility falls on their families (McKenzie et al., 2013:1750).

The higher prevalence of intellectual disabilities in lower-income countries, such as South Africa, allied with the increased life expectancy of people with ID worldwide, means that more children are surviving into adulthood, and many will continue to need lifelong support (McKenzie & McConkey, 2016:531). A research study conducted in Cape Town in 2015 found that caregivers of people with ID have an intense commitment to caregiving, and the unclear future options of care for the person with ID make them extremely anxious (McKenzie & McConkey, 2016:535). The biopsychosocial model provides a comprehensive framework for understanding the needs, desires and interactions of the person with ID and the caregiver family (McDaniel & Pisani, 2012:12).

7.3.2.3 Category 3: Caregiver resource constraints

In this category the theme that emanated relates to the participants' experiences, not only as they relate to barriers to access of resources, but also to the fact that available resources are very limited.

Theme 3: Experiences of barriers to accessing resources

Participants expressed their views and experiences with access to healthcare and other services, such as workshop placement and their need for respite care. They further explained how their lack of transport impeded their ability to access resources.

- **Subtheme 3.1 Access to healthcare, police and social work services**

In this subtheme, the participants described how they had tried to reach out for assistance and repeatedly found that the medical, police and social work services were unavailable or ill-equipped to assist them. One participant perceived a social worker as a person with a high salary but unavailable to assist her. Another participant described how she considered abandoning her child at the offices of the Social Work Services because she felt that she was not receiving any support from them. Three participants commented that reaching out to the police service for help had been in vain. One caregiver related how telling her story to the local newspaper to appeal for help from the public had been another fruitless endeavour.

> *PCP03: "The system fails us. The social workers were always unavailable. She never pitched up and was never even an apology. No professional courtesy. I mean that is their job. She has*

> *taken a fat cat salary; the children are so vulnerable and falling through the cracks and we can't get help for them."*
>
> *PCP11: "Ek het polisie toegegaan. Hulle se dat hulle kan niks doen nie." (I went to the police, and they told me that there is nothing they can do.)*
>
> *PCP12: "Soms voel ek om die kind te vat en te gaan plaas by die maatskaplike werkers in Bellville en loop weg. Hulle het nog nooit kom kyk of ek dalk die kind abuse nie. Solank soos ek vir Gillian het was hier nog nooit 'n social worker nie. Hulle het net die kind by my gelos en klaar." (At times I feel like taking this child and placing her with the social workers in Bellville and then walking away. They never came to see if the child is being abused or not. For as long as I have had Gillian in my care, there was never a social worker at my home. They just left the child with me and that was it.)*
>
> *PCP19: "The police take us to the hospital. Then the hospital tells us there are no beds available. I told them there is never a bed available when it comes to Lisa. Dan vat hulle vir haar, dan bring hulle haar net weer terug." (They would take her and bring her right back again.)*
>
> *PCP22: "I used to call the police and they just came and couldn't do much. The police stopped coming when I call because they don't know how to deal with this. He started to get aggressive and attacking us physically. We went to the Voice for help. The Voice is the newspaper – we were on the front of the Voice, I appealed to the public to help us, but it didn't help."*

The experiences described by the participants reflect the stigma and discrimination that have contributed to the barriers which caregivers of people with intellectual disability encounter when attempting to access healthcare (Mkabile & Swartz, 2020:8504). Inadequate medical and care support often form the basis of referrals to medical professionals and social workers. However, there is a shortage of appropriately qualified healthcare professionals (Coetzee et al., 2019:7).

The biopsychosocial model provides understanding of the social and psychological impact of lack of access to resources (Petasis, 2019:48). The CBT Model has been shown to be effective in treating symptoms of depression and anger (Surley & Dagnan, 2019:219-237).

- **Subtheme 3.2 Workshop and placements**

This subtheme describes the participants' frustrations with the lack of placements for people with ID. The evidence showed that, at best, the person with ID would receive a stipend from the protective workshop. Contrary to this, at other workshops, evidence revealed that the caregivers were required to pay the workshop for accommodating their child. Furthermore, one participant said that the services often did not match the support needs of the person with ID. Another participant explained how, in her view, COVID-19 was used as an excuse not to accommodate her son. Their verbatim assertions are given next: -

> *PCP09: "They must be put in a home, where I can visit him. It is too much stress for me. And every time I go to them, they tell me that there is no place, and he was second on the waiting list. So now they say it's Covid-19 and every time it is an excuse. I can't take it anymore."*
>
> *PCP17: "They get R480 for two weeks' worth of work. But my daughter doesn't understand economically, she knows she worked, and she expects that she should have money. And she expects to buy herself all sorts of things. I must improvise all the time."*
>
> *PCP18: "I was very upset when Adrian was at the Athlone workshop. I spoke to them when 6 months past because he is sitting there with pencil crayons. I had to pay for him to be there and all they do is colour in with crayons. He is blind so what use was that? He was always one side (isolated) because he can't see, and the others were doing activities. I paid them R270 per month and I had to give him lunch and drop him and fetch him. I spoke to the lady in charge and asked 'Why not let him pack in stuff?" I decided not to send him anymore."*

Regardless of what kind of education and training for independence people with ID might receive as children, they are most likely to require residential or supported living and working environments as adults (McKenzie, 2016:76). NICE Guideline 11 (Section 14.1.1) recommends self-management and for the independent functioning of the person with ID (Health, 2015). However, in the Western Cape there are limited number of workshops available. Moreover, most of those workshops will not consider a person with ID who presents with behavior that challenge (Coetzee et al., 2019:5).

The biopsychosocial model guides the researcher in adjusting the fit between the person with ID and the work or residential environment (Doyle, 2020:108). South Africa predominantly uses the medical model and therefore there is a lack of access for people with intellectual disabilities to work and residential placement (Petasis, 2019:49). The biopsychosocial model allows the researcher to provide a pragmatic intervention with the best outcomes given their profile and environment (Doyle, 2020:108). The pragmatic intervention would be the development of the psychoeducational programme. Although this does not provide them the much-needed placement, the aim is that it would assist in the alleviation of caregiver distress whilst mobilising and awaiting to access resources such as placement.

Subtheme 3.3 The need for respite care

The following subtheme the participants expressed the need for a break from caregiving. One participant explains asking others to invite her for lunch so she can get a break. Another single mother wishes her son's father would play a more active role in caregiving so she could get a break. Another participant expresses her exhaustion and need for a week or two of respite. Their responses are captured below.

> *PCP03: "I must ask people to invite us for a Sunday lunch just so that I can get a break. As I say Intellectual Disability has social stigma and you are rejected from society and people don't want us."*
>
> *PCP06:" He should let Kevin come stay by him (the father) for maybe a weekend or so or maybe every second weekend just to give me a break …if he could just go to even my sister for the day it will help. I don't have a life. I cannot go out. If I go out, he goes off"*
>
> *PCP13: "Ek is so moeg. Ek soek net a break even just for a week or two (I am so tired. I need a break, even just for a week or two)."*

The NICE guideline 11 of 2015 (within 14.3.2) recommends respite care services to be provided to caregivers of people with ID (NCCMH, 2015). Until recently the Western Cape Department of Health allocated 20 placements within two hospitals that renders services to people with ID for brief admissions with the rationale of providing a break to caregivers. However, this service has been discontinued in one of the two settings leaving less than 10 places available (Coetzee et al., 2019:7).

The strength-based approach does not ignore the problems but instead respects the client's inherent wisdom that discovers resources in the community in which he/she resides and focuses on the inherent strengths of the caregiver to mobilise these resources (Pulla, 2017:101). South Africa is poorly resourced in relation to respite care services to families of individuals with intellectual disabilities (Coetzee et al., 2019:4-9).

Where respite care is needed caregivers could mobilise support from within their family, such as incorporating siblings or other relatives as substitute caregivers to provide respite care to the full-time caregiver (Coetzee et al., 2019:4-9).

- **Subtheme 3.4 Transportation**

Four parents reported that the basic lack of transport is a barrier to accessing healthcare services for the person with ID. One parent indicated that the school bus would refuse to collect her daughter due to her problematic behaviour and that she, the (single) mother, was unable to pay for transport**.** The responses are captured below.

> *PCP05: "The workshops are in the Northern Suburbs. We have nothing, no transport; so we cannot get to it."*
>
> *PCP10: "I am still looking for a school that can help me. I found a creche in Claremont, but I can't find a transport. It is hard to find the transport."*
>
> *PCP17. "Their transport is R700 per month. Doesn't make sense?! They only working for their transport money."*
>
> *PCP19: "I didn't have traveling money. I would put her in the school combi, knowing they are going to put my child out. I could not pay, and she does not want to co-operate with nobody."*

These experiences of a lack of transport are confirmed by Coomer (2013:271-276) who noted that the challenges that caregivers of people with ID report go beyond commonly reported problems, such as sub-optimal service provision. The caregivers' challenges include the basic lack of transportation to reach healthcare services. Transportation is a specific service that needs to be improved for people with ID. Black caregivers in the Khayelitsha district of the Western Cape detailed their difficulties regarding using public transport with a person with intellectually, including the extremely high cost (Mkabile & Swartz, 2020:7). However, the strength-based approach compels the present researcher towards the upper limits of human capacity as she wants to work collaboratively with caregivers to discover all possibilities that could build their hope, aspirations and visions (Pulla, 2017:101-102).

- **Subtheme 3.5 Lack of household safety awareness**

Three participants expressed concerns about the lack of household safety awareness displayed by the person with intellectual disability in their care. This lack of household safety awareness led to the destruction of their property and placing the household at risk. The following information is captured: -

> *PCP07: "Jerre, nee, hy het al my huis verbrand. Hy het die stove aangesit dan wil hy die huis brand. As hy n entjie rook dan gooi hy die entjie neer op die klere. Toe slat die hele plek aan*

> *die brand. Dit was horrible!" (Oh no, he burned my house. He switched on the stove and burned the house. When he smokes a cigarette, he throws the cigarette on the clothes and the whole place burned. It was horrible!)*
>
> *PCP09: "And I can't handle it anymore. I don't have anything more in this house. I have no doors, my basin is cracked, he breaks everything."*
>
> *PCP25: "Ek kan nie vir hom alleen los nie! Ek vra altyd iemand om hom dop te hou. Ek vat een middag 'n middag slapie en ek word wakker met die gordyn aan die brand." (I can't leave him alone! I always ask someone to supervise him. Once I took an afternoon nap and I woke up with the curtain on fire.)*

It is important that the person with intellectual disability has an awareness of household safety skills, such as an understanding of the safe handling of poisons and household chemicals, as well as the safe use of matches and electrical appliances or natural gas (Slaggert & Jongsma, 2015:100). These skills are essential to protecting oneself from accidental injury.

Fundamental to social work interventions is the practice of empowering the caregivers, and the strength-based approach allows caregivers to play a role in their own empowerment. Based on Pulla's advice (2017:98-102), the present researcher combined her own professional skills, experience and research into psychoeducational programmes for caregivers of people with ID with the inherent wisdom of the caregivers themselves to facilitate skills development regarding home safety awareness.

7.3.2.4 Category 4: Psychosocial impact on the caregiver

This category emanated from the individual psychosocial impact caused by caregiving. The participating caregivers referred to lack of support and isolation on an individual level. Moreover, they experienced this lack of support and the isolation due to community stigma as well. Some participants shared how caregiving impacted their family relationships, as well as their ability to care for their own mental and physical health.

Theme 4: Personal impact of caregiving

Three subthemes emerged from this theme: the social support, family conflict and isolation that the participants reported, the community stigma they experienced, as well as the caregiving impact on their personal health and well-being. However, this theme also brought to the fore participants who showed resilience in their role as caregivers.

- **Subtheme 4.1 Social support, family conflict and caregiver isolation**

Participants shared the struggles in finding someone to take care of the person with intellectual disability and how they did not want to burden others, as well as the emotions of being abandoned by the child's father. One caregiver referred to being cast out by society. Others experienced family conflict due to their caregiver obligations. Their verbatim assertions are presented next: -

> *PCP06: "My daughter gets upset with me ... she will say: "He is like the King – everything revolves around the King!"*
>
> *PCP07: "Ek het altyd gesukkel om iemand te kry. Sy broer as hy nie by die College is nie, was altyd daar gewees en gekyk na hom. Hy wil nie he dat hy rond loop nie en ander mense se burden sal wees nie." (I always struggled to find someone [to take care of him]. His brother would take care of him when he was not at College..he always availed himself to take care of him. He didn't want his brother to walk around and be a burden to other people.)*
>
> *PCP10: "I am not happy about the breakup with the father. I am very sad about that. I don't have friends since 2017. Since he is born."*
>
> *PCP11: "Sy (sibling of person with intellectual disability) blameer vir my dat ek maak nie 'n plan nie vir hom om in a plek te kom nie… ek wil nie kies tussen my kinders nie." (She blames me and says that I don't have a plan to place him [in a residential facility]. I don't want to choose between my children.)*
>
> *PCP14: "I resent his father for abandoning us. But he loves his father."*
>
> *PCP17: "What I know is isolation comes in because you don't fit well into places and families you don't fit in. I avoid questions about my children. At my place of work, only three people know about my situation."*
>
> *PCP18: "He never interacted with his sister. He was aggressive towards her, so she does not come here."*

These are shared experiences of family conflict amongst informal caregivers due to their caregiver obligations. These findings concur with literature which records that caregivers of people with intellectual disabilities overwhelmingly report a lack of social support (Dada et al., 2020:6644; Ugwuanyi et al., 2022:2).

The caregivers' capacity to support the person with intellectually disability's participation in society may be linked to the social support that they, as caregivers, receive. Their experience of social support may increase social participation, as well as educational, psychological, medical and financial opportunities for the person living with ID (Dada et al., 2020: 6644). Therefore, support and intervention should be directed both at the person with ID, as well as his or her caregiver. If the family needs are not considered, the intricate and intimate network of family support may be undermined. It is important to be cognisant of the family's needs (physical, emotional and in many other respects) when considering the needs of person with ID, which would include the distribution of general resources (McKenzie, 2016:70).

The strength-based approach guides clinicians to veer away from a problem-focused lens which categorises a client as hopeless (Hammond, 2010:2; Pulla, 2017:98; Ginsburg & Jablow, 2020:353). The aim is not to deny their reality but not to view themselves as hopeless. The strength-based approach maintains that an individual possesses a range of capabilities and inherent wisdom. It also highlights that the individual has a range of experience, characteristics and roles that contribute to who they are and how they cope with a situation. This approach guided the researcher to highlight the power of the caregiver's inherent resilience in managing a challenging situation and moving towards hope (Moorkath et al., 2019:175).

- **Subtheme 4.2 Community stigma and vulnerability**

Many participants discussed the stigmatisation they experience and how they feel that this renders them vulnerable to risk. People mock them and call the person with ID names. One caregiver mentioned that her entire household was labelled as 'stupid'. Another caregiver mentioned her child being physically assaulted and his bicycle being damaged by the children of the community. Yet another participant mentioned that her child was scared to leave the home due to being mocked and taken advantage of.

> *PCP08: "They tell him he is stupid and that he goes to a stupid school and then he does not want to go to school. I am just scared that one day that when I am not here, he may become a gangster. The disability makes him vulnerable."*

> *PCP15: "Jonathan is scared to go out. The people take advantage of him, asking him for money. Shouting at him. They will ask him for 50 cents, and he gives a two rand."*
>
> *PCP17: "I walk with my kids in the mall. In public people mock and point at my kids. I tell myself to stay strong. I have realised society has casted them out. They call us the "house of stupid people" and they labelled my house. People can call you names and it can stick like glue!"*
>
> *PCP19: "Most of the people in the area don't understand this. They stare at her and then she attacks them. Then she has meltdowns, and the people laugh at her. I need to explain, and I must always defend her. The Government forgets about children like this and when they have their meetings, they must make a point of the people who are making fun of people with disabilities."*
>
> *PCP22: "The public don't know how to deal with intellectual disability. They think it is an illness. Sometimes the doctors don't know how to deal with it either."*
>
> *PCP23: "n Seun in die gemeenskap het hulle hond vir hom laat byt. Die merke is nog steeds op sy bene. Die kinders gooi sand in sy broek en hulle was baie mean met hom..ek kan ook nooit vir hom op sy eie buite laat nie want die kinders het vir hom gebully. Hy het a fiets gehad en hulle het al twee sy wiele af gebreek." (A boy in the community had his dog bite him and the marks are still on his legs. The kids would throw sand down his pants, and they are very mean to him. I can never leave him on his own as the kids would bully him. He had a bike, and they broke off both wheels.)*

The experience of community stigmatisation is substantiated by Scior et al. (2020:165-175). High levels of stigmatisation remain a reality in many places. Both the caregiver and the individual with intellectual disabilities have an emotional need for belonging. The caregiver longs for his or her child to have the experience of belonging in a school, workplace, congregation, neighbourhood or community group. However, this experience often evades them (Gona et al., 2011:181) - due to the ever-present community stigmatisation (Scior et al., 2020:165-175). The current interventions to address ID-related stigmatisation are inadequate and more needs to be done globally to reduce this negative labelling. In many parts of the world chances of a meaningful life for people with ID often appear still very poor, and support and advocacy are almost entirely their families' responsibility (Scior et al., 2020:165-175).

The strength-based approach avoids the use of stigmatising terminology and labelling language: for example, "house of stupid people." Caregivers may become accustomed to such terms, accept them, and then develop a sense of helplessness at the thought of changing the situation (Hammond, 2010:2; Moorkath et al., 2019:175;). The researcher adopted a manner of communicating that instills hope and enhancement of strengths.

- **Subtheme 4.3. Personal psychological and physical health**

This subtheme emerged from participants revealing their own psychological distress. One mother described how it emotionally hurt her when her child was constantly fighting with her and refusing to hug her. Another participant confessed that she told her son with ID that she wished he would die. One caregiver explained that caregiving disrupted her sleep, and she was receiving treatment for depression. Three participants were experiencing psychosomatic ill-health conditions that they ascribed to their caregiving obligations. The responses are as follows:

> *PCP07: "Hy stoot vir my weg as ek a drukkie vir hom wil gee. Alles is op sy terms, nie jou terms nie. Dit is wat seer maak. ek is sy ma en ek moet vir hom sorg but the way hy vir my treat en die way hy vir my wegstoot maak hy vir hart baie seer. Hy baklei al die tyd met my. Ek kan nie niks doen nie en so gaan dit aan. Dit maak vir a mens siek om al die tyd te baklei." (He pushes me away whenever I try to hug him. Everything is on his terms, not on my terms. This hurts me. I, as his mother, am trying to take care of him but the way he pushes me away, hurts my heart. He is always fighting with me and there is nothing I can do about it; but that is how it goes. The constant fighting can make one ill.)*
>
> *PCP11: "Partykeer voel ek moedeloos. Hoekom moet ek met die kind regop sit?!. Dan se ek die Here moet my vergewe dat ek so dink. Ek het hom al gese, ek wens jy wil vrek!. En hy raak daardie Woensdag siek. My dogter het my gese om die woorde wat ek oor Ashley gepreek het terug te trek. Ek het die Here vergiffenis gevra." (At times I feel despondent. Why do I have to deal with this child?! Then I ask the Lord to forgive me for thinking like this. I told him 'I wish you would die!' He then fell ill on the Wednesday thereafter. My daughter requested that I withdraw the words I had spoken over Ashley. I asked the Lord for forgiveness.)*
>
> *PCP12: "Ek slaap nie rustig nie. Ek worry my te veel oor my kinders. Ek kan nie ordentlik slaap nie. Ek het 'n angina hart, and high blood, cholesterol, ek het n hartkwaal. En baie depressed. Ek is onder die psychiatrist doctor by die daghospitaal. Die depression is as gevolg van haar." (I don't sleep well. I worry too much about my children. I cannot sleep well. I have an angina heart, high blood pressure, cholesterol, and a heart condition. I am very depressed. I am seeing a psychiatrist at the community clinic. I am depressed because of her."*
>
> *PCP15: "I have cholesterol and high blood pressure. I think it's stress related. I stress a lot especially when it comes to Jonathan. I stress too much so then it affects my blood pressure and I get headaches."*

> *PCP18: "I am diabetic and high cholesterol. Also, I have a pacemaker. It's not working properly and it's not synchronising with the heart; so I am dreading the time that I will be out of action."*

These shared experiences illustrate the psychological distress of caregiving, as well as the impact on and neglect of the caregivers' physical wellness. They are consistent with other studies which have also found high levels of psychological distress and neglect of personal health among caregivers of people with intellectual and developmental disabilities (Lafferty et al., 2016:19; Dawson et al., 2016:553-563). The researcher used the strength-based approach in the design of her intervention programme as its goal is to develop the individual and natural abilities and strengths of caregivers to the point where it will diminish their need to engage in maladaptive behaviours (Ginsburg & Jablow, 2020:354). The aim is to improve self-care abilities and self-esteem (Pulla, 2017:100).

- **Subtheme 4.4 Resiliency**

Some participants found their role as caregiver to be rewarding. The researcher explored what helped them do well.

Two participants referred to their belief that their caregiving role came from a higher calling as evident in their verbatim quotes:

> *PCP14: "Someone told me that God chooses special mothers to look after HIS special children. There is a special quality to a person to do this. God gave me the patience to be able to look after him. In all the things that I have been through in my life, this only made me stronger."*
>
> *PCP17: "God looked down on earth and said I have kids to throw down. 'Who can I bless?' He was standing on His throne looking for a mother. 'I'm looking for a mother. I'm looking for a mother' and says 'Uhhh! There's a mother that can cope with this one!' I appreciate my children and God. God has a plan, and I am in that plan."*

Three participants presented with a calm and resilient demeanour, more especially when the person with ID displayed challenging behaviour. The following are their verbatim quotes on how they manage behaviour that challenges.

> *PCP17: "Yes, there are times that they are aggressive. Every night my husband and I reflect on the day and whilst we are talking, the one just starts acting out. I know not to pay too much attention. The more I rise the more I am just putting baking powder on the situation. When they get aggressive, I calm down. Cause if I raise the yeast, they raise the baking powder. Because they go to the extreme, I must be able to calm the situation down."*

> *PCP24: "I put myself higher than what she is. I will show her that I am older than her and I look after her and not her look after me. I speak firmly to her, and I go into that mood where I ignore her and she also goes into that buzz and we leave each other alone. Then later, I will speak to her and tell her that she was wrong."*
>
> *PCP25: "Hy het anger outburst. Hy breek die vensters en gooi die vullisdromme om. Maar ek weet hoe om vir hom te manage. Ek wag tot hy kalm is dan na n tyd, ek gaan praat met hom in n kalm way. Ek sal vir hom se jy is die kind, en ek is die ma – jy sal nie met my so praat nie."*
>
> *(He has anger outbursts. He breaks the windows and overturns the rubbish bins. However, I know how to manage him. I wait until he is calm. Then I will talk with him in a calm way. I will tell him 'You are my child, and I am the mom-you will not speak to me like that.)*

One participant referred to making her selfcare a priority: -

> *PCP14: "I just have to take care of myself - that energy. I like a Spa Day, like going for a massage every 3 months."*

Three participants described how they have embraced their role as caregivers.

> *PCP08: "They have a mind of their own and we need to be patient with them. We need to be accepting of people that are different – what do we call different? There is nothing wrong with them – they are God's people as they are your way to Heaven. They are special people."*
>
> *PCP14: "There were a lot of challenges in the beginning. I learnt a lot as I got older, but now it's like a daily thing. It is part of my life. I don't call it a challenge. I love him so much!"*
>
> *PCP17: "You know what! There must be an explanation, scientifically. But is it going to change your situation? Nooo! How do you deal with it? Accept. How best can you make the situation and then move on. The same Person that gave you…is going to sort it out. That's how I look at it."*

One participant believes in acting as her children's advocate. She fought for her child to be accepted in a special school and, furthermore, believes that the Government should terminate the disability grant and should, instead, provide employment for persons with ID like her adult children with ID:

> *PCP17: "I went to toyi-toyi in Pinelands at the Department of Education. I fought for my child to be accepted at a special school … Do you need to read and write to collect rubbish bins? Who is challenging Governments? I want to tell the Government: Keep your disability grant; give my children a job! I went to the ward councilor and said to her 'What are you doing? How many people with disabilities are sitting at home, and yet people with Matric are picking up rubbish bins.' I wish people can see the light."*

Three participants told of their efforts to empower their children with ID. One participant described how she taught the person with ID to use public transport independently. Two participants indicated their resourcefulness. Their verbatim quotes are given next:

> *PCP08: "I asked the neighbour when he works cars to include him, so he will pass this or he will pass that (spanner, etc.), and he likes helping with cars. It keeps him busy rather than focusing on kids that tease him."*
>
> *PCP17: "We can discuss things all the time, even watching TV. I use every opportunity to educate my kids."*
>
> *PCP24: "I try my utmost best to show her things – like how to get to hospital – like you get off there. I am not going to live forever. I am now doing research to find more things for her to do because I do not want her to become idle. You cannot hold onto someone like her. You must allow her to explore."*

These findings are relevant as literature indicates that the more resilient the caregivers are the more, they will be an active part of their children's rehabilitation (Rajan et al., 2018:297-306. Caregiver's locus of control greatly impacts their resiliency. Professionals need to help parents to develop an internal locus to improve their resilience. An internal locus of control served as a protective mechanism against their stress associated with raising a child with disability (Rajan et al., 2018:297-306). The strength-based approach guides the researcher in a deliberate planned and sustained use of strengths that promotes resilience as opposed to deficits (Pulla, 2017:99-100; Hammond, 2010:6). The desired outcome of strength-based approach is resilience building (Hammond, 2010:6).

7.4 SUMMARY

This chapter has presented the findings derived from interviews with 25 informal caregivers of people with intellectual disabilities who took part in Phase one, the qualitative phase of the research. The findings reveal that they were mostly females, with 57% being lone caregivers, while 43% were supported by partners or other family members. Furthermore, these results also correlate with literature which indicates that parents of people with ID report higher than average rates of stress, depression and anxiety.

The data analysis suggests that a lack of understanding of intellectual disability and the absence of psychoeducation for caregivers is a contributing factor to caregiver distress. Due to a lack of information, they have to derive their own conclusions as to the cause of their loved one's intellectual disability. Some indicated that they believed their family had been cursed. Others admitted to being in denial of the diagnosis. Many commented that the limited information received from professionals in the field forced them to do their own research. Many participants mentioned that, when their child was identified as having an intellectual disability, while still at a mainstream school, the latter had no information or care plan for their child moving forward. Many caregivers also did not receive psychoeducation regarding the management of troublesome behaviour in a person with intellectual disability and resorted to desperate measures to manage such behaviour.

The data analysis also highlighted the socio-economic impact on the caregivers who described the financial constraints of being a caregiver. Many expressed concerns about future care and provision for the person with intellectual disability.

Experiences of barriers to accessing resources were also mentioned. The safety risk implications of a non-friendly home for persons with disability were also identified.

Some caregivers showed resilience and resourcefulness in their caregiving. They believed in being their child's advocate, in taking care of themselves and creating opportunities for learning and development for the person with ID. Some believed that their role of caregiving was a special gift bestowed on them from a higher Being and they find comfort in this belief.

The next Chapter outlines the psychoeducational programme developed out of the in-depth literature review and qualitative empirical data.

CHAPTER 8

PSYCHOEDUCATIONAL PROGRAMME FOR CAREGIVERS OF PEOPLE WITH INTELLECTUAL DISABILITY

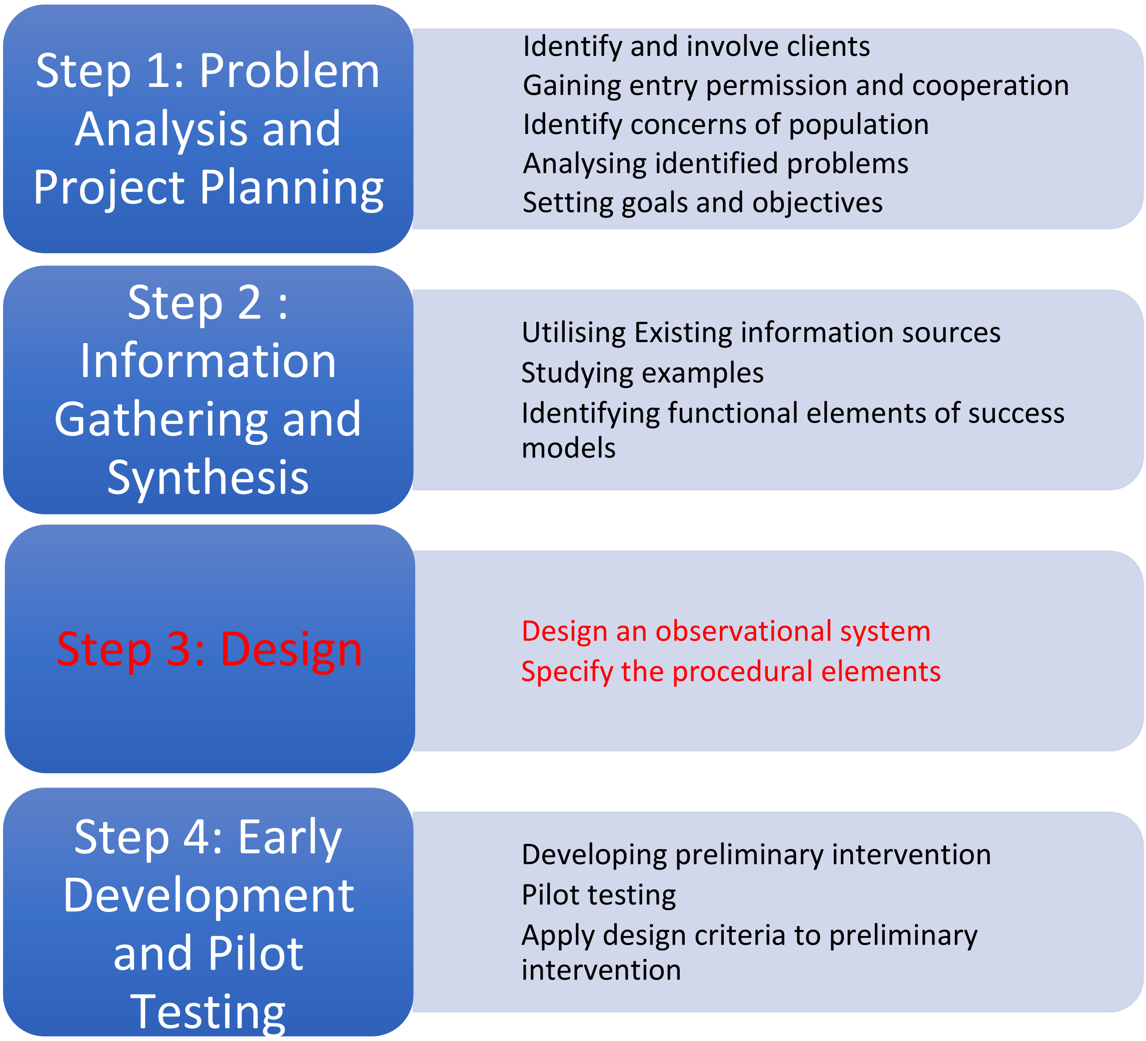


Figure 16: Graphic representation of the phases of the intervention research. Adapted from Rothman and Thomas (1994:28); Fraser and Galinsky (2010:459-466).

8.1 Introduction

According to the literature, 98% of people living with intellectual disability are being taken care of by caregivers in the Western Cape (McKenzie et al., 2016:45-54). These caregivers often sacrifice their own aspirations in devotion to the person living with intellectual disability, with little to no monetary reward and recognition.

Often, they neglect themselves emotionally, as well as physically, and this can lead to burnout and depression (Kench, 2016:163; Coetzee, 2016:157; Perkins, 2009:11). The researcher sought to understand the issues that lead to caregiver burnout and depression and to develop a solution with the help of a targeted psychoeducational programme for caregivers.

This chapter will outline the psychoeducational programme developed out of the in-depth literature review and qualitative empirical data.

8.2 Programme Design

In this phase, a psychoeducational manual on caregiving for people with intellectual disability was designed as informed by the data (Fraser & Galinsky, 2010:459-466). The manual was composed of session-by-session content: each session with its goals, the essential content of each session, and activities that reinforce the content (Fraser & Galinsky, 2010:459-466).

Once the first draft had been developed, experts within the field of intellectual disability in the Western Cape reviewed it. Amongst those experts were persons from the Division of Intellectual Disability in the Department of Psychiatry at the University of Cape Town. The researcher reworked the manual until all the comments and recommendations of the reviewers had been addressed (Fraser & Galinsky, 2010:459-466; De Vos & Strydom, 2011:482-483).

8.3 The Outline of the Psychoeducational Programme for Caregivers of People with Intellectual Disability

Table 14: Overview of the psychoeducational programme for people with intellectual disability

Module	Sessions	Content
A. Psychoeducation of the caregiver regarding ID	Understanding intellectual disability	Definition of ID
		The care needs of people with ID
		The importance of medication adherence
		Caregivers' possible cognitive distortions of ID
B. Psychosocial impact on the individual caregiver	The resilient caregiver	Caregiver coping strategies
		Daily challenges of the caregiver
		Developing resilience
		Self-care exercises
		Emotional acceptance and commitment therapy
		The 'good enough' caregiver

		Developing an internal locus of control
C. Strengthening the family unit	The empowered family	Managing behaviour that challenges
		Identifying behaviour that challenge
		Causes of behaviour that challenges
		How to respond to behaviour that challenges
		Managing family conflict
		House safety skills
D. Accessing and development of resources	Caregiver toolkit	Identify your support team.
		Train your team.
		The importance of record-keeping

8.3.1 Module A: Psychoeducation of the Caregiver on Intellectual Disability

Session 1: Understanding intellectual disability

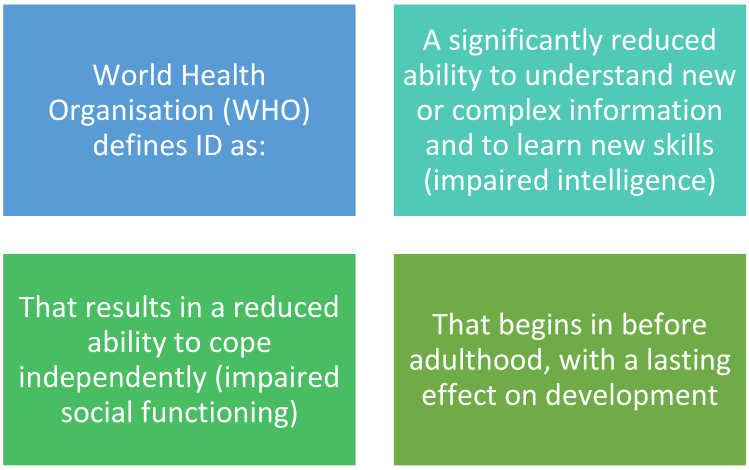
8.3.1.1 Goal of this module

This module aims to address any misconception caregivers may have, by discussing the definition of intellectual disability and possible cognitive distortions of it that the caregiver may have.

The module also addresses the care needs of people with intellectual disability and the importance of medication adherence.

Session 1.1 Definition of intellectual disability

The formal caregivers are able to explore and clarify their understanding of the definition of intellectual disability.



World Health Organisation (WHO) defines ID as:

A significantly reduced ability to understand new or complex information and to learn new skills (impaired intelligence)

That results in a reduced ability to cope independently (impaired social functioning)

That begins in before adulthood, with a lasting effect on development

Figure 17:Definition of intellectual disability (WHO [sa])

People living with intellectual disability have a significantly reduced ability to understand new or complex information and to learn and apply new skills (World Health Organisation (WHO) [s.a.]). This results in a reduced ability to cope independently (impaired social functioning) and begins before adulthood with a lasting effect on further development (WHO [s.a.]).

People with intellectual disability will need lifelong support, and most often this responsibility falls on their families (McKenzie et al., 2013:1750).

Session 1.2 The care needs of people with Intellectual disability

Table 15: Care needs of people with ID

Developmental	Scholastic skills Occupational therapy Physiotherapy Life skills
Pharmacological Needs	Adherence Monitoring 'Outpatients' follow-ups
Emotional Needs	Family relationships Informed family members Home environment
Environmental	Safety from physical, sexual, verbal abuse Community participation
Assistance in Daily Living	Grooming Feeding Incontinence Physio-aid, e.g., wheelchair
Financial	Application for disability grant Application for ID documents Importance of Final Will

Session 1.3 The importance of medication adherence

It is important that caregivers collaborate with the rest of the household to ensure that the person with ID ingests the medication as prescribed to manage medical conditions, such as a physical pain that person with ID may not be able to articulate fully (Slaggert

& Jongsma, 2015:118). It's important to note that not all persons with ID are necessarily on medication and if they are, medication should be adhered to as prescribed.

The following suggestions will enable medication adherence of the person with intellectual disability (Slaggert & Jongsma, 2015:118): -

Ensuring medication adherence

- Assess the person's ability to take personal responsibility for adhering to the medication as prescribed.
- Supervise the adherence to taking medications as prescribed.
- Request the pharmacist to provide information to the person with intellectual disability regarding the importance of taking the medication as prescribed.
- Introduce the person into a peer support group where they can discuss their physical or mental concerns.
- Cooperate with psychological assessments to identify the reason for (or barriers which cause) resistance to taking the medication as prescribed.

Session 1.4. Possible cognitive distortions

Willner (2009:416-419), as well as Yurica and DiTomasso (2005:117-122), explain some common cognitive distortions that caregivers of people with intellectual disability may present with.

Table 16: Cognitive distortions

Cognitive distortions	Description
Mind reading	Caregivers assume that they know what the person with intellectual disability is thinking.

Reading the future	Caregivers may predict the future by expecting that the worst will happen.
Catastrophising	Caregivers may believe that anything that can or will happen is going to be so disastrous that they will not be able to overcome it.
Labelling	Caregivers may see blanket negative traits both within themselves and possibly within the person living with intellectual disability.
Negative filter	They may see many more of the negatives and rarely notice the positives or strengths of a situation.
Dichotomous thinking	They view events, or people, in all-or-nothing terms.
Personalising	Caregivers may blame themselves disproportionately much for negative events and fail to see that the person with intellectual disability may hold some responsibility as well.
Emotional reasoning	They allow their feelings to guide their interpretation of reality. For example, "I feel stupid; so I must be stupid."

Distorted thinking gives rise to caregiver stress, which, in turn, increases the likelihood that the parent or caregiver will engage in maladaptive parenting behaviours (Kennedy, 2012:52).

Cognitive reappraisal is about reframing our thoughts (Wright et al., 2006:173-197; Harris, 2019:310-313).

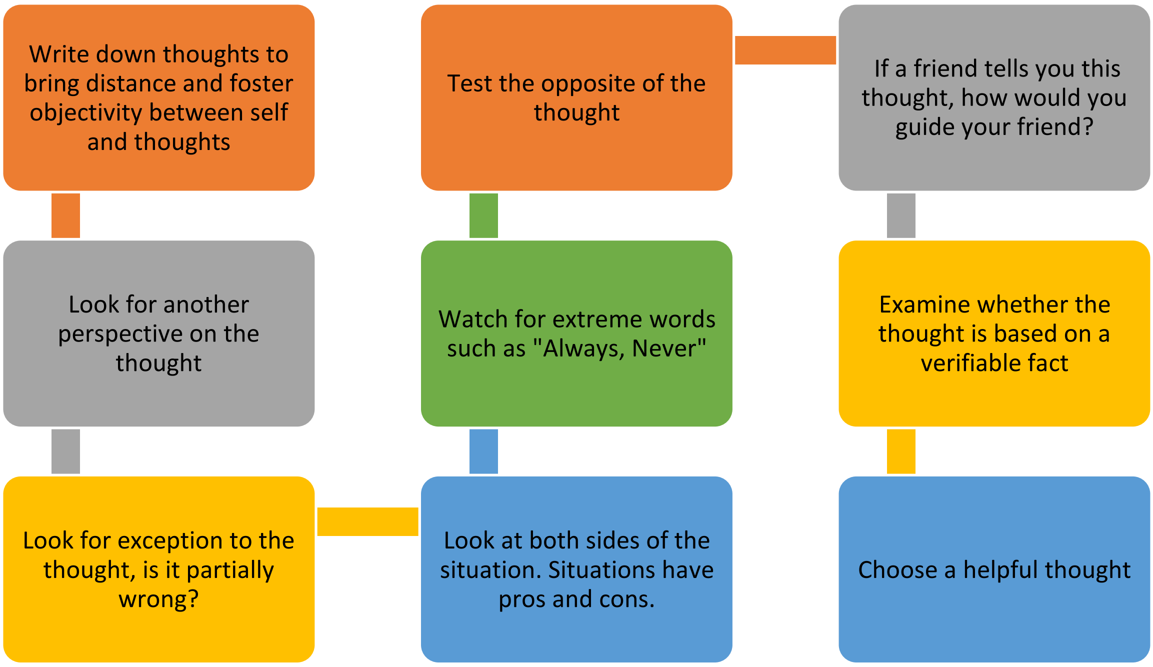


Figure 18: Graphic representation on how to cultivate rational thoughts. Adapted from Wright et al. (2006:173 -197); Harris, (2019:310-313)

Reframing an unhelpful thought into a rational thought (Wright et al., 2006:173 -197; Harris, 2019:310-313)

- Write down thoughts to create distance and foster objectivity between self and thoughts.
- Look for another perspective on the thought.
- Look for exceptions to the thought: Is it partially wrong?
- Assess both sides of the situation. All situations have advantages and disadvantages.
- Examine evidence for your thought: Is the thought truthful?
- Evaluate whether the thought is in your best interest and choose helpful thoughts.

8.3.2 Model B. Psychosocial Impact on the individual Caregiver

Session 2: The resilient caregiver

8.3.2.1 Goal of this module

This model aims to address the various psychosocial issues that impact the caregiver. Daily challenges are discussed, as well as caregiver coping strategies. The caregivers also have the opportunity to learn about the development of resilience in addition to self-care exercises. The researcher used the strength-based approach which improves self-care abilities and self-esteem (Pulla, 2017:100). The caregivers are also introduced to the concept of emotional acceptance and commitment therapy, as well as what to strive for as a 'good enough' caregiver. Furthermore, they practise the development of an internal locus of control.

Session 2.1. Caregiver coping strategies

Caregiving can be very strenuous, and if caregivers neglect to take care of themselves, they could be prone to depression and anxiety (Coetzee, 2016:157). In this section, the caregivers receive psychoeducation on the different coping styles (Gona et al., 2011:179-181; Panicker & Ramesh, 2019:1-14; Ginsburg & Jablow, 2020:262; Auriemma, Ding, Zhang, Rabinowitz, Shen & Lantier-Galatas, 2022:51-63).

They learn and discuss the difference between a problem-focused coping style and an emotion-focused coping style.

Problem-focused coping style: -

This entails using everyday problem-solving skills to engage the problem actively by:-

- reaching out for help for your child, e.g., psychologist and/or doctor,
- reaching out for help for yourself,
- engaging in bibliotherapy (reading and gaining knowledge),
- establishing a routine for self and for the person being cared for,
- planning for events – prepare individual, be prepared, and
- mobilising respite care.

Emotion-focused coping style: -

According to McAdam (2021), this entails making efforts to change or reduce the negative emotions associated with stress, such as: -

- personal faith and belief system,

- self-pampering (bubble bath, tea with honey),
- support group, talk to someone,
- regular exercise, e.g., walking,
- ‘mind dumping’ (writing down emotions),
- breathing exercises,
- crying,
- finding ways to have fun, e.g., watching your favourite TV show, and
- doing locus-of-control exercise.

Psychoeducation on coping styles includes discussing some of the more maladaptive coping mechanisms (Ginsburg & Jablow, 2020:262):

- substances abuse, e.g., cigarettes, alcohol,
- screaming, lashing out, being impatient, or
- bullying the individual with intellectual disability; or other members of household.

Session 2.2. Daily challenges of the caregiver

Literature indicates that caregivers of people with intellectual disabilities overwhelmingly report a lack of social support (Dada et al., 2020: 6644; Ugwuanyi et al., 2022:2).

This section affirms the caregiver’s circumstances by discussing some of the challenges they face and ways to cope with them.

Some of the challenges that will be discussed are: -

- community stigmatisation,
- isolation (cannot go anywhere),
- lack of support by family and friends,
- physical exhaustion,
- financial strain (give up employment, services are expensive), and
- worry about the safety of the child and its future.

Session 2.3 Developing resilience

Resilience has been found to be the key factor of successful adaptation of caregivers of people with ID (McConnell & Savage, 2015:100; Lafferty et al., 2016:15).

Figure 19: Graphical Depiction of the 7C Model of Resilience (Ginsburg & Jablow, 2020:39-48).

The researcher used the 7C model of resilience as a framework for building resilience in caregivers of the persons with ID (Ginsburg & Jablow, 2020:39-48).

The 7C model of resilience is a set of building blocks for creating resilience.

Table 17: The 7C Model of Resilience (Ginsburg & Jablow, 2020:39-48)

Building Block	***7C model of resilience***
• ***Competence***	This building block deals with handling a situation or task effectively. It refers to specific skills or a personal passion regarding a topic, such as intellectual disability.

• ***Confidence***	Caregivers need to believe in their own abilities. It is about perceiving challenging situations as opportunities for growth and learning.
• ***Coping***	Coping refers to skills and self-confidence when dealing with stressful situations. It is about the caregiver's developed ability to overcome adversities in life.
• ***Control***	This is knowing that one has some control over one's life and environment. Caregivers' decisions and actions may have an influence on the outcome. Control also refers to taking personal responsibility for actions and decisions made.
• ***Character***	Character is shaped by a solid set of personal morals and values, as well as having a caring attitude towards others.
• ***Connection***	This is about knowing that the caregiver is not alone in challenging situations, which creates a sense of security. Having close ties to family, a social group, and a sense of community, are foundations for developing creative solutions.
• ***Contribution***	This is about the caregiver's insight into the importance of their personal contribution to their world. The experience of helping others makes it easier to request assistance when one is in need.

Session 2.4 Self-care exercises

As discussed in the notes on Session 2.1, aspects of self-care incorporate both problem-focused coping styles and emotion-focused coping styles. The caregivers are provided some examples of self-care exercises, reflected in the manual. These examples of self-care also offer points for discussion in terms of which self-care exercises they already make use of and which they wish to implement after the training: -

- reaching out for help for yourself,
- engaging in bibliotherapy (reading and gaining knowledge),
- establishing a routine for self and for the person being cared for,
- self-pampering (bubble bath, tea with honey),
- engaging in bibliotherapy (reading and gaining knowledge),
- support group (talk to someone),
- personal faith and belief system,
- regular exercise (e.g., walking),
- establish a routine for self and for the person you care for,
- plan for events – prepare individual, be prepared
- find ways to have fun (e.g., watching your favourite TV show),
- doing locus of control exercise (McAdam, 2021) and
- respite care.

Session 2.5 Emotional acceptance and mindfulness

In this section, the caregivers are provided psychoeducation on the meaning of emotional acceptance and commitment therapy as it relates to their daily challenges. Leoni et al. (2016:59-73) state that interventions for formal caregivers should also include emotional acceptance and commitment therapy as it has shown to reduce occupational stress, even when there has been no change in the challenges of the workplace.

Cognitive and emotion focused therapy, as well as mindfulness, has been used to assist parents of persons with intellectual disabilities with the reducing off depression (Ugwuanyi et al., 2022:3). Using mindfulness as well as emotional acceptance and commitment therapy as part of the intervention has been found to have a positive psychological impact on both the person with intellectual disability, as well as his or her caregiver (Singh et.al., 2020:99-111; Leoni et al., 2016:59-73). The caregivers would also be provided with some affirmations to repeat to themselves that may assist them emotionally when challenges arise.

The caregivers are taken through a simplified explanation of ACT (Harris, 2019:252):-

- The foundation of ACT is a willingness to feel emotions.
- Drop the struggle with your emotions.
- Emotions prevent you from living the life you value.
- Learn to acknowledge feeling negative emotions so that they do not have the power to control you and decide how you behave.
- Our decisions should be based on our values and not our emotions.
- Do not force anxiety to disappear; this just locks you in a struggle with anxiety.
- Make space for negative feelings, such as anxiety. Do not judge yourself for having a negative emotion.
- Acceptance is a present-moment experience.
- Put down the sword and walk away from the fight.
- Start where you are at.

The researcher developed caregiver affirmations based on the philosophy of the acceptance and commitment therapy.

Affirmations

- I am allowed to feel this.
- It’s ok to feel this.
- These feelings cannot hurt me.
- I am noticing that I am having the thought of wanting to… (when having a negative thought).
- My behaviour is based on my values not my emotions.

Session 2.6 The ‘good enough’ caregiver

As discussed in Section 4.3.2.6, caregivers of people with ID often strive to be perfect in their caregiver obligations. They have the tendency and desire to want to do everything for the person with ID (Young, 2012:11). It is best practice for professional support to caregivers to encourage them to strive for being ‘good enough’ (Young, 2012:11).

Flood (2019:3) explains that the ‘good enough’ caregiver stands in contrast to the “perfect” caregiver and acknowledges that it is not possible to be perfect in caregiving.

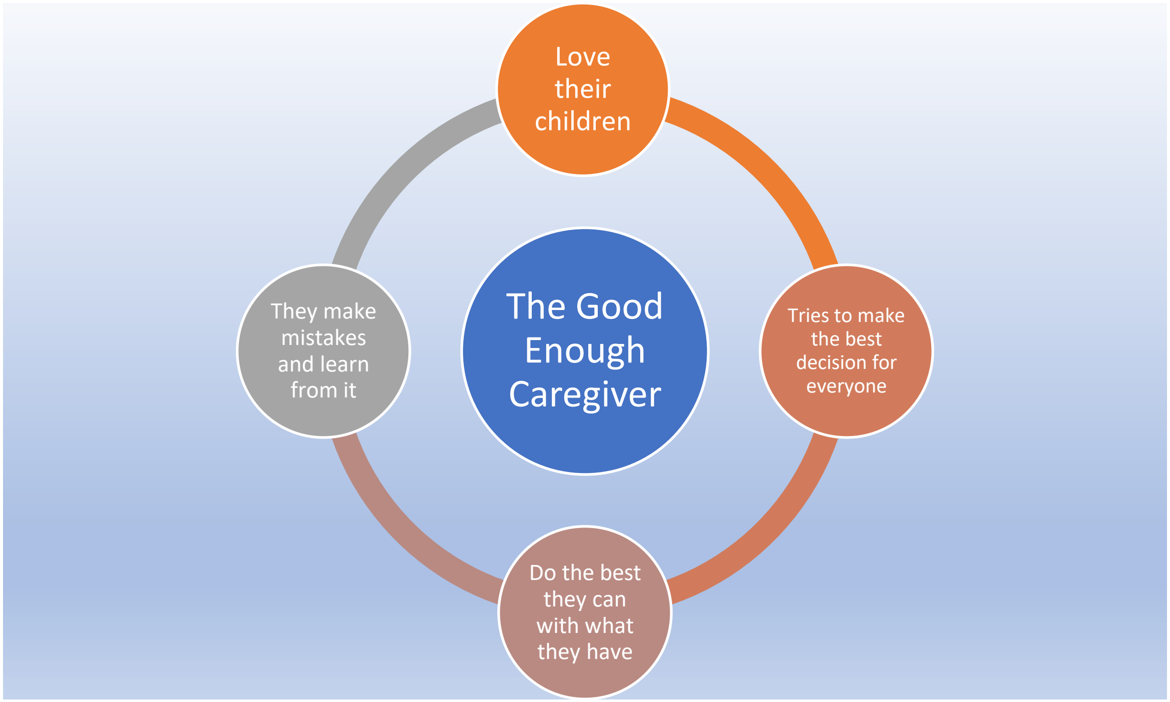


Figure 20: Graphical depiction of a ‘good enough’ caregiver. Adapted from Young (2012:11-12)

Session 2.7. Developing an internal locus of control

This activity educates the caregivers to develop an understanding of the dichotomy of control.

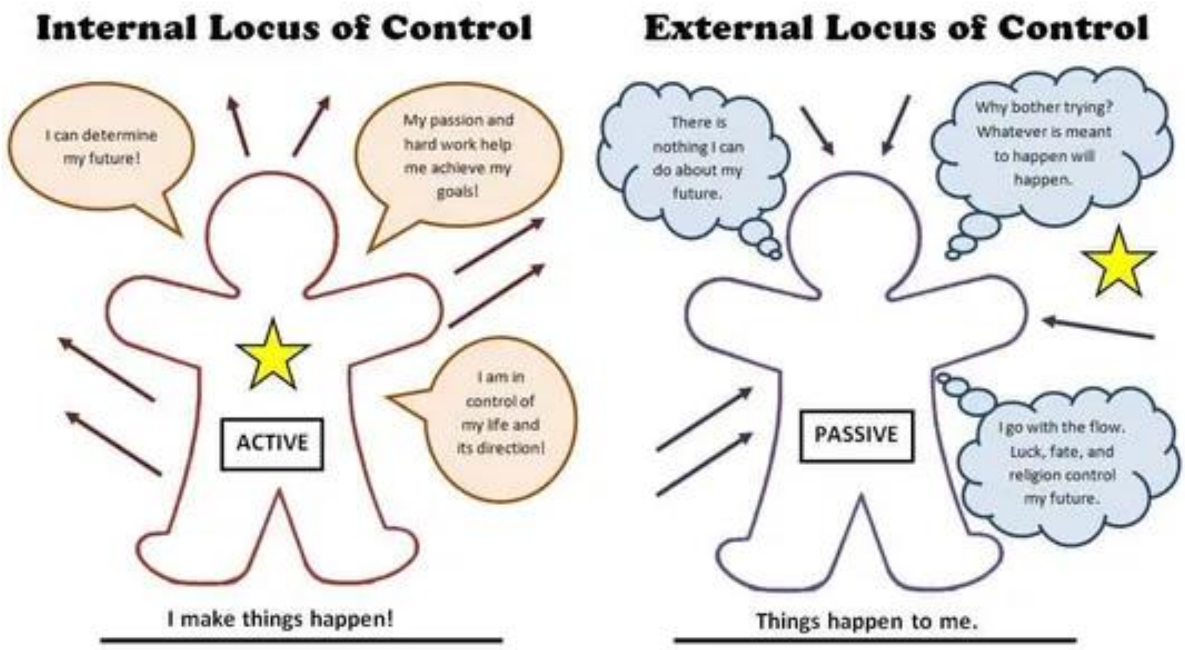


Figure 21: Illustration of internal vs external locus of control: Google Images

The Locus of Control Exercise

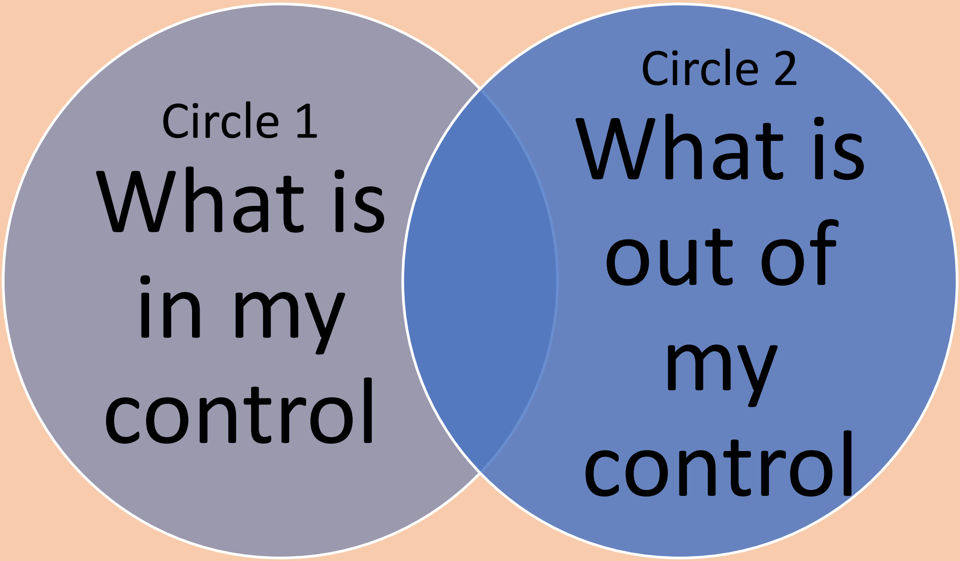
As discussed in Section 5.3.2.7, understanding the dichotomy of control is what distinguishes a resilient and empowered individual (Hammond, 2010:6; Harris, 2019:102). The skill is to determine what we can control and what we are unable to control.

The programme includes a short and easy exercise to help caregivers decrease anxiety and increase a sense of safety and calm. They will be taught to direct their efforts and actions into their realm of influence and control, namely into the process of caregiving. They are not to emphasise obsess about the outcome - which is beyond their control (McAdam, 2021).

The exercise can be used for any challenging situation, e.g., fears about the future, family conflict problems, marital problems, financial problems, difficult colleagues, etc. The exercise proceeds in the following manner:

The caregivers are split into groups of ten. Each group chooses a challenging situation which they have dealt with in the workplace or in one of the respondents' personal lives, and then selects one person from the group to present how he or she would manage the problem using the locus of control exercise (McAdam, 2021).

Drawing it on paper clarifies their role and what they can or cannot control (McAdam, 2021).



Process **Outcome**

Directions for the locus of control exercise

Step 1. Draw two intersecting circles.

Step 2. Write the problem at the top of the page.

Step 3. In Circle 1, write down what is out of your control.

THINGS THAT ARE OUT OF MY CONTROL:

For Example:

- My child's diagnosis
- Whether my child is motivated or not
- I cannot control the actions and choices of others.
- I cannot control other people's thoughts.

- I cannot control the outcome of a situation.
- Whether my child will be accepted in the workshop or not
- I cannot control the |Government.

Step 4. Within Circle 2 [on the right-hand side], write down what is in your control.

THINGS THAT ARE WITHIN MY CONTROL:

For example: -

- I can control what I say.
- I can choose my behaviour.
- I can inform myself.
- I choose to eat healthy meals.
- I control my boundaries.
- I can control the process of improving myself.

Step 5: In the area where the circles intersect, write a list of aspects that are under your influence. This circle can *influence* the actions of others but cannot *control* people's actions. It can *influence* the outcome but not *control* it.

THINGS THAT ARE WITHIN MY REALM OF INFLUENCE

For example: -

- The boundaries I set
- My behaviour that I model
- How I use social media
- Educating others
- The requests I make
- Having important conversations with people who could possibly assist

Figure 22: Locus of Control: Adapted from McAdam (2021) Locus of Control: Quick Coping Skill for Anxiety.

8.3.3 Module C: Strengthening the Family Unit

Session 3: The empowered family

8.3.3.1 Goal of this module

This module aims to strengthen the family unit of the caregiver. Low levels of family support are associated with low resilience in caregivers of persons with intellectual disability (Lafferty et al., 2016:15). Having strong familial relationships is considered a key protective factor in maintaining caregiver resilience, particularly as families can pool their resources, maintain good communication, stay connected and share caregiving responsibilities (Lafferty et al., 2016:15). Furthermore, this module aims to empower the caregiver with the skills to manage any challenging behaviour of the person with intellectual disability.

Session 3.1 Managing behaviour that challenges

An empowered family consists of informed family members. It is important that a psychoeducational plan for caregivers should have a responsive plan for managing challenging behaviour of people with intellectual disability (Leoni et al., 2016:59-73). This session is about acknowledging, by means of case discussions, the difficult positions in which caregivers often find themselves as they attempt to manage problematic behaviour. The next four sessions provide tools for managing challenging behaviour in people with ID.

Session 3.2 Identifying behaviour that challenges

Behaviour that challenges is socially unacceptable behaviour that can cause harm to self and others. Consequently, such behaviour can cause an individual to be excluded from community facilities. When identifying problematic behaviour, factors such as abnormal intensity, frequency or duration, are also considered.

Some examples of what would be considered problematic behaviour, as recorded by Newcomb and Hagopian (2018:96-109) and Deutsch and Burket (2021:110017) are given below: -

- The use of foul language
- Physical aggression
- Being disruptive
- Destroying of property
- Inappropriate sexualized behaviour
- Screaming and repeated crying
- Hurting of self (head banging etc.)
- Repetitive stereotypic behaviours
- Hyperactivity

Session 3.3. Causes of behaviour that challenges

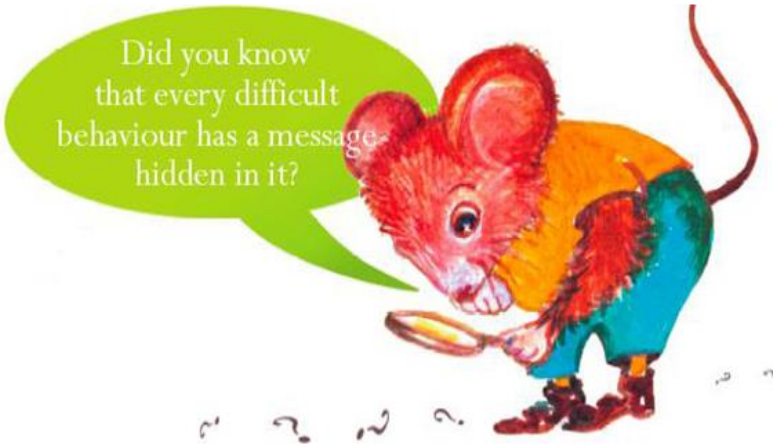


Figure 23: Illustration of "Every difficult behaviour has a hidden message." (Google Images)

Every problematic behaviour has a message hidden in it. Causes of challenging behaviour can be biological, psychological or social factors. It is important for the caregiver to investigate the cause of the challenging behaviour to address it.

According to Koritsas and Iacono (2012:243), some causes of problem behaviour are:-

- Unexpected change to daily routine
- Caregivers' disengagement
- Physical pain
- Wanting attention

- Poor coping skills and understanding
- Anxiety
- Wanting food, cigarettes, other objects
- Psychotic causes – needs psychiatric intervention
- Avoiding undesirable tasks
- Chemical dependency

Session 3.4. How to respond to behaviour that challenges

Ginsburg and Jablow (2020:358) advise that parents praise their children when they do well?) well and redirect them when they are not.

The caregivers are able to explore and discuss the following tools for managing unacceptable behaviour based on positive behavioural support intervention (Carr et al., 2002:1-13; Koritsas & Iacono, 2012:243; Singh et al., 2016:1-13; Kincaid et al., 2016:69-73; Bowring et al., 2020:193-203; Deutsch & Burket, 2021:110017).

Positive behavioural support intervention

- Prepare in advance any emerging changes to their routine.
- Cognitive reframing
- Emotional acceptance
- Identifying and minimising environmental triggers
- Medication not to be as a first response and in isolation of other interventions
- Psychological input/seeking professional assistance
- Consistency of care
- Boundary setting
- Give rewards for desirable behaviour - rewards based on individual’s likes and desires, e.g., watching TV.
- Praise when behaviour is appropriate - catch them doing well.
- No rewards following undesirable behaviour
- Low arousal approach - remaining calm during an outburst
- Sexuality awareness in people with intellectual disability

- Time out - providing space
- Ensure routine
- Tone of voice - no patronising
- Use demonstration and modelling as a learning tool.
- Accept and respect the person as an individual.
- Be patient and persevere.
- Try to build personal competency.
- Have a family household culture of acceptable behaviour.

Session 3.5. Managing family conflict

Slaggert and Jongsma (2015:80-90) explain that frequent arguing among family members of a person with intellectual disability could be due to:

- Lack of communication among the family members and the person with intellectual disability
- Unresolved grief, blame, guilt or denial among family members related to the person with intellectual disability condition
- Overly controlling or overly involved family members or caregivers
- Frustration of family members due to the lack of opportunities, support and resources available
- Separation among family members because of the anxiety related to the duties of caring for a person with intellectual disability
- Burnout of family members due to the stress of being the person with intellectual disability's primary caregiver
- Inability of elderly caregivers to continue caring for the person with ID and the lack of residential placements
- Discipline problems due to lack of caregiving skills

McKenzie (2016:70) emphasises the importance of considering the needs of the family during interventions as this impacts the intricate and intimate network of family support for the person with the intellectual disability.

To resolve family conflict and increase communication, as well as greater collaboration amongst family members, Slaggert and Jongsma (2015:90-94) make the following suggestions: -

- Family members should attend family therapy with a social worker, family counsellor or psychologist who is knowledgeable regarding intellectual disability. This would address the breakdown in communication and unresolved emotions amongst the family members, including siblings around the person with intellectual disability.
- Family members must become informed about person with ID’s condition and treatment plan.
- All individual family members should identify the family's strengths and capabilities - and identify highlights in their family history.
- All individual family members should draw up a list of endearing qualities of each other, including the person with intellectual disability.
- Families are encouraged to attend support groups for family members.
- Family members should utilise spiritual support and guidance.
- The family should determine short- and long-term family goals that foster the improved independence of the person with intellectual disability – and should identify steps towards facilitating these identified goals, set approximate target dates, and assign family members who will take active steps towards the goals.
- Family members should engage in social and recreational activities with the person with intellectual disability to keep the family relationships strong.
- Family members are to give each other permission to attend to themselves.
- Families should have the assertiveness to coordinate respite care and to request assistance from other family members or trusted neighbours and friends.
- It is understandable and acceptable to need a break from your family members at times.

Session 3.6 House safety skills

When a caregiver is overprotective of the person with ID this could lower the latter's household safety skills (Slaggert & Jongsma, 2015:100). To enhance the disability-friendliness of a home, it is important that the caregiver empowers the person with ID with an awareness of household safety skills, such as understanding the safe handling of poisons and household chemicals, as well as the safe use of matches and electrical appliances or natural gas (Slaggert & Jongsma, 2015:100). These skills are essential to protecting oneself from accidental injury.

- Caregivers must model the use of items, such as the kettle, and request the person with intellectual disability to imitate what is being modelled.
- Progress made in learning should be reinforced – perhaps with rewards.
- Have a safe place for matches.
- Instruct the person with intellectual disability concerning the need to avoid hot water and hot objects. Model safe handling of hot objects, such as an iron or heater.
- Observe the person with ID handling chemicals and matches and provide constructive feedback; also model how the chemicals are to be used. Quiz person with ID on his or her understanding of the dangers thereof.
- Have emergency phone numbers close by, such as on the fridge. Teach the person with intellectual disability how to dial those numbers.
- Provide pictures of burns or cuts and allow the person with intellectual disability to identify the injury.
- Remember to seek out lifelong learning opportunities.

8.3.4 Module D: Accessing and Development of Resources

Session 4: Caregiver toolkit

8.3.4.1 Goal of this module

The empirical data of the qualitative phase indicated that caregivers are often frustrated with the lack of resources for caregivers of and for people with ID. This module aims to equip caregivers with the skills of resourcefulness. Resources include internal strengths, such as resilience and resourcefulness (Moorkath et al., 2019:175; Young, 2012:22;). Resourcefulness in caregivers includes identifying resources and being assertive and proactive regarding their needs through record-keeping. This module also aims to assist the caregiver in enhancing his or her mindset regarding developing own resources by, for instance, personally training a support team.

Session 4.1 Identify the caregiver support team

Caregivers need to formularise a team of people on whom they could count when they need assistance. This includes family, friends, neighbours, professionals (doctors, advocates, social workers), etc.

The manual advises caregivers to draw up a list of their support team, which would include the following (Young, 2012:37; Lafferty et al., 2016:16): -

- Trusted family members
- Trusted neighbours
- Other caregivers and parents
- Home repair professionals
- Medical professionals
- Respite arrangements
- Mental health professionals
- South African Police
- Community health clinic (CHC)
- Western Cape Forum for Intellectual Disability (WCFID)

Session 4.2 Training the caregiver-support team

The manual advises the caregivers to train, and therefore empower, their support team regarding the following (Young, 2012:38): -

- Making a list of names of professionals who are experts on ID
- Encouraging the caregiver support team to read up on the diagnosis of intellectual disability

- Educating the support team on your research and what you need from them

Session 4.3 The importance of record-keeping

As discussed in Section 4.3.4.3, it is advisable that the caregiver has a ring binder with the following information that should be updated annually (Young, 2012:24): -

- Picture of the person with intellectual disability
- Height, weight, birthmarks
- Likes and dislikes
- Emergency contact numbers
- School and workshop information
- Name of medical professionals
- List of medication
- Environmental triggers
- Positive reinforcements to use
- Preferred activities

8.4 SUMMARY

The psychoeducational manual on caregiving of people with ID was designed as informed by the data collection phase of the research. The outline of the programme covers the psychoeducation of the caregiver on intellectual disability, the psychosocial impact on the individual caregiver, strengthening the family unit of the caregiver and assessing and developing resources.

The manual comprises session-by-session content; the goal of each session is highlighted, and the content is reinforced with activities and discussions.

Module A provides the definition of intellectual disability, the care needs of people with ID, the importance of medication adherence, and cognitive distortions.

Module B provides caregiver self-care and coping strategies, the challenges and impact of caregiving, developing resilience, the ‘good enough’ caregiver, and the development of an internal orientation to control. Acceptance and commitment therapy, which is the most dominant in the recent third wave of cognitive behavioural therapy, is also covered in Module B. Acceptance and commitment therapy is an evidence-based intervention which has been shown to reduce stress and burnout, as well as increase the well-being of caregivers of people with ID.

Model C focuses on strengthening the family unit by empowering the family to identify and establish the cause of challenging behaviour, as well as how to manage and respond to such behaviour. This module also includes managing family conflict and the development of household safety skills.

Module D deals with accessing and developing resources by identifying and training of a support network and emphasises the importance and content of record-keeping.

The next chapter provides the findings of the second phase, namely the quantitative research.

CHAPTER 9
EMPIRICAL FINDINGS OF QUANTITATIVE RESEARCH - SECOND PHASE

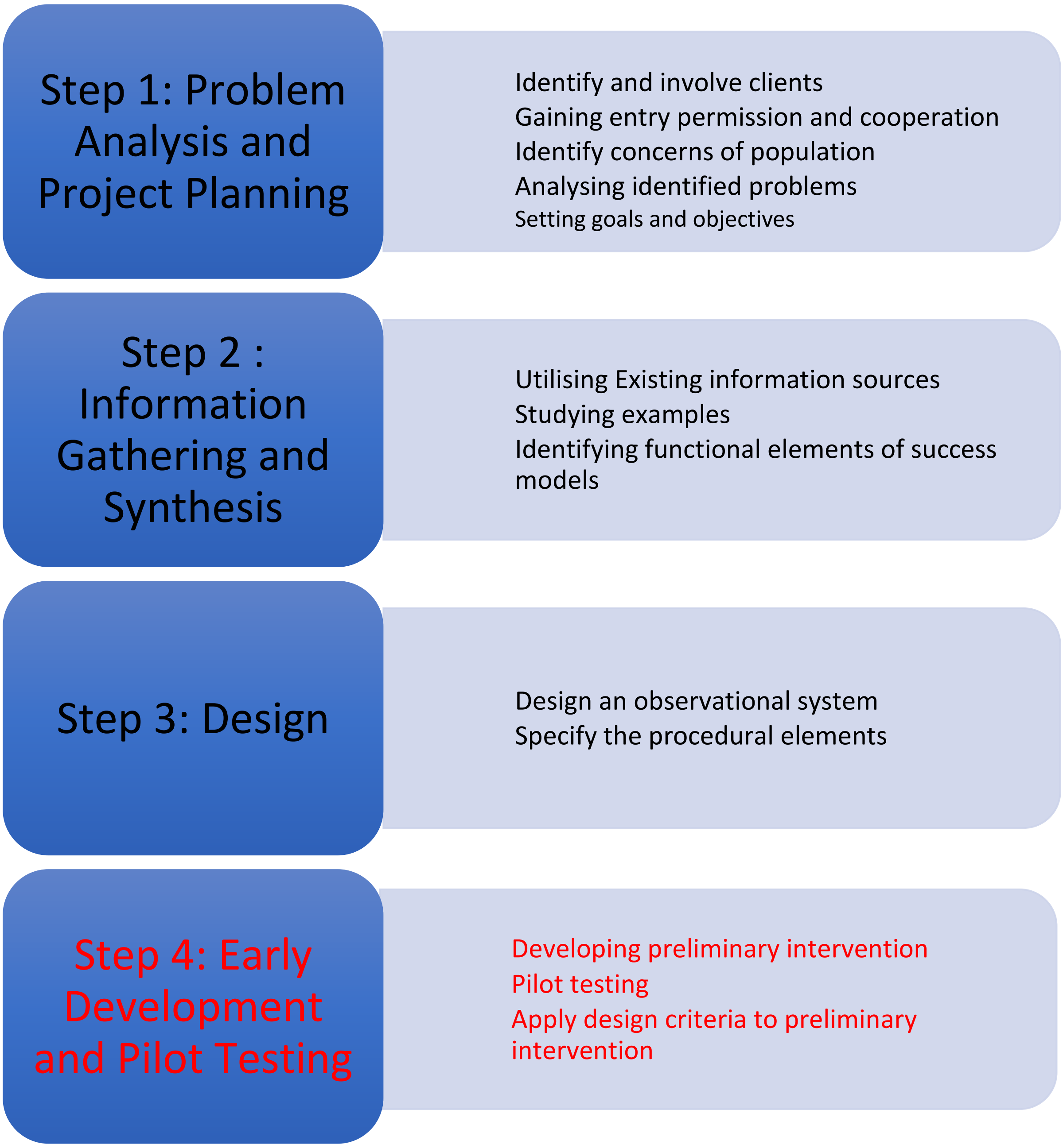


Figure 24: Graphic representation of the phases of the intervention research. Adapted from Rothman and Thomas (1994:28); Fraser and Galinsky (2010:459-466).

9.1 INTRODUCTION

Chapters 3, 4 and 5 provided a literature review on conceptualising intellectual disability, caregivers of people of intellectual disability, and the core elements of a psychoeducational programme. This literature background provided the underpinning of the study which was necessary to meet the research goal. The present research is a mixed-methods intervention study presented in two phases. The qualitative first phase was discussed in Chapter 7 and involved informal, unpaid caregivers. It played a major role in the development of the programme, which was then piloted in the second, and quantitative, phase.

Chapter 9 focuses on this second phase in which the programme was presented to the respondents - who were all formally employed caregivers - with a pre-test and a post-test questionnaire. Chapter 9 provides the empirical findings of this second phase of the study.

9.2. EMPIRICAL FINDINGS- SECOND PHASE (Quantitative)

In the following section, the researcher will provide a description of the research results. One hundred formally employed caregivers attended the full training course and completed both the pre- and post-tests. The empirical results are presented next.

9.2.1 Section A: DEMOGRAPHIC DETAILS OF THE RESPONDENTS

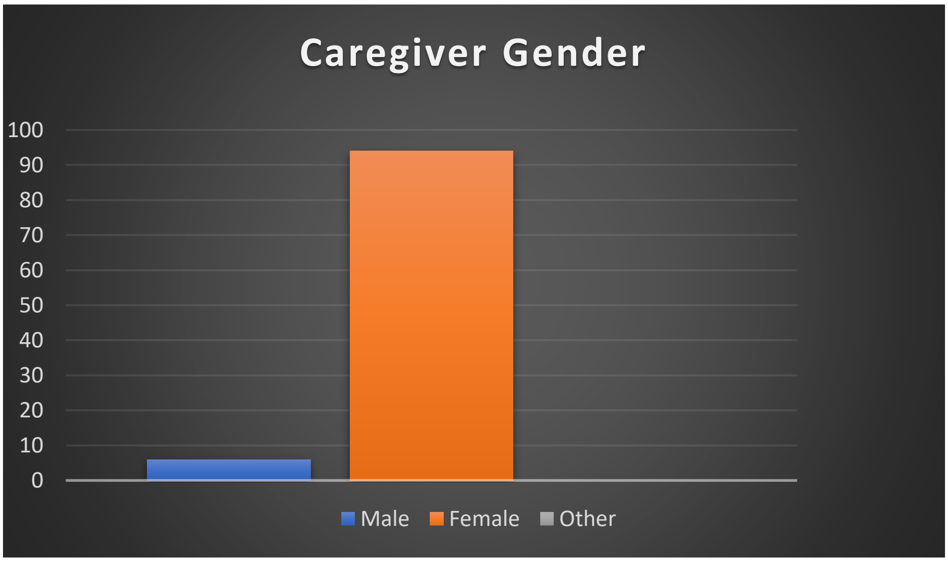


Figure 25: Gender

It was predominantly female caregivers (94%) who took part in the research training, and only 6% of the caregivers were men. These findings are consistent with literature which indicates that most caregivers of persons with intellectual disability are female (Mak & Cheung, 2008:543; Lafferty et al., 2016:13; McKenzie, 2016:67-78; Ezeonu et al., 2021).

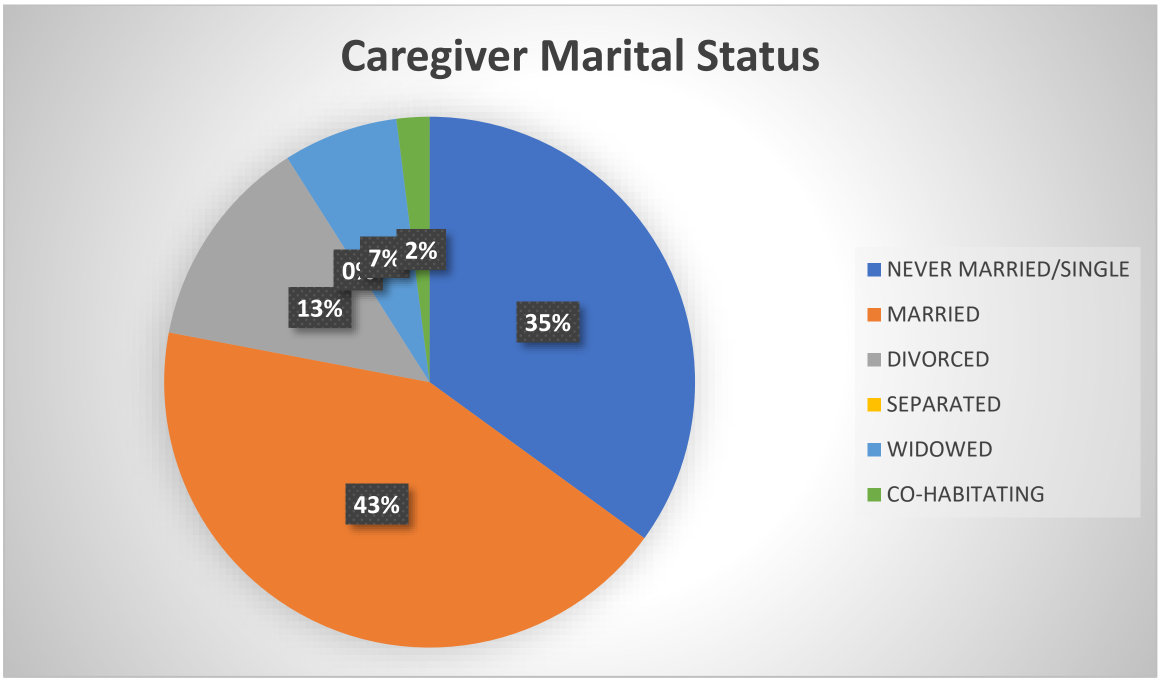


Figure 26: Marital

Of the caregiver-respondents, 45% had partners, which included those who were married (43%) and others who cohabitated (2%). Lone caregivers accounted for 55% of the respondents. These findings also confirm literature which reports that most caregivers of persons with intellectual disability are lone caregivers (Lafferty et al., 2016:13).

Note: These biographical data were captured and have been included here in order to provide the briefest sketch of the respondents' background and have no relevance to their experiences as caregivers of persons with intellectual disabilities.

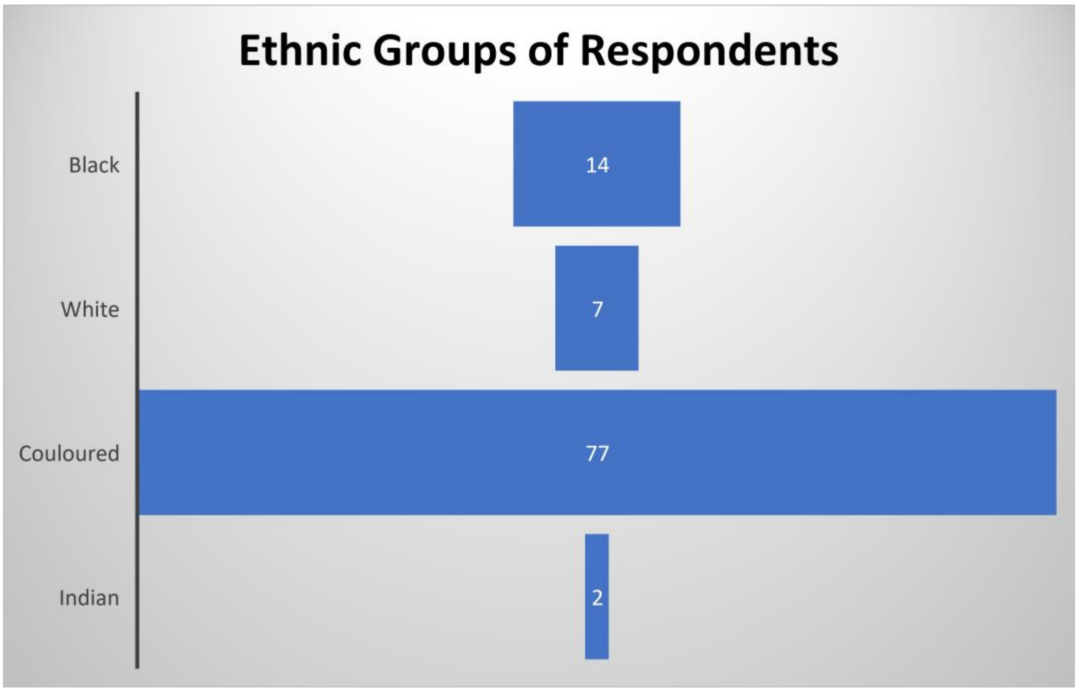


Figure 27: Ethnic Groups of Respondents

The cohort of respondents comprised the following ethnic groups: Coloureds (77%), Blacks (14%), Whites (7%) and Indians (2%). The literature does not clearly define the ethnic groups of caregivers of people with intellectual disability, neither their respective numbers. However, the literature does state that, in terms of socio-economic factors in the Western Cape, approximately 98% of people with intellectual disabilities are living with their families and caregivers in the community, and with an informal unpaid arrangement. The remaining 2%, predominantly from the Coloured and White culture rather than the Black culture, are living in residential group-home facilities being taken care of by formally paid caregivers (McKenzie et al., 2016:45-54).

The researcher is of the opinion that the 77% Coloured caregivers reflect the predominantly Coloured population of the Western Cape. In the entire country, the Coloured population comes to about 3,730,000 people of whom 85% reside in the Western Cape (*The Coloureds of Southern Africa*, 2008).

All attendees were employed at a workplace that renders services to people with intellectual disability as per the following table: -

Workplace	***Number of respondents***	***Percentage***
Group-home (residential),	45	45%
Protective workshop	1	1%
Day-care centre	11	11%
Education centre	39	39%
Other (not specified)	4	4%
Total	**N=100**	**100%**

Table 18: Place of employment

The following graph shows their various occupations: -

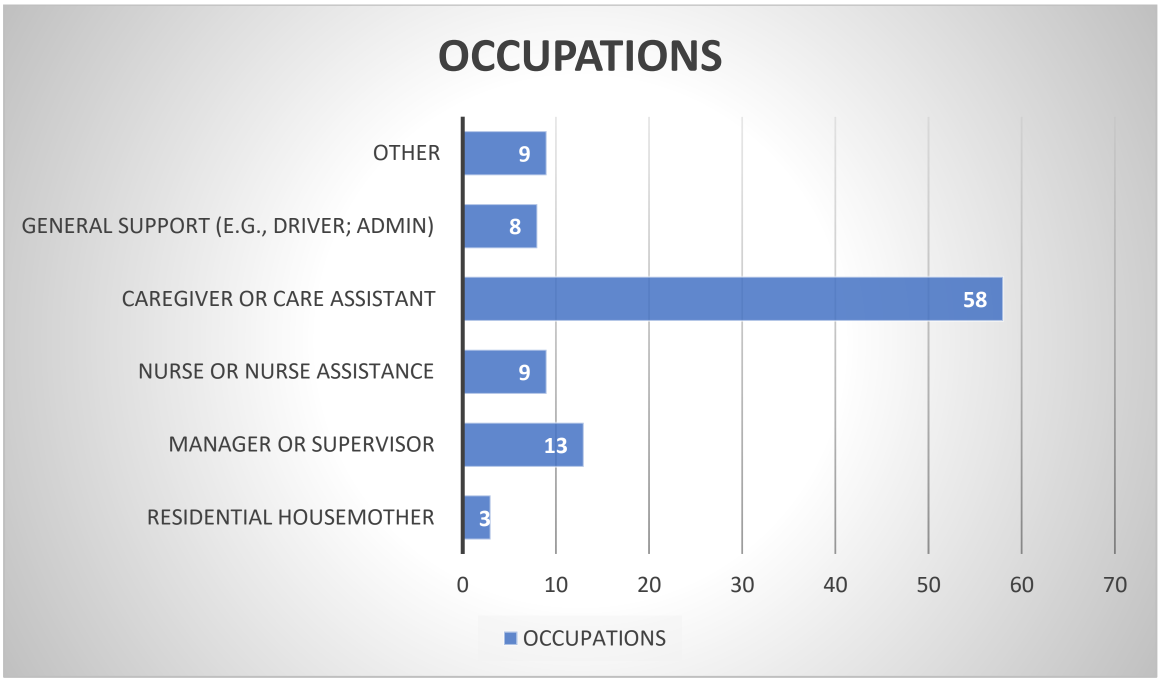


Figure 28: Occupations

The majority of the respondents were employed as caregivers or care assistants (58%), three were residential housemothers (3%), thirteen were managers and supervisors (13%), nine were employed as nurses or nurse assistants (9%), whilst eight were general support workers (8%), such as the driver of the bus, administrative staff and cleaners. Nine attendees (9%) indicated the option of ‘Other’, two of whom specified that they were an occupational therapist and a speech therapist; the rest did not specify.

For this study, all respondents, irrespective of their various occupations, are referred to as formal caregivers.

In the next section the caregivers were asked to indicate (tick the relevant box) whether they 'learned on the job' with no formal training relating to intellectual disability, had a caregiver qualification that included intellectual disability, or had a caregiver qualification that did not include this specific training. The questionnaire also offered the option of 'Other', which asked them to elaborate. The bar graph below summarises their responses.

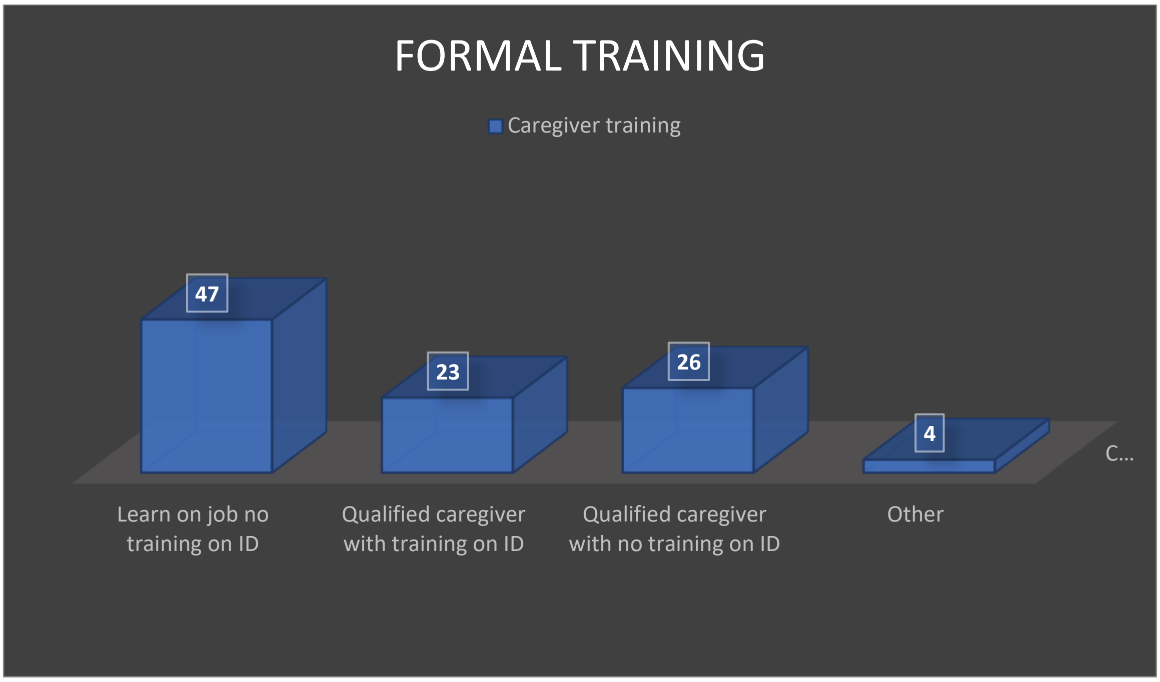


Figure 29: Formal training in caregiving and ID

Figure 29 shows that most of the respondents (47%) learned in the workplace with no formal caregiver training. Furthermore, they had no training in intellectual disability. Forty-nine respondents (49%) indicated having a formal qualification as caregiver; however, the qualification of 26 of them (26%) did not include intellectual disability. Therefore, 73% of the respondents had no training regarding intellectual disability.

Two indicated that they were a speech therapist and an occupational therapist, and the other two did not specify.

Table 18, Figure 28 and Figure 29 yield important research results which correspond with literature, namely that formal paid caregivers include care assistants and housemothers of residential homes for people with ID, supervisors in protective workshops for people with ID and nurses caring for people in small or large institutions (Coetzee, 2016:157-158, Kench, 2016:163). However, caregivers may or may not have formal qualifications in caregiving (Coetzee, 2016:157-158).

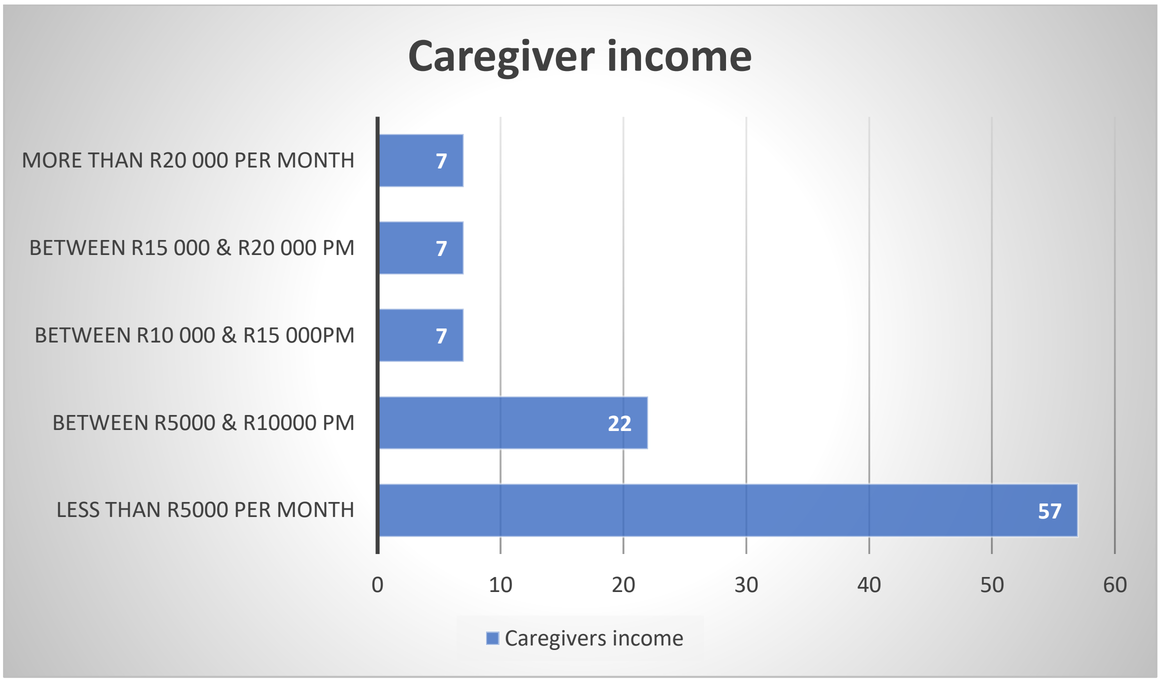


Figure 30: Caregiver income

Figure 30 shows that fifty-seven respondents (57%) earned less than R5000 per month. This correlates with Figure 28 showing that 58% of the respondents are employed as caregivers. It can therefore be deduced that, of the respondents, those who were employed as actual caregivers earned less than R5000 per month.

The researcher wishes to highlight the link between formal training and caregiver income and gender. Her findings coincide with the Statistics South Africa’s Report on Poverty Trends in South Africa (2017:19-111) which categorises people vulnerable to poverty. The report indicates that the predominant category of adults vulnerable to poverty includes females and those with no education. The present research results, therefore, reflect the poverty trends in South Africa.

In the next section, the caregivers were asked to indicate the health concerns they had at the time, which included problems, such as headaches, sleep problems, appetite problems, anxiety, depression, high blood pressure, high cholesterol, obesity, diabetes and coronary heart disease. Should they have none of these health concerns, they should indicate 'no health concerns'. Figure 31 is a summary of their answers.

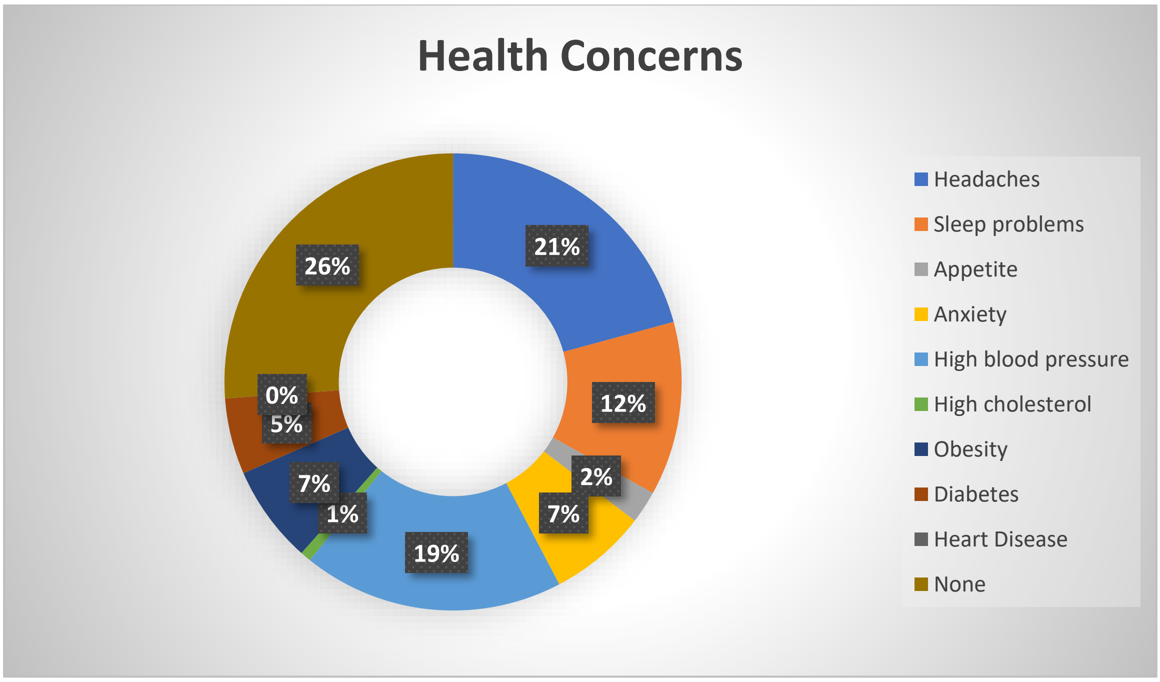


Figure 31: Caregiver health concerns

The predominant health concern amongst the caregivers was high blood pressure (19%), followed by headaches (21%) and sleep problems (12%). None suffer from heart diseases, and 26% of respondents indicated that they had no health concerns. When asked whether it was their opinion that health concerns were exacerbated by work stress, the respondents answered in the following way.

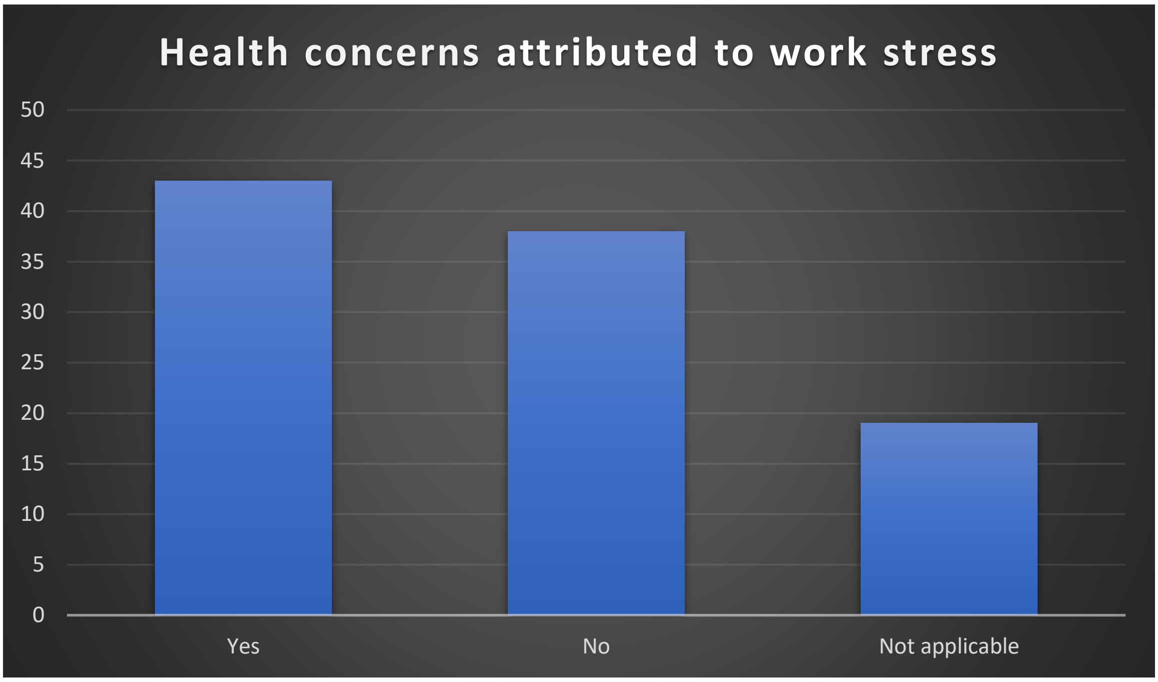


Figure 32: Health concerns attributed to work stress

Of the 100 respondents, 43 agreed and stated that their health concerns were due to work stress. On the other hand, 38 of them disagreed, with some indicating that they had had the health condition before starting to work with people with intellectual disabilities. From the biopsychosocial model perspective, these findings correlate with literature which has established that caregivers of people with intellectual and developmental disabilities tend to neglect their own physical health (Lafferty et al., 2016:19; Dawson et al., 2016:553-563). Furthermore, the literature indicates that chronic work stress can be detrimental to a caregiver's health and can lead to depression, anxiety and burnout (Favrod et al., 2018:1-12).

The caregivers were requested to elaborate on their answers. Only 13 respondents completed this section.

The reader needs to be cognisant of the fact that, for many caregivers, English was a second language, and this may have impacted the sentence formulation. The digits before every comment are the respondents' number code.

The following are their verbatim answers: -

- 011: “Because I like what I do.”
- 014: “I do experience a lot of stress.”
- 017: “I struggle with my back.”
- 019: “’n Mens vergeet om na jou gesondheid om te sien. Soms is die werkstres te veel.” (One forgets to take care of one’s health. At times the work stress is too much.)
- 029: “Sometimes it’s due to work stress.”
- 035: “It’s not the sole factor, but a contributing factor.”
- 039: “I work so hard, and I am always tired.”
- 040: “I hardly have time to eat when I’m at work. It’s very busy.”
- 049: “The workload is a lot.”
- 050: “I’ve been diabetic before I started at my workplace.”
- 058: “Some problems can’t be solved. They shift the problems.”
- 065: “Not really; mostly come from my family and trauma I went through.”
- 066: “Sometimes it’s work stress.”

Learning expectations of the caregivers

The following empirical data refer to the learning expectations expressed by some of the respondents as obtained from an open-ended question in the pre-test questionnaire.

The caregivers were asked: “What do you hope to learn today?”

- 001: “I hope to understand how to work with people with Intellectual Disability.”
- 002: “Psychoeducational programme sounds very interesting.”
- 004: “How to work with disability of each learner.”
- 005: “To get to know more as a caregiver.”
- 008: “I hope to learn more about disability & their special needs.”
- 009: “I hope to learn more about intellectual disability.”
- 010: “I want to learn more about intellectual disability.”
- 011: “I want to know more about intellectual disability.”
- 012: “Learn more about intellectual disability.”
- +013: “I will like to learn about intellectual disability people.”

- 014: “I’m open for new insights.”
- 015: “More about intellectual disability.”
- 016: “How to handle difficult intellectual disability people.”
- 017: “I have an honours in Educational Psychology.”
- 018: “Anything that will make my residential place a better place.”
- 019: “Hoe om enige situasie beter te hanteer.” (How to manage the situation better)
- 020: “I hope to gain information on how to improve working with disabled children.”
- 021: “More about intellectual disability.”
- 022: “I hope to have a better understanding.”
- 024: “Understand their needs.”
- 025: “More experience on how to handle difficult disability.”
- 026: “I want to learn more about how to handle intellectual disability.”
- 027: “More things about caregivers.”
- 028: “I want to learn more about intellectual disability.”
- 029: “More about intellectual disability.”
- 030: ““More about intellectual disability.”
- 031: “I want to learn more experience on how to handle intellectual disability.”
- 032: “I want to learn more about intellectual disability.”
- 033: “To learn about difficult people and how to handle them.”
- 034: “Information to equip myself better.”
- 035: “New skills to better equip me.”
- 039: “I want to have more knowledge.”
- 040: “More about children with ID. I don’t have information about them.”
- 041: “How to help people that cannot help themselves.”
- 042: “I want to learn more about people who live with intellectual disabilities.”
- 043: “To better manage and understand the disabled client.”
- 046: “To learn more about resources available for caregivers.”
- 048: “To better understand ID.”
- 049: “How to be resilient.”

- 050: “How to work with children with ID.”
- 051: “To implement what I’ve learnt today to the best of my ability.”
- 053: “How to treat ID persons.”
- 054: “I want to learn solutions in problems with intellectuals.”
- 055: “I want to learn to be more patient.”
- 058: “Anger challenges.”
- 059: “How understand people with disabilities.”
- 062: “Behaviour of the children.”
- 063: “To understand people with intellectual disability better.”
- 064: “To understand people with intellectual disability better
- 065: “I hope to learn people with ID.”
- 066: “I hope to learn to be better in my job today.”
- 067: “Something that can help to work with disability.”
- 068: “To learn better ways to communicate and interact with special needs.”
- 069: “To better understand learners with a barrier.”
- 070: “To provide learners with stimulating education to reach their full potential.”
- 073: “How to understand someone with a disability.”
- 075: “To understand the person better.”
- 077: “I want to know more about intellectual disability.”
- 078: “I want to know more about intellectual disability.”
- 079: “To know more about intellectual disability.”
- 084: “More about intellectual disability.”
- 087: “To understand how does it occur and the causes.”
- 088: “To learn more on intellectual disabilities.”
- 089: “Hope to learn more on ID, so that I can do my job perfectly.”
- 090: “To improve my knowledge for ID persons.”
- 091: “I want to learn more so that I can do my job the best.”
- 095: “Coping skills, where applicable.”
- 096: “Everything about intellectual disability.”
- 097: “I’m not qualified as a caregiver.”
- 100: “To understand the needs (non-verbal) of intellectual disability.”

Daily experiences of caregivers

The caregiver respondents rated their answer to the following question on the four-point Likert Scale questionnaire.

"In the last four weeks I experienced the following when caring for someone with intellectual disability."

Note: See Section 13 of Appendix 8, the pre-test questionnaire for which the above statement is applicable from Figure 33 to Figure 37.

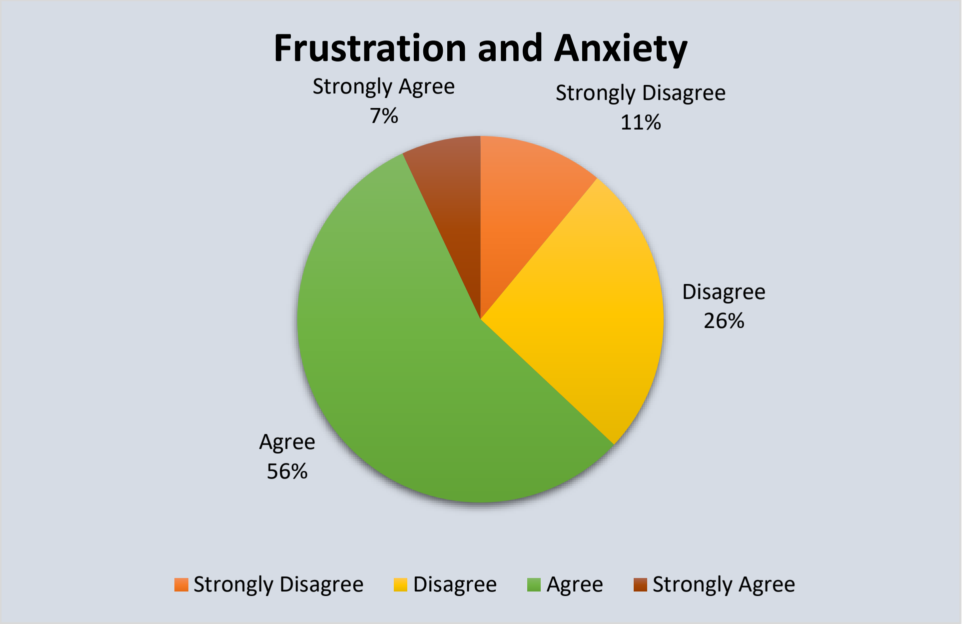


Figure 33: Frustration and Anxiety

This pie chart shows that 63% of respondents indicated that they agreed/strongly agreed that, within the previous four weeks, they had experienced frustration and anxiety when taking care of someone with intellectual disability. Other respondents (37%) disagreed/strongly disagreed that they had experienced frustration and anxiety in the previous four weeks while taking care of someone with intellectual disability.

These results are corroborated by research which revealed that caregivers of people with ID reported to have higher than average rates of stress, depression and anxiety (McConnell & Savage, 2015:100; Panicker & Ramesh, 2019:1-14). Moreover, literature argues that symptoms of stress, depression and anxiety can be reduced through psychoeducation, as well as adopting and practising coping tools (Field et al., 2015:206-220; Kazantzis et al., 2018:349-357; Wright et al., 2006:80).

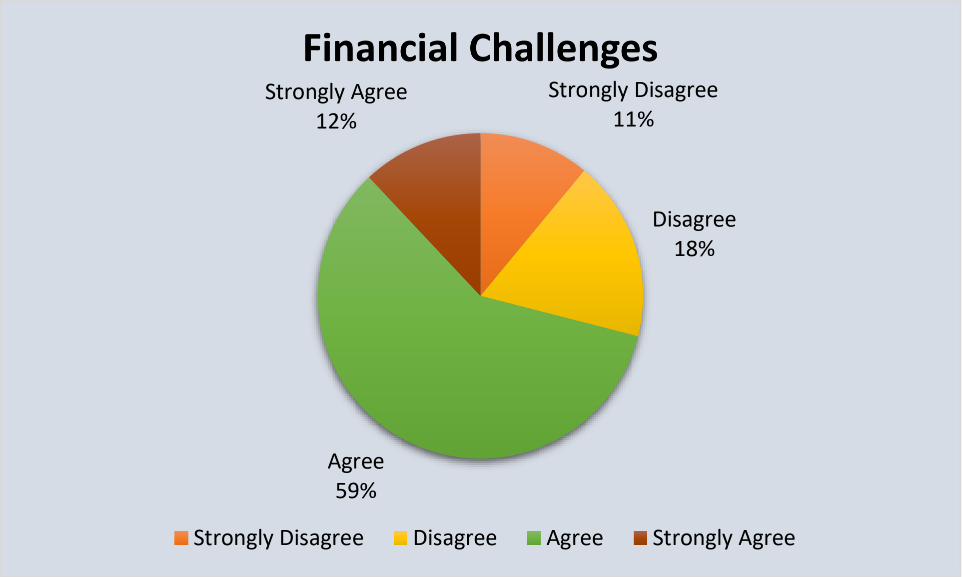


Figure 34: Financial Challenges

Figure 34 shows that 71% of the attendant caregivers indicated that they agreed/strongly agreed that they had experienced financial challenges as caregivers of people with ID over the previous four weeks. However, 29% of the respondents disagreed/strongly disagreed with the statement. As the research results in Figure 30 indicate: formal caregivers of people with ID earn very little money. This is substantiated by literature which found that often financial resources to people with ID are sorely lacking (Petasis, 2019:49). The researcher asserts that this includes lack of funding to the service providers of people with ID.

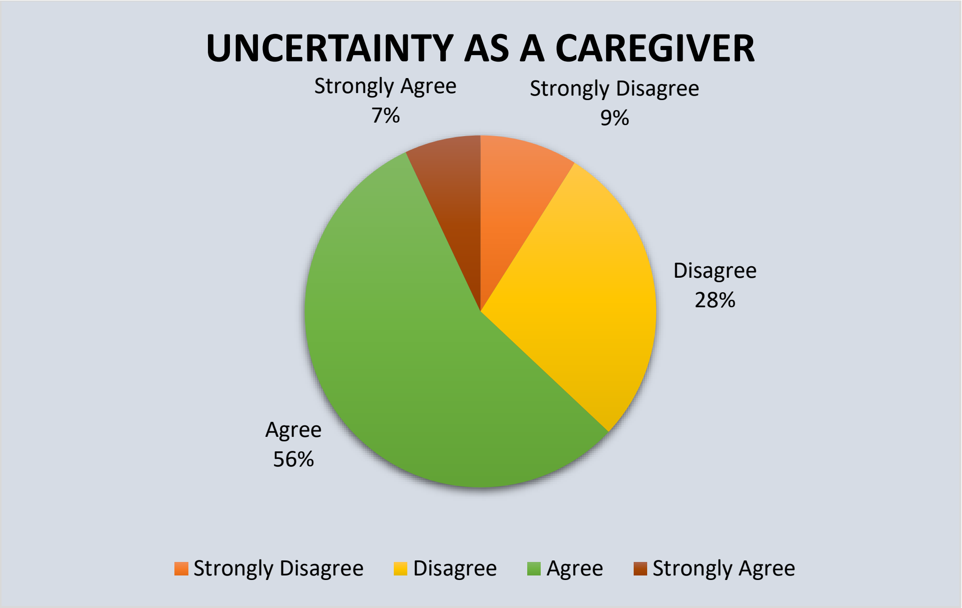


Figure 35: Uncertainty as a Caregiver

According to Figure 38, the majority (63%) of the respondents agreed/strongly agreed that they had experienced uncertainty in their position as caregivers within the previous four weeks, whereas 37% of them disagreed/strongly disagreed with the statement.

The present study aims to contribute to enhancing the knowledge, insight, and skills of caregivers to alleviate the associated stress related to uncertainty in caregiving. The strength-based approach supports the notion that individuals who face crises, learn skills to overcome adversities. It views challenges as opportunities to practise resourcefulness (Moorkath et al., 2019:175).

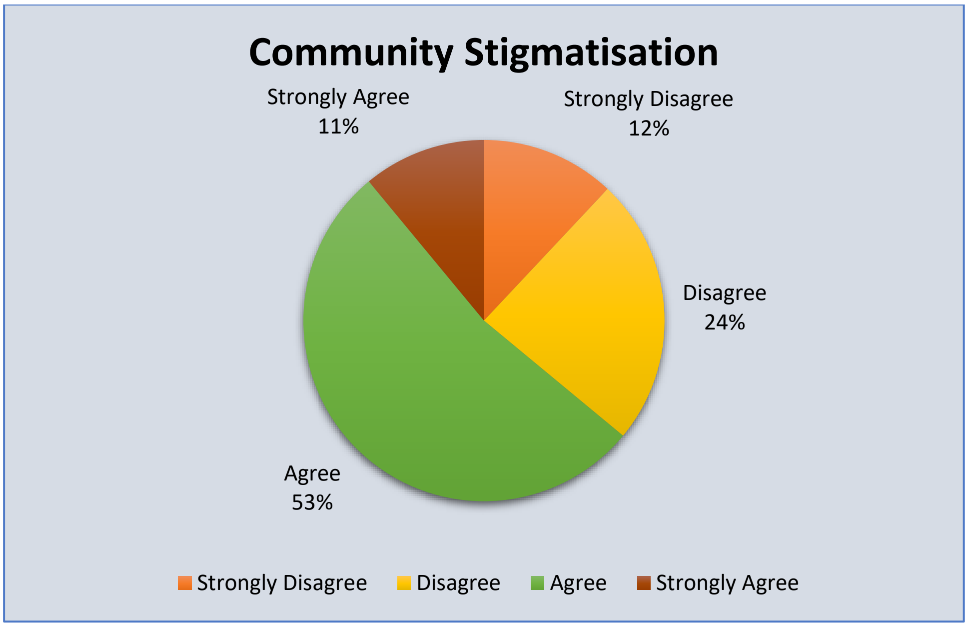


Figure 36: Community Stigmatisation

According to Figure 39, 65% of the attendant caregivers indicated that they agreed/ strongly agreed that they experienced community stigmatisation as caregivers of persons with ID in the previous four weeks. However, 35% of them disagreed/strongly disagreed with the relevant statement in the questionnaire. Community stigmatisation does not only affect the person with ID but his or her caregiver as well (Mak & Cheung, 2008:532). For the caregiver, just to be associated with the disability, may lead to an internalised sense of stigma, as he or she, being affiliated to the person with ID, feels unhappy and helpless (Mak & Cheung, 2008:532-533).

The strength-based approach allows the facilitator to assist the caregiver in understanding that vulnerabilities and power dynamics exist, but that there are many points of choice and resistance. The strength-based approach helps the caregiver recognise the power within themselves (Pulla, 2017:109).

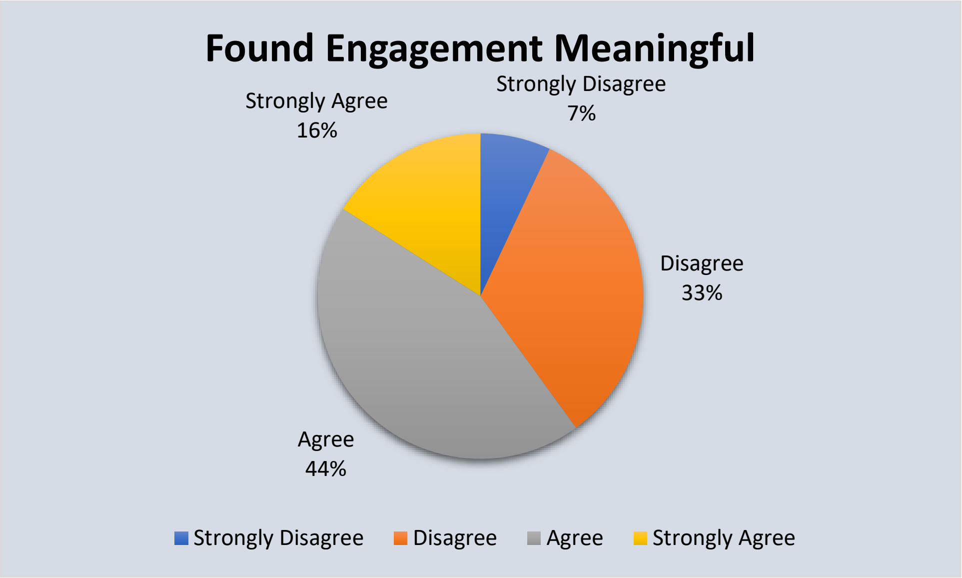


Figure 37: Meaningful Engagement

Most formal caregivers (60%) had found their care of people with ID to be meaningful in the timespan indicated, whereas, according to Figure 37, 40% of the respondents disagreed/strongly disagreed that they had found their engagement with the person with intellectual disability meaningful.

These results correlate with findings of a study done by Hastings and Horne (2004:53-62) which reported that formal caregivers found it rewarding to take care of persons with ID. The study indicated that some contributing elements to formal caregivers' work satisfaction included the support they received from work colleagues, learning about the needs of people with ID and learning to adjust to aspects they could not change.

The respondents were also asked to elaborate on their answers. Here are the verbatim answers: -

- 006: "It is a lot of challenging. I work with different children with disability."
- 008: "It's tough to have these challenges, but I hope to learn some meaningful things."
- 009: "We are a team, so it's teamwork."
- 010: "Experiences and new challenges everyday."
- 011: "Every day is a new challenge at work."

- 012: “It’s very hard to work with intellectually disabled people, because you must think for them.”
- 015: “Because you have to be patient.”
- 016: “Sometimes you force yourself to go to work, ‘cause of staff shortages.”
- 018: “It’s very challenging in a way that learn everything new always.”
- 019: “Dit is baie moeilik, want jy moet heeltyd op jou hoede wees.” *(It’s challenging. One must always be hyper-vigilant.)*
- 020: “In some cases, I don’t know what to do and how to help with the outbursts.”
- 022: “Found my engagement meaningful.”
- 026: “To understand everyone’s moods.”
- 034: “Work can be uncertain sometimes.”
- 035: “I’m frustrated in a sense.”
- 043: “What you do is always analysed and sometimes not recognized. It’s very challenging.”
- 045: “I’m working in admin.”
- 050: “I feel that I’m not fully equipped to work with these children and handle their emotions and behaviour.”
- 051: “I want to help better their lives and situations.”
- 065: “Caring for someone is challenging.”
- 064: “I have not had training on how to work with people with ID.”
- 066: “I have financial challenges.”
- 080: “If the child is hungry, he is crying.”
- 087: “It gives me mixed feelings on a daily basis.”
- 089: “Caring for someone makes a difference in their lives.”
- 092: “I’m willing to learn today.”

The caregiver-respondents rated their answer to the following question on the four-point Likert Scale questionnaire: -

"How challenging, if at all, do you find it being a caregiver of someone with intellectual disability". Note: See Section 14 of Appendix 8 of the pre-test questionnaire.

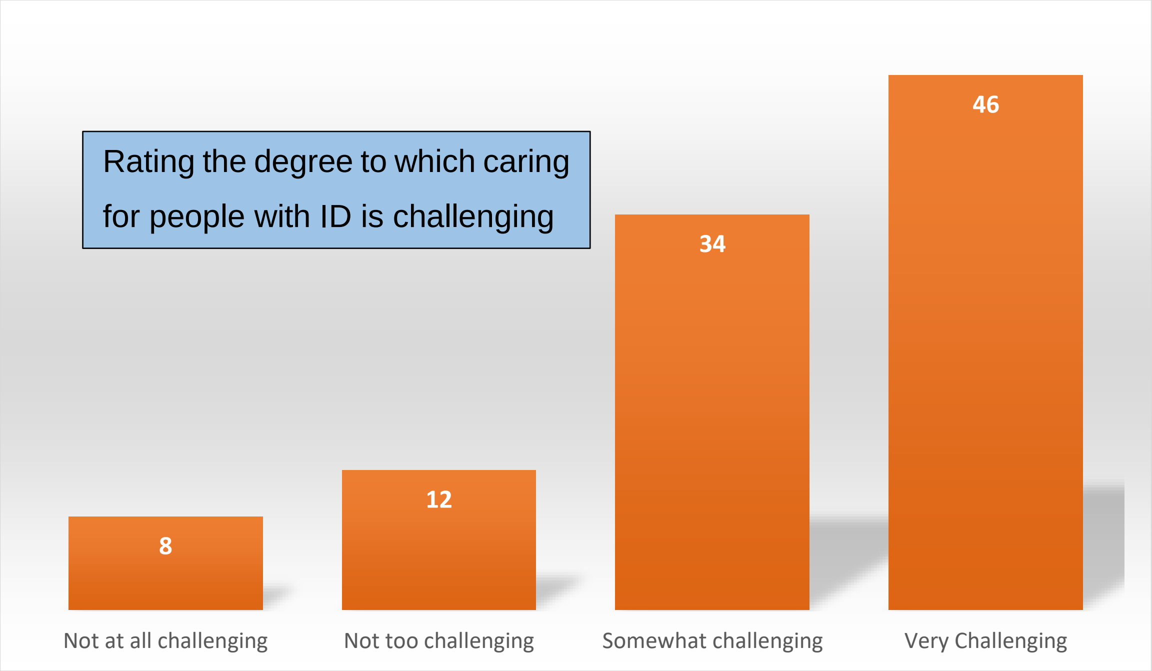


Figure 38: Degree of Challenge in Caregiving

The graph indicates that 46% of respondents found that caring for persons with intellectual disabilities was very challenging.

The caregivers were asked to elaborate on their answer: -

008: "It's not too challenging. I love to work with people with disability."
009: "Just be patient and have respect."
010: "They have lots of needs and assistance."
011: "Because they have lots of cares and needs."
012: "Very hard to work with intellectual disabled people, because you must think for them."
015: "You have to be patient and in control of yourself."
016: "There are people with strong autism that is out of control."
019: "Omdat mens soms moedeloos voel." *(Because one feels despondent at times)*
020: "In some cases I don't' know what to do with his outbursts."
034: "You don't always know what emotions you are dealing with."
040: "I love my job as a caregiver."

043: “I do not have proper support and knowledge.”
045: “I had a child with ID.”
050: “I still need some training to assist me to know how they are feeling.”
051: “One faces different challenges each day.”
055: “We have to listen to them.”
057: “Their moods are not always the same.”
060: “Working with disabilities is soothing.”
065: “We don’t always understand what the person wants or what they are referring to.”
068: “It’s overwhelming and challenging.”
069: “Parents that are not actively involved, are challenging.”
070: “Working with an ID client one must be patient, understanding and have a passion.”
073: “I have experience on how to work with people with disability.”
075: “It’s challenging when you don’t understand the person and he doesn’t understand you.”
081: “To look after the patient is your responsibility, because the patient can’t do nothing for themselves.”
082: “Some of the patients’ moods change all of the time.”
087: “Not knowing how to cope and what you need to do.”
092: “It’s challenging because of the situation they come from.”
095: “As a manager I need to understand their heart and soul and be for them.”
097: “It’s a little challenging.”

9.2.2 Section B: PRE-TEST VERSUS POST-TEST QUESTIONNAIRE

The researcher utilised the paired *t*-test to test for significant differences between the pre-test and the post-test results. The paired *t*-test is a popular statistical technique widely used for its suitability in many practical applications and is appropriate in the present instance, as the researcher aims to compare the average scores on the same quantitative variables (topics) within a single sample (caregiver respondents) at two different times (pre- and post-test) (Pietersen & Maree, 2011c:225).

The caregivers were asked to rate their confidence in their knowledge of the following topics: -

Note: See Section 12 of Appendix 8, the pre-test questionnaire is applicable for the rating in their confidence of their knowledge in various topics depicted from Figure 39 to Figure 47.

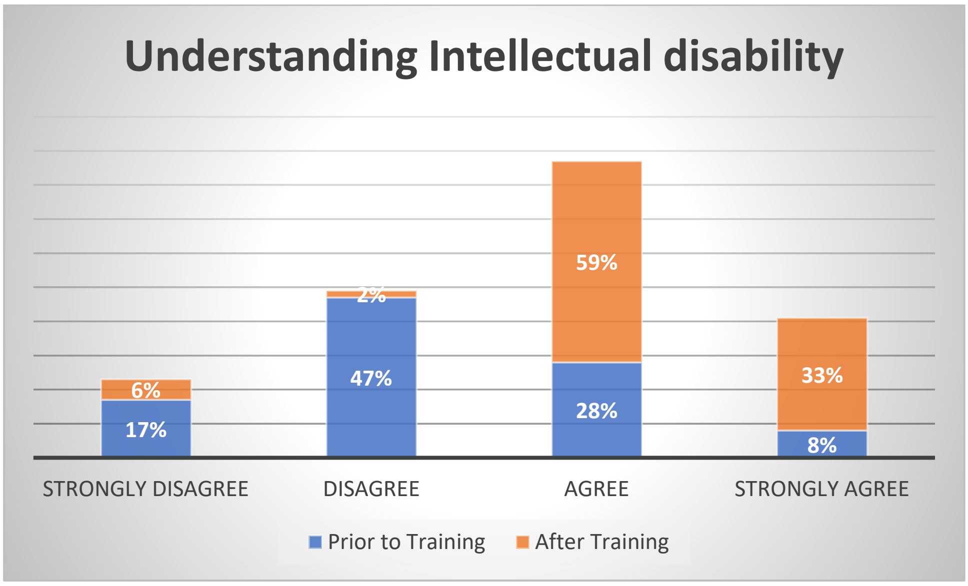


Figure 39: Understanding Intellectual Disability

Figure 39 shows that, prior to training, 64% of respondents disagreed/strongly disagreed that they were confident in understanding intellectual disability prior to training.

After the training, 92% of attendees agreed/strongly agreed that they had greater confidence in their understanding of intellectual disability. However, 8% of them disagreed/strongly disagreed that they now had greater confidence in understanding intellectual disability.

These results correlate with literature that indicates a lack of psychoeducation and understanding of ID among the relevant caregivers. Many do not have any idea of what the causes of intellectual disability are (Ezeonu et al., 2021). Consequently, caregivers have attributed various reasons to intellectual disability, some believing that disability is a punishment from God, others believing in superstition and bewitchment, and yet others seeing it as a spiritual attack or demon possession (Mkabile et al., 2021:5; Ezeonu et al., 2021). Understanding intellectual disability will assist caregivers to cope better with the challenges of caring for persons with ID (Ezeonu et al., 2021).

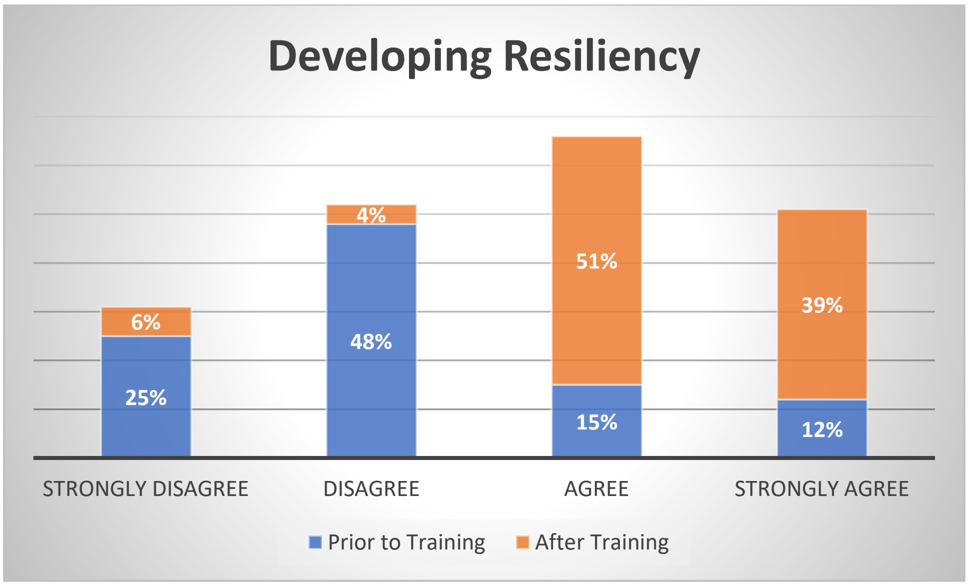


Figure 40: Developing Resilience

Prior to the training, 27% of the respondents agreed/strongly agreed that they had confidence in their knowledge of developing resilience (Figure 40), and 73% of them disagreed/strongly disagreed that they were confident in their knowledge of developing resilience. After the training, 90% of the caregivers present agreed/strongly agreed that they had greater confidence in their knowledge of developing resilience, while 10% disagreed/strongly disagreed that they were now more confident in their knowledge of developing resilience.

It is vital that caregivers come to appreciate the importance of developing resilience, which has been found to be the key factor in caregivers' successful adaptation to the challenges of caring for people with ID (McConnell & Savage, 2015:100; Lafferty et al., 2016:15). Resilience is a critical human characteristic that can be acquired through multiple processes, such as meaning-making, benefit-finding, mindfulness-meditation, physical exercise, cognitive behavioural therapy, emotional acceptance and commitment therapy, social-emotional training and expressive journaling (Bennett et al., 2018:1339-1346).

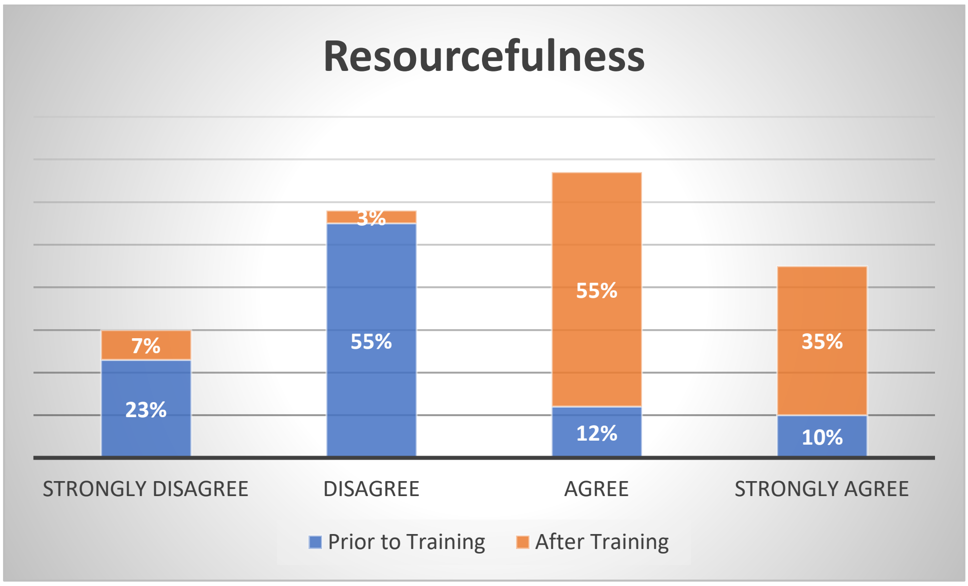


Figure 41: Resourcefulness

Prior to training, very few of those present (22%) agreed/strongly agreed that they had confidence in the knowledge of resourcefulness (Figure 41), whereas 78% of respondents disagreed/strongly disagreed that they were confident in their knowledge of resourcefulness. After training, 90% of respondents agreed/strongly agreed that they had greater confidence in their knowledge of resourcefulness, while 10% of them still disagreed/strongly disagreed that they now had greater confidence in their knowledge of resourcefulness.

It is important for caregivers to understand that resources are not only external, physical assets, but also internal developing assets, such as the skillsets of resilience and resourcefulness (Young, 2012:22; Moorkath et al., 2019:175).

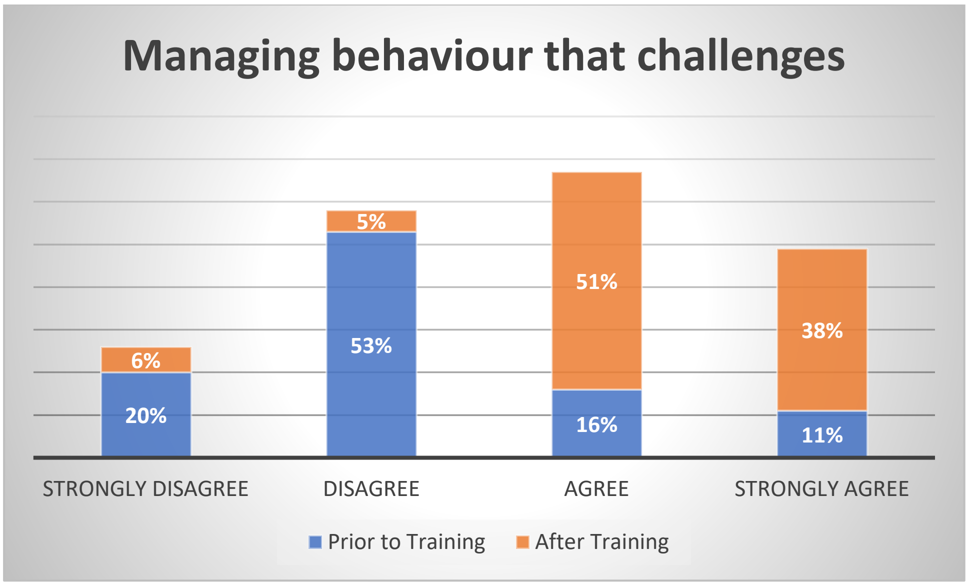


Figure 42: Managing behaviour that challenges

Figure 42 shows that, prior to training, 27% of attendees agreed/strongly agreed that they had confidence in their knowledge of managing challenging behaviour, while 73% of them disagreed/strongly disagreed that they were confident in their knowledge of managing unacceptable behaviour. After the training, 89% of attendees agreed/ strongly agreed that they had greater confidence in their knowledge of managing challenging behaviour. However, 11% of them disagreed/strongly disagreed that they were now more confident in their knowledge of managing such behaviour.

Leoni et al. (2016:59-73) explain that a psychoeducational plan for caregivers should include a responsive plan in managing challenging behaviour of people with intellectual disability. Formally paid caregivers of people with ID regularly experience challenging situation in the workplace as facing distressing experiences is a daily routine in ID facilities (Leoni et al., 2016:59-73). Being repeatedly exposed to these incidents can lead to maladaptive coping tools, such as unhealthy life choices, mental health and psychological problems, higher absenteeism, and low productivity (Leoni et al., 2016:59-73). Therefore, the psychological distress of caregivers can be very costly to the work organisation (Leoni et al., 2016:59-73).

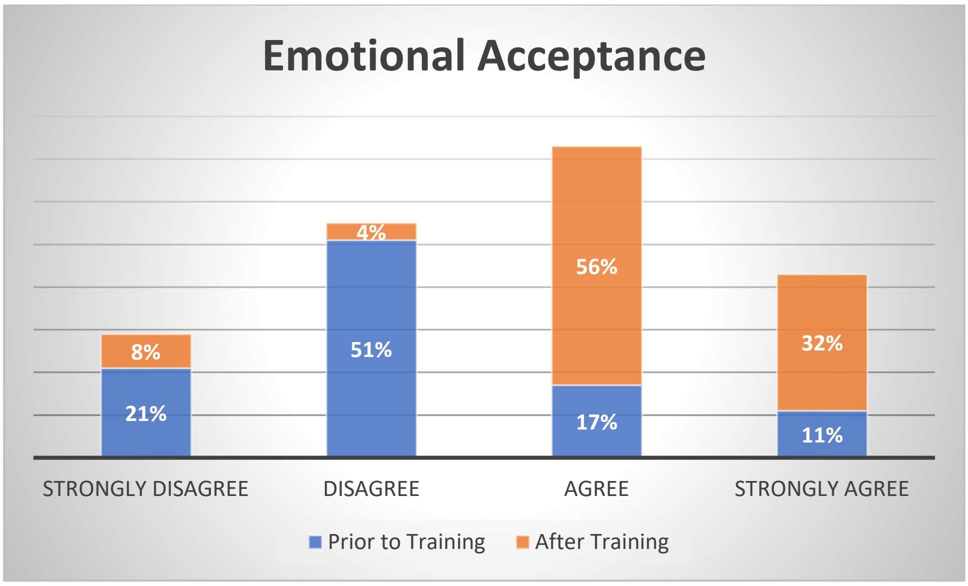


Figure 43: Emotional Acceptance

Prior to training, 28% of the respondents agreed/strongly agreed that they had confidence in their knowledge of emotional acceptance, and 72% of them disagreed/ strongly disagreed that they were confident with regard to knowledge of emotional acceptance (Figure 43). After the training, 88% of the respondents agreed/strongly agreed that they had greater confidence in their knowledge of emotional acceptance. However, 12% of the respondents disagreed/strongly disagreed that their confidence in their knowledge of emotional acceptance had grown.

Acceptance and commitment therapy is the most dominant trend in the recent third wave of cognitive behavioural therapy (Harris, 2019:3; Leoni et al., 2016:59-73; Philip & Cherian, 2022:78-82). Emotional acceptance and commitment therapy is an evidence-based intervention which has been proven to reduce stress and burnout, as well as increase the well-being of caregivers of people with intellectual disability (Leoni et al., 2016:59-73). Therefore, the researcher thought it important to include the most recent and dominant therapeutic intervention in the psychoeducational training programme.

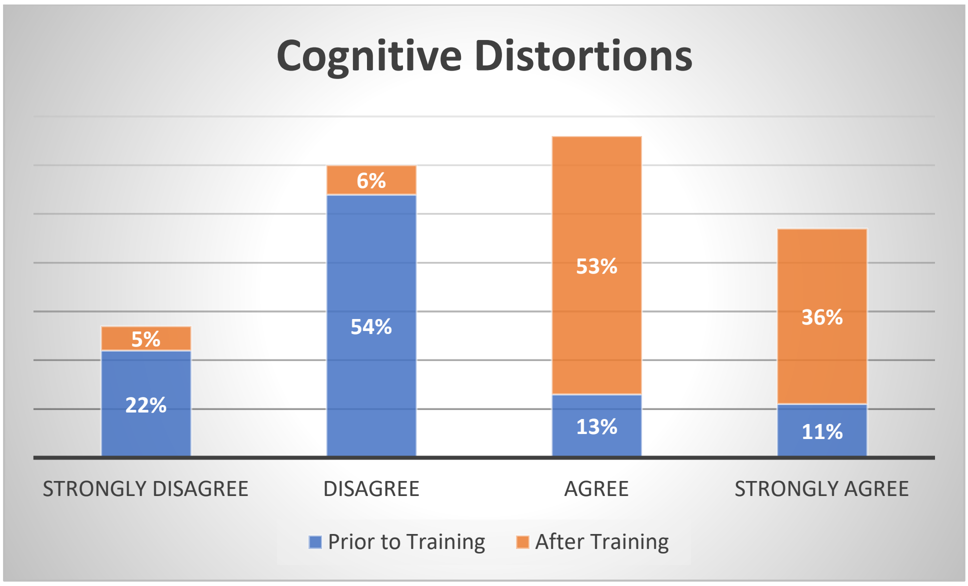


Figure 44: Cognitive Distortions

According to Figure 44, and prior to training, 24% of respondents agreed/strongly agreed that they were confident in their knowledge of cognitive distortions, while 76% of respondents disagreed/strongly disagreed that they were confident in their knowledge of cognitive distortions. After the training, 89% agreed/strongly agreed that their confidence in their knowledge of cognitive distortions had grown. However, 11% of respondents disagreed/strongly disagreed that they now had greater confidence in their knowledge of cognitive distortions.

A cognitive distortion is an exaggerated or irrational thought pattern that can lead to the onset or perpetuation of psychopathological states, such as stress, depression and anxiety (Helmond et al., 2015:245-262; Surley & Dagnan, 2019:219-237). Thought patterns that are unhelpful can contribute to caregiver distress, as the caregiver, having entertained such thoughts over a period of time, is not aware that they are distorted. Once caregivers can identify their cognitive distortions, they are able to gain authority over these thoughts and change the way they feel (Wright et al., 2006:89-99).

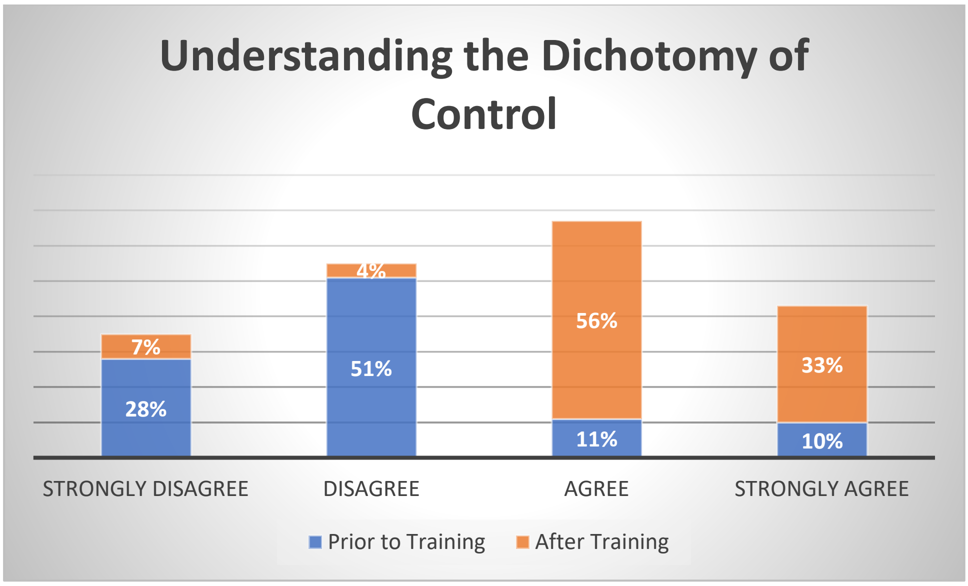


Figure 45: Understanding the Dichotomy of Control

The bar graphs in Figure 45 reveal that, prior to training, 21% of caregivers present agreed/strongly agreed that they were confident in their understanding of the dichotomy of control, and 79% of the caregivers disagreed/strongly disagreed that they were confident with regard to understanding the dichotomy of control. However, after the training, 89% of them agreed/strongly agreed that their confidence with regard to understanding the dichotomy of control had improved. Yet, 11% of the caregivers disagreed/strongly disagreed that they were more confident in their understanding of the dichotomy of control.

Understanding the dichotomy of control is what distinguishes a resilient and empowered individual (Hammond, 2010:6; Rajan et al., 2018:297-306; Harris, 2019:102;). It is part of acceptance and commitment therapy to train caregivers to focus on what they can and cannot control (Harris, 2019:102).

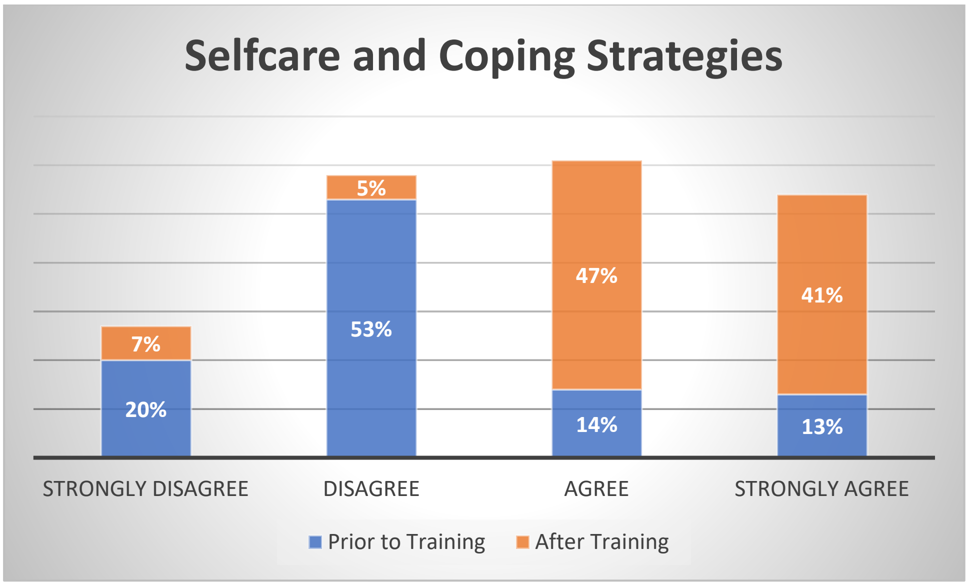


Figure 46: Selfcare and Coping Strategies

In the pre-training assessment, 27% of respondents agreed/strongly agreed that they were confident in their knowledge of self-care and coping strategies (Figure 46), while 73% of respondents disagreed/strongly disagreed that they were confident regarding their knowledge of self-care and coping strategies. After the training, however, 88% of respondents agreed/strongly agreed that they were now far better versed in self-care and coping strategies. However, 12% of respondents disagreed/strongly disagreed that they were more confident in their knowledge of self-care and coping strategies.

Literature (Panicker, & Ramesh, 2019:1-14) reiterates that caregivers' mental health plays an important role in the quality of care they provide to the person with intellectual disability and having an appropriate coping style will diminish the symptoms of depression and stress.

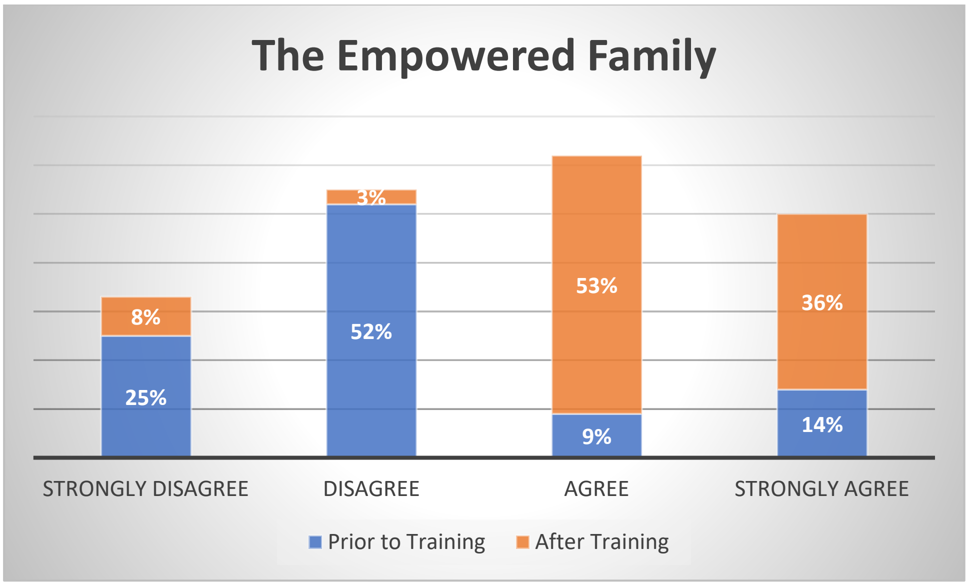


Figure 47: The Empowered Family

Figure 47 reveals that, prior to training, 23% of respondents agreed/strongly agreed that they were confident in their understanding of the concept ‘an empowered family’, whereas 77% of respondents disagreed/strongly disagreed that they were confident in their understanding of this concept. After the training, 89% of respondents agreed/ strongly agreed that they understood the concept. However, 11% of respondents disagreed/strongly disagreed that they had greater confidence in their knowledge of ‘an empowered family’.

Low levels of family support are associated with low resilience in caregivers of persons with intellectual disability (Lafferty et al., 2016:15). Having strong familial relationships is considered a key protective factor in maintaining caregiver resilience, particularly as families can pool their resources, maintain good communication, stay connected and share caregiving responsibilities (Lafferty et al., 2016:15).

Table 19:Conclusion of the paired t-test

Conclusion of the paired *t*-test

Topics	***t*-value**	***p*-value**
Understanding intellectual disability	8.309	0.0000
Developing resilience	9.293	0.0000
Resourcefulness	10.427	0.0000 0.0000
Managing behaviour that challenges	9.398	0.0000
Emotional acceptance	8.152	0.0000
Cognitive distortions	9.863	0.0000
Understanding the dichotomy of control	9.536	0.0000
Self-care and coping strategies	8.579	0.0000
The empowered family	8.398	0.0000

- The intervention of the psychoeducational programme was applied after the pre-test and before the post-test.
- A significant number of respondents moved from a negative response in the pre-test to a positive response in the post-test.
- All p-values are far less than 0.001; thus, they all show significant paired differences.
- It can be concluded that the intervention of the psychoeducational programme was the reason for the positive responses.

POST-TEST QUESTIONNAIRE: SUMMARISED REFLECTIONS ON THE PSYCHOEDUCATIONAL PROGRAMME

The caregiver respondents rated their answer to the following question on the three-point Likert Scale questionnaire: -

“In your view would you recommend this psychoeducational programme?”

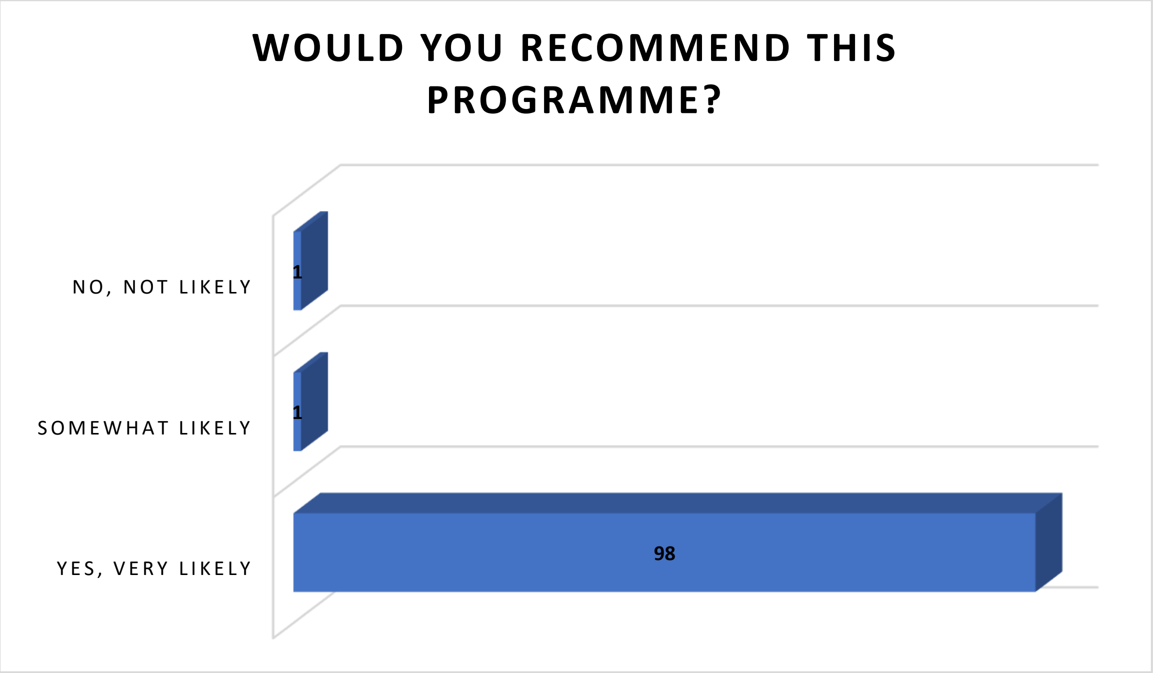


Figure 48: Recommendation of the programme

Of all the respondents at the training, 98 indicated that they would recommend this programme, whilst one indicated that she would *perhaps* (‘somewhat likely’) recommend the programme and another respondent was ‘not likely’ to recommend it.

The respondents were asked to elaborate on their answer; however, 45 of them refrained from writing a comment. The following are the written comments: -

Would you recommend this programme?

- 001: “Enjoyable. Changed my view on some tasks and provided me with tools that could be used.”

- 002: “I learnt a lot.”
- 004: “Die program leer ons hoe om konflik op te los. Hoe om op die kind se vlak te kom.” (This programme teaches us how to resolve conflict. How to engage on the level of the child.)
- 005: “Yes, it’s meaningful.”
- 007: “It is very helpful, and I learned a lot.”
- 008: “I learned I am not a failure.”
- 009: “This course helps a lot to be helping the person with ID more patiently.”
- 013: “This is something everyone should know.”
- 016: “The notes are very well put out. It is given in a practical way.”
- 017: “Meaningful to know what to do.”
- 018: “The lessons were so interesting.”
- 019: “Yes, it is very helpful.”
- 022: “The programme was understandable and helpful.”
- 023: “Yes, it’s not all the facilities that there’s psychoeducational training.”
- 024: “Was very well presented.”
- 025: “I really learnt things that I didn’t know that was interesting.”
- 026: “Yes, it will help you to learn a lot about yourself and your patient.”
- 027: “This course covers a lot of things we handle on a daily basis, personally and in the workplace.”
- 030: “The programme teaches you more about intellectual disability.”
- 031: “Yes, it was very empowering.”
- 032: “It is a therapeutic intervention for patients and their loved ones.”
- 033: “The content is informative and explained on a level that is understandable. Examples added a nice touch.”
- 035: “Everyone can learn a lot if they listen.”
- 036: “This is very helpful information.”
- 039: “It gives you options in different parts of coping.”
- 040: “I learned a lot more about what the caregiver must do.”
- 041: “It was extremely informative and exciting. I really learnt and enjoyed it.”
- 042: “Yes, I will recommend. This will be very helpful in the future.

- 043: “This programme will be beneficial to anyone working with people with intellectual disability.”
- 044: “It was learningful.”
- 045: “Yes, most definitely.”
- 046: “It is very interesting.”
- 047: “Yes, because it’s very helpful.”
- 049: “Fully understanding a child with intellectual disability.”
- 051: “Next time include the parents of the children with ID.”
- 052: “It was very helpful and I’m glad I came here.”
- 053: “It helped a lot.”
- 060: “Especially carers – more active with residents.”
- 063: “To train the course for the community in the outside world.”
- 066: “It was very helpful.”
- 067: “Helpful. I did enjoy myself.”
- 070: “This programme/training it’s very good. I learnt a lot today. Even realised what I should work on.”
- 072: “Very useful and easy to make use of and to relate to one’s everyday life.”
- 073: “The training is too long and need more practical activities.”
- 074: “I learned something new from this training and I’m sure others will too.”
- 078: “Yes, it was very helpful.”
- 080: “I will recommend to everyone who want to attend.”
- 083: “It was very learningful.”
- 085: “Course was very well presented and helpful.”
- 086: “Learning new things that I was not aware of.”
- 087: “Yes, definitely.”
- 088: “It was clear to understand how to deal with intellectually disabled.”
- 090: “I’ve learned so much about people with ID.”
- 092: “I would like to have more training in ID.”
- 094: “I’m very motivation.”
- 096: “It was very helpful and inspiring.”
- 097: “It was very uplifting.”

- 100: "It provided an opportunity to reflect on myself and how I have been doing my job."

The respondents were also asked to elaborate on the question: "Would this programme assist you as a caregiver of a person with intellectual disability?" Forty-nine respondents did not write a comment. Here below are the written comments of the other respondents: -

Would this programme assist you as a caregiver?

- 001: "Yes, provided me with tools to assist me, did some soul searching as well."
- 004: "Die person na wie ons kyk het ook gevoelens en verdien om gehoor te word." (The person we are taking care of has feelings and deserves to be listened to.)
- 005: "Understanding the person now, understanding their needs."
- 006: "I understand better now."
- 007: "I learned a lot on how to handle a person with a disability."
- 008: "I learned to understand the patient."
- 010: "I learnt stuff I never knew about people with intellectual disability."
- 013: "This programme gave me clarity on some situations."
- 014: "Programme helps a lot."
- 017: "The programme assists me to recognise the problem and to work on it, if possible."
- 019: "We need to learn every day."
- 020: "The programme is very useful."
- 023: "Yes, because there's a lot of information that I didn't know."
- 026: "The programme assists me to know more about the ID."
- 027: "It helps me to make sound decisions on behalf of my client."
- 028: "I'm now more equipped to understand people with ID."
- 030: "I know more about intellectual disability than before."
- 031: "I have gained so much knowledge with this programme."
- 032: "Yes, it gives you more clarity of the line of job."

- 033: “The material is designed to equip the caregiver, but also equip the person with ID to function better.”
- 034: “Very good content.”
- 035: “Keeping this programme at hand in your job will help.”
- 036: “This will definitely help me in my workplace.”
- 040: “Yes. Now I know what to do with intellectual disability.”
- 041: “It did assist me in my role as a caregiver to be better in control of my emotions.”
- 042: “It will help me to work with them.”
- 043: “Yes, I will most definitely be more patient and take my time with each client.”
- 044: “It will be helpful.”
- 045: “Being informed like this is mind changing.”
- 046: “Yes. Now I know more how to handle people with intellectual disabilities.”
- 047: “I now understand the need of the person with ID.”
- 049: “Empowering families. Coping skills. Caregivers are good people.”
- 051: “Now I have more knowledge about ID.”
- 056: “I understand a bit about today’s course.”
- 062: “Please present at different residential facilities.”
- 066: “I learned more about the person with ID.”
- 072: “One can use it daily, everyday to improve environment of learners.”
- 073: “There’s so much info I didn’t know.”
- 074: “The programme will assist you to be more understanding.”
- 078: “Yes, because I can understand the person better.”
- 080: “Yes.”
- 083: “This was my first training. Everything I knew, I learned on the job.”
- 085: “Absolutely. Most caregivers have done a short course in caregiving, but do not have the tools and this programme made it possible.”
- 086: “Yes, I learned a lot in this programme.”
- 088: “This programme was very useful.”
- 089: “I enjoyed the programme for a caregiver.”

- 090: “I can use the knowledge I learned here to add into my day-to-day duty of being a carer.”
- 094: “Yes, thank you very much.”
- 095: “Valuable tools were provided regarding coping strategies, understanding your own needs, etc.”
- 096: “I can use it to my knowledge.”
- 098: “It teaches ways on how to check in with myself.”
- 099: “Being more in tune with myself and empowering the person with ID.”
- 100: “It provided me with tools and strategies to cope and also clarified my role.”

In the following section the researcher aimed to ascertain the respondents’ views on where the training programme could improve. The section asked: -

- What other areas of training are still needed?
- Provide recommendations in terms of course content.

Twenty-six respondents did not respond to this question. The suggestions of the other 74 respondents are given here below (verbatim): -

Views on improvement of programme. Areas of training still needed.

- 001: “Different handicaps and the symptoms.”
- 002: “I would like to learn more about children.”
- 004: “Dat daar ‘n werkswinkel beskikbaar is waar ons fisies met die intellectual disability mense werk.” (There should be a workshop where we should physically work with the person with intellectual disability”)
- 005: “Communication in the workplace.”
- 006: “I learned to strive to be a good enough caregiver and not to strive for perfection.”
- 016: “Content is brilliant, but I’m concerned about implementation.”
- 017: “More of challenging behaviour problems.”
- 019: “How to work with different kind of disabled people, like down syndrome, alcohol syndrome and autism. Please do more practical exercises.”

- 021: “How to work with alcohol and autism people.”
- 022: “The training was well prepared. I’m willing to learn more if there will be another training. Parents should be invited to the training.”
- 023: “We need training at our facility. Our caregivers did not do this training where they come from.”
- 026: “Autism and Huntington Disease.”
- 027: “This course covers a lot of things we handle on a daily basis, personally as well as in the workplace. It’s very educational.”
- 028: “I would like to do any other related trainings. Maybe use more tools.”
- 029: “The colostomy bag, like how you put it in and how you clean it.”
- 030: “Please organise more programmes so that others can sit in and learn about intellectual disability.”
- 031: “Focus more on sexuality part of intellectual disability.”
- 033: “Staff wellness is a field that needs to be addressed. Staff members at our facility will definitely benefit from this programmes.”
- 034: “Helping the autistic or intellectually challenged adult.”
- 036: “The different types of record keeping and the incident form.”
- 038: “The sessions covered most topics I wanted to know.”
- 039: “Sexuality behaviour.”
- 042: “Schizophrenia and Huntington Disease.”
- 043: “The contents of this course cover all major aspects of caring for the intellectually disabled.”
- 044: “Autism and Huntington Disease.”
- 045: “Self-discipline.”
- 046: “About intellectual clients who are gay.”
- 047: “People with bodily disabilities.”
- 048: “Yes, I need another training.”
- 049: “Very much appropriate and helps a lot.”
- 050: “The course was very helpful.”
- 051: “It was very helpful, and I gained more knowledge on ID children.”
- 053: “It was very helpful.”
- 054: “I did enjoy it.”

- 055: “Was a very helpful programme.”
- 056: “It was very interesting.”
- 057: “Autism.”
- 058: “Medication.”
- 059: “I still need training in autism.”
- 060: “I would prefer workshop to be done at individual facilities. Workshop very informative.”
- 061: “Programme was helpful. Workshop to be given at each home.”
- 062: “Helpful information.”
- 063: “Train all facilities for carers.”
- 064: “Autism.”
- 065: “Dit was baie helpful.” (It was very helpful)
- 068: “Have CDs, posters, calendar with pics.”
- 069: “Steps to take when you find ID patients were molested and there’s no physical evidence.”
- 070: “For now this is enough for me. Keep doing what you do, love. God bless.”
- 071: “It’s very helpful.”
- 072: “A role of caregiver when reporting sexual abuse, trauma, mishandeling (abuse).”
- 073: “Attendees must be in shifts.”
- 074: “Reporting and justice to abuse someone, other than Form 22.”
- 075: “It was a good training.”
- 076: “It was very helpful.”
- 077: “I still want to learn more about AIDS.”
- 079: “HIV and AIDS.”
- 080: “I want more of schizophrenia.”
- 082: “Huntington Disease.”
- 083: “How to recognise different types of medication.”
- 084: “I would like to learn about Downs Syndrome people.”
- 085: “Course was very well presented and was helpful.”
- 087: “It was very interesting.”

- 088: "It was very informative."
- 089: "I still want to hear more."
- 090: "I would recommend that someone with ID attend the course."
- 091: "More activities and small group discussions. Caregivers are not used to sitting still for so long."
- 092: "Need more lessons."
- 095: "Split course into 2 days in order to get more practical experience."
- 096: "I think everything was fine. I learned a lot."
- 098: "Sexuality. Everything else was talked about."
- 099: "Do role-play."
- 100: "Time-management."

In the following section the researcher aimed to ascertain the respondents' views on which parts of the course content they found most helpful; they were asked to motivate their answer. Fourteen respondents did not offer a comment. The following are the written comments of the other respondents: -

What was most helpful of the programme?

- 003: "Locus of control. I have learnt so much of everybody who talk about their experiences of control."
- 004: "As iets buite jou beheer is, kan jy dit nie verander nie, maar jy kan dinge verander wat binne jou beheer is." (One cannot change something that is out of your control - only what is in your control.)
- 006: "Resilience. The 7 things that builds you as a person."
- 007: "I learnt that you need to ask for help and if you can't handle it anymore, you need to take a break and find ways to have fun. Most helpful was understanding intellectual disability."
- 008: "I learned more about the patient."
- 009: "Empowered family."
- 010: "Emotional acceptance."

- 011: “All of it. I came here for knowledge and that’s exactly what I got. Thank you!!!.”
- 013: “I found learning about coping styles most helpful. It helps me solving more problems; it reduces negative emotions associated with stress.”
- 014: “Understanding intellectual disability, because now I know more about it.”
- 016: “I’m going to use the dichotomy of control in our organisation.”
- 017: “This was a learning opportunity. I learned how to show them to be independent by doing things for themselves.”
- 019: “The practical exercises were helpful.”
- 020: “Family empowerment was most helpful.”
- 021: “I found the course most helpful.”
- 022: “Caregiver coping strategies and emotional acceptance and commitment therapy.”
- 023: “Strive for a good enough caregiver and not a perfect caregiver.”
- 024: “Self-care and coping.”
- 026: “The Model of Resilience. Because it helps me to control myself and in that the ID person.”
- 027: “Everything was helpful. Was also helping myself how to control work and myself.”
- 028: “All the content was helpful. The person with ID is also a human being; just a special one, with special needs.”
- 029: “Self-care and coping strategies. Now I know how to deal with the problem.”
- 030: “How to control your feels and how to gain input as to why the person is acting so.”
- 031: “I think this programme filled all the areas. It was well understood and laid out.”
- 032: “Challenging behaviours. To learn about it made more sense.”
- 033: “The presenter had insight in ID, but more so in the different needs that people with ID have. It is important that carers read situations before addressing challenging behaviour.”
- 034: “Yes, especially the part about resilience.”

- 035: “Control.”
- 036: “As a caregiver working with ID, it can get frustrating and stressful, and I’ve learnt good ways of coping.”
- 037: “Everything.”
- 038: “Understanding intellectual disability. I learned so much about it.”
- 040: “Competence in resilience. Do I communicate in such a way that empowers the child”?
- 041: “Empowered family.”
- 042: “I enjoyed the part where we talked about the different types of intellectual disability.”
- 043: “Understanding intellectual disability, especially learning about their different types of needs.”
- 044: “Locus of control.”
- 045: “The whole course.”
- 046: “Cognitive distortions. The part about managing behaviour challenges. We sit with situations like that.”
- 047: “Internal locus of control.”
- 049: “Most helpful where your focus should be at internal control, and not to waste time on out of control.”
- 050: “The caregiver coping strategy.”
- 051: “Everything was helpful to me, and the lecturer explained everything clear. I enjoyed the workshop.”
- 052: “Caregiver coping strategies.”
- 053: “Caregiver coping strategies.”
- 054: “Control and thinking and helping others. Being able to listen to what they are saying.”
- 055: “Control thinking exercise. Definition of intellectual disability.”
- 056: “How to manage behaviour that challenge.”
- 057: “Cognitive distortions.”
- 058: “Resilience.”
- 059: “Caregiver coping strategies.”
- 060: “Locus of control.”

- 061: “Locus of control.”
- 062: “Locus of control exercises.”
- 063: “Locus of control.”
- 064: “Understanding intellectual disability.”
- 065: “Self-care and coping strategies. The empowered family.”
- 066: “I learned about how to handle stress and look after my health.”
- 068: “Thinking trap” (cognitive distortions).
- 070: “I can go back to my workplace even in my personal life with feedback on what I learnt today.”
- 072: “Understanding intellectual disability as a whole.”
- 073: “I was never trained deep into ID. There are so much helpful points on how to cope with an ID adult.”
- 074: “Understanding ‘Dichotomy of control’. Emotional acceptance.”
- 075: “Caregiver copying strategies. Control exercise.”
- 076: “How to manage behaviour that challenge.”
- 077: “I enjoyed all of the courses.”
- 078: “The locus of control.”
- 079: “The thinking trap.”
- 080: “It was very helpful. Thinking trap.”
- 081: “I found skills and confidence to deal with stressful situations.”
- 082: “The thinking trap, because it’s all in the mind.”
- 083: “It gave me a better understanding of what I can control and what I cannot control.”
- 084: “The thinking part.”
- 085: “Coping strategies. We tend to forget about ourselves and need to be reminded.”
- 086: “How to handle a child with challenge behaviour. I was struggling a lot.”
- 088: “How to empower family dealing with intellectual disability was most helpful.”
- 089: “The control exercise and the ID course.”

- 090: “I found the most helpful is, emotional acceptance and commitment therapy, because I, myself, struggle to let my emotions out. I learned today that it’s okay to cry and let it out.”
- 091: “Cognitive distortions provided useful practical skills that can be applied daily.”
- 092: “Resilience.”
- 094: “Found most helpful the developmental needs, like scholastic skills and occupational therapy.”
- 095: “Self-care exercises.”
- 096: “Very helpful and very inspiring.”
- 098: “Really enjoyed the way we as attendees could communicate and share ideas. It was also presented very well.”
- 099: “It was most helpful that I don’t have to be great every day.”
- 100: “The discussion about terms used.”

In the following section, the researcher aimed to ascertain the respondents’ views on whether they felt more equipped to take care of a person with intellectual disability after having attended the training.

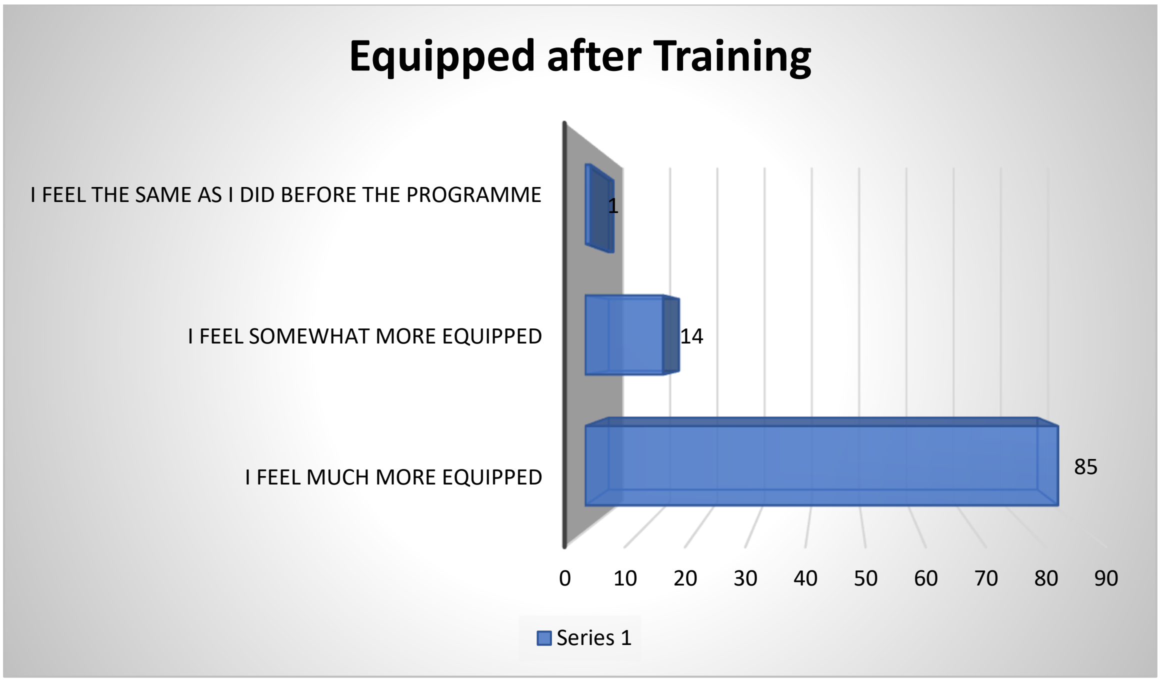


Figure 49: Degree of feeling equipped after training

According to Figure 49, 85 respondents felt much better equipped to take care of a person with intellectual disability after the training; fourteen felt ‘somewhat more equipped’, and one person felt the same after the training as before it.

The respondents were asked to elaborate on their answers, and only 55 of them commented. The following are their written comments: -

After attending this programme, do you feel more equipped in taking care of a person with intellectual disability?

- 004: “Verstaan nou beter hoe om mense met intellectual disability te hanteer.” (Understand better how to manage people with intellectual disability.)
- 005: “I can take the lead now. I now know not to control them, but to handle them with care.”
- 006: “It was nice being involved in this programme.”
- 007: “I learned a lot of skills.”
- 008: “I can help more people now.”
- 013: “This programme helps me see the bigger picture.”
- 016: “It makes me realise that I need to look after myself to be able to look after others.”
- 019: “I learned how to handle a person with intellectual disability.”
- 023: “I feel more equipped because of all the information.”
- 025: “Will now be a pleasure to take care of someone with intellectual disability.”
- 026: “You know now how they feel and how to handle them.”
- 027: “I learn to create a more splendid environment.”
- 030: “I feel more equipped because I learned new skills.”
- 032: “The stuff we learned today that I didn’t know the meanings. Now I’m up to date.”
- 033: “The content is compiled to assist the carer personally, as well as equip them with the task needed to work with the person with ID.”
- 040: “Yes, I feel more to taking care of intellectual disability.”
- 042: “I learned more about ID and will know better when working with an ID patient.”

- 043: “This is the first course about intellectual disability that I attended.”
- 046: “I learnt things I never knew.”
- 047: “I can take this to my workplace.”
- 048: “Yes, I need more equipment at the day-centre.”
- 049: “Now I know what to do and whom to contact when I need help.”
- 050: “I learned a lot of new things.”
- 051: “I enjoyed the exercise about locus.”
- 055: “I found the key factor of success.”
- 056: “I did learn something.”
- 057: “I have a better understanding of ID.”
- 058: “It was very helpful.”
- 059: “I understand more what to do.”
- 062: “Learned a lot about ID.”
- 063: “Can practice it.”
- 064: “Understand ID so much better now.”
- 066: “Learned more about people with ID.”
- 067: “Now I know how to handle a person with disability.”
- 068: “Need more of these programs.”
- 070: “I learned new research.”
- 072: “I learned new information to carry out and practice and make use of.”
- 074: “Activities to their need in the moment, not to stay on schedule.”
- 075: “Yes, I do feel more equipped to take care of an ID person.”
- 076: “I feel protected. I feel more care for a person.”
- 077: “We don’t get it all the time and such opportunities (for training) doesn’t fall out of the blue.”
- 080: “I have more greater perspective.”
- 083: “I will need a few more training sessions”
- 086: “I feel more equipped. I can go back knowing what to do.”
- 087: “I feel more equipped, because I can try to be more patient.”
- 088: “Made me much more aware how to deal with intellectual.”
- 089: “I feel better as a care worker.”

- 090: “I’ve learnt stuff I never knew before.”
- 093: “I feel much better. Thank you.”
- 094: “It is good and very motivating.”
- 095: “Gained valuable tools for coping strategies.”
- 096: “I can use the information.”
- 098: “Yes, I am aware that I am in control most times.”
- 100: “I received strategies of better handling my situations.”

In the following section the researcher aimed to establish whether the respondents thought that the programme might have a positive impact on alleviating caregiver distress.

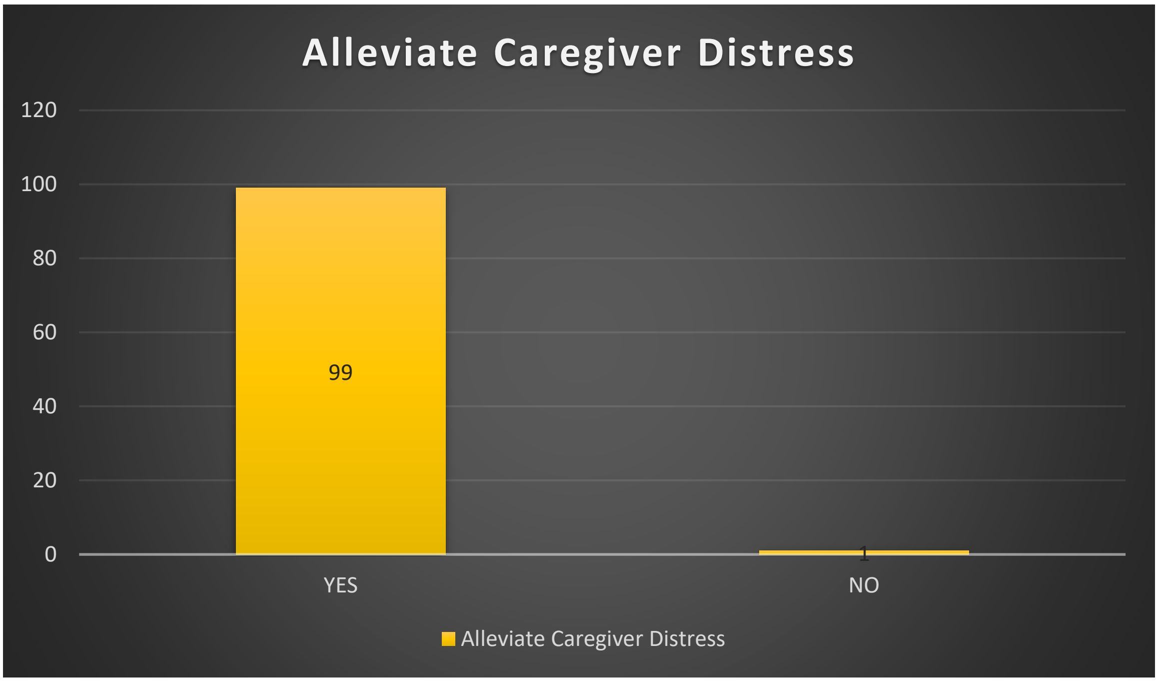


Figure 53: Alleviate caregiver distress

According to 99 respondents, the psychoeducational programme would have a positive impact in alleviating caregiver distress. However, one person did not think it would be beneficial for alleviating caregiver distress. These findings coincide with literature which states that a targeted psychoeducational programme that (a) provides education on disability, (b) provides practice guidelines in problem-solving and (c) renders opportunities for social support with others who have similar experiences, will, in turn, alleviate caregiver distress (Smith Da Walt et al., 2018:251-263).

The respondents were requested to elaborate on their selection; only 47 respondents commented. The following are their written comments: -

Would this psychoeducational programme have a positive impact on alleviating caregiver distress?

- 001: “Yes. Found ways to cope with stress and the need for self-care.”
- 003: “Absolutely. I enjoy and learn so much.”
- 005: “Now I can take care of myself and my health and handle my stress.”
- 006: “Helps me to look at things differently to stay calm.”
- 007: “I learned to have control over my boundaries.”
- 008: “The facilitator should keep on with what she’s doing.”
- 012: “I learned how to take care of people with ID.”
- 023: “Yes, because they didn’t do this training and know nothing about intellectual people.”
- 026: “It helps me to know how to handle my stress and my behaviour towards the residents.”
- 027: “I learned we can control how we feel in the workplace.”
- 028: “I have more knowledge now to take care of myself in my social life and the workplace.”
- 030: “I now know how to handle my feelings and how to put myself at ease.”
- 031: “Most definitely.”
- 032: “We learned so much today about taking care of ourselves.”
- 033: “Definitely!!!.”
- 034: “Especially the part about resilience.”
- 035: “I think so!.”
- 040: “Distress, yes. We learned more how to deal with a lot of disability.”
- 042: “I learned not to stress about things that are not important.”
- 043: “Yes, especially the part of resilience, and about the 7 C model of resilience.”
- 044: “Now I know how to handle my stress levels.”
- 046: “We learned things we never knew.”

- 047: “I now understand more about ID.”
- 048: “Yes, motivation.”
- 049: “Now I know where the focus should be, internal control and not to waste energy on out of control.”
- 050: “The course has made a huge difference.”
- 051: “I know now how to cope with stress.”
- 055: “I learned to strive to be a good enough caregiver.”
- 056: “I feel relieved.”
- 064: “Understand ID so much better.”
- 066: “Yes, because the caregiver is empowered with more knowledge.”
- 068: “Thinking of the second training session. Keep up the good work!!.”
- 072: “Yes, as it equips with useful techniques to do in order to destress.”
- 074: “The new ideas help me to deal with challenges and stress of the day.”
- 075: “Emotional acceptance and commitment therapy.”
- 076: “I feel more relieved.”
- 077: “I can be more useful to my patients.”
- 080: “I am less distressed now.”
- 082: “Yes, this program has a positive impact on distress.”
- 086: “Informative. It will give support.”
- 088: “Yes, it’s definitely positive.”
- 089: “I learned a lot of things as a caregiver.”
- 090: “We know better now; we can actually do better.”
- 091: “It’s important to engage in group sessions with other organisations to identify common issues and challenges.”
- 093: “Enjoyed it. Thanks.”
- 094: “Good and say thank you. Know what happened with intellectual disability.”
- 098: “Program has good strategies.”
- 099: “Caregiver to do some introspection.”

CONCLUSIONS FROM ABOVE

- The empirical findings of the second phase (quantitative approach) have been discussed. Most of the respondents believed the training yielded positive results and that they found it helpful.
- In most sections there was an increase in knowledge gained.
- Most indicated that this programme would be beneficial in alleviating caregiver distress.
- Most caregivers indicated that they received tools that empowered them as caregivers.
- This is an indication that the psychoeducational programme, as compiled in the present study, is effective in imparting knowledge.
- Further refinement of the programme is still required.

9.2.3 Section C: Qualitative Data derived from the Respondents' Views on the Psychoeducational Programme

At the end of the questionnaire itself there were questions which invited the respondents to evaluate, by means of written comments, certain aspects of the programme, as well as its possible value as a whole. Some respondents did not make use of this opportunity; however, most of them did, and their comments are given verbatim here below. The following categories and themes emerged from their responses: -

9.2.3.1 Reasons why the psychoeducational programme enables caregivers to take better care of a person with intellectual disability

The respondents noted that they felt more confident and better equipped in their function as caregivers, as the programme enhanced their understanding of intellectual disability, which contributed to their ability to take care of a person with ID. The following verbatim responses confirm that they believed they now had a better understanding of intellectual disability.

Theme 1.1 Conceptualising intellectual disability and understanding the needs of persons with ID

- "I really learnt things that I didn't know that was interesting."
- "Understanding the person now, understanding their needs"
- "I learned a lot on how to handle a person with a disability."
- "I learnt stuff I never knew about people with intellectual disability."
- "I know more about intellectual disability than before."
- "I have gained so much knowledge with this program."
- "I now understand the need of the person with ID."

Theme 1.2 Enablement of the caregivers to manage challenging behaviour

- "Changed my view on some tasks and provided me with tools that could be used."
- "This programme teaches us how to resolve conflict. How to engage on the level of the child."
- "This course helps a lot to be helping the person with ID more patiently."
- "I learned a lot more about what the caregiver must do."
- "Learning new things that I was not aware of."
- "I'm now more equipped to understand people with ID."
- "The material is designed to equip the caregiver, but also equip the person with ID to function better."
- "Now I know more how to handle people with intellectual disabilities."

9.2.3.2 Reasons why the psychoeducational programme will assist caregivers in regulating their personal emotional well-being

Theme 2.1 Alleviation of caregiver distress

- "I learned I am not a failure."
- "Meaningful to know what to do"

- “It provided an opportunity to reflect on myself and how I have been doing my job.”
- “This program gave me clarity on some situations.”
- “It helps me to make sound decisions on behalf of my client.”
- “Being informed like this is mind changing.”
- “I found the most helpful is, emotional acceptance and commitment therapy, because I, myself, struggle to let my emotions out. I learned today that it’s okay to cry and let it out.”

Theme 2.2 Development of self-care and coping tools and strategies

- “It gives you options in different parts of coping.”
- “Provided me with tools to assist me, did some soul searching as well.”
- “Valuable tools were provided regarding coping strategies, understanding your own needs, etc.”
- “It teaches ways on how to check in with myself.”
- “Being more in tune with myself and empowering the person with ID”
- “I found learning about coping styles most helpful. It helps me solving more problems; it reduces negative emotions associated with stress.”
- “Self-care and coping strategies. Now I know how to deal with the problem.”
- “I learned about how to handle stress and look after my health.”
- “Coping strategies. We tend to forget about ourselves and need to be reminded.”
- “Yes, this program has a positive impact on distress.”

Theme 2.3 Building resilience and internal orientation of control

- “It was very empowering.”
- I learnt a lot today. Even realised what I should work on.”
- “It was very uplifting.”
- “It did assist me in my role as a caregiver to be better in control of my emotions.”
- “I learned to strive to be a good enough caregiver and not to strive for perfection.”

- “Resilience. The 7 things that builds you as a person.”
- The Model of Resilience. Because it helps me to control myself.”
- “Yes, especially the part of resilience, and about the 7 C model of resilience.”

Theme 2.3 Empowerment of their support network

- “Empowering families. Coping skills. Caregivers are good people.”
- “This course covers a lot of things we handle on a daily basis, personally as well as in the workplace.”
- “I have learnt so much of everybody who talk about their experiences of control.”
- “I learnt that you need to ask for help and if you can’t handle it anymore, you need to take a break.”
- “Most helpful- Empowered family.”
- “Family empowerment was most helpful.”
- “How to empower family dealing with intellectual disability was most helpful.”
- “Now I know what to do and whom to contact when I need help.”

9.2.3.3 Recommendations regarding programme content

Here below follow further comments regarding the programme content: -

Theme 3.1 The need for a psychoeducational programme

- “It’s not all the facilities that there’s psychoeducational training.”
- “To train the course for the community in the outside world.”
- “This was my first training. Everything I knew, I learned on the job.”
- “Most caregivers have done a short course in caregiving, but do not have the tools and this program made it possible.”
- “I was never trained deep into ID. There are so much helpful points on how to cope with an ID adult.”
- “This is the first course about intellectual disability that I attended.”

- “Yes, because they didn’t do this training and know nothing about intellectual people.”

Theme 3.2 Theoretical content of the programme

Many comments and recommendations were requests for specific theoretical content. Some of these requests, such as specific training on autism fell outside the scope of the research study. (People with autism spectrum disorder do not necessarily have a dual diagnosis of intellectual disability.) However, these requests do highlight the need for caregiver training.

- “How to work with different kind of disabled people, like down syndrome, alcohol syndrome and autism.”
- “How to work with alcohol and autism people.”
- “Autism and Huntington Disease.”
- “The colostomy bag, like how you put it in and how you clean it.”
- “Focus more on sexuality part of intellectual disability.”
- “Schizophrenia and Huntington's Disease.”
- “About intellectual [disabled] clients who are gay.”
- “I still want to learn more about AIDS.”

During the very interactive training the question of sexuality regarding people with intellectual disability was discussed. The researcher briefly discussed the topic, as well as educating persons with ID on private and public touch and body parts, etc. The researcher referred the caregivers to the comprehensive course of Rebecca Johns from the WCFID on sexuality in intellectual disability.

Theme 3.3 The practical integration of programme content

- “Please present at different residential facilities.”
- “There should be a workshop where we should physically train with the person with intellectual disability.”
- “Content is brilliant, but I’m concerned about implementation.”
- “Please do more practical exercises.”

- "Have CDs, posters, calendar with pics."
- "The practical exercises were helpful."

Theme 3.4 Duration of the training

Three respondents made comments regarding the duration of the training. Two felt that the training was too long, and another suggested that the information be split over two days for more practical activities.

- "The training is too long and need more practical activities."
- "More activities and small group discussions. Caregivers are not used to sitting still for so long."
- "Split course into 2 days in order to get more practical experience."

Many respondents considered the training so informative that they requested the training to be done at their facility. Some asked to be contacted should the training course be offered again. Many recommended that the training be provided to the parents and informal caregivers of the people with intellectual disabilities.

Considering that the respondents worked in very diverse positions at their place of work (Figure 28), it would not have been possible to address all their various needs. However, the general comments of the respondents were positive and encouraging, as is borne out by these remarks:

9.2.3.4 Other remarks

Herewith some of the remarks: -

- "It was extremely informative and exciting."
- "The content is compiled to assist the carer personally, as well as equip them with the task needed to work with the person with ID."
- "Gained valuable tools for coping strategies"
- "Keep doing what you do, love. God bless"
- "Thinking of the second training session. Keep up the good work!!"
- "Program has good strategies"

9.3 SUMMARY

Most respondents indicated that the psychoeducational programme provided valuable knowledge and would be helpful in alleviating caregiver distress. They believed that the training yielded positive results and that they found it helpful.

Furthermore, the research yielded data on respondents' health and well-being. The most often mentioned health concerns amongst the caregivers were high blood pressure (19%), headaches (21%) and sleep problems (12%). However, 26% of respondents indicated no health concerns. Furthermore, 43% attributed their health concerns to work stress.

The research findings also yielded data on the caregivers' financial circumstances. A monthly salary of less than R5000 was indicated by 57% of the attendees for being caregivers of people with intellectual disability, and 71% of them admitted to experiencing financial challenges as caregivers. Lone caregivers (widowed, single, divorced) made up 55% of the group, which implies that there was not necessarily a second income at home. These research results were substantiated by academic literature which had established that most caregivers of ID are lone caregivers.

Notwithstanding the given challenges, the research results also indicated that most formal caregivers found their caregiving of people with ID, meaningful.

Prior to the training, most formal caregivers indicated a lack of understanding with regard to intellectual disability. However, after the training the quantitative data analysis showed an increase in understanding of this disability. The qualitative data analysis indicated that the caregivers were able to conceptualise intellectual disability and understand the needs of persons living with ID. It is important to note that, according to the data, most of them viewed the programme as having given them greater confidence and having equipped them better in their role and function as a caregiver.

Caregivers felt enabled to manage behaviour that challenges. The psychoeducational programme also alleviated caregiver distress by providing self-care and coping strategies, as well as building resilience and an internal orientation to control.

Moreover, the programme also focused on empowerment through social support and caregiver resourcefulness. Finally, the need for a psychoeducational programme was highlighted by the respondents who also made recommendations regarding further refinement of the programme by integrating practical components into the content of the programme.

The next chapter concludes the thesis.

CHAPTER 10
SUMMARY, CONCLUSIONS AND RECOMMENDATIONS

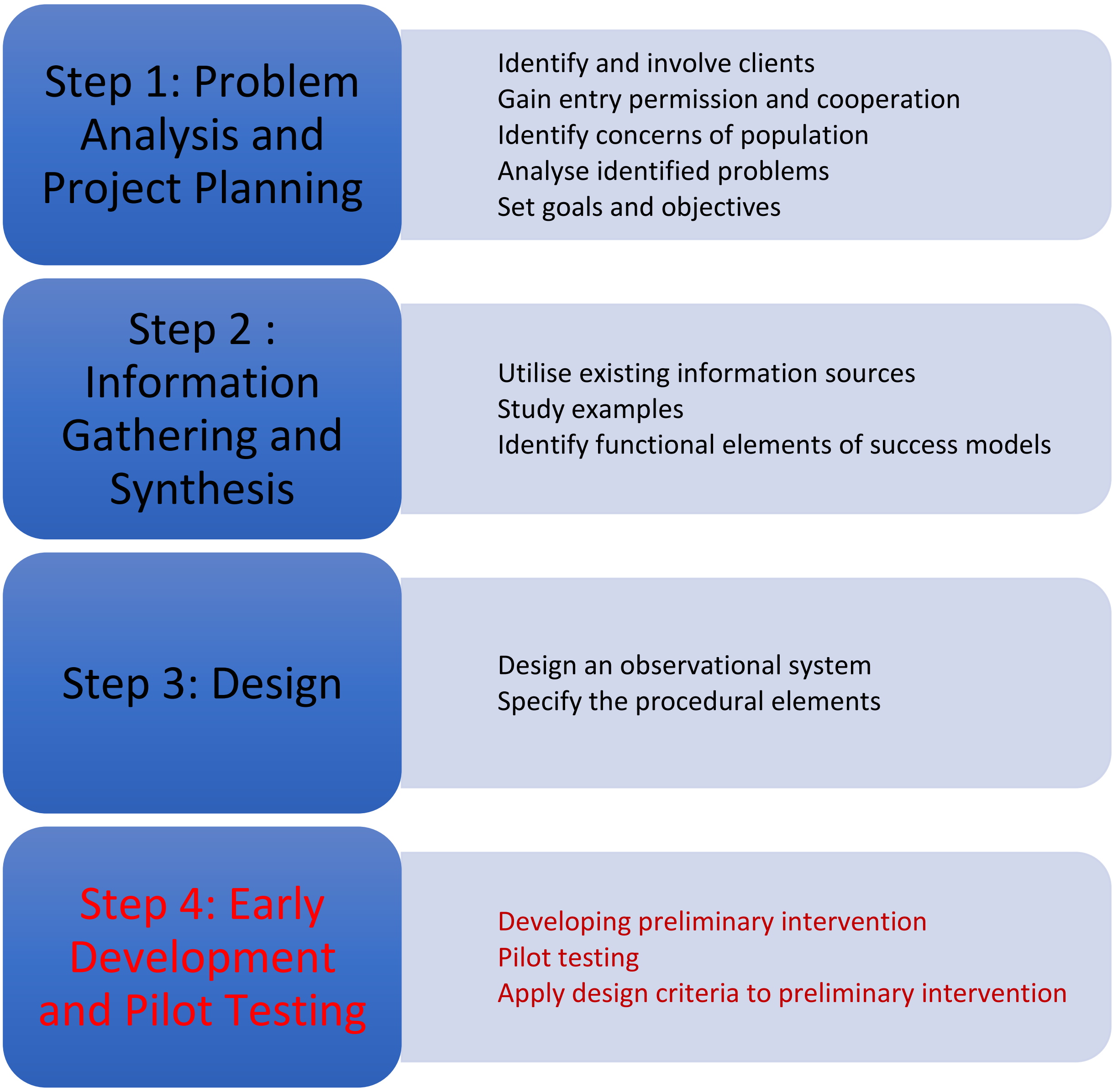


Figure 50: Graphic representation of phases of the intervention research. Adapted from Rothman and Thomas (1994:28); Fraser and Galinsky (2010:459-466)

10.1 INTRODUCTION

This research report consists of nine chapters.

Chapter 1 provides the introduction of the study, as well as the problem formulation, research goal, objectives and hypothesis. The chapter also describes definitions of key concepts. Limitations of the study are also highlighted.

In Chapter 2, an in-depth discussion of the theoretical framework underlying the study is provided, namely the strength-based approach and the biopsychosocial model. Cognitive behavioural therapy within the strength-based approach is also discussed as this provides the practice framework for the development of the psychoeducational programme.

Chapters 3, 4 and 5 offer an in-depth literature review on three core concepts. Chapter 3 is a literature review conceptualising intellectual disability. Chapter 4 focuses on previous research regarding the care needs of people with intellectual disability and the resultant impact on the caregiver. Main concepts, such as caregiver distress and caregiver burden, are also described. Moreover, applicable legislations are also provided. Chapter 5 provides a literature overview on the significance of a psychoeducational programme for caregivers of the people with intellectual disability, and the core elements that should be included to enhance caregiving skills and alleviate caregiver distress.

Chapter 6 contains a detailed discussion of the research methodology that was applied in the study, more specifically the research approach, the type of research, and the phases of intervention research that were followed. The chapter also describes the research population and sampling method.

Chapter 7 provides an analysis of the empirical findings of the qualitative phase of the research. Valuable information derived from the literature reviews, together with the empirical findings of the in-depth interviews with informal caregivers, formed the basis of the content of the psychoeducational programme outlined in Chapter 8.

As stated, Chapter 8 captures the outline of psychoeducational programme which comprises of four modules namely, psychoeducation of the caregiver; psychosocial impact on the individual caregiver; strengthening the family unit and accessing and development of resources.

Chapter 9 provides the empirical findings of the quantitative phase of the research and discusses the research data after the formal caregivers had completed the psychoeducational programme. The analysis of the data is presented and discussed in identified themes, and the paired *t*-test further validates the findings.

In this chapter, Chapter 10, the researcher will conclude the study. Firstly, she will ascertain whether the goal and the objectives of the study were achieved, and answer the question posed by the study. Secondly, the key findings will be discussed, followed by the conclusions drawn. The researcher will, furthermore, provide recommendations for practice and research.

10.2 RESEARCH GOAL AND OBJECTIVES

The goal of the study was to: -

(i) develop,
(ii) implement,
(iii) and evaluate a psychoeducational programme for Western Cape caregivers of people with intellectual disability, the former being the unit of analysis in the study.

This goal was achieved through the development of a psychoeducational programme based on the findings of the first phase, which was then implemented and evaluated in the second phase. The attendant caregivers each completed a pre- and post-test questionnaire. It became clearly evident that there was a need for a psychoeducational programme for caregivers of people with intellectual disability in the Western Cape.

Furthermore, the goal of the study was achieved by meeting the objectives of the study which were categorised into two phases, namely the qualitative and the quantitative phases, and which are briefly discussed here below.

10.2.1 Realisation of the objectives of the first (qualitative) phase

The realisation of the four objectives of the first and qualitative phase are summarised below.

Objective 1: To contextualise caregiving of people with intellectual disability based on the biopsychosocial model and strength-based approach

In Chapter 2 the in-depth discussion focuses on the contextualising of caregiving of people with intellectual disability employing the theoretical framework of the biopsychosocial model and strength-based approach.

In the context of caregiving of people of intellectual disability three aspects, namely the biological, psychological and social ones, were individually covered. The biopsychosocial model examines how the three aspects play a role in a person's well-being, and furthermore emphasises the interconnectedness of these factors.

The strength-based approach was discussed by contextualising caregiving of people with intellectual disability within the core-strength principles of social justice, transparency, empowerment, collaborative partnership, resilience and strength building. Cognitive behavioural therapy, from a strength-based perspective and as a practice framework for the development of a psychoeducational programme for caregivers of people with intellectual disability, was also covered.

Therefore, the exploration and discussion led to the achievement of this objective.

Objective 2: To explore the experiences of caregivers caring for people living with intellectual disabilities

In Chapter 6, the first-hand experiences of informal and unpaid caregivers were explored by interviewing 25 participants. The following experiences were covered: -

- Lack of information at diagnosis
- Beliefs, causes and denial of intellectual disability
- Educational transition plan

- Difficulties in managing behaviours that challenge
- Financial constraints of the caregiving persons
- Concerns about future care of and provision for the person with intellectual disability
- Barriers to accessing healthcare, legal and social services
- Barriers to protective workshop placements
- Barriers to placements in residential group homes
- The need for respite care
- The lack of transportation
- Difficulties with safety and maintaining a disability-friendly home
- Social support, family conflict and caregiver isolation
- Community stigmatisation
- Personal psychological and physical health
- Resilience

The literature review regarding these said experiences was presented in Chapters 3 and 4. Therefore, the exploration and discussion led to the achievement of this objective.

Objective 3: To gather information regarding the care needs of people living with intellectual disabilities and the impact thereof on caregivers

In Chapter 3, an in-depth literature overview pertaining to the care needs of people with intellectual disability, and the impact this has on caregivers, was offered. Caregiver burden and applicable legislation were also discussed.

The following topics were covered and their role and impact on caregivers: -

- Developmental needs
- Pharmacological needs
- Emotional needs
- Environmental needs
- Assistance with daily living
- Financial needs

Objective 4: To ascertain the specific knowledge and skills required by caregivers of people living with intellectual disabilities

In Chapter 4, a literature overview of specific knowledge and skills to be included in a psychoeducational programme for caregivers in the management of people with intellectual disability is provided.

The following was covered:

- The significance of a psychoeducational programme for caregivers of people with ID
- Psychoeducation of formal caregivers
- Psychoeducation of informal caregivers
- Knowledge on intellectual disability
- The resilient caregiver
- The resilient family
- The resilient community

The following discussion focuses on how the objectives of the second phase were realised: -

10.2.2 Realisation of the objectives of the second (quantitative) phase

The purpose of this phase was to design, implement in a pilot test and subsequently evaluate a psychoeducational programme for caregivers of people with intellectual disability. This entailed meeting six further objectives.

Objective 5: To design a psychoeducational programme for caregivers of people with intellectual disabilities based on the needs identified in the first phase

The psychoeducational programme was designed based on an extensive study of literature, as well as the findings of the first qualitative phase during which several needs and skills required by caregivers of people with ID, were identified. The researcher developed a training manual which consists of four modules comprising several topics. The manual and questionnaires were first piloted with a smaller group of respondents to address any ambiguity that might exist and that could impact the research results of the larger group. The programme was implemented in step 4 which is the early development and pilot-testing of intervention research with a one-day training workshop and, therefore, still needs further refinement. The contents of the manual are discussed in more detail in Chapter 7 which, for the purposes of the thesis, was shortened to provide an overview.

Objective 6: To conduct a pre-test measurement with attendant caregivers regarding their knowledge of caregiving of people with intellectual disabilities

The second phase of the mixed-methods research was based on the quantitative approach in which the researcher used the pre-experimental design, namely the 'one-group pre-test post-test design'. This design facilitated valuable interpretations and comparisons regarding the impact and value of the psychoeducational programme. The researcher aimed to assess whether the psychoeducational programme, the independent variable, had a positive impact on the caregivers' understanding of intellectual disability, one amongst other dependent variables. The researcher used a Likert-scale questionnaire with the format of the items in the questionnaire being both closed-ended (e.g., multiple-choice or ranking) and very basically open-ended (short-answer questions). Before the commencement of the training, the respondents completed this pre-test questionnaire so that the researcher could measure and assess their understanding of intellectual disability. The researcher then conducted the psychoeducational training programme.

Objective 7: To implement the psychoeducational programme through training of caregiving during a one-day session

Formally employed caregivers of people with ID were invited from all the regions of the Western Cape. The psychoeducational training programme was conducted in the venue of a special-needs education centre for children with intellectual disability in Stellenbosch, Cape Town. Being cognisant of COVID regulations and venue size, the researcher split the 100 respondents into two groups and offered the one-day training programme on two consecutive days. The programme was very interactive, including a colourful and creative PowerPoint presentation, lively discussion of the content, and practical exercises, such as the breathing exercise and locus of control exercise. Each participant received a manual. Details are captured in Chapter 9.

Objective 8: To conduct a post-test measurement with the caregivers regarding their knowledge of caregiving of people with intellectual disabilities after completion of the training

Once the training programme had been concluded, the respondents completed a post-test questionnaire which enabled the researcher to measure and assess whether their understanding of ID had improved. The results indicated that a positive change had occurred and, therefore, the researcher concludes that the intervention, the psychoeducational programme, was the cause of this improvement. Details have been captured in Chapter 8.

Objective 9: To analyse the effectiveness of the programme by comparing pre- and post-test results

The respondents provided valuable feedback details of which are discussed in Chapter 9. Many caregivers requested the training to be done at their facility for their colleagues who were unable to attend due to caregiver-work obligations. Some caregivers also requested that the training be done virtually for caregivers in more far-flung regions of the Western Cape for whom travelling would have posed a problem.

Objective 10: To draw conclusions and make recommendations based on the research findings for further refinement and implementation of the proposed psychoeducational programme

The researcher is of the opinion that Objective 10 has been achieved through the scope of developing, pilot-testing and implementing the preliminary psychoeducational programme. Conclusions and recommendations have been made based on literature and the empirical findings. The recommendations assent to the applied research which was the scientific planning of induced change in a troublesome situation. Objective 10 is addressed at the end of this chapter where recommendations are provided.

Based on the above information, it is evident that the goal and objectives of the present study have been realised.

10.3 TESTING RESEARCH QUESTIONS AND HYPOTHESIS

Research question

This study asked the following **main research question**:

“What constitutes a psychoeducational programme for caregivers of people living with intellectual disability?”

The research question was answered during the data collection and data analysis phases of the mixed-methods research process.

The following **sub-questions** informed the main research question: -

- *What is the nature, extent, cause, and impact of caregiver distress amongst caregivers of people with intellectual disability?*

  The researcher was able to answer this sub-question from literature, feedback from experts and empirical data and comprehensively fleshed out throughout this thesis. More specifically in Chapter 6, the nature, extent, cause and impact of caregiver distress amongst caregivers of people with intellectual disability was categorised and is extensively discussed with regard to the following factors: -
    - ➢ The lack of psychoeducation of the caregiver
    - ➢ Socio-Economic impact
    - ➢ Caregiver resource constraints
    - ➢ Psychosocial impact on the caregiver

- *What core elements should be included in a psychoeducational programme that would alleviate caregiver distress?*

The researcher was able to answer this sub-question from literature discussed in Chapter 5, as well as from the input of experts and the analysis of the empirical data. A manual was developed based on a collaborative approach of experts and caregivers and underpinned by literature. The manual comprises the following four modules, as described in Chapter 8.

- Psychoeducation of the caregiver on intellectual disability
- Psychosocial impact on the individual caregiver
- Strengthening the family unit
- Accessing and developing resources

Based on the discussion above it is evident that the research question and sub-questions have been answered.

Research hypothesis

Hypothesis testing is the process of inferring from sampling to population (Pietersen & Maree, 2011a:203).

Hypothesis

If caregivers participate in the psychoeducational programme developed during this study, this will have a positive impact on the alleviation of caregiver distress, and their level of knowledge and resilience skills will improve as they render caregiving services to people with intellectual disabilities in the Western Cape.

Sub-hypothesis

A psychoeducational programme for caregivers will improve their knowledge and skills, as well as have a positive impact on alleviating caregiver distress of caregivers of people with intellectual disabilities in the Western Cape.

Empirical research

The researcher tested the hypothesis and sub-hypothesis in the first four phases of the intervention research. An intervention programme was developed and implemented in the current study. The researcher used the pre-experimental design, namely the 'one-group pre-test post-test design' which was effective in testing the hypothesis and sub-hypothesis.

The researcher collected data whilst the respondents attended a one-day training programme. The pre-test questionnaire was administered prior to the preliminary intervention programme. When the intervention programme had been concluded the post-test questionnaire was administered to measure whether the programme had increased the respondent's knowledge and whether they believed that it would make a positive impact on the alleviation of caregiver distress.

Responses were given on a four-point Likert scale ranging from 'strongly disagree' to 'disagree', and from 'strongly agree' to' agree' on both the pre- and post-test questionnaire. The pre- and post-test results were merged and analysed. The researcher was able to make valuable interpretations and comparisons regarding the impact and value of the psychoeducational programme.

The statistical findings revealed that there was an increased level of knowledge after the intervention programme. Furthermore, 99% of attendees indicated that the psychoeducational programme would have a positive impact in alleviating caregiver distress. The research results also show that 85% of attendees felt much better equipped to take care of a person with intellectual disability after the training.
Therefore, the hypothesis has been empirically tested. It can be concluded that the preliminary psychoeducational programme yielded positive results and confirmed that it is effective in increasing knowledge and decreasing caregiver distress.

10.4 KEY FINDINGS

The study indicated the following key findings as categorised here below: -

10.4.1 Key Findings in Triangulation between the Qualitative and Quantitative Phases

The researcher analysed the data of the qualitative and quantitative phases and made the following observations: -

- Research findings suggest a lack of understanding of intellectual disability and psychoeducation in both the informal and formal caregivers prior to training.
- Caregivers of people with ID are predominantly female: 94% of the formal caregivers (quantitative phase) and 84% of the informal caregivers (qualitative phase) were females.
- Caregiving of people with ID can be financially costly, as 66,7% of the informal caregivers were unemployed and 57% of the formal caregivers earned less than R5000 per month. Furthermore, 71% of all caregivers involved in this research indicated having experienced financial challenges as caregiver.
- Moreover, 55% of the formal caregivers (quantitative phase) and 57% of the informal caregivers (qualitative phase) were lone caregivers.
- The research results also indicated expressed levels of anxiety in both informal and formal caregivers, with 63% of the formal caregivers admitting that they had experienced frustration and anxiety when taking care of someone with intellectual disability.

10.4.2 Key Findings when correlating the pre-test and post-test Questionnaires

A significant number of respondents moved from a negative response prior to the intervention of the psychoeducational programme to a positive response after the training.

- Prior to the training, 36% of the attendees believed that they were confident in their understanding of intellectual disability. After the training, 92% of attendees believed that their confidence in understanding intellectual disability had increased.
- Whereas only 27% of attendees indicated, before the training, that they were confident in their knowledge of developing resilience, this percentage increased to 90% after the training.
- Before the training programme, 22% of the respondents felt confident with regard to their knowledge of resourcefulness. After the training programme, 90% of respondents indicated that they were confident in their knowledge of resourcefulness.

- While, before the training, 27% of the respondents had confidence in their knowledge of managing troublesome behaviour, after the training, 89% of the respondents indicated that they were more confident with regard to managing such behaviour.
- Prior to training, 28% of the respondents indicated that they were confident in their knowledge of emotional acceptance. After the training, 88% of respondents indicated that they were confident in their knowledge of emotional acceptance.
- Prior to training, only 24% of the attendant caregivers were confident in their knowledge of cognitive distortions. However, this percentage rose to 89% after the training.
- Prior to training, 21% of the respondents indicated that they understood the concept of the dichotomy of control. This percentage rose to 89% after the training.
- Only 27% of respondents indicated, before the training, that they were confident in their self-care and coping strategies. However, after the training, 88% indicated that they believed they were well-informed regarding self-care and coping strategies.
- Prior to training, 23% of attendees believed that they were confident in their knowledge of the empowered family. This percentage rose to 89% after the training.

10.4.3 Key findings regarding the psychoeducational training programme

- The psychoeducational training programme is an effective intervention tool for caregivers of people with ID.
- There was a significant increase in confidence with regard to caregiving after the intervention of the training programme, with 85% of respondents indicating that they felt much better equipped to take care of people with ID.
- As for recommending the programme, 98% of respondents indicated that they would certainly recommend it.

- Most respondents, a total of ninety nine percent (99%) indicated that the psychoeducational programme would be beneficial for alleviating caregiver distress.
- The qualitative findings indicated that further refinement of the programme was required.

10. 5 Challenges and Strengths of the Study

10.5.1 Challenges

Limitations of the study were discussed in Section 1.8. The following were found to be further challenges to the study: -

- The research was relatively costly. The venue was provided for free; however, the printing of training materials and questionnaires, the stationery and refreshments were funded by the researcher.
- The language barriers of the respondents may also have hampered the study as the questionnaires were in English which, for most of the respondents, was their second language. This could have impacted the outcomes of the research as it relates to how the questions were understood and answered.

10.5.2 Strengths

Notwithstanding the mentioned limitations, the strengths of the present study were identified as follows:

- This study adds to the – presently very inadequate - body of knowledge on training caregivers of people living with ID.
- The strength of this study lies in the implementation of the intervention progamme which has proved to reduce caregiver distress. The respondents reported that feelings of social isolation, hopelessness, depression, anxiety and low self-esteem, which increase the sense of burden in caregivers, had been reduced.
- The psychoeducational programme applied in the present study, was underpinned by two strong theoretical frameworks, namely the biopsychosocial theoretical framework and the strength-based approach.

- In addition, the various exercises and discussions around each topic, as well as the questionnaires that allowed the caregivers to provide feedback, were other strengths of this study.
- Furthermore, an additional benefit of the study is that it can assist organisations that provide residential care to people with intellectual disability. The management of these authority structures are able to develop a greater awareness of the disposition and inner struggles of the formal caregivers to whom they entrust the care of the persons with intellectual disabilities. The information would provide management with the opportunity to reassess the mechanisms in place at their facilities: Do they adequately address the plight or needs of the formal caregivers? Does management provide them with the necessary tools to enhance their work-related skills?
- Another strength is the utilisation of the mixed-methods approach that contributed to its being a comprehensive study. The advantage that accrued from integrating the two forms of data was that the researcher used the qualitative data to assess the validity of quantitative findings. The researcher also used the quantitative data to explain findings derived from the qualitative data.
- The research design and the use of reliable instruments also provided validity to the research data analysis and findings.

10.6 CONCLUSION TO THE STUDY

The study documented the nature, causes and impact of caregiver distress. Furthermore, this study highlights the importance of the psychological well-being of caregivers of people with ID. These findings illustrate the need for and value of the psychoeducational programme as it alleviates caregiver distress and enhances their psychological well-being. Future research for the sake of refining the programme is recommended.

10.6 Recommendations

The results of the research study have important implications.

10.6.1 General recommendations

- According to the results of the present study, the psychoeducational programme can educate caregivers regarding cognitive distortions, as well as provide positive coping strategies. Using these strategies in challenging caregiving situations, caregivers could develop a greater sense of ease and confidence despite resource constraints.
- The knowledge generated and present in this research yields important insights for social workers and other health professionals to render relevant intervention programmes, support and resources not only to persons with intellectual disability but also to their caregivers.
- The study allowed the researcher to address the scientific gap identified in the literature. The contribution that the study aimed to make is that it would particularly benefit people living with intellectual disability as it has the possibility of enhancing the insight, knowledge and skills of their parents, siblings, and neighbours upon whom they depend for their daily care.
- Formally employed caregivers need ongoing support and mentoring by their management based on the content of the psychoeducational programme. There should be a review of the demands placed on them and the opportunities provided to them to make decisions and to utilise their skills.

10.6.2 Recommendations for future research

The researcher considered the caregivers’ feedback for future further development of the intervention programme: -

- A critical next step is to refine the psychoeducational programme and continue educating caregivers on the most effective strategies for resilient caregiving.
- Findings from this study reinforce the need to develop further collaboration between social and healthcare service providers and caregivers to enhance the latter’s caregiving ability.
- Future research in a longitudinal study is required to establish whether the implementation of this intervention programme has had a sustained effect on the caregiver, the person with ID, their family and community.

- It is suggested that future research should focus on gaining an understanding of the phenomenon that predominately females are generally placed in the position of caregivers of people of ID.
- Creating awareness and understanding of intellectual disability that would aim at transforming stereotyping perceptions such as disability is an act of God for immoral acts could further guide future research on this topic.
- The study calls for policies, procedures and resources to be put in place to address the needs of caregivers and for future initiatives to include research that would address the structural barriers such as community stigmatisation, financial hardship and the lack of respite care.
- Drawing on the results of this study, it is recommended that further research be done into the needs of caregivers concerning resource distribution versus focusing exclusively on resources for people with intellectual disabilities.
- Social work interventions should include social support networks to caregivers of people with ID to alleviate caregiver distress. Future research could consider examining the relationship between social support structures and caregiver distress.
- Moreover, future research could investigate the creation of early intervention programmes that focus on individual acceptance counselling, social support groupwork intervention, as well as psychoeducational training for caregivers whose child has been newly diagnosed with ID.

10.7 CONCLUDING REMARKS

It is essential to understand that caregivers of people with intellectual disability have diverse needs and, therefore, a psychoeducational programme that has a “one-size-fits-all’ approach is not entirely appropriate. Caregivers should be consulted and included in programme development. The programme should be adaptable to be bespoke to the changing and cultural needs of the caregiver. This notion includes consulting caregivers with regard to health and social service evaluations. Finally, caregivers and caregiver families should be included in resources distribution which should be appropriately tailored and allocated for the use of the person with ID, as well as his or her caregiver and household.

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APPENDIX 1: Ethical clearance letter

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Faculty of Humanities
Fakulteit Geesteswetenskappe
Lefapha la Bomotho

Humanities 100.
Since 1919

09 November 2020

Dear Mrs BK Gordon

Project Title:	A psychoeducational programme for caregivers of people with intellectual disability within the Western Cape
Researcher:	Mrs BK Gordon
Supervisor(s):	Dr NJ Bila
Department:	Social Work and Criminology
Reference number:	13321252 (HUM034/0720)
Degree:	Doctoral

I have pleasure in informing you that the above application was **approved** by the Research Ethics Committee on 09 November 2020. Data collection may therefore commence.

Please note that this approval is based on the assumption that the research will be carried out along the lines laid out in the proposal. Should the actual research depart significantly from the proposed research, it will be necessary to apply for a new research approval and ethical clearance.

We wish you success with the project.

Sincerely,

Prof Innocent Pikirayi
Deputy Dean: Postgraduate Studies and Research Ethics
Faculty of Humanities
UNIVERSITY OF PRETORIA
e-mail: PGHumanities@up.ac.za

APPENDIX 2: Organisational permission letter

WCFID
Western Cape Forum for Intellectual Disability
WESKAAP FORUM VIR INTELLEKTUELE GESTREMDHEID — IQUMRHU LE NTSHONA KOLONI LOKHUBAZEKO NGENGQONDO
ADDING SKILLS • ADDING KNOWLEDGE • ADVANCING RIGHTS

27 October 2020

For attention: Bonita Gordon - Student number 13321252

Dear Bonita

RE: A psycho-educational programme for caregivers of people with intellectual disability within the Western Cape.

Thank you for sending us your preliminary research proposal and detail.

The Western Cape Forum for Intellectual Disability can confirm that we fully support your research.

We are therefore pleased to inform you that you have our permission to undertake the above-mentioned study.

We request that copy of the final report be provided to us after the completion of the study.

We would like to take this opportunity to wish you every success in your studies, and to thank you for your continued contribution to the sector.

Yours sincerely

Tessa Wood

Tessa Wood

Director

WCFID

A SUPPORT NETWORK FOR TRAINING - ADVOCACY - RESOURCES
☎ 021 510 4686 021 510 4687 www.wcfid.co.za www.facebook.com/wcfid
ASAT HOUSE, Alexandra Hospital, 8 Annex Road, Maitland 7405 PO Box 142, Maitland 7404
Reg. No: 000-888 NPO PBO No: 18/11/13/2392 VAT No: 4100 211772
est. 1971
NLC NATIONAL LOTTERIES COMMISSION LOTTO FUNDED

APPENDIX 3: Informed consent

UNIVERSITEIT VAN PRETORIA
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YUNIBESITHI YA PRETORIA

Faculty of Humanities

Department of Social Work & Criminology

Introduction: Invitation to participate in research project titled:

A psychoeducational programme for caregivers of people with intellectual disability within the Western Cape.

Dear Caregiver

I am a qualified social worker, enrolled for a doctoral degree at the University Pretoria. I am undertaking the development of a psycho-educational programme for caregivers of people with intellectual disability within the Western Cape and conducting research to meet this aim.

As a caregiver of people with intellectual disability, you are in the ideal position to provide us first-hand information from your own perspective.

You are therefore invited to take part in the research study. If you are willing to participate, please find the informed consent form for additional detail. Please do not hesitate to contact me if you have any queries on 0835050756.

Warm regards
Bonita Gordon

Fakulteit Geesteswetenskappe
Lefapha la Bomotho

Researcher: Bonita Gordon
Tel: 083 5050756
Email: Bonitakgordon@gmail.com

INFORMED CONSENT

1. **RESEARCH TITLE:** A psychoeducational programme for caregivers of people with intellectual disability within the Western Cape.

2. **PURPOSE OF THE RESEARCH STUDY:** The study aims to develop, implement and evaluate a psychoeducational programme for caregivers of people with intellectual disability, within the Western Cape.

3. **PROCEDURES:** I understand that as a caregiver to a person living with intellectual disability, I will participate in the interview or completion of the questionnaire with regards to the aim of the study that will approximately be for the duration of 30-45 minutes of my time.

4. **RISKS INVOLVED IN THE RESEARCH STUDY:** I understand that I will not be subjected to any harm and that the researcher will make every effort to conduct this research in a manner that will minimize possible harm. I understand that should the question be of a sensitive nature; I do not have to answer it. I will inform the researcher should I be negatively affected by the research. I understand that the researcher will refer me to professional counsellor, Kay Cikizwa. The counsellor, Kay Cikizwa will render counselling sessions free of charge can be contacted at 021 503 5079. I understand that the researcher guarantees confidentiality.

   I understand that I have the right to withdraw from the research at any time without having to explain why. I can ask questions about the proposed study before signing consent. I have the right to access my data. I understand that the researcher will when writing up the research results, comply with UP's policies regarding plagiarism.

5. **BENEFITS OF THE RESEARCH STUDY:** I understand that I will not be paid for participating in this research project. However, I do understand and support that the long-term benefits are that the outcome of the research will be contributing towards a

proposed psychoeducational manual that would be meaningful to caregivers and organisations that works with people with intellectual disability.

6. **VOLUNTARY PARTICIPATION:** Although the researcher seeks my permission to be part of the research, it does not obligate me to do so. My participation is voluntary. I will be free to withdraw my participation at any point and will experience no negative consequences.

7. **RECORDS OF PARTICIPATION IN THIS RESEARCH:** I understand that the information provided will be protected and my responses will be kept confidential. Filled questionnaires will be stored in a locked cabinet. The only individuals who will have access to this information will be those directly involved with this research project that have been trained in methods to protect confidentiality. The research information will be safely stored at the Department of Social Work and Criminology, University of Pretoria for a period of fifteen years. The results of this research may appear in publications, but I will not be identified.

8. **AGREEMENT TO PARTICIPATE IN THE RESEARCH STUDY:** My signature indicates that I have read, or listened to, the information provided above and that I received answers to my questions. I have freely decided to participate in this research, and I know I have not given up any of my legal rights.

9. **CONTACT DETAILS OF THE RESEARCHER:** Bonita Gordon can be contacted at 0835050756 at any time or I can e-mail bonitakgordon@gmail.com if there are any questions or concerns relating to the research study.

CONTACT DETAILS OF THE SUPERVISOR OF RESEARCHER: I understand that the researcher is being supervised by Dr Nontembeko Bila who can be contacted on 0214202599 during office hours. Alternatively, I can send an email to Dr Bila on Nontembeko.bila@up.ac.za

I, the undersigned, understand my rights and I voluntarily consent to participate in this research study. I understand what the study is about and how and why it is being done.

To be completed by the researcher and the participant:

Participants' name: ……………………………………………………………

Participants' signature: ……………………………………………………………

Researcher's name: ……………………………………………………………

Researcher's signature: ……………………………………………………………

Date: ……………………………………………………………

I hereby freely give my permission to participate in this research project.

This document was signed at _____________________________ on the __________day of

__________________________________2021/2

APPENDIX 4: Social worker counselling letter

Kay Cikizwa
Alexandra Hospital
c/o Annex and Alexandra Roads
Maitland
7450
12 July 2020

Bonita Gordon
28 Rose Innes road
Bloubergrant
Blouberg
Cape Town
8000
Dear Mr./Ms

RE: Counselling sessions for participants/respondents of research studies

I am a qualified social worker, working with people living with Intellectual Disability and their families for the past 16 years.

I acknowledge the research conducted by the student, Bonita Gordon (student number: 13321252) for the research entitled: "A psycho-educational programme for caregivers of people with intellectual disability within the Western Cape".

I will render counselling sessions for any participant or respondent that are partaking in the above-mentioned research project. These counselling sessions will be rendered free of charge.

Sincerely

Kay Cikizwa

Social worker

021 503 5000/79

Structural Interview Schedule

Interview schedule

1. **Biographic information**

1.1 Biographic information (Unpaid Caregiver)

Age :
Gender :
Marital status :
Number of children :
Religion :
Home language :
Highest qualification :

1.2 Biographic information (Person with Intellectual disability)

Age :
Gender :
Marital status :
Number of children :
Religion :
Home language :
Highest qualification :

2. **Knowledge of intellectual disability**
   - What does intellectual disability mean?
   - First place visited for assistance for formal health support
   - Involvement in care plan and understanding of the care plan?

3. **Mental health and the family**
   - Tell me about your family member who is living with intellectual disability
   - When and how did you find out that your family member had intellectual disability
   - Can you tell me about your experiences within the family home, living with a person with intellectual disability?
   - What are some of the behaviors that challenges if of the person with intellectual disability?
   - Did you have to deal with sexual inappropriate behavior with the person with living with Intellectual disability? Tell me about that
   - Did you ever have to deal with legal involvement due to behavior of the person with intellectual disability?
   - How has the

4. **Burden of care and coping**

- What are your feelings about caring for a person with intellectual disability? Anger? Resentment? Grief? Incompetency?
- What impact has caring for your family member had on the different areas of your life? Financially
- Describe your daily role as caregiver
- What valuable lessons have you learnt in your time caring for your family member?
- Family support to you as caregiver? Relatives?
- What do you do to cope with your role as caregiver? Self-care routines?
- What do you need help with?
- Any positive experiences?
- What do you think you do well?

5. Resources Services

- What resources are there in community for psychiatric treatment or care?
- What services are there in your community for people living with intellectual disability?
- Are these services accessible? Please explain how you have to access these services?
- What services are there in your community that provides support and education to caregivers?
- Are there a manual that you are aware of that could assist you as a caregiver of someone with intellectual disability?
- How has the community treated your loved one?

6. Social work intervention

- Any interaction with/referral to a social worker regarding loved one?
- What kind of assistance did they give?
- Your experience of their intervention?

7. Recommendations

- Do you have any recommendations for programmes for caregivers in your community?
- What are the needs do you have that you wish a manual could address?

APPENDIX 5: Structural interview Schedule

Interview schedule

8. Biographic information

1.1 Biographic information (Unpaid Caregiver)

Age :
Gender :
Marital status :
Number of children :
Religion :
Home language :
Highest qualification :

1.2 Biographic information (Person with Intellectual disability)

Age :
Gender :
Marital status :
Number of children :
Religion :
Home language :
Highest qualification :

9. Knowledge of intellectual disability

- What does intellectual disability mean?
- First place visited for assistance for formal health support
- Involvement in care plan and understanding of the care plan?

10. Mental health and the family

- Tell me about your family member who is living with intellectual disability
- When and how did you find out that your family member had intellectual disability
- Can you tell me about your experiences within the family home, living with a person with intellectual disability?
- What are some of the behaviors that challenges if of the person with intellectual disability?
- Did you have to deal with sexual inappropriate behavior with the person with living with Intellectual disability? Tell me about that
- Did you ever have to deal with legal involvement due to behavior of the person with intellectual disability?
- How has the

11. Burden of care and coping

- What are your feelings about caring for a person with intellectual disability? Anger? Resentment? Grief? Incompetency?
- What impact has caring for your family member had on the different areas of your life? Financially
- Describe your daily role as caregiver
- What valuable lessons have you learnt in your time caring for your family member?
- Family support to you as caregiver? Relatives?
- What do you do to cope with your role as caregiver? Self-care routines?
- What do you need help with?
- Any positive experiences?
- What do you think you do well?

12. Resources Services

- What resources are there in community for psychiatric treatment or care?
- What services are there in your community for people living with intellectual disability?
- Are these services accessible? Please explain how you have to access these services?
- What services are there in your community that provides support and education to caregivers?
- Are there a manual that you are aware of that could assist you as a caregiver of someone with intellectual disability?
- How has the community treated your loved one?

13. Social work intervention

- Any interaction with/referral to a social worker regarding loved one?
- What kind of assistance did they give?
- Your experience of their intervention?

14. Recommendations

- Do you have any recommendations for programmes for caregivers in your community?
- What are the needs do you have that you wish a manual could address?

APPENDIX 6: Confidentiality agreement

INIVERSITEIT VAN PRETORIA
INIVERSITY OF PRETORIA
'UNIBESITHI YA PRETORIA

Faculty of Humanities
Department of Social Work & Criminology

March 2021

The research topic is as follows: A psychoeducational programme for caregivers of people with intellectual disability within the Western Cape.

CONFIDENTIALITY AGREEMENT

In contemplation of my active involvement in the study conducted by Ms BK Gordon in my capacity as a research assistant.

I fully understand that I shall keep all the information strictly confidential. I shall not disclose the details and identity of the participants.

I shall not disclose the findings of the study. I fully understand that the disclosure of any information of the study is the breach of this contract.

The agreement is binding, and I will adhere to it.

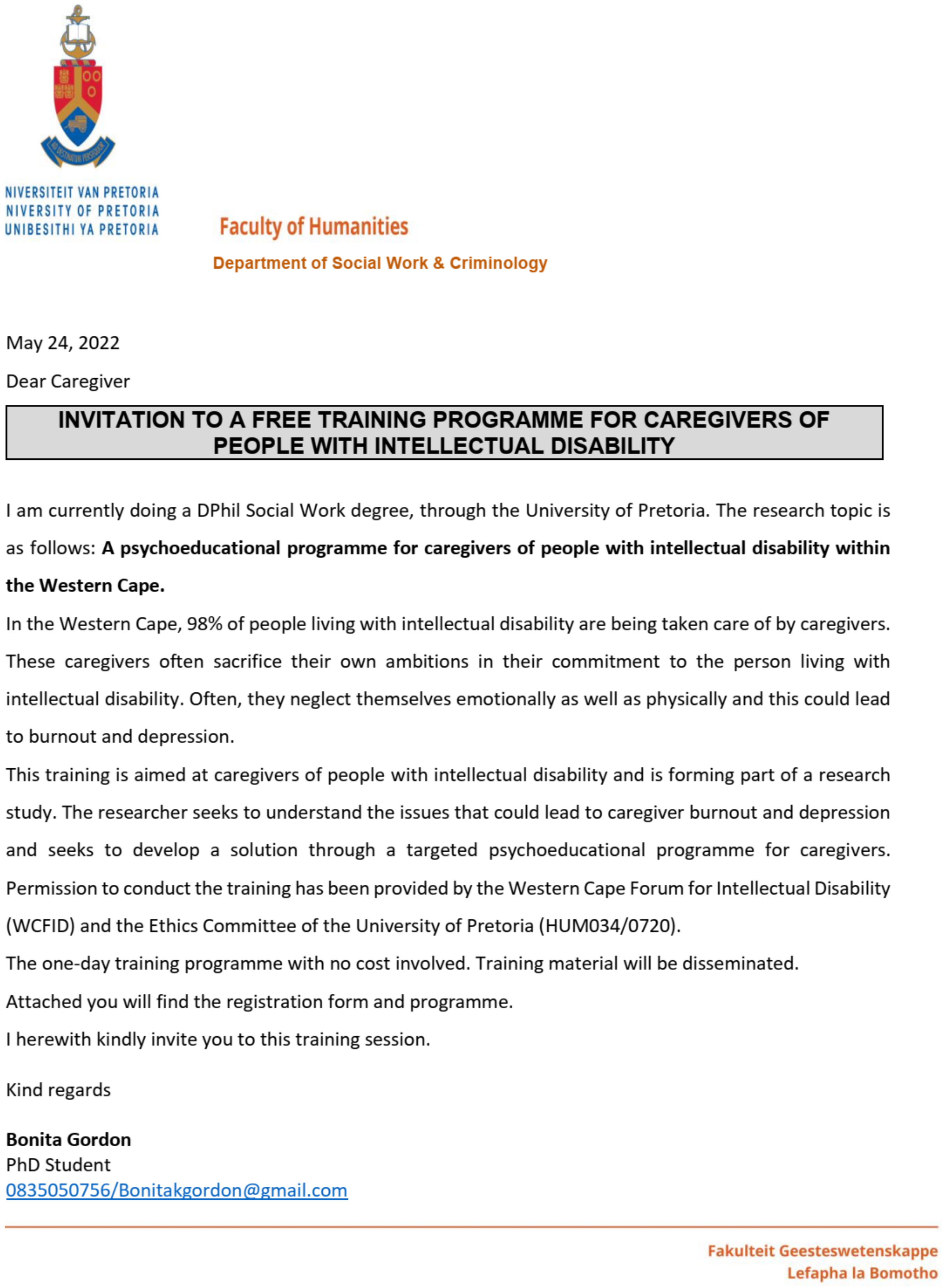
Signed at _______________this day of _____________2021

Signature

____

Fakulteit Geesteswetenskappe
Lefapha la Bomotho

APPENDIX 7: Invitation to research



NIVERSITEIT VAN PRETORIA
NIVERSITY OF PRETORIA
UNIBESITHI YA PRETORIA

Faculty of Humanities
Department of Social Work & Criminology

May 24, 2022

Dear Caregiver

INVITATION TO A FREE TRAINING PROGRAMME FOR CAREGIVERS OF PEOPLE WITH INTELLECTUAL DISABILITY

I am currently doing a DPhil Social Work degree, through the University of Pretoria. The research topic is as follows: **A psychoeducational programme for caregivers of people with intellectual disability within the Western Cape.**

In the Western Cape, 98% of people living with intellectual disability are being taken care of by caregivers. These caregivers often sacrifice their own ambitions in their commitment to the person living with intellectual disability. Often, they neglect themselves emotionally as well as physically and this could lead to burnout and depression.

This training is aimed at caregivers of people with intellectual disability and is forming part of a research study. The researcher seeks to understand the issues that could lead to caregiver burnout and depression and seeks to develop a solution through a targeted psychoeducational programme for caregivers. Permission to conduct the training has been provided by the Western Cape Forum for Intellectual Disability (WCFID) and the Ethics Committee of the University of Pretoria (HUM034/0720).

The one-day training programme with no cost involved. Training material will be disseminated.

Attached you will find the registration form and programme.

I herewith kindly invite you to this training session.

Kind regards

Bonita Gordon
PhD Student
0835050756/Bonitakgordon@gmail.com

Fakulteit Geesteswetenskappe
Lefapha la Bomotho

INVITATION TO A FREE TRAINING PROGRAMME FOR CAREGIVERS OF PEOPLE WITH INTELLECTUAL DISABILITY

Programme of the Day

8:30 Tea/Coffee

8:45 Introduction

9:00 Pre-training assessment- check in

9:30 Module 1: Psychoeducation of the caregiver on ID	✓ Definition of ID ✓ The care needs of people with ID ✓ The importance of medication compliance ✓ Possible Cognitive distortions of Caregivers

10:45 Tea

11:00 Module 2: Psychosocial impact of the individual caregiver	✓ Caregiver coping strategies ✓ Daily challenges of the caregiver ✓ Developing Resiliency ✓ Self-care exercises ✓ Emotional acceptance and commitment therapy ✓ The good enough caregiver ✓ Developing an internal locus of control

12:30 Lunch

13:00 Module 3: Strengthening the family unit	✓ Managing behavior that challenge ✓ Identifying behaviour that challenge ✓ Causes of behaviour that challenges ✓ How to respond to behaviour that challenges ✓ Managing Family conflict ✓ House safety Skills

14:00 Tea

14:15 Module 4: Accessing and Development of resources	✓ Identify your support team ✓ Training up your team ✓ The importance of recordkeeping

15:00 Post-test assessment - check in

15:30 Closure

Registration closes on Tuesday, 31 May 2022

Registration and Bookings

The training is free of charge, but booking is essential due to a limited number of seats.

Telephonic enquiries

Bonita Gordon (researcher) 0835050756

Lynn Smerdon (research assistant) 0832886022

Email enquiries

bonitakgordon@gmail.com

lynnevenitasmerdon@gmail.com

Venue

Dorothea Special School

42 Last Rd, Cloetesville, Stellenbosch, 7600

Date of Training: 7 & 8 June 2022

- -

Registration form

Complete all your details.

Full name(s) ____

Calling name ____

Surname ____

Employer____

Telephone area code_______________________

Telephone number_________________________

Cellular number___________________________

Please complete and send this registration form via

E-mail bonitakgordon@gmail.com or lynnevenitasmerdon@gmail.com

by 31 May 2022

APPENDIX 8: Pre-test Research Questionnaire

Dear Respondent

Welcome to the psycho-educational programme for caregivers of people living with intellectual disability.

Kindly please complete the questionnaire below as it will assist is establishing the appropriateness of the programme.

Please be aware that the content of your completed questionnaire will be kept confidential.

Instruction:

Read the instruction with each question and respond by marking with an X by your chosen answer within the shaded area.

Your cooperation in this regard is appreciated.

PRE-TEST QUESTIONNAIRE

For office use:

Respondent no:

Date: ________________________________ V0 ☐

1. Please select your age by selecting age group

18-35	1
36-50	2
51-60	3
66 and older	4

V1 ☐

2. Please indicate your gender

Male	1
Female	2
Other	3

V2 ☐

3. Please indicate your marital status

Never married (single)	1
Married	2
Divorced	3
Separated	4
Widowed	5
Living Together (Cohabitating)	6

V3 ☐

4. Indicate your race

Black	1
White	2
Coloured	3
Indian	4
Other (Specify)	5

V4 ☐

5. Please select your respective occupational category as caregiver

Residential Housemother	1
Manager or Supervisor	2
Nurse or Nurse assistance	3
Caregiver or care assistant	4
General support (e.g., Driver; Admin)	5
Other (specify)	6

V5 ☐

6. Please indicate where you work

Group home (residential)	1
Protective workshop	2
Day-care centre	3
Special Needs Education Centre	4
Other (specify)	5

V6 ☐

7. Indicate your income

I earn less that R5000 per month	1
I earn between R5000 and R10000 pm	2
I earn between R10 000 and R15 000pm	3
I earn between R15 000 and R20 000 pm	4
I earn more than R20 000 per month	5

V7 ☐

8. Please tick if you have any of these health issues

a. Headaches	1
b. Sleep problems	2
c. Appetite problems	3
d. Anxiety	4
e. Depression	5
f. High blood pressure	6
g. High Cholesterol	7
h. Obesity	8
i. Diabetes	9
j. Coronary Heart disease	10

V8.a ☐
V8.b ☐
V8.c ☐
V8.d ☐
V8.e ☐
V8.f ☐
V8.g ☐
V8.h ☐
V8.i ☐
V8. J ☐

9. Is it your opinion that these health issues are exacerbated work stress?

Yes	1
No	2
Motivate	

V9 ☐

10. What is your training in Intellectual Disability?

I learn on the job; I have no formal training on intellectual disability	1
I have a qualification as a caregiver that includes intellectual disability	2
I have a qualification as a caregiver, but it did not include training on intellectual disability	3
I have a qualification as a caregiver, but it did not include training on intellectual disability	4
Other explain….	5

V10 ☐

11. What do you hope to learn today?

____

____

____

V11 ☐

12. I feel confident in my knowledge of these:

	Agree	Strongly agree	Disagree	Strongly Disagree
a. Understanding intellectual disability	1	2	3	4
b. Developing resiliency	1	2	3	4
c. Resourcefulness	1	2	3	4
d. Managing behavior that challenges	1	2	3	4
e. Emotional acceptance	1	2	3	4
f. Cognitive distortions	1	2	3	4
g. Understanding the dichotomy of control	1	2	3	4

V12.a ☐
V12.b ☐
V12.c ☐
V12.d ☐
V12.e ☐
V12.f ☐
V12.g ☐
V12.h ☐
V12.i ☐

h. Self-care and coping strategies	1	2	3	4
i. The empowered family	1	2	3	4

13. In the last four weeks I experienced the following when caring for someone with Intellectual disability:

	Agree	Strongly agree	Disagree	Strongly Disagree
a. Frustration and Anxiety	1	2	3	4
b. Community Stigma	1	2	3	4
c. Personal family conflict	1	2	3	4
d. Financial challenges	1	2	3	4
e. Uncertainty as a caregiver	1	2	3	4
f. Felt unsupported	1	2	3	4
g. Felt isolated	1	2	3	4
h. Neglected my health	1	2	3	4
i. Found my engagement meaningful	1	2	3	4

V13.a	☐
V13.b	☐
V13.c	☐
V13.d	☐
V13.e	☐
V13.f	☐
V13.g	☐
V13.h	☐
V13.i	☐

Elaborate on above answers____________________________________
____
____

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14. How challenging, if at all, do you find it being a caregiver of someone with intellectual disability?

Not at all challenging	1
Not too challenging	2
Somewhat challenging	3
Very challenging	4
Motivate	

V14	☐

APPENDIX 9: Post-test Research Questionnaire

Dear Respondent

Thank you for completing the psycho-educational programme for caregivers of people living with intellectual disability.

Kindly please complete the questionnaire below as it will assist in establishing the appropriateness of the programme.

Please be aware that the content of your completed questionnaire will be kept confidential.

Instruction:

Read the instruction with each question and respond by marking with an X by your chosen answer within the shaded area.

Your cooperation in this regard is appreciated.

POST-TEST QUESTIONNAIRE

For office use:

Respondent no:

Date: ______________________________ V1 ☐

2. In your view would you recommend this psycho-educational programme

Yes, very likely	1
Somewhat likely	2
No, not likely	3
Motivate	

V2 ☐

3. Would this programme assist you as a caregiver of a person with intellectual disability?

Yes	1
No	2
Motivate	

V3 ☐

4. Please indicate other areas of training still needed: -

V4 ☐

5. Please provide recommendations in terms of course content:

V5

6. I feel confident in my knowledge of these: -

	Agree	Strongly agree	Disagree	Strongly Disagree
a. Understanding intellectual disability	1	2	3	4
b. Developing resiliency	1	2	3	4
c. Resourcefulness	1	2	3	4
d. Managing behavior that challenges	1	2	3	4
e. Emotional acceptance	1	2	3	4
f. Cognitive distortions	1	2	3	4
g. Understanding the dichotomy of control	1	2	3	4
h. Self-care and coping strategies	1	2	3	4
i. The empowered family	1	2	3	4

V6.a
V6.b
V6.c
V6.d
V6.e
V6.f
V6.g
V6.h
V6. I

7. Which part of the course content did you find most helpful and why?

V7

8. After attending this programme, do you feel more equipped in taking care of a person with intellectual disability?

I feel much more equipped	1
I feel somewhat more equipped	2
I feel the same as I did before the programme	3
Motivate	

V8 ☐

9. Would this psychoeducational programme have a positive impact on alleviating caregiver distress?

Yes	1
No	2
Motivate	

V9 ☐

APPENDIX 10: Letter from the independent coder

Dr Corrie Uys
Manager: Centre for Postgraduate Studies
Centre for Postgraduate Studies
Cape Peninsula University of Technology
mailto:UysC@cput.ac.za

30 June 2022

To whom it may concern

<u>Confirmation of independent coding</u>

I hereby confirm that I acted as independent statistician for Ms. Bonita Gordon during June 2022. The research topic: A psychoeducational programme for caregivers of people with intellectual disability within the Western Cape.

Regards

CUys.

Dr Corrie Uys

APPENDIX 11: Letter from the editor

Monika Rohlwink
Cell: 027-72 242 1236 / Tel. 021-919 3702
Email address: mrohlwink@outlook.com

4 November 2022

To whom it may concern

This is to confirm that I have proofread and edited the following doctoral thesis:

A psychoeducational programme for caregivers of people with intellectual disability within the Western Cape

Researched and written up by Mrs Bonita Karen Gordon (13321252).

Kind regards

M Rohlwink

(Mrs) Monika Rohlwink

My qualifications (from the University of Cape Town) are as follows:

B.A. (English Literature and Language History III) - 1971
B.A. (Hons) (English Language History) - 1972
Secondary Teachers' Diploma - 1973

Master's Degree in Design (Education in Quantitative Literacy)
(Cape Peninsula University of Technology) - 2016

Certificate in Copy Editing and Proofreading - 2006