Promoting family-school-community partnerships to foster learner-centred transition into adult life for youth with severe intellectual disability

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Thesis accepted for the degree *Philosophae Doctor* in *Educational Psychology* at the North-West University

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Graduation: July 2022

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DECLARATION

I the undersigned, hereby declare that the work contained in this dissertation / thesis is my own original work and that I have not previously in its entirety or in part submitted it at any university for a degree.

Handtekening / Signature

Datum / Date

25 October 2021

ACKNOWLEDGEMENTS

This work is dedicated to my children. Marietjie and Mpho, my two young adults with cerebral palsy of whom I am immensely proud and who have inspired me to make a difference in the lives of others with similar challenges; Moira-Marie, who was always ready and willing to assist me with technical challenges like illustrations; Magdi, an occupational therapist, who shares my passion for people with disabilities; Danie, the pastor, whose serene, encouraging demeanour always has a calming effect on me; and Thinus, the philosopher, whose sharp mind guided me to find an appropriate paradigm in which to ground my work. I also want to express my heartfelt thanks to my elderly parents for always believing in me. They never doubted for a second that I was going to complete my PhD, even when I was ready to call it a day and go back to being a teacher instead of a researcher.

Then, of course, there is my other set of children and family: The Alma learners, staff and parents, especially the group of special people who were willing to participate as members of the Action Learning Set. Thank you for going many extra miles for me, especially during the stressful challenges we faced during the Coronavirus pandemic. Without you, there would have been no research, no results, and no transition plan for our adolescents with severe intellectual disabilities.

To my supervisors, Lesley Wood and Mariëtte Koen, you were both excellent. You always returned my work promptly and reviewed it so thoroughly that, despite being a novice researcher and academic writer, I could rest assured that the fruit of my labour was of a high standard. Every word, every concept, every account of every detail was scrutinised and constructively criticised. Although it was exhausting, it was necessary and a reflection of your professional competence.

Lastly, I would like to express my sincere hope that the study will make a real and practical difference in the lives of young people with severe intellectual disability and that their parents will be able to proudly witness how they become fully accepted and valued members of society.

ABSTRACT

The aim of this study was to explore ways to promote family-school-community partnerships to improve transition outcomes for youth with severe intellectual disability in South Africa. Both sides of the proverbial coin that are instrumental in securing a quality adult life after school were viewed as vitally important: on the one hand, *learner-centredness*, and on the other, *family-school-community partnerships.* The learners' unique challenges, required support, wishes and dreams had to take centre stage, but at the same time, a person with severe intellectual disability needs the stakeholders in the ecologies surrounding them to take hands to facilitate them to be the best young adult they can possibly be.

I chose a participatory action learning and action research (PALAR) design, which is aimed at learning and change. The participants in the action learning set, a group of colleagues and parents at the school at which I teach, agreed that we needed to research, reflect on and learn about ways to improve our school's transition planning, since it was clear that the post-school outcomes of learners with severe intellectual disability left much to be desired. We selected five learners whose challenges, needs and strengths were representative of the diverse population of the school. Our transition-related journey with these five learners was central to the research. Quality of life and Bronfenbrenner's ecological systems theory were the two main guiding theories for the research.

Since action research is cyclical and iterative in nature, the research consisted of three cycles. Each cycle endeavoured to answer one of the critical questions. In Cycle 1, we focused on addressing the following question: *What are the challenges and resulting support needs of adolescents living with severe intellectual disability regarding transition to adult life?* During this cycle, I conducted convergent interviews with stakeholders who already had experience related to the challenges and support needs of young adolescents with severe intellectual disability making the transition from school to adult life. This data was brought to the group, who discussed emerging points of interest. After data analysis, three themes were selected: dignity, empowerment and inclusion. Other activities that were commenced during this cycle were learner assessments and parent interviews.

During the second cycle, we turned our attention to the issue of partnerships. The aim was to answer the second critical question: *How can family-school-community partnerships better meet the support needs of adolescents living with severe intellectual disability before and during transition?* We found that the first and most challenging barrier towards forging supportive partnerships was that there was a serious breakdown of the family-school partnership, a challenge that could render all other transition-related efforts from the school's side fruitless. We explored the causal mechanisms that might be behind these challenges. We discovered that, for

learners eligible to be placed in employment, an after-school support gap was apparent. This gap could, in most cases, not be filled by the parents, and, due to time and human resource constraints, the school could not fill it either. We concluded that there was a dire need for job coaches, who could render this kind of support. We encountered several challenges in the public service domain, where we found that there was a disconnect in service delivery since each government department had a different service delivery focus area, and collaborative support was a huge challenge. We found that the creation of community-based support nets around families of young people with severe intellectual disability, in the spirit of Ubuntu, would be ideal for inclusive support. However, community bias remains an ever-present threat to such efforts.

While all these discussions around partnerships and support were ongoing, we worked on transition plans for the five learners we had identified for the practical leg of the study. Two of the learners were placed in employment, with job coaching, with good results. The work with the other learners was held up by wave after wave of the Coronavirus pandemic. However, we managed to do some transition preparation, more specifically skills building, with two of the learners (car washing and baking). The fifth learner, a girl with multiple challenges (with cerebral palsy, who was non-verbal and with severe intellectual disability) took part in a project where she painted and sold key holders. She was allowed to take the money home and go shopping; something she had never done, since her parents always kept her indoors. This was a life-changing experience for her, her parents and some school staff members, since all stakeholders tended to infantilise her and were inclined to under-estimate her abilities.

In Cycle 3, the cases of the five learners were then comprehensively analysed and discussed by the action learning set to get to an answer, or answers, to the third critical question: *How can the knowledge created by this team enhance sustainable learner-centred transition planning for learners with severe intellectual disability?* We found that individualised, learner-centred transition plans were instrumental in reaching quality-of-life goals, such as improved employability and home living skills, a positive self-concept, and better community integration and social relationships. The team also utilised the data of the study to create a transition process model. We identified the unique role that each partner needs to play in the transition process and discussed how change in the minds of stakeholders could be brought about to make transition efforts more sustainable.

KEY TERMS

Challenges, dignity, empowerment, inclusion, learner-centredness, PALAR, partnerships, severe intellectual disability, support needs, transition, quality of life.

LIST OF ABBREVIATIONS AND ACRONYMS

Abbreviation/ Acronym	Meaning
AAC	Alternative and augmentative communication
AAIDD	American Association on Intellectual and Developmental Disabilities
ALS	Action Learning Set
APA	American Psychiatric Association
DBE	Department of Basic Education
D-Caps	Differentiated Caps (curriculum)
DoE	Department of Education
DSM	Diagnostic and Statistical Manual of Mental Disorders
FAS	Foetal Alcohol Syndrome
HPCSA	Health Professions Council of South Africa
IADL	Instrumental Activities of Daily Living
ICD	International Classification of Diseases
ICF	International Coaching Federation
IDEA	Individuals with Disabilities Education Act
IEP	Individual Education Plan
ITP	Individual Transition Plan
JOBS	Job Observation and Behaviour Scale
LSEN	Learners with Special Educational Needs
MEC	Member of the Executive Committee
NTACT	National Technical Assistance Centre on Transition
OSERS	Office of Special Education and Rehabilitation Services
PALAR	Participatory Action Learning and Action Research
PECS	Picture Exchange Communication System
PPCT	Process-person-context-time
SEQOL	Self Evaluated Quality of Life (questionnaire)
SGB	School Governing Body
SIAS	Screening, Identification, Assessment and Support
SID	Severe Intellectual Disability
SIS	Supports Intensity Scale
SPID	Severe and Profound Intellectual Disabilities
Stats SA	Statistics South Africa
UNCRPD	United Nations Convention on the Rights of Persons with Disabilities
VRBO	Visual Representation Boundary Object
WHO	World Health Organisation

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CHAPTER 1:
CORE CONCEPTS, CONTEXT AND METHODOLOGICAL OVERVIEW

1.1 INTRODUCTION AND RATIONALE

The term 'transition' is commonly used to describe the process of moving from the protected life of a child to the autonomous and independent life of an adult (Foley et al., 2012). Transition is particularly challenging for adolescents with severe intellectual disability (SID) and their parents (Hetherington et al., 2010). Especially in Western countries, a substantial body of research on questions surrounding the transition of adolescents with SID into adulthood exists. Examples of ground-breaking American studies are Epstein and Sanders (2000), Blacher (2001), Kohler and Field (2003), Wagner et al. (2005) and Neece et al. (2009). Beamish et al. (2010) investigated the transition practices of schools in Queensland, Australia. Xu et al. (2014) explored the views of Chinese parents and teachers on school-to-work challenges. Pallisera et al. (2014) researched transition partnerships in school and post-school services in Spain. In South Africa, Steyn and Vlachos (2011) conducted a study to develop a vocational training and transition planning programme for students living with SID.

Yet, despite the abundance of academic research on the topic, countless barriers preventing satisfactory transition into adulthood remain. These challenges increase significantly when adolescents with SID live in contexts of poverty and social disadvantage (Neille & Penn, 2017). In such environments, their challenges are compounded by some or all the following: a lack of appropriately trained teachers, parents who need guidance regarding the special needs of their children, poverty, and biased attitudes in communities towards people with disabilities. In such circumstances, some young adolescents with SID might even end up on the streets, vulnerable to exploitation by criminals involving them in drug trafficking, crime and sex work (Neille & Penn, 2017).

My personal experience of transition planning for my daughter, who lives with SID, was, to put it mildly, highly unsatisfactory. I happened to be a teacher at the very same school my daughter was attending. One day, the principal called me in, wanting to interview me in my capacity as parent. My daughter was going to be entering the so-called 'School-to-work Phase' the next year. The principal informed me that the only skill they thought she would be able to master was filling bags with dirt in the school's plant nursery. I was shocked and upset. She was a young lady, who did not like dirt on her hands.

She had no interest at all in gardening. Clearly, there was a glaring dissonance between the principal's view of her abilities and my vision for her. Had I only been involved earlier in her transition planning, a much more appropriate plan could have emerged from such collaboration.

Even in the earliest transition studies, it is widely accepted that high levels of family involvement in transition planning lead to more successful post-school outcomes (Kohler, 1998). However, Wilt and Morningstar (2018), in their scoping review of parent engagement during transition into adulthood, identified barriers to effective school-family partnerships, such as language barriers, past negative experiences, and approaches unresponsive to the family's culture. This is especially relevant in a community with culturally and linguistically diverse parent populations, as in South Africa. Okeke (2014) identifies the following barriers that tend to influence family-school partnerships negatively:

- Professional attitudes, as in the case of my daughter's principal, who saw his own opinion of my daughter's transition preparation as more valid than that of herself and me, her parent.
- Diversity concerns, for example communication barriers and insensitivity regarding cultural and racial issues.
- Contextual barriers, such as poverty, single parenthood, fatigue, transportation difficulties and long working hours.

Despite these barriers, Okeke (2014) recommends some strategies to help strengthen parental involvement, such as training programmes for parents, parent-teacher associations, home visits and an atmosphere of warm acceptance where the value of partnerships with parents is recognised. Parents should actively participate in the decision making, planning and implementation of any actions taken regarding their child (Bryan & Henry, 2012).

A point that my daughter's principal was unaware of was that, according to research in the field, transition programmes should be learner-centred. Kohler et al. (2016) stress that all educational decisions, including those leading to transition into life after school, should be based on student goals, visions and interests. Utilising the term 'student-focused planning', these authors maintain that planning focused on the learner ensures that the young adult develops self-awareness, learns how to set long- and short-term goals, acquires self-advocacy skills and develops self-determination (Kohler et al., 2016).

Another problem I had with the school's Individual Transition Plan (ITP) – or lack thereof – was that there was no long-term view of my daughter's future. No community partnerships had been forged to offer ongoing support. Even if she had loved filling bags with dirt in the school's nursery, was there a nursery in the community in which I lived that was willing to employ a girl living with cerebral palsy and SID?

If so, it would have helped if the school had fostered a partnership with the employer and supported her in the transition process. In their seminal work, Epstein and Sanders (2000) stress that community partnerships for transition extend beyond the purpose of employment and include church activities, sports, music, arts, health, recreation and training (Epstein & Sanders, 2000).

A literature review on transition for adolescents living with SID revealed the following gaps (Foley et al., 2012):

- Research that involves young people with severe intellectual disabilities themselves is sparse.
- Most studies focus on young adolescents who have mild (not severe) intellectual disability.
- Most research focuses on employment as a transition outcome, instead of taking a more holistic view.
- There is very little research from low- and middle-income countries regarding transition for youth with SID.

The rationale for my study then is to address these gaps. My study focused on transition planning for learners living with SID (cf. transition process model, Chapter 7). It was conducted in a collaborative way to ensure that meaningful school-family-community partnerships were fostered to make transition planning more relevant and more sustainable. I viewed learners as central to the research, and so worked from a holistic view, considering both challenges and strengths. Their personal goals and dreams were an integral base for each learner's ITP. I hope to contribute to the alleviation of the unique transition challenges in the South African education system and society, where barriers such as diverse languages and cultures, as well as poverty, cause learners with intellectual disabilities to be even more disadvantaged.

1.2 CORE CONCEPTS, STATISTICS AND CONTEXT

To put the challenges of learners with intellectual disabilities into perspective, I will endeavour to create context by presenting some statistics and explaining several core concepts. Worldwide, about 200 million people live with intellectual disability. This means that it is the world's most prevalent disability (World Health Organization & World Bank, 2011). Among those with intellectual disability, 85% are mildly impaired, 10% moderately impaired, 4% severely impaired and 2% profoundly intellectually impaired (Maulik et al., 2011). Intellectual disability is more prevalent in low- and middle-income countries, such as South Africa (Maulik et al., 2011).

According to Statistics South Africa (Stats SA) (2014), 3.2% of people aged five years and older have mild difficulties and 1% of people in this age group have severe difficulties "remembering or concentrating" (Stats SA, 2014, p. 34). However, given that the census did not include persons in institutional care (Adnams, 2010), and further, that South Africa's prevalence rate of Foetal Alcohol Syndrome at 6 to 9% is one of the highest in the world (Urban et al., 2008), the probability is high that the prevalence of intellectual disability in South Africa is much higher than the percentages available from Stats SA.

During the last 15 years, an intense debate has raged regarding the appropriate way to determine, define and classify the challenges of people with intellectual disability (Carulla et al., 2011). The Diagnostic and Statistical Manual of Mental Disorders (DSM-V), published by the American Psychiatric Association (APA) (2013), changed the term 'mental retardation', used in DSM-IV, to 'intellectual disability' in DSM-V because of the negative connotation of the term 'mental retardation' (Weis, 2017). Likewise, the World Health Organization (WHO) decided to replace the concept 'mental retardation', used in the previous International Classification of Diseases (ICD-10) with 'intellectual developmental disorders' in ICD-11 (Carulla et al., 2011). However, this has led to a hot debate about whether intellectual impairment should be viewed as a disability, or as a disease. If intellectual developmental disorders are to be viewed solely as disabilities and not as health conditions, they would have to be deleted from the ICD. However, the ICD is used by 194 WHO member countries to determine the responsibilities of governments to specify which people are eligible for what health care, educational and social services, and under what conditions (Carulla et al., 2011). For this reason, removing intellectual developmental disorders from the list of health conditions would have a major impact on the services available to this vulnerable population (Carulla et al., 2011). The term 'intellectual disability' is widely used for policy, administrative and legislative purposes and

reflects the general movement away from the medical model of disability. Therefore, for the purpose of this study, I will use the term ‘intellectual disability’.

The following is a summary of the diagnostic criteria for the term ‘intellectual disability’, according to DSM-V (APA, 2013):

- Deficits in intellectual functioning, such as reasoning, planning, abstract thinking and problem solving (IQ < 70).
- Deficits in adaptive functioning. To be diagnosed with intellectual disability, the child has to have impairment in at least one of the three domains of adaptive functioning: conceptual skills (communication, counting, telling the time, solving maths problems), social skills (interpersonal skills, following rules, social problem solving, understanding others) and practical skills (activities of daily living such as self-care, safety and using money).
- The onset of intellectual and adaptive functioning must have started to become evident during the developmental period.

In DSM-V, the *severity* of intellectual disability is specified by assessing the level of adaptive functioning. Deficits are described and grouped under the headings ‘mild’, ‘moderate’, ‘severe’ and ‘profound’ (Weis, 2017, pp. 92–93). However, in another approach, the American Association on Intellectual and Developmental Disabilities (AAIDD), in its categorisation of intellectual disability, emphasises ‘needed supports’. For example, a child with intellectual disability might need ‘extensive support’ in educational situations, but only ‘intermittent support’ in social situations (Weis, 2017, p. 94).

It is important to note that no learner-centred planning is possible without a thorough baseline evaluation, due to the extremely varied needs of youth with severe intellectual disability. For example, Learner A, although attending a school for learners with SID, might have intellectual capabilities bordering on the ‘mild’ spectrum. Learner A might have no physical impairments, good self-care skills, but may be lacking in social skills. Learner B might be living with SID and cerebral palsy, displaying limited self-care skills, but good social skills. Learner A might have very challenging socio-economic circumstances and a single mother working long hours, whereas Learner B might have wealthy parents that are very involved and have access to a variety of support systems. Clearly, Learner A will need different supports to Learner B, a fact that will influence transition planning significantly. The DSM-V, although helpful and necessary, rigidly categorises people into having mild, moderate and severe levels of intellectual disability. However, the reality is that human beings in real life mostly defy categorisation. Each adolescent with an

intellectual disability is as unique as their fingerprint, their functioning is not only shaped by their intellectual and physical capabilities, but also by a complex combination of home and community influences. A more holistic, individualised approach is clearly needed to achieve transition success.

Regarding the employment of people with intellectual disabilities, research has shown that youths with intellectual disabilities are three to four times less often employed, and that they are more likely to work in sheltered work or segregated settings, compared to their neurotypical peers (Verdonschot et al., 2009). Individuals with intellectual disability usually work in entry-level positions, earn lower wages and work fewer hours than their neurotypical peers (Petner-Arrey et al., 2016). It is estimated that only 14 to 22% of people with intellectual disabilities manage to obtain paid, integrated employment (Simonsen & Neubert, 2013). It can be assumed that this number will be far less in middle- and lower-income countries, such as South Africa, although current reliable statistics to confirm this are hard to come by (Visser et al., 2016).

Despite all these bleak outcomes, several early studies have already shown that holistic, collaborative transition programmes make a difference. White and Weiner (2004) report the findings of a transition programme called 'Model for Seamless Transition' that made use of highly collaborative supported employment partnerships in 14 school districts in California. This transition programme reported a 63% employment rate for 234 transitioning students (White & Weiner, 2004). White and Weiner's study showed that adolescents with intellectual disabilities could learn job skills through non-paid and paid work experience, but that communication skills, independent living skills, public transportation skills, social skills and self-determination skills should be part of the transition programme (White & Weiner, 2004). As early as 2003, Kohler and Field proposed a shift from disability-focused, deficit-driven programmes to an education and service-delivery approach based on abilities, options and self-determination (Kohler & Field, 2003). More recently, Taylor et al. (2019) stress the need for transition services to support young adolescents with disabilities to develop meaningful goals and to coordinate transition activities, informed by multidisciplinary planning teams.

Transition to adulthood remains a very complicated process for youth with intellectual disabilities, due to a myriad of factors affecting them in their lives after school, such as family and student characteristics, economic conditions, the community context and the availability of services. The fact that many of these variables cannot be controlled, presents significant challenges for conducting transition planning (Kohler & Field, 2003). It calls for an approach similar to that of Epstein (1987) and Epstein and Sanders (2006),

who developed a model of overlapping spheres of influence. To address the myriad of factors at play that influence the transition of learners with intellectual disability, there is a need for institutional and individual lines of communication across the boundaries of school, home and community. Shared responsibilities and overlapping influence mean that parents do not need to bear the entire burden of figuring out what direction to take after their child with SID has completed their schooling. Rather, educators, parents and members of communities should combine efforts to create a coherent programme to help students succeed (Epstein & Sanders, 2006).

In summary, the transition of adolescents living with severe intellectual disabilities from school to adult life is a multi-layered challenge. If not addressed successfully, manifold problems develop that have a negative ripple effect on the individual's wellness and quality of life, the family's psychological, social and economic wellbeing, and the social and economic wellbeing of communities (Neille & Penn, 2017). Having a well-researched transition programme helps schools improve their education of learners living with severe intellectual disabilities, as their teaching and individual education plans (IEPs) will become more transition-focused and practical (Kohler & Field, 2003). Based on my experience as a teacher in the field, and as parent of two children with intellectual disabilities, I believe the problem in South African schools is that transition programmes for learners with intellectual impairment, if they exist, are of limited scope. If they are implemented, the concept of fostering strong family-school-community partnerships for the purpose of transition is not usual practice. Consequently, schools that experience initial success with their transition programmes find that these are not sustainable due to a lack of carry-over by parents and a strong bias in community organisations and businesses against providing opportunities for people with intellectual disabilities. Years after my daughter has left school, I now have an opportunity, through this study, to contribute towards the improvement of transition planning at her school, and ultimately in a wider context. I hope that the findings from this study can be my legacy to help teachers, parents and young adults with intellectual abilities plan more effectively for their transition from school to work or society.

1.3 PURPOSE OF THE STUDY

The purpose of the study is to foster family-school-community partnerships as a support measure for the transition process of adolescents with SID into adult life.

1.4 CRITICAL QUESTIONS

To guide my research, I formulated the following questions:

Main question:

How can family-school-community partnerships be promoted to foster learner-centred transition to adult life for youth with intellectual disabilities?

Sub-questions:

- *What are the challenges and resulting support needs of adolescents living with severe intellectual disability regarding transition to adult life?*
- *How can family-school-community partnerships better meet the support needs of adolescents living with severe intellectual disability before and during transition?*
- *How can the knowledge created by this team enhance sustainable learner-centred transition planning for learners with severe intellectual disability?*

1.5 THEORETICAL FRAMEWORK

According to Chowdhury (2019), a theory is "an explanation of a particular phenomenon that has been established through evidence from a research- or evidence-based study" (Chowdhury, 2019, p. 102). I have chosen three theories to frame my study. Two of the theories guided the primary participant group and the action learning set (ALS) in direct research and action with regard to supportive partnerships towards the transition planning for learners with intellectual disability. These two theories are the quality-of-life theory (Ventegodt et al., 2003) and Bronfenbrenner's ecological systems theory (Bronfenbrenner, 1986). The third theory, transformative learning theory (Mezirow, 1997), served as a backdrop for the discussions of the ALS regarding sustainable, lasting change in the school culture and the attitudes of staff members who need to implement the transition programme.

1.5.1 Quality-of-life theory

In the Danish Quality of Life Survey, 10 000 people were asked about their quality of life with the validated Self Evaluated Quality of Life (SEQOL) questionnaire with more than 300 questions on their quality of life (Ventegodt et al., 2003). Ventegodt, a ground-breaking quality-of-life theorist, found that executives or knowledgeable professionals do not feel better than unskilled workers. Money, power or learning did not seem to contribute to quality of life. There is no consensus on a specific definition of quality of life, but it is generally viewed as multifaceted, comprising both objective and subjective dimensions. For young adults with intellectual disability, McIntyre et al. (2004) have identified quality-of-life goals such as increased independence and autonomy, satisfying vocational pursuits, community living opportunities and increased social networks and support. The

findings of McIntire et al. (2004) imply that transition planning for learners living with SID should be approached holistically as opposed to narrowly focusing on employment outcomes. It is a well-documented fact that employment outcomes for people with SID are poor (Bush & Tassé, 2017) and that those with multiple disabilities are unlikely to obtain employment in the open labour market. However, that does not make them less human or less entitled to a good life. Quality-of-life theory provided a way for the action learning group in this study to remain focused on appropriate transition goals in a holistic way and, from there, establish how family-school-community partnerships could support these goals.

1.5.2 Ecological systems theory

Bronfenbrenner, a Russian-born American psychologist, was well known for his ecological systems theory of child development (Bronfenbrenner, 1979), which I utilised to refer to the different support nets for adolescents with intellectual disability during the period of transition. This theory defines the following 'layers' of environment that have an impact on the individual's development: the microsystem (family, school, neighbourhood), the mesosystem (the connection between the child's parents and their teacher), the exosystem (parent workplace schedules) and the macrosystem (cultural beliefs). The chronosystem relates to the dimension of time, which includes transitions (Bronfenbrenner, 1986). Darling (2007) stresses that the 'person in the centre' (for this study, the adolescent with SID) is actively responding to all these different environments. She also stresses the phenomenological nature of Bronfenbrenner's theory, citing Thomas and Thomas (1929, p. 542): "If men define situations as real, they are real in their consequences". The real and unique challenges, but also the strengths and preferences of each adolescent with SID, should be considered to determine the required supports for transition. Research has shown convincingly that it is vital for the role players in the microsystem (family, school and neighbourhood or community) to work together to support successful person-centred transition (Epstein & Sanders, 2000). Factors in the exosystem (parent work schedules, transport) and macrosystem (culture, beliefs) are to be considered in transition planning. The ecological systems theory provided me with a framework for fostering family-school-community partnerships, which is a central theme of my study.

1.5.3 Transformative learning theory

Mezirow (1997) defined transformative learning as the process of effecting change in the structures of assumptions through which we understand our experiences. The

assumptions or frames of reference comprise both habits of mind (habitual ways of thinking, feeling and acting) and viewpoints. Learning is transformative when people are enabled to reflect critically on their assumptions. These reflections are key to transforming one's frame of reference to facilitate change (Mezirow, 1997).

Taylor (2017) shed light on three alternative perspectives on transformative learning in addition to Mezirow's psycho-critical approach: the psychoanalytic, psycho-developmental and social emancipatory approaches. The third approach, the social emancipatory approach, is applicable to this study. This is a theory of existence that views people as subjects, not objects, who are constantly reflecting and acting on the transformation of their world to transform it to a more equitable place for all to live (Taylor, 2017).

In this study, not only the learners with intellectual disability, but also the collaborators in the ALS, were participating in a transformational process. Each participant in the action learning group had a frame of reference with regard to learners with intellectual disability, their parents and the community. The dynamics of the group discussions and collaborative actions we took caused each person to examine that frame of reference and reflect on the need to change some of our habits of mind.

1.6 METHODOLOGY

In a study of this nature, where the aim is to facilitate change, the methodology inevitably revolves around a collaborative and participative research design. I also needed a paradigm that provided a balanced view on disability as reality and provided a framework for exploring deep-seated causes of phenomena. Starting with the paradigm, I will proceed to discuss the methodology of the study.

1.6.1 Paradigm informing the study

I understand a paradigm as a philosophical lens – a world view – framing a study (Sefotho, 2015). The paradigm I have chosen is critical realism (cf. section 4.2). Critical realism originated as a scientific middle path between positivism and constructivism, but utilises elements of both methodological strains (Fletcher, 2017).

Regarding *ontology*, critical realism maintains that the world exists independently of our knowledge of it (Easton, 2010). Critical realists do not believe that we 'construct' reality. Phenomena are 'made sense of', 'interpreted', 'comprehended', 'framed' or 'called to attention' (Fleetwood, 1999, p. 6).

Regarding *epistemology*, interpretivists are criticised by critical realists for sustaining "the epistemic fallacy" (Fairclough, 2005, p. 923). Simply put, this term refers to the flawed premise that reality itself is the same thing as 'knowledge about' reality (Bhaskar, 1989). For this study, I believe that we need to acknowledge that people with intellectual disabilities have challenges that are very real. During our research, we investigated these realities (regarding the learners themselves, their families and the community context) to facilitate partnerships to enhance transition planning. As critical realism is very much concerned with causality (Bhaskar, 1989), underlying causes for phenomena such as transition challenges were investigated to work on reality-based solutions.

Regarding *axiology*, critical realism maintains that social science can never be value-neutral (Gorski, 2013). As a result, researchers should admit and deliberately include their cultural orientation and personal values in the research process (Oppong, 2014).

As a mother of two young adults with intellectual and physical disabilities, I have a very specific value set in relation to disability. As a Christian, I see people with disabilities not as accidents of nature, but as unique creations of God. I believe that these individuals should be treated with dignity. Their opinions and preferences need to be respected. They should be enabled to make choices about their own futures. I believe that they do not need pity. They need to be taught that society needs citizens who are prepared to live up to certain values and standards, such as keeping promises, being on time, having good manners, working diligently. As group facilitator, I believe in humility and servanthood; in respecting the opinions of others, even though they may differ from mine. I believe in having empathy for people – especially family members of adolescents with intellectual disabilities, who have often faced harrowing challenges as they raise their children

Critical realism as a paradigm resonates with participatory action learning and research (PALAR) (cf. section 1.6.3) in that PALAR is a research design where the collaborative nature of the process facilitates learning. This results in change (Zuber-Skerritt, 2011). Priestly (2011) points out that, for critical realism, cultural forms, social structures and individual capacities are causal factors that influence change. Priestly (2011) cites Archer (1988), referring to three possible outcomes of the interaction of these factors:

1. The new idea supplants the old (morphogenesis).
2. The old ideas are maintained and the new rejected (morphostasis).
3. Common elements of the new merge with elements of the old, leading to a form of morphogenesis.

It can be argued that that the interaction of the different individuals of the ALS, who have different social and cultural backgrounds and different individual capacities, brought about morphogenesis in the opinions and ideas of the group.

1.6.2 Nature of inquiry: Qualitative

For this study, I have adopted a qualitative mode of inquiry. Qualitative research is concerned with people's subjective experiences, their ideas, goals and actions in local contexts (Baxter & Jack, 2008). Qualitative researchers study participants' knowledge and practices and take into consideration that viewpoints and practices in the field are different because of the different subjective perspectives (frames of reference) and social backgrounds related to them (Flick, 2018). Qualitative data can provide rich insight into human behaviour (Guba & Lincoln, 1994). Researchers collect rich descriptive data with the intention of developing an understanding of what is being observed or studied (Maree, 2014). This study enabled the viewpoints and experiences of various participants (teachers, therapists, learners, parents and community members) in the field of intellectual disability to be voiced and understood.

1.6.3 Research design

This study was framed by a PALAR design (cf. section 4.3). The term has been created by combining different concepts: action research, participatory action research and action learning (Zuber-Skerritt 2011). Zuber-Skerritt (2011) defines the underlying concepts of PALAR as follows:

- Action research: A cyclical iterative process of action and reflection on and in action.
- Participatory action research: Action research where all relevant parties are involved in examining and discussing relevant issues and consequently work towards bringing about change through collaborative actions.
- Action learning: Learning from and with each other in small groups or 'sets' from action and concrete experience in the workplace or community situation. Learning means more than just an accumulation of knowledge. It involves solving problems and thinking creatively.

Wood and Zuber-Skerritt (2013) stress the three Rs of PALAR: relationship, reflection and recognition. *Relationship* involves building trusting, supportive and authentic relationships between participants; *reflection* refers to continual critical reflection within a collaborative learning context; and *recognition* refers to the celebration and recognition of the

achievements of all participants through their contributions and findings with wider audiences.

The PALAR design, as is the case with any participatory action research, is cyclical in nature. According to Wood and Zuber-Skerritt (2013), these cycles involve a collaborative identification of needs, deciding on the best course of action, implementation of the action and, lastly, an evaluation of the result of the course of action. Based on the participants' critical reflection on the process, a decision is taken regarding any further action (Wood & Zuber-Skerritt, 2013). The following cycles were part of the PALAR process in this study:

- Cycle 1: Determination of the challenges and support needs of the specific adolescents living with SID involved in the study.
- Cycle 2: Fostering family-school-community partnerships as support measures to meet the support needs of youths with SID while transitioning to adult life.
- Cycle 3: Case studies of actions taken with the five selected learners involved in the study, based on the data collected in the first two cycles. Evaluation of learning and change resulting from these actions.

A more detailed discussion of the PALAR methodology utilised in this study will follow in Chapter 4.

1.6.4 Research methods and strategies

To provide some context, I start this section with a description of the research setting.

1.6.4.1 Research setting

The site of my study was the school at which I teach, which is a school for learners with SID. About 340 learners attend the school. The learner population is very diverse in terms of their different physical and cognitive challenges, as well as their socio-cultural backgrounds. The cognitive abilities of learners within the SID scope vary widely. For example, some learners can carry messages, read and write on a basic level and are independent with regard to activities of daily living, whereas others are unable to carry out instructions appropriately, will never read or write, and wear diapers or need to be reminded to go to the bathroom. Some have no physical challenges, whereas other learners have challenges such as autism, cerebral palsy, behaviour disorders or syndromes (e.g. Down Syndrome), in addition to SID. The school is well resourced, due to numerous fundraising initiatives to supplement funds. Resources such as wheelchairs, adapted chairs and communication aids are supplied by the school. Each class teacher is

supported by a class assistant, who does caregiving and supervision and helps with classroom activities. Most of the learners come from very underprivileged circumstances. Roughly a third of the learners get full exemption from school fees and about 60 learners out of the 340 make use of the school feeding scheme. Learners come from Pretoria and its surrounds, although some travel as far as 100 km each day, leaving their homes as early as 04:00 every morning to attend school.

1.6.4.2 Participant selection

For this study, the participants were selected via purposive sampling. Purposive sampling is generally utilised in situations where participants are selected with a specific purpose in mind (Creswell, 2015). In this instance, members of the ALS were the primary participants.

The members of the ALS all had first-hand experience with the transition challenges of adolescents with SID, some in their professional capacity and others in their personal capacity. I recruited the following persons to participate in the study as ALS members: the principal, the vice principal, a Setswana-speaking teacher, the departmental head of the Senior Phase, a therapist and two parent members. I recruited the ALS members myself, as I had already built long-term trusting relationships with them, due to my being an 'insider' for more than 12 years. From previous informal discussions about the school's transition challenges, I believed that these specific participants would be enthusiastic about transition planning. The two parents that I approached had both been members of the School Governing Body (SGB). The occupational therapist, who is also a qualified play therapist, is very skilled in handling our senior learners and assisted with the purposive sampling of learners for assessment and involvement in the real-life actions conducted in the third cycle.

The secondary participants comprised the following:

- Five learners, selected to represent the variety of challenges experienced by young adolescents with SID.
- The parents of the five selected learners.
- Eleven interviewees that had some transition-related experience or who were directly involved in facilities catering for young adults with SID (cf. section 4.6).

The learners with SID (cf. Table 4.4) could not be part of the ALS, as the functional cognitive level of the learners did not allow them to participate meaningfully in discussions of that nature. However, their dreams and preferences emerged during individual informal assessments by one of the ALS members, P5. Their ITPs were framed by the results of

these assessments. All actions that were undertaken with the five learners were learner-centred in that all actions were based on their ITPs. The results of these actions were brought to the group for discussion and analysis. In that sense, the learners were viewed as secondary participants.

1.6.4.3 Data generation strategies

Four main data generation strategies were utilised, of which the action learning set discussions and the visual representations created by the group yielded the primary data.

Interviews

An interview, according to Maree (2014) is “a two-way conversation in which the interviewer asks the participant questions to collect data and to learn about the ideas, beliefs, views, opinions and behaviours of the participant” (Maree, 2014, p. 5). Compared to questionnaires, interviews are much more powerful in eliciting rich narrative data (Murray, 2018). Two groups of secondary participants were interviewed:

- Stakeholders in the disability field with transition experience
- Parents of the five selected learners

For the former group, convergent interviewing was utilised, whereas individual semi-structured interviews were conducted with the latter group: the parents (cf. section 4.4.3.1). The convergent interviewing aimed at bringing data to the ALS discussions that could prompt discussion, whereas the data of the parent interviews fed into the five learners’ ITPs.

Action learning group discussions

Pedler and Trehan (2010, p. 420) stress the following principles regarding action learning:

- Action learning is a problem-solving exercise, where people reflect on their attitudes and actions when solving real organisational problems. In this study, the research problem under discussion in the group will be on ways to foster school-community-parent partnerships to enhance transition planning.
- Action learning is based on the premise that there is no learning without action and no sober and deliberate action without learning. Learning, in my study, took place through the actual planning and implementation of transition plans for learners.

- The tensions, contradictions, emotions and power dynamics that inevitably exist in a group lead to critical thinking and self-development. This became evident during the ALS discussions of this study.
- Critical reflection should result in change. This collaborative study contributed to changes regarding the attitudes and frames of reference of the participants.
- The facilitator's degree of expertise and the range of competencies within the group determine the extent to which participants will take ownership of problems.

Wood and Zuber-Skerritt (2013) stress that it is vital to build relationships right from the start-up workshop to ensure that participants get to know and trust each other and recognise that they have a common purpose that unites them. Fortunately, the group already had existing professional relationships before the commencement of the study, since the Coronavirus pandemic, which hit shortly after the start-up workshop, limited our interactions – so we had to remain focused on the task at hand whenever we met. The action learning group held regular discussions (virtual as well as in-person) to reflect critically on progress, decide on new actions and reflect on results emerging from each cycle of events as they occurred. All discussions were recorded, transcribed and analysed.

Visual representations

Webb (2020) maintains that the use of a visual representation boundary object, such as a diagram or a chart, may facilitate communication and problem solving within a group. Visual methods facilitate the opportunity for reflection and allow participants to create artefacts that are used to prompt discussion. Visual representations in this study mainly consisted of drawings generated by the group to depict findings arrived at towards the end of each cycle and to facilitate discussions around core issues.

The purpose of this study was to determine the relationship between verbal communication and group meaning through the use of a visual representation boundary object (VRBO) during team problem solving. The knowledge the researcher gained from this study may offer new insight into how verbal interactions influence team thinking and problem solving.

Reflective field notes in a research diary

Reflection is the second of the three Rs in the PALAR process. Pomeroy et al .(2021, p. 113) view reflective journaling as a "way of knowing", in other words, part of the learning process. The skill of self-reflection, which involves thinking about why we think, act and feel the way we do in response to certain experiences and situations, is critically important

in action research, where the researcher has a subjective role and is emotionally and socially immersed in the research process (Zuber-Skerritt et al., 2015). The purpose of the research diary is to document these reflections. Field notes, written in my research diary helped me to decide on the next steps and contributed to my own learning. members were requested to post their reflections on the ALS group via voicenotes. In that way, all could learn and grow together, and dialogue was stimulated.

1.6.4.4 Data analysis strategies

The first two cycles of the study followed the principles of thematic data analysis. Data was coded, classified, labelled and organised into themes and sub-themes (cf. section 4.3.3), according to the steps set out by Vaismoradi et al. (2016). The third and final cycle utilised critical realist data analysis to arrive at causal mechanisms or reasons for the results emerging during this cycle (cf. section 4.3.3). I made use of the steps set out by Bygstadt and Munkvold (2011), described more comprehensively in Chapter 4.

1.6.5 Trustworthiness

If a study is trustworthy, the given set of findings can be acted upon with confidence – that is, the findings are worth 'paying attention to' (Guba & Lincoln, 1994). Herr and Anderson (2005) proposed the following five quality indicators for action research:

- Outcome validity: This refers to the extent to which the actions solved the original problem posed.
- Process validity: Have the problems been framed and solved in such a way that ongoing learning is promoted?
- Democratic validity: To what extent has research been conducted in collaboration with all stakeholders?
- Catalytic validity: This refers to the extent to which the research process has re-oriented the participants towards their knowledge of reality. Has transformation taken place?
- Dialogic validity: This refers to peer review. Do peers consider the findings to be appropriate and useful?

The questions around these quality indicators are set in the context of the specific study in Chapter 4 (cf. section 4.4.5).

1.6.6 Ethical principles

Bertram and Christiansen (2014) refer to three important ethical principles to which I had to adhere in my study: autonomy, non-maleficence and beneficence.

Autonomy refers to the respect and dignity of each participant taking part in the study (Bertram & Christiansen, 2014). I obtained the informed consent of every person taking part in the study. Each participant needed to make an informed choice to participate voluntarily in the research and had the freedom to withdraw at any time. The parents of the five selected learners granted permission for me to involve these learners with SID in the research. Learners provided assent by means of a simple picture-based questionnaire that was explained and presented to them by someone not involved in the research. Permission to conduct research was obtained from the Gauteng Department of Basic Education (DBE) and goodwill permission was granted by the principal and SGB of the relevant school.

Non-maleficence means to 'do no harm' (Bertram & Christiansen, 2014). The research should do no physical, emotional, social or other harm to any person. Since the study involved vulnerable individuals (minors with SID), extra care had to be taken to undertake all actions in an ethical manner. I therefore utilised the wealth of experience and training of the occupational therapist who works with them daily to conduct the assessments and provide guidance regarding all planned actions.

Beneficence means that the research should be of benefit, either directly to the research participants, or more broadly to other researchers or to society at large (Bertram & Christiansen, 2014). Adolescents with SID who participated in the study gained transition-related skills and two of the learners were placed in employment. These actions were aimed at the enhancement of their quality of life. The parents entered supportive partnerships during the study that could lighten their burden related to the planning of their children's future. The ALS grew in their personal capacities and as educators due to the collaborative learning that took place. The school became better equipped to deal with the transition of young adolescents with severe intellectual disability into adult life. Lastly, in the long term, society at large can reap the benefits from adults with intellectual disabilities who are more economically and socially active and, where possible, more independent.

All participants were assured of the privacy and the confidentiality of the information they supplied. Data has been presented in such a manner that the individual participants cannot be identified. Participants were typified by means of codes (e.g. P1, L2, M4). Data was

anonymised, labelled, backed up regularly and stored safely on a device that is password protected.

1.7 OUTLINE OF THE CHAPTERS

The study has been framed in the following manner:

Chapter 1: Overview of the study

Chapter 2: Discussion of concepts around learner-centredness and quality-of-life theory

Chapter 3: Discussion of concepts around partnerships and ecological systems theory

Chapter 4: Theoretical discussion of research methodology

Chapter 5: Discussion of the findings of Cycle 1: What are the challenges and resulting support needs of young adults with SID about to transition into adulthood?

Chapter 6: Discussion of the findings of Cycle 2: Utilising family-school-community partnerships to meet learner needs

Chapter 7: Discussion of the findings of Cycle 3: Implementation of learner-centred transition planning

Chapter 8: Summary, reflections, suggestions for further study and practice, and conclusions

1.8 CHAPTER SUMMARY

In this chapter, I set the scene for the study. I introduced the reader to the context and rationale for the study and discussed some core concepts. I set out the methodological framework of the study concisely, covering aspects such as the critical questions, research paradigm, research design, methods, ethical considerations and trustworthiness. In the next chapter, I will commence the theoretical discussion. Since the study is learner-centred, the discussion in Chapter 2 revolves around the learner. Moreover, I will show how quality-of-life theory provided a holistic framework for the actions undertaken by the ALS.

CHAPTER 2:
TRANSITIONING THE UNIQUE INDIVIDUAL WITH SEVERE INTELLECTUAL DISABILITY TOWARDS A QUALITY ADULT LIFE: WHERE TO START?

2.1 INTRODUCTION

In this chapter, the adolescent with SID is at the centre of the discussion. As learners with severe disabilities have extremely heterogeneous needs (Carter et al., 2014), transition programmes need to be built around the needs of each unique individual learner (Hughes & Carter, 2011). Therefore, I will focus on good-practice principles emerging from previous research regarding the concepts of learner-centeredness, self-determination, assessment for transition purposes and quality of life. Quality of life is one of the guiding theories of this study. Previous research has identified quality of life as a broad transition goal for youth with intellectual disabilities (Nota et al., 2007; Buntinx & Schalock, 2010; Mihai et al., 2018). Before proceeding to the discussion of the different transition principles around the individual SID adolescent and their unique needs, I will commence the chapter by referring to the development of transition practices for adolescents with intellectual disability since 1984.

2.2 TRANSITION: BENCHMARKING GOOD-PRACTICE PRINCIPLES FROM RESEARCH IN THE FIELD

Challenges around poor post-school outcomes experienced by youth with intellectual disability and their families have prompted transition research from a variety of angles for more than 30 years, with the USA on the forefront of these initiatives. The work of Will (1984) formed the foundation of the transition model proposed by the Office of Special Education and Rehabilitation Services (OSERS), which viewed transition as a bridge between school and adult life. Will's model was based on three different types of services offered to students with disabilities upon leaving school: transition *without* special services, transition with *time-limited* services and transition with *ongoing* services to support employment. Will's model was largely focused on transition support towards employment (Will, 1984).

Halpern (1985) expanded the OSERS model to reach beyond the focus on transition from school to employment to include *community adjustment*, as well as *social and*

interpersonal networks. Halpern (1985) recommended including quality of life as a focus of transition outcomes and stressed that instructional strategies should include equipping students with the skills and self-determination necessary to achieve their adult roles (Halpern, 1985). This research was mandated when the Individuals with Disabilities Education Act (IDEA) of the United States Congress (1990) expanded legislation regarding special education to include the need for transition services from the age of 16 years. These services were to focus on post-school outcomes such as post-secondary education, vocational training, integrated employment, supported employment, continuing and adult education, adult services, independent living and community participation, including interagency linkages if needed (United States Congress, 1990). The law stated that community agencies that may be involved with the student should be included in the transition planning process. According to this mandate, schools should develop relationships with community agencies that could provide transition services to students with disabilities (Morningstar et al., 1999).

Kohler and her colleagues conducted three reviews of best transition practices (Rusch et al., 1992; Kohler, 1993; Kohler et al., 1994). In the first investigation (Rusch et al., 1992), final reports of 42 employment-focused transition programmes were analysed to identify project purposes, activities, outcomes and barriers. In the second investigation (Kohler, 1993), 49 documents related to transition were reviewed, utilising the following criteria:

- The extent to which the practice has been underpinned in existing literature, grounded in theory and supported empirically
- The extent to which the practice is associated with meaningful, socially valid outcomes

According to this review, three practices (vocational training, parental involvement and interagency collaboration) were cited in over 50% of the documents analysed (Kohler, 1993). A further three practices (social skills training, paid work experience and individual transition plans) were supported in at least a third of the literature reviewed.

The third study (Kohler et al., 1994) analysed 15 evaluation studies focused on exemplary programmes and practices pertaining to transition.

Emerging from all this work, a conceptual framework or model of best transition practices was developed, called a taxonomy of transition programming (Kohler & Kohler, 1996). This taxonomy is illustrated in Figure 2.1:

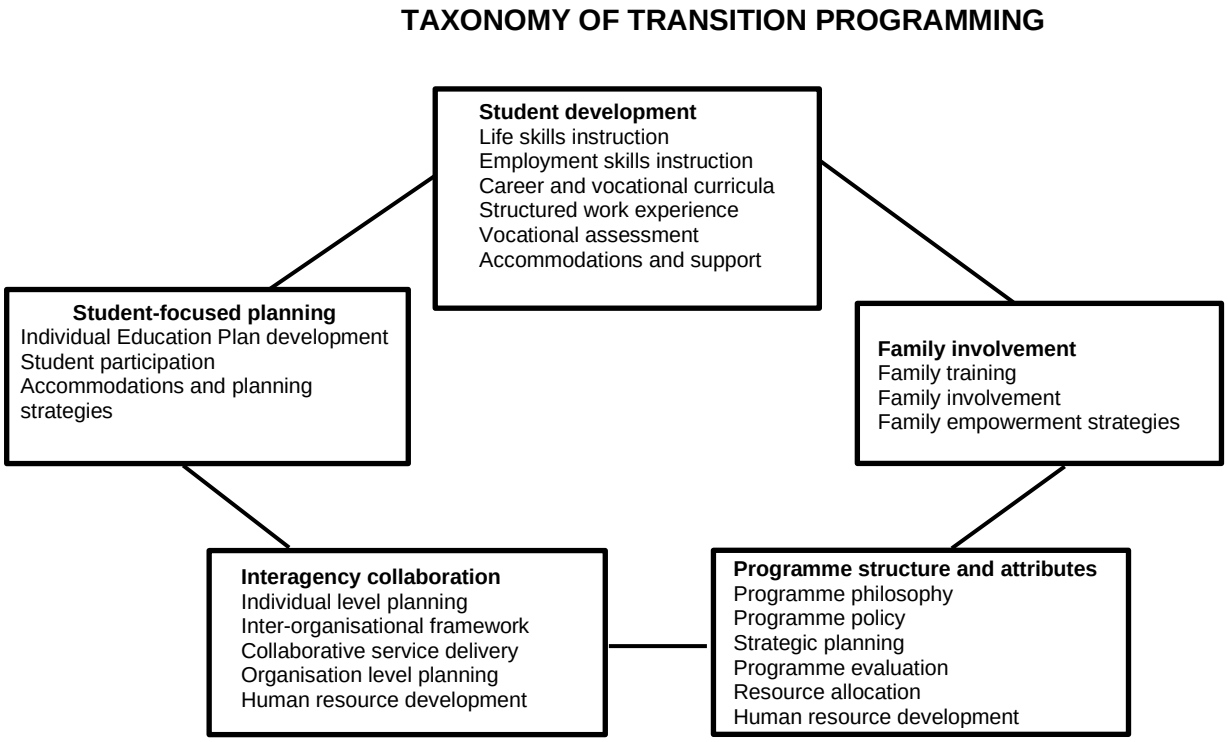


Figure 2.1: The taxonomy of transition programming (Kohler & Kohler, 1996, p 137)

Kohler stressed the importance of *transition-focused education* (Kohler & Field, 2003). She emphasised that the teaching of practical life skills as part of the curriculum might ensure meaningful community participation in typical settings. Instead of viewing transition planning as an add-on activity for learners with intellectual disability when they reach the age of 14 or 16, Kohler maintained that, in special needs education, a shift from deficit-driven, disability-focused programmes to an approach based on abilities, self-determination and adult outcomes is needed (Kohler & Field, 2003).

Kohler's findings have been widely utilised in further research and subsequent articles by an array of authors. The principles of early research on transition practices are still highly relevant and have prompted significant shifts regarding professionals' views on core concepts in the field of intellectual disability over the past 30 years (Buntinx & Schalock, 2010). Three inter-related concepts have been central to these changed views: The construct *of intellectual disability*, views on the importance of a person's *quality of life* and the way *individualised supports* may facilitate a person with disabilities to overcome transition-related challenges (Buntinx & Schalock, 2010). Rather than viewing intellectual disability narrowly as a limitation in intelligence and adaptive skills, it is now viewed as *a*

problem of the whole person in their life situation, impacting health, community participation and societal roles (Buntinx & Schalock, 2010).

Thus, each person with intellectual disability must be viewed as a unique individual with unique needs. Quality of life and its manifestation in the life of individuals with intellectual disability in transitional contexts has been widely researched (Kraemer et al., 2003; Nota et al., 2007; Schalock, et al., 2010; Mihai et al., 2018). Quality-of-life theory describes ways in which the individual can experience satisfaction, wellbeing, the fulfilment of needs and the realisation of potential. That is why I have chosen quality-of-life theory as one of the direction-giving theories of this study.

The construct of individualised supports has emerged from a person-centred approach that has been advocated in the literature from the 1990s onwards (Morningstar et al., 1999; Carter et al., 2014). In these studies, as well as in more recent literature, it has been shown that a person-centred approach should be characterised by an educational context that enables the development of self-regulated and goal-directed action, referred to as self-determination (Burke et al., 2019). I shall now discuss person-centred planning and self-determination, after which, I shall point out how these concepts can be linked to quality of life. Lastly, I shall discuss how the assessment of learner strengths and needs for the purpose of transition planning may be framed in order to plan holistically.

2.3 THE INDIVIDUAL IN THE CENTRE: A GOOD PLACE TO START

Person-centred planning places the learner at the centre of the planning process. The focus of person-centred planning is on the student's strengths and preferences. It is concerned with ways to identify a variety of individualised supports to achieve the dreams of the learner and their family (Morningstar et al., 1999). The study of Morningstar et al. (1999) conducted a review of five person-centred transition planning models and identified four components common to all of these: group support, a positive description of the learner, focusing on strengths and preferences, the development of a vision for the future, and an action plan to reach this vision.

The construct of *self-determination* is closely connected to person-centred planning. Carter et al. (2009) maintained that self-determination is evidenced when youth can *identify* their interests, strengths and preferences, *communicate* their goals for the future to others, *evaluate* their options and make important life *choices* (Carter et al., 2009). After having made their choices, they should be able to take steps to *achieve* this vision, *advocate* for needed supports and services, *reflect* on their progress towards life goals and *adjust* efforts where needed (Carter et al., 2009). However, in the study of Carter et al. (2009), teachers

reported that youth with severe intellectual and developmental disabilities demonstrated fairly limited knowledge about self-determination and the behaviour it requires, and had a limited ability to perform this behaviour. Youth with SID were perceived to have greater support needs in tasks related to self-management, self-evaluation, problem-solving and adjustment, which are the more cognitively demanding components of self-determination (Carter et al., 2009).

As teachers generally expect learners to acquire self-determination skills incidentally over time, explicit instruction on these skills is rarely delivered in schools (Raley et al., 2018). In my experience as an educator in the SID school that was the research site, educators tend to under-estimate their learners' capacity for self-determination and do not view the inclusion of explicit instruction in these skills as a priority. However, recent research on self-determination for learners with intellectual disability has revealed the need for *high-quality instruction* on skills associated with self-determination (Shogren et al., 2016). This research has led to the so-called self-determined learning model of instruction (Shogren et al., 2017). The teacher guide for this instruction model proposes that teachers facilitate learners to become more self-determined by teaching them to consider the following questions concerning educational and life goals: What do I want to learn? What do I know about it now? What must change for me to learn what I do not know? What can I do to make it happen? (Shogren et al., 2017). Fostering self-determination and self-advocacy skills in learners with intellectual disability is vitally important for successful learner-centred transition planning. Without these skills, learners with SID leave school without a vision for their future. They do not know their needs, are not aware of their interests and lack the skills to make meaningful choices (Martin, 2003).

To keep the individual's transition planning person-centred and dream-based, the American National Technical Assistance Centre on Transition (NTACT) proposes, in its age-appropriate transition assessment toolkit, the use of a so-called 'dream sheet', where the learner has to answer questions such as the following: Where would you like to live? What job would you like to do? (NTACT, 2016). Another very useful instrument, proposed by the same centre, is the Career Clusters Interest Survey (NTACT, 2016), where the learner indicates their career-related interests. Because these instruments are informal and thus not standardised, they could be reviewed for South African circumstances and should, with the help of the therapist who will be part of the ALS of this study, be adapted somewhat for learners with SID. Many of these learners are unable to read or have communicative challenges, so adding pictures or photographs could make the instruments much more user-

friendly. The adapted dream sheet and Career Clusters Interest Survey will empower the individual with SID to indicate their own preferences and make choices.

Research has shown that self-determination is correlated with quality of life (Nota et al., 2007). I will now take a closer look at quality-of-life theory and how researchers have developed this construct in the field of transition planning for the adolescent with SID.

2.4 QUALITY OF LIFE: FROM PHILOSOPHICAL THEORY TO LIFE GOAL AND MEASURABLE CONSTRUCT IN TRANSITION PLANNING FOR ADOLESCENTS WITH SID

Ventegodt et al. (2003) described the theoretical and philosophical framework of the concept of quality of life in a paper following the Danish Quality of Life Survey. Quite simply put, the authors define quality of life as a "good life" (Ventegodt et al., 2003, p. 1 031). They distinguish between an existential quality of life, an objective quality of life and a subjective quality of life. Existential quality of life refers to how good life is at a deeper level and may include spiritual and religious aspects. Subjective quality of life refers to the individual's subjective experience of how good a life they have (how they feel about their quality of life). This includes meaning in life, happiness, satisfaction with life and wellbeing. Objective quality of life refers to how one's life is perceived by the outside world. 'Objective' here refers to conditions of life that many observers can rate identically (Ventegodt et al., 2003). Objective quality of life factors include biological order, realisation of life potential, fulfilment of needs and factors such as cultural norms as status symbols that are needed to be a good member of a specific culture (Ventegodt et al., 2003).

Researchers in the field of intellectual disability have been researching ways to use quality of life as a conceptual framework to plan and assess the outcomes of support programmes (such as transition programmes) for individuals with intellectual disability (Verdugo et al., 2005). Verdugo et al. (2005) identified ten quality-of-life domains: interpersonal relations, social inclusion, personal development, physical wellbeing, self-determination, material wellbeing, emotional wellbeing, rights, environment (home, residence, living situation), family, recreation and leisure, and safety and security. Quality-of-life measurement can focus on the subjective component (level of satisfaction experienced) and/or objective indicators of these life experiences. (Verdugo et al., 2005). A later study by some of the same authors (Schalock et al., 2010) reduced these domains to eight and grouped them as follows:

Table 2.1: Quality-of-life domains (Schalock et al., 2010, p. 20)

Factor	Domains
Independence	Personal development
	Self-determination
Social participation	Interpersonal relations
	Social inclusion
	Rights
Wellbeing	Emotional wellbeing
	Physical wellbeing
	Material wellbeing

The different indicators of these domains were tabled as follows:

Table 2.2: Quality-of-life conceptual and measurement framework (Schalock et al., 2011, p. 19)

Domain	Literature-based indicators
Personal development	Education, performance, personal competence
Self-determination	Autonomy, personal control, goals and personal values, choices
Interpersonal relations	Interactions, relationships, supports
Social inclusion	Community integration and participation, community roles, social supports
Rights	Human rights (respect, dignity, equality) and legal rights (citizenship, access, due process)
Emotional wellbeing	Contentment, self-concept, lack of stress
Physical wellbeing	Health and health care, activities of daily living, leisure
Material wellbeing	Financial status, employment, housing

Petry et al. (2007) revised the quality-of-life framework proposed by Verdugo et al. (2005). These authors found that the quality of life of people with *profound multiple disabilities* could best be assessed by using five domains, first identified by Felce and Perry (1996): physical wellbeing, material wellbeing, social wellbeing, development and activity, and emotional wellbeing. The research resulted in a very comprehensive list of indicators, which I will attempt to summarise in Table 2.3.

Table 2.3: Operationalising quality of life for people with profound and multiple disabilities (Petri et al., 2007)

Domain	Indicators
Physical wellbeing	Mobility: Spasticity, deformities, positioning, moving to other rooms or outside, stimulations of independence regarding mobility Health**:** Physical and mental health status, medication side effects, treatment of pain, self-injury, sensory impairments, treatment Hygiene: Clean, well-groomed, comfortable and appropriate clothing, independence, teeth checked regularly Nourishment: Sufficient food and fluids, balanced diet, preparation of food (temperature, variation), positioning, feeding problems Rest: Consistent sleeping pattern, too much sleep – boredom
Material wellbeing	Living environment: Room geared to needs (temperature, lighting, decoration, privacy), wheelchair-friendly, limited number of people Technical aids: With regard to communication, independence, mobility, health, sensory functioning, activities and leisure
Social-emotional wellbeing	Communication: The person shows or expresses that they are happy/unhappy, feel well/unwell, want/do not want something, have an opportunity to express their feelings, needs and wishes. Support staff is responsive to communicative signals (e.g. facial expression, glance and direction of eyesight. Person is addressed appropriately for age, level of functioning. Treatment: The person gets individual attention during personal care, mealtimes, activities, therapy. Basic security: The person has a key worker or stable team of support staff – has a bond with them. Environment: Predictable and safe (daily structure) Family bonds: The person has a good relationship with parents, siblings and other family members. Contacts are made possible and supported. Social relationships: The person has meaningful social contacts with people outside the context of support. The person makes use of community services and facilities.
Development and activities	Engagement in activities: The person actively participates in individual and group activities. Activities presented correspond with the person's individual needs, capabilities and limitations. Influence and choices: The person influences their physical and material environment. The person makes choices with or without support with regard to mobility, clothing, food, etc. Development: The person has developed new competencies communication, motor development, social development, etc.

Table 2.3 illustrates that, no matter how grave a person's disability, their needs and preferences should still be in the centre of transition planning. Although the research site is a school for SID learners, some learners with profound and multiple disabilities are being accommodated as well, due to the lack of provision for their educational needs elsewhere. According to DSM-V (APA, 2013), an individual is viewed as being profoundly intellectually impaired when they are dependent on others for all aspects of their daily physical care and have co-occurring physical and sensory difficulties that are barriers to participation and social inclusion (APA, 2013). It is highly unlikely that these learners will be employable, yet, like anyone else, they have a right to a quality life.

Kim and Turnbull (2004, p. 54) put forth the following principles regarding person-centred transition planning for learners with severe intellectual impairment:

- Choice: The person is informed. The person chooses services and supports.
- Goals: The person chooses and attains their goals.
- Rights: The person exercises their rights.
- Security: The person has economic resources.
- Satisfaction: The person is satisfied with their services and life situations.

The subjective perspective of quality of life is about the individual's personal experiences and highlights the need to allow the SID individual to speak for themselves. One girl with SID put it as follows: "… you can never have a good life if nobody ever has a dream for you, unless you learn to have a dream for yourself" (Schalock, 1990, p. 11). It is good practice for a learner-centred approach to start with the learners' preferences and interests. However, for transition assessment to be holistic, a more comprehensive, multi-faceted approach is needed to create an overview of a learner's support needs and strengths.

2.5 TRANSITION ASSESSMENT: THE NEED FOR A HOLISTIC APPROACH

Schalock et al. (2018) have, in a more recent study, proposed a *holistic theoretical view* on intellectual disability. These authors stress that a multi-dimensional approach is vital when addressing the complexity of the challenges facing the individual with SID (Schalock et al., 2018). Some of the challenges referred to in their study are the following: environmental (e.g. impoverished environments), dietary or nutritional, medical or surgical, community engagement, parenting, staff and teacher development, educational, rights affirmation and policy reform (Schalock et al., 2018). These challenges are experienced as follows at the research site at which I teach:

Table 2.4: Comparison of challenges at research site to challenges identified by Schalock et al., 2018

Challenge identified by Schalock et al. (2018)	**Related challenges at the research site**
Environmental	A large percentage of the learners come from very impoverished environments. Many are parented by single mothers, who do not have adequate funds for necessities like food and diapers.
Dietary or nutritional	Roughly a third of the learners are making use of the school's feeding scheme.
Medical or surgical	Learners with physical disabilities are often in need of surgeries. Some of the learners with syndromes have associated medical conditions or sensory and behavioural challenges. More than 100 learners take chronic medication, which is administered at the school clinic.
Community engagement	The school engages the community by involving different stakeholders in fundraising activities. This presents an opportunity to foster partnerships aimed at transition support.
Staff development	The school has an internal development programme. Tertiary institutions in the country present very little expert training for teachers of learners with special needs. As a consequence, teachers from mainstream schools enter an SID school without the required specialised knowledge about the diverse needs of the learners.
Rights affirmation and policy reform	The legislative framework in South Africa entrenches the educational rights of learners with disabilities. Examples are section 29 of the Constitution (South Africa, 1996a), section 12 of the South African Schools Act (South Africa, 1996b) and Education White Paper 6: Special Needs Education (Department of Education, 2001). Yet, the concept of transition to adult life has not yet been prioritised in educational policies. This gap contributes to the poor post-school outcomes of South African learners.

Table 2.4 illustrates that the challenges at the research site are diverse and call for a holistic approach regarding assessment aimed at transition planning.

The American age-appropriate assessment toolkit (NTACT, 2016) explains that assessment for the purpose of transition planning can be formal or informal. Formal assessment is conducted with standardised instruments, whereas informal assessment lacks a formal norming process, and reliability and validity information (NTACT, 2016). Informal assessment needs to be used on an ongoing basis and by more than one person to improve its validity. Examples of informal assessment include interviews, questionnaires, direct observations, anecdotal records, environmental or situational analysis and curriculum-based assessment (NTACT, 2016).

Because formal assessment is more challenging to conduct with SID learners and because of the qualitative nature of the study, I made use of several different kinds of informal assessment to get a holistic view of the individual learners' transition support needs. These include holistically framed interviews, a questionnaire and observation conducted by different role players.

Interviews: Using the supports needs intensity scale as a holistic framework

The purpose of transition assessment is to identify the SID individual's support needs. A support need is created by a mismatch between a person with SID's competency and environmental demands (Thompson et al., 2009). Individualised supports, on the other hand, are based on thoughtful planning and can be seen as a bridge between 'what is' and 'what can be' (Thompson et al., 2009).

Responding to the need for a standardised, reliable and valid measure of support needs, the Supports Intensity Scale (SIS) was developed to measure the support needs of adults with intellectual disability aged between 16 and 64 in a holistic way (Thompson et al., 2004). The SIS consists of items organised into six support need domain subscales. Each of these domains includes eight or nine items rated on three dimensions: frequency, daily support time and type of support. However, instead of using these ratings, these domains can be utilised as guidelines for open-ended questions to be posed during semi-structured interviews with learners, parents, teachers and other stakeholders. The six support need domains of the SIS that cover different items are summarised in Table 2.5.

Table 2.5: The Supports Intensity Scale domains with corresponding skills items (Thompson et al., 2004).

SIS domain	Items covered (in interviews)
Home living (corresponds with the quality-of-life domains of independence and physical wellbeing)	Using the toilet Taking care of clothes (including laundering) Preparing food Eating food Housekeeping and cleaning Dressing Bathing and personal hygiene, grooming Operating home appliances
Community living (corresponds with the quality-of-life domain of social inclusion)	Transportation Community leisure activities Using public services Going to visit family and friends Participating in church activities Shopping and purchasing goods Interacting with community members Accessing public buildings and settings

SIS domain	Items covered (in interviews)
SIS domain	**Items covered (in interviews)**
Lifelong learning (corresponds with the quality-of-life domains of rights, personal development and self-determination)	Interaction with others during learning Participation in educational decisions Problem-solving strategies Using technology Accessing educational settings Functional academic skills (reading signs, counting change) Health and physical education skills Self-determination skills Self-management
Employment (corresponds with the quality-of-life domain of material wellbeing)	Need for accommodations Learning and using specific job skills Interacting with co-workers Interacting with supervisors or coaches Acceptable work speed Acceptable work quality Changing job assignments Seeking information and assistance from employer
Health and safety (corresponds with the quality-of-life domain of physical wellbeing)	Taking medication Avoiding health and safety hazards Obtaining health care services Ambulating and moving about Learning how to access emergency services Maintaining a nutritious diet Maintaining physical health and fitness
Social activities (corresponds with the quality-of-life domains of interpersonal relationships and social inclusion)	Socialising within the household Participating in leisure activities with others Socialising outside the household Making and keeping friends Communicating about personal needs Using appropriate social skills Engaging in loving relationships Engaging in volunteer work

Some challenges have been identified when conducting interviews with SID individuals. Taylor and Bogdan (1990) have warned that individuals with SID tend to under-report in interviews with open-ended questions. In addition, Hume et al. (2018) have pointed out that the perceptions of key stakeholders, such as parents and teachers, concerning the skills and support needs of adolescents tended to show only low to moderate agreement to the perceptions of the adolescent themselves on the same issues. Therefore, Hume et al. (2018) propose that different reporters are needed to obtain adequate information for a holistic understanding of the adolescent's functioning.

Questionnaire: The adolescent autonomy checklist

The adolescent autonomy checklist is one of the instruments proposed by the NTACT (2016). This checklist is very appropriate to identify support needs regarding daily living skills – including housekeeping skills, healthcare skills, community skills and leisure skills (NTACT, 2016). The questionnaire has been compiled in a very practical way and includes numerous skills that family members can help the individual to attain – skills that, despite being seemingly very simple, can make a huge difference. Examples are to make the bed, choose decorations for a room, change a light bulb, take out the trash, use a fire extinguisher, know how to turn the water off, know community emergency telephone numbers, go shopping, maintain privacy in the bathroom, etc. (NTACT, 2016).

Observation

Situational observation or direct observation should be conducted in the natural school, home, community or employment setting (NTACT, 2016). For this study, the parent interviews were conducted in the homes of the participants to observe the socio-economic circumstances of the family, the interaction between the adolescent and their family and their interpersonal skills.

Learners who are placed in supported employment situations, including job shadowing and job sampling, may be observed in terms of Brady and Rosenberg's Job Observation and Behaviour Scale (JOBS) subscales (Brady & Rosenberg, 2002). The JOBS is a work performance evaluation instrument that is organised according to three subscales: work-required daily living, work-required behaviour and work-required job duties. The subscales and related items can be summarised as follows.

Table 2.6: JOBS classification of work-related skills (Brady & Rosenberg, 2002)

Work-required daily living	Work-required behaviour	Work-required job duties
Attendance Punctuality Personal hygiene or grooming Travel Verbal communication Non-verbal communication Money handling Functional reading and maths skills Self-identification Maintaining a schedule	Stress tolerance Interpersonal work interactions Interpersonal social interactions Changes in routines Honesty Reaction to criticism Work initiative Work endurance	Quality of work Quantity of work Speed of learning new tasks Performance on previously learned tasks Multiple task performance Organisation of work tasks Safety procedures Cleanliness of work environment Employee motivation

2.6 THE INDIVIDUALISED TRANSITION PLAN

In 2004, the American Individuals with Disabilities Education Act (United States Congress, 1990) was revised to include transition services for children with disabilities. The ITP is a document included in the IEP. When a child with a disability reaches the age of 16, a transition plan needs to be in place (United States Congress, 1990). According to IDEA, the ITP should include transition assessments, measurable post-secondary goals based on these assessments, and transition services needed to accomplish these goals (Takajo, 2018).

In contrast to the direction-giving legislation, a rich pool of research and impressive records of good practices in Western countries, no legislation and policy guidelines specific to the transition of learners with intellectual disabilities seem to exist in South Africa. Despite searching diligently, I could find only one reference to something similar to the ITP in South African legislation and policy documents. This was in the Policy on Screening, Identification, Assessment and Support (SIAS), a document on support needs and strategies for learners with special education needs. There is one sentence stating that the policy aims at guiding legislative provision to determine "appropriate school exit strategies and accompanying transition to work programmes" (Department of Basic Education, 2014, p. 19). A study by Grigal et al. (1997), conducted way back in 1997, evaluated the different components of transition programmes. These authors stressed the need for clear, adequately described goals, timelines and the identification of support staff to ensure that these goals are reached. During this study, the ALS will have to rely on the IDEA's guidelines and studies based on these guidelines to frame an outline of the ITP.

In the absence of policy and legislation guiding transition planning in South Africa, I asked myself whether some schools for learners with SID nevertheless have programmes to transition their learners into adult life. What would such a school's transition planning look like and can this study utilise the knowledge such schools have attained? A search for South African academic articles on transition planning for learners with SID resulted in one article, a study by Steyn and Vlachos (2011).

I will conclude this chapter by discussing this article critically and comparing its findings with those of the salient American and European authors on transition planning to see whether it sheds any light on the (South African) road ahead.

2.7 TRANSITION PLANNING FOR SOUTH AFRICAN ADOLESCENTS WITH SID: THE STEYN AND VLACHOS STUDY

The study (Steyn & Vlachos, 2011) followed a mixed-methods design and was conducted as a case study, involving three adolescents aged around 17 years. The study utilised the different steps of programme development, as described by Sparg et al. (1999), as a theoretical framework: needs analysis, planning and development of a programme, implementation and evaluation of the programme (which includes managing the work, managing the resources and managing the people) and evaluation of the programme. The researcher started with a needs assessment and proceeded to develop the learners' knowledge, skills and values. This was done by means of internal work placement (within the school campus). The research concluded by conducting quantitative measurements of the progress the learners made with regard to their knowledge, skills and values (Steyn & Vlachos, 2011).

On the positive side, although I did not see it in any of the salient transition literature that I have read, some good transition principles were present. The learners were involved and were encouraged to make choices regarding their job preferences. The families were involved as well and gave their views on what their children would or should do as adults. The programme structure was well planned and executed, and the learners were being developed towards their transition goals, which included skills, knowledge and attitudes. However, in comparison to the literature in the field, some gaps were present. These are the following:

- The transition assessment, planning and programming started too late. The American IDEA requires learners to start transition programming at 14 to 16 years of age.
- Learners' preferences regarding work placement were taken into account, but in practice, they could only do what was available on the school campus.
- The goal setting is reminiscent of a bridge with only one leg: the bridge is not reaching over the school walls into society or the world of work.
- The transition planning is too narrowly focused on employment and, although some other aspects of the learners' development towards adulthood were addressed, the approach was not holistic enough.
- The case study design is not ideally suited to facilitate transformative learning. PALAR methodology is more suited to get staff members serving in the ALS enthusiastic and committed to making the transition programming work.
- One of the five principles in Kohler's taxonomy of transition planning, interagency collaboration, is absent.

Despite all the gaps I have pointed out, I need to stress that this author did ground-breaking work in a country where transition planning is still far from being viewed as a priority. As I know Dr Vlachos and the school at which the research was conducted, I know the school's transition programming has made great strides since the study was published. The school's learners are now being transitioned into the open labour market. However, during a telephone conversation with the author, she shared with me that the main challenge of their school's transition programme was its sustainability. As soon as the learners left school, the parents would not follow through with what had been done and all the hard work seemed to have been in vain. I believe that the missing link that influences the sustainability of transition planning negatively might be Kohler's interagency collaboration, or, put differently, the fostering of school-family-community partnerships.

2.8 CHAPTER SUMMARY

In this chapter, I referred to the work of salient authors on the topics of transition planning, quality of life, support needs and learner-centredness. Literature about learner-centredness and self-determination revealed that the best way to start transition planning is by starting with the learner. Challenges, strengths, and preferences should be identified by encouraging the learner to express their thoughts about their own future. Informal instruments such as the dream sheet and an adapted Career Clusters Interest Survey questionnaire could be extremely helpful in this regard. Quality-of-life principles point towards holistic transition planning, starting with holistic assessment. The Supports Intensity Scale provides an excellent framework for holistic assessment. Because of the qualitative nature of this study, semi-structured interviews utilising open-ended questions based on the SIS and a tick list, the adolescent autonomy questionnaire, will play an important role in revealing the support needs of young SID adolescents in a wide range of post-school settings. Observation by different stakeholders at learner homes, in schools and in employment-related settings will complete the puzzle to reveal a holistic picture of the individual learners' support needs. Based on this holistic view of the learner, developmental goals can be identified, and transition planning should commence, resulting in the Individual Transition Plan. In the absence of any South African legislation and policies on transition planning, I concluded the chapter by reviewing a South African transition study to identify important gaps that could direct this study towards developing more sustainable transition planning in South African schools for learners with SID. Chapter 3 will focus on such an aspect: family-school-community partnerships. I will start Chapter 3 by discussing Bronfenbrenner's ecological systems theory, which underpins this important transition principle.

CHAPTER 3: WORKING TOWARDS SUSTAINABLE TRANSITION GOALS BY MEANS OF FAMILY-SCHOOL-COMMUNITY PARTNERSHIPS

3.1 INTRODUCTION

In Chapter 2, the discussion revolved around the individual with severe intellectual disability; the person in the centre. Evidence-based studies have shown that person-centred assessment, planning and transition strategies can lead to a quality life, including satisfaction with services, an enhanced sense of autonomy, choice and self-determination, and higher rates of employment (King et al., 2005). However, in this chapter, my focus will shift from the individual with intellectual disability towards those who surround him, more specifically the family, school and community. Small et al. (2013) warn that person-centred transition planning for youth with intellectual disabilities, although crucially important, when conducted in isolation, may transpose an individualist ideal to a group of people whose needs might be served better by acknowledging the importance of interdependence between the young adult and those who need to support them in the journey towards adulthood. Therefore, an ecological approach, involving family-school-community partnerships, has been advocated widely by an array of authors from as early as the 1990's (Epstein, 1995; Kim & Turnbull, 2004; Epstein & Sanders, 2006; Bryen et al., 2007; Quezada et al., 2018; Epstein, 2019).

The idea of partnerships is not new in the field of special education. Summers et al. (2005) defined partnerships as "mutually supportive interactions between families and professionals, focused on meeting the needs of children and families, and characterised by a sense of competence, commitment, equality, positive communication, respect and trust" (Summers et al., 2005, p. 3). Bryan and Holcomb-McCoy (2007) see partnerships as collaborative relationships where school professionals, families and community-based organisations (such as businesses, churches, libraries and social service agencies) partner to implement programmes and activities to provide needed support for students to be able to succeed.

Indeed, research has shown that family-school-community partnerships enhance learners' chance to be successful, not only in school, but also in life (Epstein, 2019). The ecological approach, which relies heavily on partnerships, emphasises the importance of supporting the participation of youth in real-life activities and experiences (King et al., 2005). The National Longitudinal Transition Study (Wagner, 1993) reported that community-based work experience was more useful than school-based programmes, as real-life situations are required for the generalisation of skills.

The ecological approach also seeks to bring about change on a broad, community level by means of community education and advocacy (King et al., 2005).

I will start the chapter by discussing Bronfenbrenner's ecological systems theory (Bronfenbrenner, 1986) and how the theory might be helpful to view the ecology of and relationships between the different role players around the individual with SID. I will then proceed to discuss the school's role in establishing partnerships with families and community-based organisations. Regarding community partnerships, I will discuss the issue of employment (Hart Barnett & Crippen, 2014) and touch on the concepts of social networks (Simplican et al., 2015; Baumgartner et al., 2012), social inclusion (Buntix & Schalock, 2010) and social capital (Trainor, 2008). Views of African researchers on inclusion and the concept of Ubuntu (Phasha et al., 2017) will be discussed to establish how to approach the inclusion of young adolescents with intellectual disability in South African society. Biased views about disability in traditional African communities (Walton, 2018), as well as poverty (which may be barriers preventing inclusion in society), will be discussed next. I will end the chapter with a visual representation that serves as a summary of the core ideas emerging from the literature.

To lay the foundation for this chapter's discussion, I will discuss Bronfenbrenner's ecological systems theory (Bronfenbrenner, 1986), which underlies the construct of partnerships.

3.2 BRONFENBRENNER'S ECOLOGICAL SYSTEMS THEORY

It is safe to assume that Bronfenbrenner is one of the most quoted theorists in the field of educational psychology. However, Tudge et al. (2009) correctly chastise authors who base their research upon early versions of his work without considering the key elements of the more "mature version" of the theory (Tudge et al., 2009). Claiming to base a study on Bronfenbrenner's theory without specifying exactly which version of his theory is meant amounts to a misrepresentation of this renowned author's work. Bronfenbrenner's theory has evolved considerably since the publication of his book *The ecology of human development* (Bronfenbrenner, 1979). In one of his publications, he wrote: "I have been pursuing a hidden agenda: that of re-assessing, revising and extending – as well as regretting and even renouncing – some of the conceptions set forth in my 1979 monograph" (Bronfenbrenner, 1986, p. 187, cited in Tudge et al., 2009). To avoid the pitfall of misrepresenting Bronfenbrenner's theory, I have made use of the summary of the "mature version" of his theory, offered by Tudge et al. (2009).

Tudge et al. (2009) point out that the process-person-context-time (PPCT) model became central to the later version of Bronfenbrenner's theory. The term 'process' refers to the interaction between the individual and the persons, objects and symbols in their environment resulting in human development (Tudge et al., 2009). This interaction, according to these authors, has to occur regularly and over extended periods of time. Regarding the 'person', Tudge et al (2009) describe three types of characteristics that, according to Bronfenbrenner's theory, the individual brings into any social situation: demand, resource and force characteristics. Demand characteristics may influence interactions because of the immediate impressions created initially – such as age, gender, skin colour and physical appearance. Resource characteristics relate to mental and emotional resources, such as social and material resources, past experiences, intelligence and skills. Force characteristics are connected with factors such as motivation, persistence and temperament skills (Tudge et al., 2009).

To relate the first two concepts (process and person) of Bronfenbrenner's PPCT model to this study, I would like to illustrate by using two individuals with intellectual disability close to me. The interaction between the individual with intellectual disability and their environment (process) has a profound influence on their development. The case of my adopted son could serve as an example. He has severe cerebral palsy, rendering him unable to even sit up on his own. This boy had been born to a poverty-stricken family. His mother had passed away and his father was largely absent due to his job as a road worker. Up to the age of 7, he lay on the floor of the shack that was his home and stared at the roof. When he became part of our family, he had no concept of basic objects in his environment, such as trees, animals, shops or cars. No doubt, if this situation had continued, it would have had a profound detrimental influence on his development. Today, because of his exposure to a more stimulating environment, he is a young man with an excellent vocabulary, a good sense of humour and normal conversational skills.

With regard to personal characteristics in the context of transition planning and social interaction, my biological daughter could serve as an example. She walks with difficulty and her speech is unclear, due to her cerebral palsy. Due to these demand characteristics, people tend to conclude that her intellectual capacity is much more limited than it actually is. Because of her communication challenges, her social resources are very limited, as people do not understand her. These challenges make it very difficult for her to function in the open labour market. However, she is an extremely motivated young lady (force characteristics) and has managed to start her own small business making party packs for children's parties. If transition planning for an adolescent with similar challenges is conducted, these demand characteristics need to be considered carefully before any decisions regarding job placement are taken.

The ‘context’ part of Bronfenbrenner’s PPCT model refers to the four well-known systems most sources on Bronfenbrenner’s ecological systems theory refer to: microsystem, mesosystem, exosystem and macrosystem. Microsystems are settings in which the individual spends a lot of time and with which they have direct interactions or experiences, such as the family and the school (Bronfenbrenner, 1979). A mesosystem refers to the interaction between the different microsystems in the individual’s life, for example a teacher contacting the parent to discuss the learner’s schoolwork (Tudge et al., 2009). An exosystem is a setting in which the focal individual does not participate directly, but that has a direct influence on them – for example, if the mother is unhappy in her work environment, she may be tired and impatient when she arrives home, which has an influence on the child. Lastly, the macrosystem refers to a “culture, subculture or other extended social structure” (Bronfenbrenner, 1993, p. 25, as cited by Tudge et al., 2009).

Regarding the last concept of the PPCT model, ‘time’, Tudge et al. (2009) refer to Bronfenbrenner and Morris (2006), who distinguished between micro-time (time span of a specific activity or interaction), meso-time (the consistency of the interactions that happen repeatedly in the person’s environment) and macro-time (historical or other major events that have an influence on the person’s development) (Tudge et al., 2009). In Bronfenbrenner’s earlier work, macro-time is also referred to as the chronosystem (Bronfenbrenner, 1986). To cite an example in the South African context, the 2019 South African education system looks entirely different in comparison to the education system of pre-1994 South Africa, when the apartheid government was still in power – a fact that has to have an influence on the development of young adolescents with intellectual disability.

For this study, I built upon Bronfenbrenner’s ecological systems theory, based on his PPCT model (Bronfenbrenner, 1993), in the following way:

Process: The interaction between the young adolescent and their environment was observed throughout the study. For example, the parent interviews were conducted in the home environment of the parents, who graciously received me in their homes. During these visits, the family’s challenges and strengths became clear. These factors had a profound influence on the transition planning of the young individual with intellectual disability.

Person: The young adult was assessed thoroughly (cf. Chapter 2) to determine what their challenges and strengths were in terms of the demand, resource and force characteristics (Tudge et al., 2009). This assessment directed decisions regarding their preparation for placement in an appropriate social or work setting during the transition period.

Systems: An important focus of this study was to determine how the different systems in the life of the individual with intellectual disability may serve as supports as they transition into adult life. Therefore, the ALS not only relied on support within the ecology of the young adult with SID, but also endeavoured to step up and create partnerships, where the partners were a support net for these adolescents. In this venture, two *microsystems,* the family and the school, need to interact to partner and become a strong *mesosystem*. Together, they should ideally enlist community stakeholders (often functioning in the individual's *exosystems*) as partners. The influence of the *macrosystem*, the cultural and current socio-political setting (especially regarding disability legislation and policy) in South Africa will be reviewed in this chapter (and emerged during data collection as well). The influence of this macrosystem is a profound force that cannot be ignored.

Time: Unfortunately, this study is not longitudinal. However, I believe that, over the time span of the study, the effect of the preparation for transition and the enlistment of partnerships on the quality of life of the individual with intellectual disability became evident. It is hoped that, over time, as these transition practices become part of the policy framework of the DBE, people with disabilities will have a better chance to be included in society as South Africans in their own right.

With so many researchers framing their work according to Bronfenbrenner's ecological systems theory, it is inevitable that some varied views of this theory will emerge. I found one of these variations, proposed by Neal and Neal (2013), very useful as a possible foundation for the construct of social networking as a support measure.

3.3 THE SOCIAL NETWORK MODEL: TOWARDS MAPPING PARTNERSHIPS AS SOCIAL SUPPORT

Neal and Neal (2013) proposed a variation of Bronfenbrenner's nested ecological systems in the PPCT theory. Bronfenbrenner originally viewed these systems as a set of concentric circles nested within each other (Bronfenbrenner, 1979). However, Neal and Neal (2013) argue that these systems should rather be portrayed as *networks*, in terms of the *social relationships* surrounding the focal individual. These networks may overlap, but not in a nested way. These authors call this model the social network model (Neal & Neal, 2013). An example of such a network is displayed in the figure below:

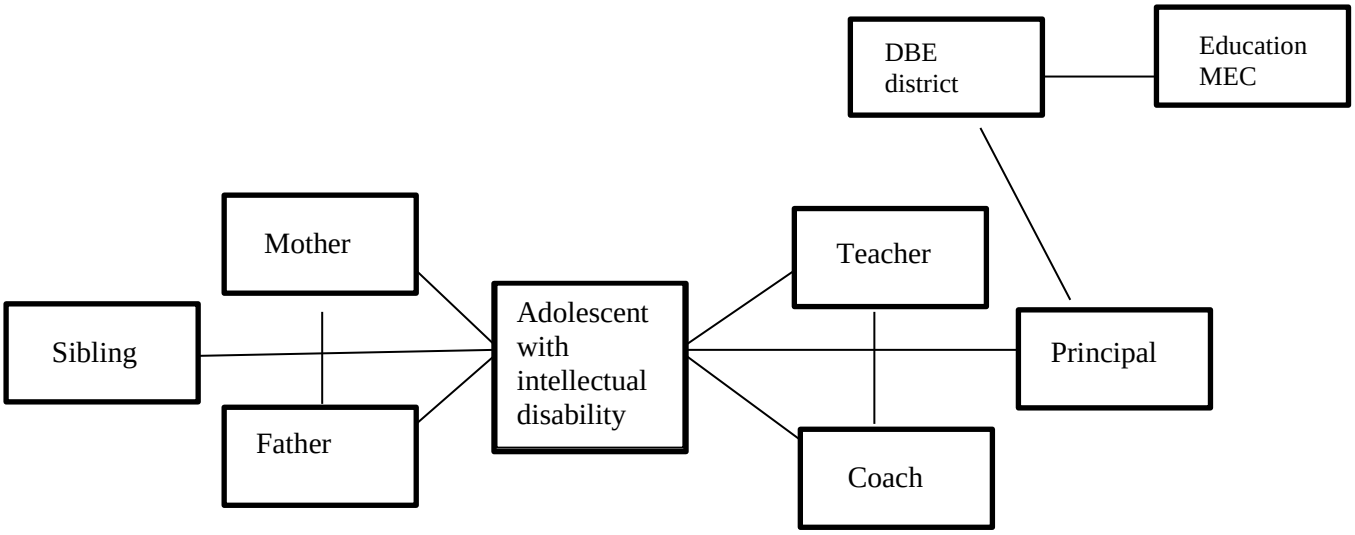


Figure 3.1: Social network model based on Bronfenbrenner's theory (1979)
(adapted from Neal and Neal, 2013, p. 730)

In the illustration above, the adolescent and their family (mother, father and sibling) are part of a microsystem, as are the adolescent, their teacher, coach and principal, who represent the school. The interaction between school and family will be a mesosystem. The district office and Education Member of the Executive Committee (MEC) are part of an exosystem, which will influence the adolescent's school environment, although they are not part of the exosystem. Neal and Neal (2013) do not portray the macrosystem (culture, policies and legislation) and the element of time in their model. However, the social network model makes it possible to portray the important supportive social relationships in the life of the individual and how the different systems are linked to create partnerships more accurately than the traditional nested illustration.

During transition planning, it is very important to determine which stakeholders or partners are important in the individual's social network and even which exosystems they have connections in. For example, in the case of my daughter, her sister is an occupational therapist, who knows companies that make assistive devices and wheelchairs; aids that my daughter may need in future. Via a sibling or another family member of a learner, the school may foster partnerships for the support not only of that specific learner, but possibly others with similar needs as well. Baumgartner et al. (2012) recommends the use of *eco-maps* to depict the support system of a learner with intellectual disability. An eco-map is a graphic representation of a social support network and can be a very useful tool in transition planning. Lines, shapes and colours are used to describe the support available to the adolescent in different contexts (Baumgartner et al., 2012).

Data of this study indicated that it is vitally important for the learner's successful transition that the school fosters strong partnerships with families as a first step before attempting to progress towards school-community partnerships for transition-related outcomes (cf. chapters 6 and 8). With these factors in mind, I will now discuss the importance of and challenges regarding family involvement in transition planning; a topic that has already been widely researched.

3.4 THE FAMILY-SCHOOL PARTNERSHIP: DO WE SEE EQUALITY, MUTUAL RESPECT AND TRUST?

The transition from school to adulthood affects not only the young adolescent with intellectual disability, but also those closest to them. During this stressful period, growth and change are accompanied by increased challenges and uncertainties, not only for the learner, but also for their family (Kim & Turnbull, 2004). The parents and extended family usually remain in supportive roles long after the learner's exit from school (Morningstar et al., 1995). Moreover, because of the cognitive and communication limitations of adolescents with severe intellectual disability, parent and family perspectives are a very important source of information regarding their transition needs and experiences (Neece et al., 2009). Neece et al. (2009) maintain that family wellbeing is closely related to transition success. High parental involvement is associated with better post-school outcomes, such as employment, and living and participating in the community (Wagner et al., 2005). It follows then, that transition planning in the absence of effective family-school partnerships will be a futile exercise. But what does real-life family-school collaboration look like? How do the role players of this mesosystem view each other?

Unfortunately, research shows that there is much room for improvement in general regarding parent-teacher collaboration in the field of special needs teaching. Luckner and Hanks (2003) refer to the 'Goldilocks' perception: Teachers usually view parental involvement as 'too involved', 'too uninvolved' or 'just right' and are inclined to blame parents for either being unable to accept the child's condition or non-caring. Wilt and Morningstar (2018) have found that, especially in the case of culturally and linguistically diverse families, the parents tend to be reduced to passive partners regarding their children's education and future planning. These parents reported that professional attitudes made them feel isolated, distrustful and left out. Teachers, on the other hand, are often not aware that what they may perceive as parental apathy or indifference may be due to exhaustion, difficulties with logistics, discomfort regarding interaction with professionals and a feeling of disempowerment due to cultural differences (Luckner & Hanks, 2003).

Findings pointing to challenges regarding parent-teacher collaboration have been noted by South African researchers as well. Makgopa and Mokhele (2013) have found that a lack of parental involvement is not due to a lack of interest, but rather to challenges such as poverty, single parenthood, lack of English literacy, the effects of the HIV/AIDS pandemic and cultural and socio-economic isolation. Heystek (1999) has recorded feelings of inferiority towards teachers, demographic factors, teachers' negative actions and attitudes, as well as negative attitudes towards the school from the parents' side.

Effective partnerships with families, aimed at the achievement of successful transition for learners with intellectual disabilities, are only possible if the vicious cycle of mistrust that so often exists can be broken. To repeat what I have written in the introduction, any partnership should be characterised by *competence, commitment, equality, positive communication, respect and trust* (Summers et al., 2005). The school and parents, when addressing transition planning, should collaborate in the planning, coordination and implementation of the individual adolescent's programme at home, at school and in the community (Bryan & Henry, 2012). This means that the partners (school, family and learner, community stakeholders) have to *share* decision making, ownership and responsibility for the transition goals and outcomes. This is a considerable shift from the usual tendency of schools to design programs and interventions *for* rather than *with* students and families (Bryan & Henry, 2012). But how does one achieve that?

After comprehensive research, Bryan and Henry (2012) arrived at a seven-stage partnership model that may serve as a road map for the fostering of school-family partnerships. These seven stages are preparing to partner, assessing needs and strengths, coming together, creating a shared vision and plan, taking action, evaluating and celebrating progress, and maintaining momentum (Bryan & Henry, 2012). Bryan and Henry (2012) stress the fact that the process of building a family-school partnership should be preceded by a preparation process, which involves an attitude change and buy-in of school staff, as negative attitudes may be a barrier towards creating a shared vision and moving forward in a sustainable manner (Bryan & Henry, 2012). Cote et al. (2012) point out that respect for family values and cultural competence is an important factor when working on partnerships. For example, culturally and linguistically diverse families may have an entirely different concept of the continued role of the family in the life of the individual with intellectual disability, as opposed to the individualistic Western culture (Cote et al., 2012). Okeke (2014) agrees with this view, stating that dissonance between the cultural capital of the parents and that of the school may result in participatory apathy, which is a very dubious foundation for a school-family partnership (Okeke, 2014)

Creating a shared family-school vision and plan for the future of the young adult with intellectual disability is no simple matter. Blacher et al. (2010) found that family expectations, knowledge and worries may vary according to the diagnostic group of the adolescent with intellectual disability. Parents of youths diagnosed with autism felt apprehensive about their transition into adulthood, realising that they had to prepare themselves for a lifelong commitment of care. In contrast, families of individuals with Down Syndrome were more optimistic, characterising them as sociable and able to elicit positive interactions with family members. Parents of learners with cerebral palsy reported high levels of depression and anxiety (Blacher et al., 2010). Understanding each adolescent's disability-specific challenges can potentially help families and support staff manage expectations and plan cooperatively in a realistic way (Blacher et al., 2010).

The most recent taxonomy for transition planning of Kohler et al. (2016) distinguishes between *family involvement*, *family empowerment* and *family preparation*. According to these authors, *family involvement* necessitates, among other points, the following:

- Families should participate in the entire transition planning process.
- Families should participate in setting up a natural support network.

Family empowerment, according to Kohler et al. (2016), involves transition information being provided to the family timeously (well before the transition process commences). This information should be shared in their ordinary language and in a culturally responsive and respectful manner. Families should be linked to adult service providers to make informed decisions (Kohler et al., 2016). The authors also stress the importance of *family learning and preparation* in terms of matters such as legal issues and the facilitation of community experiences for youth with disabilities (such as safety, transportation, social skills and mobility) (Kohler et al., 2016).

In summary, research has shown that family-school partnerships are sadly often hampered by challenges such as negative attitudes, demographic factors and cultural insensitivity (Heystek, 1999; Luckner & Hanks, 2003; Makgopa & Mokhele, 2013). It is vitally important that school staff members reach out to parents to ensure that attitudes on both sides are shifted towards *shared ownership and responsibility* with regard to transition planning (Bryan & Henry, 2012). The seven-stage partnership model of Bryan and Henry (2012) provides an excellent framework to outline the steps to be followed to create and maintain a working family-school partnership based on trust and mutual respect (Bryan & Henry, 2012). The *diverse needs and corresponding anxieties* or expectations of parents with regard to the challenges of different disability groups should not be under-estimated

(Blacher et al., 2010). Lastly, Kohler et al. (2016) stress the *empowerment* of *parents*, providing them with information timeously and preparing them for the transition period of the young adult with SID.

After having attended to the important first step, building a trusting and empowering partnership with the family, more specifically the parents of the individual with SID, the next daunting task is to facilitate partnerships with community stakeholders that are aimed not only at employment, but also at social inclusion and the creation of a sense of belonging, which is an important quality-of-life domain (cf. Chapter 2). This topic is under discussion next.

3.5 SCHOOL-COMMUNITY PARTNERSHIPS: DISCUSSION AROUND THE CONSTRUCTS OF COMMUNITY, COMMUNITY PARTNERSHIPS, EMPLOYMENT PREPARATION, INCLUSION, SOCIAL RELATIONSHIPS, NETWORKS AND BELONGING

It has already been established that respect, trust, communication and commitment are characteristics of any partnership (Summers et al., 2005). However, before looking at ways in which schools and parents can possibly foster partnerships with community stakeholders, it is necessary to establish what the concept 'community' refers to in this context. There is little doubt that inclusion in a community is a human right (Walker, 2013). The question is how the term 'community' should be defined. McCausland et al. (2016) differ from the widespread assumption throughout intellectual disability literature and policy that 'community' refers broadly to the general population or wider society. Instead, these authors see bonding between people and having a sense of belonging as core qualities of a collection of people called a 'community'. Influences such as geographic location or proximity and shared interests or culture bring people together. A sense of belonging is cultivated through reciprocal and interdependent relationships between community members (McCausland et al., 2016). A community, for McCausland et al. (2016), is thus *not* the general population, but a group of people often staying in close proximity to each other; people with shared interests and a similar culture or people who have a bond of some nature between them. This view fits in well with Bronfenbrenner's ecological systems theory (Bronfenbrenner, 1979) and places the individual with an intellectual disability within an ecology or network of relationships (Neal & Neal, 2013). Fostering a way forward by building upon these existing relationships to facilitate the inclusion of the adolescent with an intellectual disability into the community should be viewed as an integral part of transition planning.

However, the term 'community partnerships' is also utilised to refer to collaborative partnering with stakeholders such as local businesses, government departments and non-profit organisations.

Haines et al. (2015) identified a number of reciprocal community partnerships, for example partnerships with universities, social service organisations, local businesses, non-profit organisations and local municipalities. These authors stress that partnerships need to be *reciprocal* in nature in the sense that not only the school, the learner and the family, but also the community partner should benefit from the partnership. It is with regard to this reciprocal nature of partnerships that the thorny issue of successful transition into employment surfaces. As early as 2003, Millington et al. (2003) pointed out the sobering realities with regard to the employment of individuals with intellectual disabilities. They stress that, for employers, the moral imperative involved in employing such an individual is secondary to maximising profit and minimising cost (Millington et al., 2003). Quite simply, the business needs the best worker at the lowest expense. As a seller of labour who competes with all other neurotypical workers, the person with an intellectual disability may invariably end up unemployed (Millington et al., 2003). The question is: Is there any *benefit* for the employer in hiring a person with a disability? Can a person with an intellectual disability be an asset instead of a burden?

Millington et al. (2003) are of the opinion that the employer may benefit by building their image as a good corporate citizen with disability-friendly values. Other benefits may be personal satisfaction and the personal growth of business employees (Haines et al., 2015). However, for learners with an intellectual disability who have the potential to secure a job, it is of vital importance to be appropriately prepared for employment in order to *earn* sustainable job placement (Hart Barnett & Crippen, 2014). Relying on the employer's need to come across as a good corporate citizen or to promote the personal growth of employees will have limited results in terms of job security unless the business partner knows the adolescent well and wants to be of assistance. However, even then, the person with an intellectual disability should not be a *burden*, but an *asset* to the employer.

Hart Barnett and Crippen (2014) have identified eight steps that aim at a high-quality vocational skills programme to prepare learners with an intellectual disability for employment.

These steps are the following:

1. Observe other programmes and collaborate with other schools or teachers.
2. Align your programme with core academic standards that are functional and outcomes-oriented.
3. Involve learners in the planning process by allowing them to make their own choices.
4. Connect the programme to real-world experience by utilising a realistic vocational setting.

5. Create training materials and pre-vocational tasks that mimic real-world processes.
6. Use research-based training methods.
7. Integrate your programme within the school community – e.g. run a coffee delivery service for teachers to practice sub-skills needed in a restaurant.
8. Use authentic 'real-word' reinforcement such as social praise or even a 'pay cheque' system.

However, a school-based vocational skills programme, although good practice, will not prepare learners sufficiently to achieve satisfactory employment outcomes. Southward and Kyzar (2017) conducted a literature review to determine which transition-related activities can be associated with the attainment of competitive employment for youth with intellectual disabilities. They identified seven transition-related predictors of competitive employment:

- Paid employment while attending high school
- Vocational skills instruction
- Family expectations
- High school completion
- IEP goals relating to competitive employment
- Self-determination
- Participating in post-secondary education

Of these predictors, *paid employment experience* was the best predictor of post-school employment, whereas good *vocational skills instruction* (as described in the eight steps above by Hart Barnett & Crippen, 2014) was the second-best predictor. Four of the seven studies suggested that paid work experience more than *doubles* the likelihood of securing post-secondary competitive employment for people with an intellectual disability (Hart Barnett & Crippen, 2014).

To summarise: In order to provide an employer with an employee who, despite their intellectual disability, will be able to compete fairly with other labourers and render beneficial service to the employer, the first key to success is proper preparation during transition. The learner needs a well-planned vocational training programme, *as well as* real-life (preferably paid) work experience. However, Wilton et al. (2018) warn against a narrow focus on paid employment as a sole social inclusion goal. Social inclusion, as a transition goal, encompasses much more than just employment.

Social inclusion in a community is an important aspect of wellbeing or quality of life for people with intellectual disabilities (Buntix & Schalock, 2010). It promotes happiness, self-esteem,

confidence and mental health (Forrester-Jones et al., 2006). Haigh et al. (2013) conducted an inclusive research project, including individuals with an intellectual disability as co-researchers. These researchers identified four environmental factors that make people with intellectual disability happy. These are *choice and independence*, having *activities* to keep occupied with, having a *valuable role* to fulfil and having *meaningful relationships*.

However, McConkey (2007) points out that people with mild and severe intellectual disabilities may be most at risk of social isolation. Although people with intellectual disability may physically live in a community home or seem to be part of community activities, they often experience little sense of belonging and have very few meaningful relationships with neurotypical community members (Amado et al., 2013). To take this discussion forward, it is important to define the concept of *social inclusion.* I found the model of social inclusion proposed by Simplican et al. (2015) very comprehensive. After having reviewed social inclusion literature, these authors maintain that social inclusion consists of two important domains. These two domains, which overlap and mutually support each other, are *interpersonal relationships* and *community participation* (Simplican et al., 2015).

People with an intellectual disability need a social network, including family members, staff, friends and other acquaintances. These people may fulfil different support needs that Simplican et al. (2015) refer to as emotional, instrumental and informational. Emotional support includes love, care and trust. Instrumental support refers to “tangible aid and services” (Heaney & Israel, 2008, as cited by Simplican et al., 2015), while informational support involves “advice, suggestions and information” (Heany & Israel, 2008, as cited by Simplican et al., 2015).

Campbell and Gilmore (2014) refer to the so-called Aussie Optimism programme for learners with intellectual disability, where a learner is encouraged to create a visual representation of their social support system, an activity that may be of great help in the transition planning process. The learner is encouraged to draw themself in a circle, after which this circle is surrounded by a number of concentric circles. In the closest circle to the child, the members of the nuclear family or other most intimate sources of support are depicted. The next circle will contain close friends and extended family. This is followed by helpers such as teachers and counsellors. The more distal circles will include people such as community workers and the police. The suggestion of Campbell and Gilmore (2014) is strongly reminiscent of Bronfenbrenner’s ecological systems model, as discussed earlier in the chapter.

It makes sense to foster partnerships with people who already feature strongly in a specific learner's social network to sustain and build interpersonal relationships aimed at social inclusion in the community.

Simplican et al. (2015) distinguish between different kinds or categories of community activities, such as leisure activities (hobbies, arts and sports), productive activities (employment or education), consumption (access to goods and services – e.g. shopping), and religious and cultural activities and groups. They refer to different levels of involvement, including presence (being present physically, but having little contact with other people), encounter (fleeting meetings with strangers) and full participation, where social interaction is required and promoted (Simplican et al., 2015). However, people with an intellectual disability may experience numerous barriers to social inclusion due to cognitive and physical challenges that may render them vulnerable and dependent on support. Abbot and McConkey (2006) conducted a qualitative study that researched the views of people with intellectual disability on perceived barriers to social inclusion and community participation. These participants identified very practical ways to address these barriers, among others, the following (Abbott & McConkey, 2006):

- Appropriate skills training (e.g. budgeting, social skills, how to use public transport)
- Getting to know the neighbourhood
- Affordable and accessible public transport – using a specific named driver for safety
- Advocates and volunteers to accompany individuals in the community
- Education of the community with regard to the needs of people with disabilities
- Information on activities or events in the community that the individual may attend or participate in
- Information on and encouragement towards a healthy lifestyle

McConkey and Collins (2010) have conducted research on the views of residential or group home staff regarding support tasks for residents with SID. The researchers listed some support needs of people with intellectual disabilities with regard to activities of daily living such as learning to dress appropriately, maintaining personal hygiene, washing clothes, taking medication at appropriate times, managing a budget and getting groceries (McConkey & Collins, 2010). Wilton et al. (2018, p. 1) conducted a study that focused particularly on the significance of *shopping* and how "spaces of consumption" (p. 1) relate to social inclusion and a sense of belonging in the lives of people with SID. The researchers found that shopping gave the participants an opportunity to experience autonomy by means of social and spatial distance from parents or group home staff. Interactions with service

staff in shops, particularly when repeated over time with the same employees, offered participants valuable moments of social connection and recognition (Wilton et al., 2018).

Hall (2013) argues that the negative view of day centres as being instrumental in the segregation and resulting social exclusion of people with intellectual disabilities needs re-evaluation. For Hall (2013), these centres can be safe spaces where individuals with an intellectual disability may experience a sense of belonging. Belonging is "a personal, intimate feeling of being 'at home' in a place" (Antonsich, 2010, p. 1). Hall stresses that the making of art in protective workshops is not only therapeutic, but may also foster a sense of belonging and purpose, where these products are gifted (or, as is the case in many South African centres, sold very cheaply) to those in need of them.

Adolescents with intellectual disabilities may have an existing social network of core and extended family members, as well as other community stakeholders such as care facility staff, friends, church members and shop owners (Simplican et al., 2015). For school staff members who are tasked to facilitate learners to transition into adult life, it will make good sense to first establish what the support needs and strengths of the adolescent are, and then identify stakeholders already in their social network who may take them forward during and after the transition process. Examples of such partners could be a known and trusted taxi driver helping with transport, a sister who ensures that the person with SID is dressed neatly and appropriately, a grandmother who teaches them a craft, a soccer coach who is prepared to involve a boy with SID in soccer practice, church members who involve the individual in singing religious songs on Sundays and staff members of a care home who take care of basic needs. Building a support network well ahead of the time when the adolescent has to transition from school into adult life is akin to the concept of social capital (Trainor, 2008). Trainor cites Bourdieu (1986) to define social capital as "resources, both tangible and symbolic, that are derived from a person's connectedness to society via social networks" (Trainor, 2008, p. 150).

Building social capital in order to attain maximum independence, social inclusion, possible employment and a quality life is, of course, much easier for adolescents whose parents have a privileged lifestyle and who have more than ample support systems. However, unfortunately, the vast majority of youth with intellectual disability have grave barriers to overcome. I will now proceed to discuss some of these barriers, some of which may exist in less privileged South African communities.

3.6 BARRIERS TOWARDS SUCCESSFUL TRANSITION AND SOCIAL INCLUSION IN AFRICAN AND SOUTH AFRICAN COMMUNITIES

In the African and, more specifically, South African context, literature points towards some specific barriers regarding social inclusion as a transition goal. There include lacking policy implementation, poverty and biased attitudes towards young people with SID in African and South African communities. These three barriers will now be discussed in turn.

3.6.1 Policy implementation as a barrier

Intellectual disability is the most common childhood disability in rural African children. According to Bateman (2012), approximately 41 in every 1 000 children between the ages of 2 and 9 years have an intellectual disability. With the dawn of a new democratic dispensation in South Africa in 1994, the fresh focus on human rights seemed promising to the future of children with disabilities, of whom, by 2001, about 70% were out of school (Department of Education, 2001). The Constitution of South Africa entrenched values such as human dignity and equity, which led to the publication of White Paper 6: Special Needs Education on inclusive education (Department of Education, 2001). Sadly, as Donohue and Bornman (2015) point out, political and policy changes do not always translate into practice. Ngwena and Pretorius (2012) are stringently critical of politicians who deliver speeches that seem outwardly committed to inclusion, but do not seem to follow through on implementation. According to Donohue and Bornman (2015), the vast majority of learners with disabilities who *are* in school are still attending segregated schools for learners with special educational needs (LSEN). Support measures in classrooms that are needed to make inclusive education possible, such as teacher's aides, smaller class sizes and special equipment, are still virtually non-existent in state-funded mainstream schools (Donohue & Bornman, 2015). Children with SID are therefore dependent on LSEN schools for quality education – but these schools, few and far apart, are filled to the brim. Learners need to travel long distances at high costs to have access to education.

3.6.2 Poverty as a barrier

According to the United Nations Convention on the Rights of Persons with Disabilities (UNCRPD) (United Nations, 2006), 80% of all people with a disability live in developing countries. Pillay and Siyothula (2011) studied the living conditions of 100 consecutive attendees with intellectual disability who were seeking examinations at state mental health facilities in KwaZulu-Natal, South Africa. The findings indicated that 51% of the participants lived with moderate or severe intellectual disability.

Some 85% of these families relied on social grants. A quarter (26%) reported going to school without food for days (Pillay & Siyothula, 2011). According to Eide and Ingstadt (2011), people with disabilities are often the first to die when food and sanitary conditions deteriorate. They are the last to have an opportunity to find jobs when employment is scarce. They are also the last in a family to be sent to school if the parents battle to afford school uniforms (Eide & Ingstadt, 2011). Eide and Ingstadt (2011, p. 1) refer to the "vicious circle of poverty", since it is not only obviously the case that disability causes poverty, but also that poverty may cause disability.

Due to poverty, people may live far from medical help, which may cause birth complications to be treated too late, resulting in brain injury in some infants who then live with cerebral palsy. Unhygienic living conditions may result in disability-causing illnesses. Malnutrition due to poverty may cause a reduced resistance to infections (Eide & Ingstadt, 2011).

I cannot think of a better illustration of the at-risk living conditions of poverty-stricken children with disabilities than the case of a boy in the school that is the research site of this study. This boy contracted food poisoning after eating a contaminated 'spathlo' sandwich. By the time his parents realised that he needed medical attention, it was early evening. They did not have any transport to go to the hospital and more precious time went to waste looking frantically for transport. Arriving at the hospital, the emergency room of the state facility where they had to seek help was over-crowded and they were told to wait their turn in the queue. The boy died in the queue. His death was entirely preventable. A lack of hygiene (maybe no refrigerator), a lack of knowledge about the danger of dehydration, transport challenges, an over-crowded emergency room and inefficient service at a state facility all played a part in this tragedy.

3.6.3 Community bias as a barrier

In African countries, people with disabilities have often been marginalised, stigmatised and discriminated against (Sefotho, 2013). Van der Heijden et al. (2019) cite Goffman (1963) to define stigma as "undesired differentness" (Goffman, 1963, p. 5). For Rohwerder (2018), stigma arises when labelling, stereotyping and prejudice lead to status loss and discrimination against the individual. Rohwerder (2018) mentions several contributing factors to the stigmatisation of disability. Some cultures believe that disabilities are punishment for bad deeds (e.g. a sin of the mother), an ancestral curse or the result of witchcraft exercised by other people (Rohwerder, 2018). Some of the perceived 'bad deeds' are in actual fact superstitions, such as eating eggs or killing an animal without provocation during pregnancy (Mostert, 2016).

Research indicated that, in some African countries, it is believed that disability is due to demonic possession and that people with disabilities are not really human (Aley, 2016).

These misconceptions may have serious consequences for people with disabilities. Mostert (2016) reports that, in some African countries, infanticide of newborn children with disabilities took place because of the belief that the infant is a non-human spirit or that the child is bringing some form of a curse to the family. Paternal abandonment is another consequence of the stigma associated with children with disabilities (Rohwerder, 2018). This is evident in the school that is the research site of the study, where a large number of learners are raised by single mothers who carry the sole responsibility for their children's care. Prejudice and stigma may also lead to neglect, malnutrition, mocking, bullying and even abuse. This transpires as a result of the belief that people with disabilities are not human and therefore not entitled to be treated in a humane way (Aley, 2016). In some African countries (e.g. Cameroon, Ethiopia, Senegal, Uganda and Zambia), surveys showed that 38% of caregivers were hiding children with disabilities because of stigma and shame, preventing them from participating in social activities (Mostert, 2016).

It is clear that, where some of these misconceptions exist in communities, it is going to be extremely challenging, if not impossible, to transition an adolescent with SID towards social inclusion, much less employment. The question is, are things all doom and gloom for people with intellectual disability in South Africa? Are there customs and values in African communities that may, in fact, be of help when transitioning youth with SID into adult life? I believe there are.

3.7 UBUNTU AS INCLUSIVE VALUE IN SOUTH AFRICAN COMMUNITIES

Phasha et al. (2017) acknowledge that the negative view of disability in African culture is incompatible with the concept of 'Ubuntu'. The word 'Ubuntu' is isiZulu and means "humanness – a person is a person through other persons" (Eide & Ingstadt, 2011, p. 102). These authors quote Desmond Tutu's description of the concept of Ubuntu as follows:

> A person with *Ubuntu* is welcoming, hospitable, warm and generous, willing to share. Such people are open and available to others, willing to be vulnerable, affirming of others, do not feel threatened that others are able and good, for they have a proper self-assurance that comes from knowing that they belong in a greater whole. They know that they are diminished when others are humiliated, diminished when others are oppressed, diminished when others are treated as if they were less than who they are. The quality of *Ubuntu* gives people resilience, enabling them to survive and emerge still human despite all efforts to dehumanise them.
>
> (Eide & Ingstadt, 2011, p. 102)

Eide and Ingstadt (2011) relate the narrative of the mother of a child with a disability, born in a rural South African community in the region of Mthatha. In her community, giving birth to a child with a disability was viewed as a punishment from the ancestors because of some misdeed by the mother. Despite this stigma, the young mother was brave enough to expose her child to the community and advocate for him by talking openly about his challenges during community meetings. Eventually, she started a support group for mothers of children with disabilities and was able to break through the superstition and prejudice, releasing the spirit of Ubuntu in the community. She was able to create a support network of people willing to share experiences and resources (Eide & Ingstadt, 2011).

Phasha et al. (2017) highlight three values of Ubuntu: humanness, interdependence and communalism. *Humanness* refers to the inherent dignity of each human being. African communities where misconceptions about disability still exist need to be educated towards the realisation that people with disabilities are first and foremost *people*, humans who deserve to be treated with dignity and compassion. *Interdependence* refers to the need of people to be connected to others in mutually supportive relationships (or partnerships, if you will). *Communalism* emphasises the community and the collective nature of humanness (Phasha et al., 2017). During the course of this study, it is hoped that school-family-community partnerships will be possible through the spirit of Ubuntu. To achieve this, it is crucial to create an awareness of the humanness of people with disabilities, as opposed to the deep-seated superstitions, fear and stigma surrounding disability in some communities.

3.8 VISUAL REPRESENTATION OF LITERATURE ON GOOD TRANSITION PRACTICES IN THE CONTEXT OF AN ECOLOGICAL APPROACH

I conclude this chapter with a visual representation of the core ideas that emerged from the literature. The learner with severe intellectual disability, who is in the centre of the discussion, needs to acquire some critical skills and practice self-determination to transition to a quality life in their community (King et al., 2005). However, they do not exist in isolation and Bronfenbrenner (1979) has famously presented an ecological approach, where interaction between the individual, people around him and the environment are recognised and utilised (Tudge et al., 2009). In this study, this ecological approach is viewed as family-school-community partnerships. Each of these stakeholders is depicted in the visual representation, which I will now endeavour to explain.

The three overlapping circles represent the three main stakeholders in the person with SID's ecology – family, school and community. The family needs to provide love and nurturing well after the learner has left school (Morningstar et al., 1995) and to teach the learner activities

of daily living, such as self-care and basic housekeeping skills (McConkey & Collins, 2010). In order to have a meaningful partnership with the school, the parents need to be willing to turn up for and participate in meetings, despite a number of difficulties they may experience (Makgopa & Mokhele, 2013). The family is strongly influenced by the socio-cultural and financial setting in which it is situated (Pillay & Siyothula, 2011). With regard to family-community links, the family needs to do eco-mapping (Baumgartner et al., 2012) in order to decide which community stakeholders may possibly be part of the learner's support network as they transition into adult life (Neal & Neal, 2013). The family should provide the learner with enough real-life experiences (such as shopping) (Wilton et al., 2018). It is the family's duty to advocate for the young adolescent in community settings (Eide & Ingstadt, 2011).

The school staff is strongly influenced by legislation, policy and school culture (Donohue & Bornman, 2015). They need to reach out to the parents in a collaborative manner (Bryan & Henry, 2012), viewing the family as partners (Summers et al., 2005). Their role is not to create a transition plan for the learner and tell the parents about it, reducing the parents to passive partners (Wilt & Morningstar, 2018). To the contrary, the school needs to aim at family empowerment (Kohler et al., 2016). School staff needs to facilitate the learner to become more self-determined and has to partner with the family to do sustainable planning (Wagner et al., 2005). The school's main job is to teach the learner social skills, communicative skills, life skills and job-related skills (Bryan & Henry, 2012). They, too, need to provide as many real-life experiences as possible, for example job coaching or job shadowing in real employment situations (Hart Barnett & Crippen, 2014). In order to achieve this, they need to liaise with different community service providers (Haines et al., 2015). They also need to pave the way for the learner by means of awareness building in the community to achieve maximum social inclusion (Simplican et al., 2015).

The concept 'community' refers to spaces where the learner, the school or the family have already built relations, such as the church, nearby shops, potential workplaces, care centres and sport teams (Simplican et al., 2015; McCausland et al., 2016). It is hoped that, because of school-family-community partnerships, the adolescent with SID will experience social inclusion and a quality life (Buntix & Schalock, 2010). The community members are strongly influenced by cultural bias and may exhibit prejudice against people with intellectual disability (Rohwerder, 2018). However, in some communities, values such as Ubuntu, which is a typical South African concept, may be a great help when reaching out to foster partnerships with community stakeholders (Phasha et al., 2017). The end goal is

a quality life, where the individual with SID may enjoy happiness, self-esteem, confidence and mental health (Forrester-Jones et al., 2006).

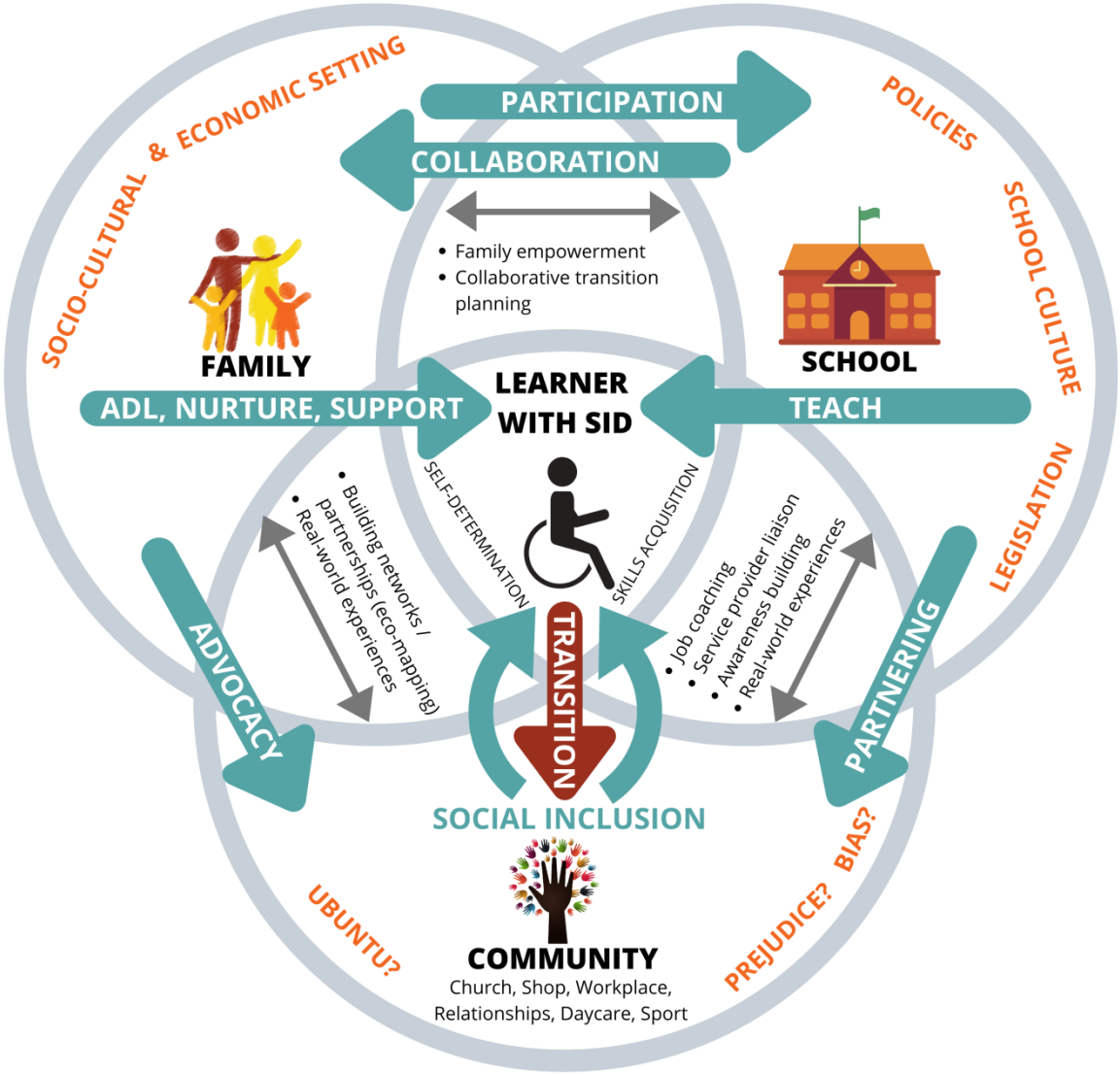


Figure 3.2: *Core ideas from the literature: Fostering family-school-community partnership in order to facilitate sustainable transition in a learner-centred manner*

3.9 CHAPTER SUMMARY

In this chapter, I reviewed literature about family-school-community partnerships, utilising the PPCT model, a version of Bronfenbrenner's ecological systems theory as guiding theory. The social network model of Neal and Neal (2013), based on the ecological systems theory, was found to be very useful to depict the support networks surrounding the young adolescent with SID. Literature on different barriers that complicate family-school-

community partnerships in a South African context was covered. Lastly, I briefly reflected on the socially inclusive value of Ubuntu in relation to young people with SID transitioning into adulthood.

Chapter 4 is a theoretical discussion of the research methodology of the study. The chapter demonstrates how the research design, PALAR, dictates the participatory nature of the data generation and analysis.

CHAPTER 4: THEORETICAL DISCUSSION OF RESEARCH METHODOLOGY

4.1 INTRODUCTION

There is a paucity of South African research on transition planning for learners with severe intellectual disability. As a teacher in the field, I have experienced that attempts to transition learners into adult roles such as employment have proved to be a challenge to sustain after the learner has left school. Having studied literature on transition, I agree with salient studies of experienced authors in the field that transition planning should not only be *learner-centred*, but also have an *ecological approach*. Although I have cited some older studies in Chapter 2 and 3, these authors have conducted ground-breaking and direction-giving research on the transition preparation of young people with SID.

Chapter 2 focused on the concept of learner-centredness and reviewed the literature on self-determination and learner assessment to identify challenges and resulting support needs, theoretically grounded in the quality-of-life theory. The aim of the study is not only to transition the learner into adult life, but to a *quality* adult life. In Chapter 3, I focused on Bronfenbrenner's ecological systems theory and how that could shed light on family-school-community partnerships as a support measure for learners with SID about to enter adult life. I reviewed literature regarding family-school-community partnerships and discussed related challenges in the South African context. Chapter 4 focuses on the 'how', 'what', 'why', 'where' and 'who' questions and serves as a methodological outline for the research in a South African setting.

The chapter starts by grounding the research in the chosen philosophical viewpoint (critical realism) and will show how this paradigm provides guiding principles for the research. I will then explain the research design (PALAR) and will conclude the chapter by looking at the quality indicators for trustworthiness and ethical requirements. Table 4.1 provides a summary of this methodology discussion, guided by the critical questions framing the study.

Table 4.1: Overview of the research methodology

CRITICAL QUESTIONS	
MAIN RESEARCH QUESTION	
How can family-school-community partnerships be promoted to foster learner-centred transition to adult life for youth with severe intellectual disabilities?	
SUB-QUESTIONS	
• What are the challenges and resulting support needs of adolescents with severe intellectual disability regarding transition to adult life? • How can family-school-community partnerships better meet the support needs of adolescents with severe intellectual disability before and during transition? • How can the knowledge created by this team enhance sustainable learner-centred transition planning for learners with severe intellectual disability?	
RESEARCH PARADIGM: CRITICAL REALISM (Bhaskar, 1975)	
RESEARCH DESIGN: PARTICIPATORY ACTION LEARNING AND RESEARCH (PALAR) (Zuber-Skerritt, 2011; Wood, 2020)	
RESEARCH METHODS	
Research setting	School for learners with severe intellectual disabilities
Participant selection	Purposive sampling of eight members to form the ALS. Purposive sampling of eleven secondary participants (interviewees) Purposive learner selection for five case studies
Data generation strategies	Transcriptions of recorded ALS meetings. Interviews: Convergent interviewing; individual semi-structured interviews Field notes of researcher Visual artefacts
Data analysis strategies	Thematic analysis (Vaismoradi et al., 2016) Critical realist data analysis (Bygstadt & Munkvold, 2011)
TRUSTWORTHINESS (Herr & Anderson, 2005)	
Quality and validity criteria: Dialogic and process validity; catalytic validity; rhetoric validity; democratic validity; outcome validity (Herr & Anderson, 2005)	
ETHICAL CONSIDERATIONS (Bertram & Christiansen, 2014)	
Ethical agreement; autonomy, non-maleficence and beneficence (Bertram & Christiansen, 2014).	

Table 4.1 serves as a framework for the chapter. Two key aspects under scrutiny in this chapter are critical realism as a philosophical paradigm and PALAR as the research design. The choice of the PALAR design dictated that data generation methods should be of a participatory nature. Critical realism is a somewhat unusual choice for a PALAR study, which is why this choice demands a thorough explanatory discussion, following in the next section.

4.2 RESEARCH PARADIGM OR PHILOSOPHY: CRITICAL REALISM

The question may well be asked why it is necessary to commence a chapter about methodology, which should be quite pragmatic, by reasoning about philosophy, which is often viewed as very theoretical. Margaret Archer, one of the founders of critical realism, wrote: “An ontology without a methodology is deaf and dumb; a methodology without an ontology is blind” (Archer & Archer, 1995, p. 28). My discussion of critical realism will commence with a concise explanation of the origins of critical realism and its epistemological and ontological assumptions. I will then show how this paradigm reflects in the study in terms of research aimed at uncovering causal mechanisms related to challenges in the disability field.

4.2.1 What is critical realism?

Critical realism, as a paradigm (cf.1.6.1), came into being because of the so-called ‘paradigm wars’ of the 1980s (Fletcher, 2017) and was viewed as an alternative to both positivism and constructivism (Wynn & Williams, 2012). The founder of this school of thought was Roy Bhaskar (Bhaskar, 1975), whose ideas were expanded upon by critical realists such as Andrew Sayer (Sayer, 1992), Margaret Archer (Archer & Archer, 1995) and Andrew Collier (Collier, 1994). Critical realism acknowledges that a reality exists that is independent of human knowledge (Wynn & Williams, 2012). Critical realists believe that ontology (what is real) and epistemology (our knowledge of reality) are two different entities (Bhaskar, 1975). ‘Real’ entities are part of the *intransitive* dimension that operates independently of humans and their ability to perceive it (Wynn & Williams, 2012). For example, the earth exists independently of humans and their ability to perceive it. However, our knowledge and beliefs about these ‘real’ entities are called the *transitive* dimension. The transitive dimension (our knowledge) is constantly subject to revision (Wynn & Williams, 2012). For example, people used to believe that the earth is flat, but have since acquired more knowledge about the earth, and have had to revise their knowledge about it, having learnt that the earth is round. Another example more related to the field of disability is the view held in some African communities that intellectual disability is a result of a curse or punishment by the forefathers for some transgression by the parents (transitive dimension) (Munyi, 2012). Yet, the medical facts are that the underlying causes of intellectual disability could be factors such as a brain injury during or shortly after birth, a chromosome anomaly and substance abuse during pregnancy (intransitive dimension) (DSM-V) (APA, 2013). This reality exists regardless of people’s cultural or religious beliefs.

4.2.2 Critical realism's stratified ontology

The concept of a stratified ontology is quite complicated. Critical realism sees reality as stratified or divided into three levels (Fletcher, 2017). Fletcher (2017) provides a concise description of these three levels, which I summarise as follows: The first level is the empirical level. This level represents objects or events that we can observe or experience. It is on the empirical level that we find the transitive and intransitive realms of reality, where the transitive represents observable real objects or events, and the intransitive represents social ideas, decisions and opinions. The middle level is the actual level. Events occur on this level whether we experience or interpret them or not. Finally, the third level is the domain of the real. At this level, causal structures or causal mechanisms exist (Fletcher, 2017).

Table 4.2 provides tabulated examples from the results of this research to illustrate how these three levels may depict reality.

Table 4.2: Critical realism's stratified ontology illustrated

Realm of reality	**Three levels of reality regarding parental involvement**
Empirical level	**What do you observe?** Parents are uninvolved, do not turn up for meetings, do not do home tasks with learners. Teachers are judgemental of parents.
Actual level	**What is happening that you don't see** Single parenthood, travelling long distances, poverty, fatigue, being psychologically overwhelmed.
Domain of the real	**What caused the event(s) that you did not see and contributed to what you saw?** Socio-cultural and economic factors, parental grief.

Utilising critical realism as a paradigm has provided me with the means to probe deeper into the causal mechanisms underlying the challenges of young adults with SID about to enter adult life. Critical realism provides a holistic paradigm for disability studies, as will be shown in the next section.

4.2.3 Critical realism and disability

According to Frauenberger (2015), critical realism is becoming a more popular paradigm in disability discourse as a solution to the dichotomy that exists between the medical and social model. The *medical model* views disability as a biological condition and society's responsibility is to 'cure' or 'care for' it. Segregated living spaces and schools are the norm for this model (Frauenberger, 2015). The *social model* maintains that people with disabilities

are merely ‘different’, and that people experience disability because of society (Wise, 2016). For example, if a person in a wheelchair is confronted by a staircase when they need to enter a building, they are ‘disabled’ by the lack of access. The environment needs to be ‘treated’ and the barrier removed, not the person. Barrier removal, according to this model, equals inclusion (Wise, 2016). While no one with a disability wants to be reduced to some medical case that needs to be ‘cared for’, Shakespeare (2014) is of the opinion that the social model tends to under-emphasise the physical challenges or impairments of people with disabilities. Shakespeare (2014, pp. 66–67) expresses his sentiments about this as follows:

> I confess to a certain discomfort when it comes to non-disabled researchers … telling me, who has two rather painful and disabling impairments, that impairment does not exist or is only the product of discourse … My problem is my physical embodiment and my experience of negative symptoms arising from impairment (pp. 66-67)

As a teacher in the field and parent of two children with disabilities, I share this discomfort with the social model. The challenges of my own children and those I teach are very real, and to imply that a mere removal of societal barriers can render them non-disabled is a statement that is out of touch with reality.

The view of critical realism regarding the transitive and intransitive dimensions of reality (Danermark, 2002) is of great value for disability discourse. The intransitive dimension refers to a world existing independently of a human being’s knowledge of it, whereas the transitive dimension, which is fallible, concerns people’s beliefs about the world (Wise, 2016). Wise (2016) uses the following example to illustrate these two dimensions in relation to disability: Down Syndrome has always been caused by an extra 21st chromosome (intransitive dimension). This is true, independent of human beings’ beliefs about the condition (Mobily & MacNeil, 2002).

John Down, who first described the syndrome, believed the cause had something to do with ethnicity and therefore called people with the condition ‘Mongoloids’ since they resembled people from Mongolia (Wise, 2016). Today, Wise (2016) points out, current research has proved that John Down’s opinion about the origin of Down Syndrome (transitive dimension) was inaccurate.

The critical realist view of reality (transient and intransient dimensions) allows for a realistic view of the physical and intellectual challenges of the person with severe intellectual disability, *as well as* recognition of the role of societal opinions on disability.

The two most important reasons for using critical realism as a paradigm are the following:

- Critical realism provides *a more balanced view* of the challenges facing learners with disabilities. It allows *for a realistic look at the physical needs and intellectual challenges* of each individual learner in order to do realistic and practical transition planning. On the other hand, it recognises that *the utilisation of the experiences and opinions of knowledgeable stakeholders in the field* are of great value – although these experiences and opinions are fallible, and measures should be taken to ensure that the research is rigorous and trustworthy (an aspect that will be discussed later in the chapter).
- Critical realism's stratified ontology provides a perspective that recognises that disability is a complex phenomenon and that *causal mechanisms* need to be researched thoroughly (Wise, 2016). This implies that the 'why' question needs to be asked often during data collection and that, during data analysis*, reasons* for challenges need to be identified to arrive at sustainable solutions.

Having motivated and explained the philosophical paradigm of the study, I will move on to a discussion of the participatory research design (PALAR) that framed the actions undertaken during this study.

4.3 RESEARCH DESIGN: PALAR

The research design of this study, PALAR, is central to the methodology of this study (cf. 1.6.3). PALAR combines the genres of action learning and action research, seeking to work towards generating knowledge through the collaborative actions and reflective learning of an action learning group, called the Action Learning Set (Wood et al., 2017). Through the participatory discussions and actions, participants 'learn how to learn' (Wood, 2020). This then becomes a lifelong skill for personal and professional improvement (Wood, 2020) and ongoing positive social and educational change (Wood et al., 2017). Translated to the context of this study, the ALS of this study worked towards improved transition planning, an educational undertaking at a specific school for learners with SID.

The PALAR process is non-linear, emergent and unpredictable (Wood, 2020). I experienced this first-hand, probably more so than other PALAR researchers before me, due to the Coronavirus pandemic that disrupted the group's well-planned efforts. The PALAR process is typically depicted by the figure-of-eight process model first developed by Zuber-Skerritt (2011). This model was more recently adapted by Wood (2020), who is of the opinion that relationship building should be central in the first cycle, after which relationships and research should feature equally in the following iterative cycles. Wood (2020) suggests that the figure-of-eight, depicted in Figure 4.1, should be viewed as an infinity sign, depicting the continuous nature of action learning and research.

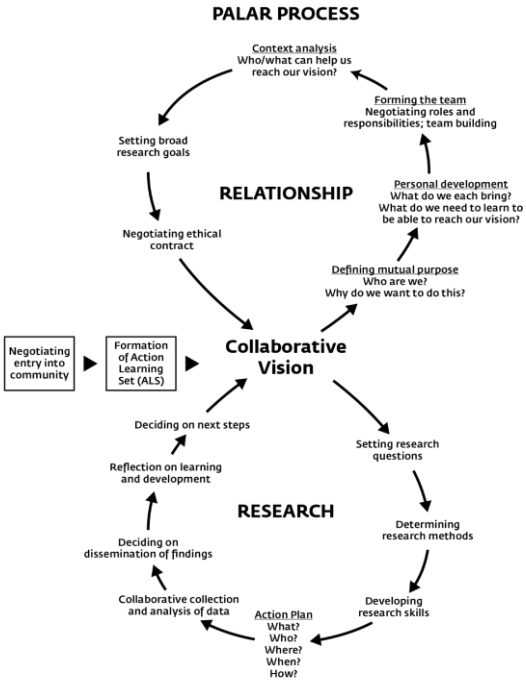


Figure 4.1: The PALAR process (Wood, 2020)

The PALAR process, as conducted in this study, consisted of three cycles, each aimed at answering one of the critical sub-questions, as shown in Figure 4.2.

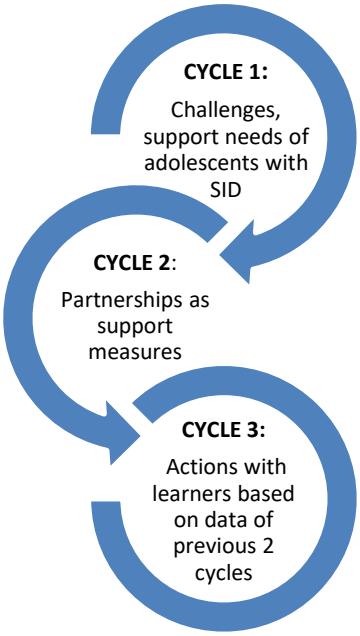


Figure 4.2: The three cycles – with core issues addressed during the cycles based on critical questions

The first cycle commenced with the start-up meeting, where aspects such as vision building and the potential contributions of the ALS participants (see Table 4.4) in terms of the study were discussed and agreed upon. The group already had well-established relations, which made it much easier to progress with the work at hand. All had the best interests of learners with SID at heart, which was a great unifying factor. Collaborative vision crafting and a visual depiction of the different roles that each person would play in terms of values, knowledge and skills formed part of the initial discussion. However, shortly after the start-up meeting, the hard lockdown due to COVID-19 took effect, and the group was forced to resort to remote communication measures to continue relationship building and communication. This proved challenging, yet possible.

These initial discussions revolved around principles guiding transition planning. Excerpts from convergent interviews conducted with stakeholders competent in the field of transition preparation and supported employment were placed on the WhatsApp group as stimuli to invoke discussion. WhatsApp discussions ensued with varied success. A Zoom meeting proved to be unsuccessful, since the participants were not yet comfortable with this mode of communication, and, as a result, mostly remained silent and hidden. Fortunately, as the infection numbers declined, in-person meetings were possible once more and face-to-face discussions could be conducted. Since the group members knew each other very well, the discussions were frank, robust and stimulating.

After the lockdown, the second part of the first cycle could finally commence. The ALS decided that, for the purpose of the identification of learner needs and challenges, as well as trust building for sound family-school partnerships, individual semi-structured parental interviews would have to be conducted during home visits. The group nominated me to take the lead in this. Another ALS member who spoke Setswana accompanied me to the homes of the parents who spoke this language, as translator. Questions regarding the parental perceptions of the learners' challenges, needs, abilities and interests were asked during the interviews. Because the study aimed to be learner-centred and to promote self-determination, the therapist undertook to have individual sessions with the five learners, during which she administered a picture-based career interest questionnaire. Based on the data emerging from the parent interview and the career interest questionnaire, three of the ALS members sat together to draw up individual support plans, which were then shared with the larger group at a next meeting for discussion, and the final plans were presented to the parents of the five learners in a follow-up meeting.

In the next cycle, the focus was on developing partnerships as a support measure for learners with SID during transition, in preparation for the implementation of the learners' individual support plans (based on the data collected regarding learner needs and challenges). The members of the ALS discussed the different partners that would need to be involved and developed roles and responsibilities based on the data generated from these discussions and the interviews with strategic partners.

Figure 4.3: The ALS generating illustrations to depict findings

During the third cycle, actions were taken by the therapist, myself and the departmental head to implement the individual transition plans of the learners, utilising the support measures that had emerged from the findings of Cycle 1. Two of the learners were placed in employment with the support of job coaches. Skills building and quality-of-life interventions were undertaken with the other three learners (see Chapter 7).

The case studies were shared with the ALS, who shared their opinions about the outcomes of the transition measures and used this data to craft a process model as a blueprint for future transition planning.

I need to point out, though, that although these cycles have been discussed above as neatly separated units, this is not the way it happened in real life. Discussions on topics related to cycles 1 and 2 often ran concurrently, as the topics came up naturally during the conversations in the meetings and were then pursued as the need arose. For example, discussions about learner challenges (related to dignity, empowerment and inclusion) happened in close relation to discussions regarding partnerships (challenges of parents, the relationship between parents and teachers). The job placements of the two school leavers (Cycle 3) could not wait until cycles 1 and 2 had been concluded. Time constraints prompted us to act on data generated from discussions before they had been formally analysed and the chapters written up. However, data analysis and final discussions that were concluded with visual depictions of the findings happened in the order explained above.

Table 4.3 depicts a timeline of the activities undertaken by the ALS during the different cycles of the research.

Table 4.3: Timeline of activities

Date	Activity	Purpose	How data was documented
February/March 2020	Request to conduct research letters signed by Head Office and District Office of the DBE, as well as the Principal and SGB Chairperson. Introductory meeting with ALS, signing of consent letters.	To obtain permission to conduct research. To obtain the informed consent of participants in ALS.	Permission and informed consent letters.
11 March 2020	Start-up meeting of ALS.	Vision building, determination of skills that participants could bring to the study.	Drawings.
30 March 2020	WhatsApp discussion (ALS).	Finalisation of vision building. Ethical agreement, research questions, the way forward.	Transcribed voice notes.
April 2020	Voice note interviews with external stakeholders with experience of transition planning and/or supported employment.	Generation of data on transition planning and supported employment to be taken to ALS for discussion.	
20 May 2020	WhatsApp discussion (ALS).	Reflection on the importance of the attitude of staff, parents and community stakeholders towards learners.	
21 May 2020	WhatsApp discussion (ALS).	Reflection on inclusion in public spaces and challenges facing parents that cause barriers in the family-school partnership.	

Date	Activity	Purpose	How data was documented
22 May 2020	WhatsApp discussion (ALS).	Discussion on the after-school support gap, job coach funding.	
28 May 2020	WhatsApp discussion (ALS).	Discussion on school-parent partnership: challenges.	
15 June 2020	WhatsApp discussion (ALS).	Reflection on the importance of self-care, home living and community living skills.	
14 July 2020	Virtual meeting (Zoom) (ALS).	Action plan of planned actions with learners.	Transcription of recorded meeting.
July to November 2020	Parent interviews Learner assessments Discussions on individual support plans Job placements of school leavers.	Implementation of transition plans with five learners.	Transcribed audio recording of interviews Field notes.
11 September 2020	In-person meeting (ALS).	Report back, discussion of next steps.	Transcription of recorded meeting.
18 November 2020	In-person meeting.	Report back, discussion of next steps.	
10 February 2021	In-person meeting.	Discussion of themes – Cycle 1. Generation of figures.	
February to April 2021	Continue learner projects/case studies of learners still in school. Follow up other learners already placed.	Implementation of transition plans with five learners.	Field notes.
10 May 2021	In-person meeting.	Final discussion of results of Cycle 2, generation of transition planning maps.	Visual representations of transition planning.
Winter holidays (at home/under Level 4 lockdown)	E-mail and WhatsApp communications.	Discussion of case study results.	Transcribed voice notes.

Date	Activity	Purpose	How data was documented
27 July 2021	In-person meeting.	Generation of process model.	Visual representation of transition process model.
October 2021	Concluding meeting (ALS).	Celebration and presentation of results, dissemination of knowledge to relevant stakeholders outside the school.	PowerPoint presentations of findings.

The research methods were chosen to supplement, support or facilitate the collaborative actions of the ALS. I will now discuss these methods, starting with the research setting and proceeding to participant selection, data generation strategies and data analysis.

4.4 RESEARCH METHODS

Following the ecological systems theory of Bronfenbrenner (1979), I see 'context' or the research setting as a system of linked contexts that may all have an impact on transition planning. The discussion on the research setting is therefore meant to place the study in the relevant context at the time of data generation and analysis.

4.4.1 Research setting

The physical setting was a school for learners with severe intellectual disability (cf. 1.6.4.1). The school has resources aimed at skills development, such as a vegetable garden, a nursery, a tea garden, a consumer skills class and an office skills class. The cognitive and physical levels of functioning of the learners vary widely. An important environmental factor that impacts the level of functioning of these learners is deprivation. According to Frame et al. (2016), South African youths are faced with multiple layers of deprivation, stemming from poverty, including poor nutrition and health, inadequate living standards and high exposure to violence. These factors are evident in the research site. At least a third of the learners in the school live in abject poverty. A substantial number of learners are subjected to challenging home circumstances and issues such as parental substance abuse, warranting a weekly visit by a social worker. For many young adolescents with SID in this school, these challenges are compounded by the issue of disability prejudice. Stereotypes, prejudice and stigma are tendencies experienced across the world, but more so in third-world countries, contributing to the exclusion of these individuals from society (Rohwerder, 2018).

The school culture has recently undergone drastic change. The school originated in the era of the medical model of disability, where it was almost inconceivable that people with SID could be employed. The focus of the medical model, now outdated, was on the intrinsic barriers of the learner. A 'one-size-fits-all' approach to remedial intervention was generally followed in schools for learners with SID (Du Plessis, 2013). However, following the more individualised approach currently prevalent in Western countries, a new curriculum, the Differentiated Caps (D-Caps) curriculum has since been phased in by DBE (2018). The implementation of this curriculum was initiated by the principal about three years ago. The new curriculum represents a shift towards more holistic interventions that require individual support, dictated by the needs of each individual learner. Since the school is still transitioning into this dispensation, resistance to the curriculum change still exists in the minds of some staff members, who find it challenging to make the paradigm shift away from the medical model and to grow into the crafting of more differentiated lesson plans based on the D-Caps curriculum.

4.4.2 Participant selection

The selection of all participants was purposive. Purposive sampling is a sampling method often utilised in small-scale qualitative studies that involves the selection of specific cases, having a specific purpose in mind (Serra et al., 2018). I will first discuss the selection of the primary participants, the ALS, after which I will explain how the ALS identified secondary participants from which they gathered data.

4.4.2.1 Primary participants: the ALS

The purposive selection of the ALS participants was meant to represent different viewpoints and include a range of capabilities in the group. The group included two parent members, two top management team members (the principal and the vice-principal), the Head of Department of the senior learners and a Setswana-speaking teacher in the Senior Phase who lived in a rural area himself. I approached the members of the group individually, discussed my intentions with the study with them and asked them if they would be willing to be members of the action learning group. All of them were quite excited and eager to participate. Table 4.4 lists the selected action learning group members and their respective fields of expertise.

Table 4.4: Selection of ALS participants

ALS MEMBER	CODE	FIELD OF EXPERTISE
Principal	P1	Management Involvement in transition programme at previous school
Vice-principal	P2	Management Discipline management Sports coaching
Head of Department, Senior Phase	P3	Skills teacher – cooking Autism experience at previous school Involvement in transition programme – previous school
Head of Department, Severe and Profound Intellectual Disabilities (SPID) (myself)	P4	Teacher of learners with multiple disabilities Parent of a daughter with SID Tasked with the continuing professional development of teachers at school
Therapist, Senior Phase	P5	Occupational therapist tasked with school exit programme Tasked with the emotional support of learners Assessment expert, knows learners Daily living skills expert
Setswana teacher, Senior Phase	P6	Skills teacher – gardening Insight into African culture Knows African languages Insight into rural life (lives in a rural village himself)
Parent 1 (male)	P7	Former SGB member Interested in disability policy reform Research experience Passionate about parental involvement
Parent 2 (female)	P8	Research experience Current Chairperson of SGB Passionate about disability rights Conscious of family dynamics in a family with an SID child (own experience)

4.4.2.2 Secondary participants

The data collected from the secondary participants contributed greatly to the learning of the ALS. These participants include five learners and their parents and stakeholders with transition-related experience.

Five learners and their parents

The case studies of the five learners were central to the whole project. P5 handled the selection of the learners since she was best placed to make this decision due the level of her involvement with the learners.

During the initial planning, the ALS agreed that she should take control of this task, since she would be able to select a group of learners who would represent the diverse school population. Participant L1 had multiple disabilities (cerebral palsy and a wheelchair user, non-verbal with only one functional hand); L2 had cerebral palsy (spastic diplegia), but was fully verbal, although he used a walker; L3 had spina bifida and SID, but was fully verbal and had the full use of both hands; L4 was on the autism spectrum, had a good receptive language ability, but spoke little; L5 bordered more on the mild intellectual disability spectrum, with the appearance of a typical teenager, fully verbal, but had auditory memory challenges. The parent and learner selection is depicted in Table 4.5.

Table 4.5: Purposive selection: five learners for case studies and their parents

Parent code	Background
M1	Mother of L1, who is non-verbal and in a wheelchair
M2	Mother of L2, who has cerebral palsy (diplegia)
M3	Mother of L3, who has spina bifida
F4	Father of L4, who is on the autism spectrum
F5	Father of L5, who has SID, but good functional skills

Community-based stakeholders with transition-related experience

During initial discussions, the ALS agreed that it would be beneficial to draw on the experiences of stakeholders in the disability field who could relate their successes and challenges regarding the transition of young adults with SID into adult life. The names of such people known to the ALS members were sent to me. Table 4.6 depicts the purposive selection of stakeholders with transition experience.

Table 4.6: Purposive selection of stakeholders with transition-related experience

INTERVIEWEE	PSEUDONYM	BACKGROUND
Post-school facility managers	FM 1	Manager of a studio for SID youths doing job placements
	FM 2	Manager of an adult facility for Down Syndrome youths focused on pre-transition and employment skills.
	FM 3	Manager of a coffee shop employing young adults with SID

INTERVIEWEE	PSEUDONYM	BACKGROUND
	FM 4	Manager of a protected workshop focused on crafts
	FM 5	Manager of a care centre focused more on care than employment
Staff members from other schools for learners with SID	S1	Deputy principal of another school for SID learners running an employment placement programme
	S2	Craft teacher at a school for SID learners
	S3	Occupational therapist employed at another school for SID learners – involved with its employment placement programme
Employee of the DBE	D1	Former teacher and award winner on transition programming
Parent of a child with special needs	F6	Parent of a young adult with SID with past employment experience
A private occupational therapist	T1	Therapist with an adult SID family member interested in transition programming

4.4.3 Data generation strategies

Data was generated by means of two types of interviews, meetings and activities of the ALS, visual representations and field notes. These strategies will be discussed next.

4.4.3.1 Interviews

Qualitative studies generally seek to elicit narrative data that allows in-depth analysis of people's views (Alshenqeeti, 2014). Alshenqeeti (2014) contends that interviewing is a powerful tool to this end since it gives interviewees a voice and an opportunity to express their thoughts and feelings. Moreover, it provides a holistic snapshot of the views of the informants (Alshenqeeti, 2014). In this study, two sets of secondary participants were interviewed for different purposes. The first group consisted of stakeholders in the field of disability who had already experienced some challenges and successes around transition planning and execution. These interviews were aimed at collecting data that could prompt discussion, challenge long-held views of ALS members and direct the group's transition-related actions. For this set of interviews, convergent interviewing was utilised through the somewhat unusual method of exchanging voice notes. This was necessitated by the Level 5 lockdown during the Coronavirus pandemic in South Africa. The second group of interviewees consisted of the parents of the five selected learners. The purpose of these

interviews was, on the one hand, to establish trust and build partnerships and, on the other hand, to collect data on the specific learners' needs, challenges and dreams. This data contributed to each learner's ITP. For this group, in-person, face-to-face semi-structured interviews were conducted. I will now discuss each of these data generation methods in turn.

Convergent interviewing

Zuber-Skerritt (2011), in her seminal work, *Action leadership: Towards a participatory paradigm*, refers to the work of Dick (2013) on data collection by means of convergent interviewing, lauding the method as an effective way for a team to reach consensus on key issues. I drew on the work of Dick (2013), adapting the interview method to the unusual circumstances following the COVID-19 lockdown. The core principles of convergent interviewing are as follows:

- As is the case with all interviews, the interview needs to be preceded by rapport building, and an explanation of the purpose of the study, as well as privacy and ethical assurances before informed consent is requested (Dick, 2013). During lockdown, I did this telephonically.
- The interview is commenced with a broad opening question such as: "Tell me more about your work regarding transition planning". The question needs to invite the person to share experiences freely without having been influenced by the researcher (Dick, 2013).
- Probing questions then follow (Dick, 2013). I tended to ask questions around challenges, needs and supports. These probing questions may become more focused and specific as the interview progresses.

Convergent interviewing includes continuous data analysis and comparison of interviews for the purpose of generating the next probing questions for following interviews, so that the researcher can ultimately arrive at emergent themes (Dick, 2013). I utilised this principle during the voice note interviews. After each interview, I transcribed the data at once and noted some of the key emerging points of interest. These assisted me to be ready with probing questions for the next person. I then compared the interviews, and if a certain point of interest kept coming up, I noted that as a topic of discussion for the ALS. For example, one such point was the issue of infantilisation, related to the dignity of learners with SID. During the interviews, this issue, which proved to be closely connected to the still prevailing medical model of disability, emerged as a key challenge. I therefore posted quotes from the interviews on the ALS WhatsApp group, together with an opening

question: *Should adolescents with SID be viewed as children or as adults*? The group would then debate the point until consensus was reached.

Individual face-to-face semi-structured interviews

Alshenqeeti (2014) explains that there are three types of interviews. The structured interview, mostly utilised in quantitative studies, is conducted around a set of pre-determined questions that would mostly require either 'yes' or 'no' as a response. The second type of interview is the open-ended or unstructured interview, which provides both the interviewer and the interviewee with freedom to allow the conversation to run its course as preferred. The semi-structured interview, however, is viewed as a more flexible version of the structured interview (Alshenqeeti, 2014). The interviewer conducts the interview around a pre-determined checklist, but has the opportunity to ask probing questions in response to the interviewee's answers, or to ask the interviewee to expand on interesting points that arise (Alshenqeeti, 2014). I opted for semi-structured interviews for my face-to-face interactions with parents since it was quite important to cover a certain checklist related to the individual transition plan, which would be set up by ALS members after the interview. Still, it invariably proved necessary to expand on matters of interest that came up during the interviews so that the interviewee could shed light on issues related to partnerships (school-family or family-community). I then analysed these issues and brought the data to the ALS for further discussion.

The ALS remained involved in various ways through all the events that unfolded during the research. To illustrate this, I will now discuss how the ALS activities were part of the data generation process.

4.4.3.2 ALS activities: Data generation through discussions and actions

In a PALAR study, the transcribed discussions and artefacts produced by the ALS constitute the main sources of data generation (Wood, 2020).

Critical reflection on existing paradigms and possible changes

Examples are the discussions on infantilisation and social inclusion, which prompted members to reflect on the way they view a child with an intellectual disability and to examine their own views on the rights and needs of these young people. These types of discussions, usually undertaken by the whole group, led to the emergence of the three themes of dignity, empowerment and inclusion during the first cycle. Another important discussion was the one on school-parent partnerships, where the Setswana teacher's contribution on parental challenges prompted the rest of the ALS to reflect on their own

biased opinions on parental participation and involvement. Discussions were recorded and transcribed, after which the data was analysed thematically, as will be explained in a later section. The second type of discussion revolved more around planning.

Discussions aimed at crafting action plans for transition preparation and execution

These discussions included either the whole group or part of the group. Examples are the following:

- Discussion about the overarching action plan and the timeline (which had to be adjusted continuously due to the pandemic)
- Decision making about learner selection
- Discussions about the individual transition plans
- Discussions about the way forward after reports about actions taken had been presented at meetings
- Discussions about transition challenges, such as the need for a job coach
- Discussions about the prioritisation of the subject Life Skills, especially community living skills

The data that emerged from these discussions led to a greater awareness about learner-centredness and the need for adequate transition preparation, and led us to be better prepared for the practical actions undertaken in the third cycle.

Reports on actions undertaken with the learners reflected in the five cases

The actual actions with the learners were undertaken by one or two ALS members per learner at a time, but they reported on these at feedback meetings. These reports were in the form of case studies that were distributed to ALS members during the Level 4 lockdown. The data emerging from the case study reports, combined with the data emerging from the previous cycles, led to the compilation of the process model for transition.

Meetings aimed at theory building

After each cycle, I presented the results of the data analysis to the ALS, who then collaboratively proceeded to craft illustrations to organise the data. This contributed to theory building. The use of visual representations is discussed in the next section.

4.4.3.3 Visual representations

During theory building sessions, conducted towards the end of each cycle, the ALS would divide into two smaller groups. Each group would be tasked to craft their visual

representation of the results on a specific topic on a large poster. For instance, in the case of the Cycle 2 discussion on partnerships, one group worked on the depiction of parent-school challenges, a topic that had evoked profound discussion, and the other group worked on a holistic overview of family-school-community partnerships.

Webb et al. (2020) use the term 'visual representation boundary object' to refer to the chart crafted at such a discussion. The chart (or VRBO) not only serves to keep the team on task (a 'boundary' for the discussion) but evokes discussion to combine individual ideas and to develop shared thinking (Webb et al., 2020). During the meetings of the ALS, where we worked on these visual representations, the group could be seen in deep discussion, working on the alignment of their ideas. We agreed that the group had to reach consensus on the decisions taken.

4.4.3.4 Field notes in a research diary

Field notes are instrumental in the construction of thick, rich descriptions of events unfolding during a study and, as such, may serve as valuable data generation tools (Phillippi & Lauderdale, 2018). I relied heavily on field notes in all cycles and especially during the actions undertaken with the learners in Cycle 3, since those actions stretched over a substantial period, and one could easily forget some important observations or confuse incidents when neglecting to take notes. Phillippi and Lauderdale (2018) point out that observations such as sights, smells and sounds in the context of a physical environment should best be recorded shortly after they occur. For instance, I was able to record the proud excitement of L3 when praised for the shiny car that he had just finished washing and the astonished vocalisations of the non-verbal learner on witnessing the proceedings of her key holder sales being put into her school bag. These notes enabled me to provide rich descriptions to the ALS, which, in turn, prompted reflection and evoked valued comments on its part.

Since PALAR is an iterative process of reflection and action, Zuber-Skerritt (2011) recommends the use of a research diary as a reflective tool. I wrote a reflective account of the events unfolding after each ALS meeting. These insights, read afterwards, helped me to inform following actions and contributed to my own learning.

4.4.4 Data analysis

Qualitative data analysis is a process where data is broken up into components to reveal links and structures so that new meanings become evident (Creswell, 2015). According to

Creswell (2015), qualitative researchers build their patterns, categories and themes “from the bottom up” (Creswell, 2015, p. 38). PALAR is typically viewed as “team research, carried out by practitioners in their own practice, rather than by specialists on their behalf from the side lines” (Zuber-Skerritt, 2011, p. 110). As such, the ALS needed to be actively involved in the data analysis phase as well.

The data analysis of the first two cycles was thematic. Since the study yielded a mountain of data that had to be coded and organised into themes (Braun & Clarke, 2020), as academic researcher, I immersed myself in the data, coded the data and organised the codes into themes. The steps of thematic analysis, tabled below as suggested by Vaismoradi et al. (2016, p. 103), apply here:

Table 4.7: Phases and stages of thematic analysis

PHASES	STAGES
Initialisation	Reading, transcription and highlighting meaning units Coding and looking for abstractions in participants’ accounts Writing reflective notes
Construction	Classifying Comparing Labelling Translating and transliterating Defining and describing
Rectification	Relating themes to established knowledge Stabilising
Finalisation	Developing the story line

After each cycle’s data analysis, I returned to the ALS to discuss the findings, structure them in a logical manner and proceed with conceptualisation by means of the visual representations. The ALS decided how the themes related to each other and how these findings needed to feed into the strategic planning that lay ahead.

In the final cycle of the study, a critical realist framework for the data analysis was instrumental in the discovery of causal mechanisms or reasons for the results of the practical work. I found that the most profound learning stemmed from this final cycle of the study. I utilised the different steps of critical realist data analysis for this phase of the study, as set out by Bygstadt and Munkvold (2011). These steps, discussed in detail in Chapter 7, were followed in the following manner:

Step 1: Description of events

The five case studies were described in detail and distributed to the ALS for comments. (For lack of space in this thesis, the case studies have been included in Appendix 4.3).

Step 2: Identification of key components

The ALS considered the roles of the main actors (school, parents and other stakeholders) and decided to name each actor to indicate their unique role. A visual representation to this effect was crafted.

Step 3: Theoretical redescription (abduction)

The ALS analysed the results of the five case studies and previous themes and compiled a process model for transition planning and execution.

Step 4: Retroduction: Identification of candidate mechanisms

The group debated the issue of change – what changes took place, and more importantly, why did they take place; in other words, what were the causal mechanisms that brought about change?

Step 5: Analysis of selected mechanisms and outcomes

The sustainability of change was debated. Ways to change deeply ingrained beliefs were discussed.

Step 6: Validation of explanatory power

The ALS delegated the task to validate our findings by means of literature on the topic of change and sustainability of change.

In the next section of this chapter, I reflect on the trustworthiness of the study. Trustworthiness is assessed by specific quality indicators in the context of action research.

4.4.5 Trustworthiness

The five quality indicators for action research (Herr & Anderson, 2005) will be referred to next in relation to this study (cf. 1.6.5). I have organised the discussion around open questions, which I believe critical readers will find reason to answer in the affirmative after reading the findings.

4.4.5.1 Outcome validity: To what extent did the actions solve the original problem posed?

If affirmative answers to the following questions, stemming from the core problems of the main research question, can be given, the original problem will have been solved:

- Was the study learner-centred? In other words, was self-determination and quality of life promoted? Were learner needs and support needs central to transition planning? Was transition planning individualised?
- Could the challenges regarding school-family partnerships be identified? Was ample relationship building with parents fostered?
- Could the school manage to foster school-community partnerships that would facilitate social inclusion and/or employment? Are there learners that have participated in the study who have been exposed to real employment situations? Is there a learner whose prospects for future employment have been improved because of these community engagements?

Learner-centredness was reflected in the individual assessments, the empathic facilitation of the learners to complete the career interest questionnaire and the individualised transition plan of each learner. Relationship building with the parents was fostered by means of trust building during home visits and open communication during the transition process of the learners. Learner-centredness in terms of learner needs and supports, as well as quality of life, are topics of discussion in Chapter 5.

4.4.5.2 Process validity: Have the problems been framed and solved in such a way that ongoing learning is promoted?

- Have the participants taken ownership of the study and its results?
- Are they enthusiastic? Are they proud of their achievements? Do they show a willingness to continue what has been started?

The growth and learning of the participants are discussed in more detail in Chapter 7.

4.4.5.3 Democratic validity: To what extent has research been conducted in collaboration with all stakeholders?

- Did the ALS collaborate actively in the planning and conducting of the research process?
- Did the learners with SID have ample opportunity to have their voices heard? Were their likes and dislikes heard and considered?
- Were the parents treated as equal partners?

- Were community stakeholders prepared to partner with the school?

Collaboration has been one of the core aims of the study, starting with the ALS members and, through their efforts, involving the parents and other stakeholders. These issues are addressed comprehensively in Chapter 6.

4.4.5.4 Catalytic validity: To what extent has the research process reoriented the participants regarding their knowledge of reality?

- Can growth and learning be observed in the ALS members? Did the research bring about positive change in the school?
- Did the learners' knowledge and level of competence and confidence grow?
- Did the parents show growth regarding their approach towards their child and their child's future prospects? Do they report a better relationship with school staff members than was the case in the past?
- Did community stakeholders change their views about people with SID? Could biased opinions about the learners be addressed? Are they better prepared to include the learner in social and community setups? Does the study have the potential to bring about change on the level of education policy and legislation?

The issues of change and learning are addressed in Chapter 7 and suggestions for practice and limitations are addressed in Chapter 8.

4.4.5.5 Dialogic validity: Was a thorough peer review conducted?

- Did the critical readers provide constructive criticism and point out valid areas where improvement of practice was needed?
- Was there ongoing critical and reflective interaction with the study leader and co-researcher

I have been fortunate to have had excellent constructive critical inputs from very competent and experienced professionals who are the promoters of my study.

Ethical considerations are discussed next. A study where vulnerable minors are involved can be a potential ethical minefield. Therefore, special care had to be taken to observe rigorous ethical practices.

4.4.6 Ethical considerations

This study has been typified ethically as having a 'greater than minimal risk', due to the involvement of vulnerable minors, learners with SID. I utilise three topics – autonomy, non-maleficence and beneficence – to briefly discuss how this was managed in the study (cf. 1.6.6).

4.4.6.1 Autonomy

Autonomy is observed when the respect and dignity of each participant in the study is protected. This involves permission to conduct research, obtained from the Tshwane-North District Office of the DBE, and goodwill permission, which was to be sought from the Chair of the SGB and the principal (see appendices 1.5 and 1.6). Participants need to make an informed choice, participate voluntarily in the research and understand that they are free to withdraw from the research at any given time. This was explained to the members of the ALS before they committed themselves to participating in the research by signing consent forms. The same procedure was followed for the interviewees who provided the supporting data. The Setswana member of the ALS assisted me to explain ethical principles to parents whose native language was not English or Afrikaans. Parents of the five learners with SID provided informed consent for the participation of their children and themselves. The learners with SID were required to encircle yes/no responses and sign an assent form where the basic ethical research principles were set out very simply, with picture communication symbols to provide clarity. An extract from the assent form is shown below as an example:

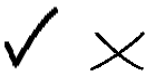
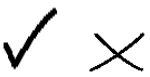
	Did anyone read the letter to you?  Yes No
	Did you understand you can choose to do this?  Yes No

Figure 4.4: Part of the assent form utilised for learners

To relieve the learner from any pressure related to power relations, a person who is not connected to teaching or the research was asked to sit with the learner to complete the form. This ensured that the learner's assent was voluntary.

4.4.6.2 Non-maleficence

Non-maleficence means 'to do no harm' (Bertram & Christiansen, 2014). The research should do no physical, emotional, social or other harm to any person. In PALAR, not only should the research do no harm, but it should be aimed at bringing positive change (Wood, 2020). This is illustrated in Chapter 7.

Privacy and confidentiality

As the study is qualitative, quotes and some demographic data, such as the gender and age of the participant, have been used when reporting about the data. However, the data has been presented in such a way that the individual participants cannot be identified. For example, participants have been given codes (such as P1 and P2) before commencing with data analysis. I also took care to ensure that I do not present the information in such a way that the identity of the participant can be deduced from the context. Staff members of the school, however, might still be recognisable to people familiar with the school, but the ALS members are aware of this and gave their consent.

Signed consent forms and other documents containing personal information about the participants have been kept separate from the documents containing data. Personal information of the participants has been saved on a secure password-protected server. When the study was concluded, all identifiable personal information was deleted. My promotors and I are the only people who had access to the information.

Hard copies with personal information and electronic data are in the safekeeping of the principal investigator (my study leader) for a period of five years. Hard copies that are no longer needed were shredded. When the results have been published, the identities of the participants will likewise be protected.

Prevention of emotional and physical harm

To prevent the evaluation procedures causing the vulnerable learners with SID any unnecessary stress, the learners were assessed in a familiar setting by the skilled therapist who works with them daily. She is a qualified occupational therapist, who has specialised in neuro-developmental therapy and sensory integration and is trained in play therapy. The therapist is well versed in ethics and is registered with the Health Professions Council of South Africa (HPCSA). The therapist was a participant in the ALS. During the third cycle

of the study, I had originally planned to take learners out to job shadowing opportunities. However, due to the Coronavirus pandemic, all outings were suspended for safety reasons, and three of the learners were limited to pre-transition measures. However, the two 18-year-olds were placed in jobs, but the responsibility for the transport and safety of the learners was undertaken by the parents themselves.

4.4.6.3 Beneficence

Beneficence means that the research should be of benefit, either directly to the research participants, or more broadly to other researchers or to society at large (Bertram & Christiansen, 2014).

The *direct benefits* to the primary and secondary participants were as follows: Adolescents with intellectual disability participated in a transition programme that was aimed at facilitating them into society and, in so doing, improved their chances of having a quality post-school life. For parents, the burden of having to make plans for the future of their children was lightened by the fact that supportive partnerships were fostered during the study. The ALS developed in their personal and professional capacities due to the collaborative action learning that took place.

Indirect benefits for society at large or for the school were as follows: Society at large can reap the benefits from adults with an intellectual disability who are more economically and socially active and, where possible, more independent. By getting more community stakeholders involved, an awareness of the needs and strengths of people with intellectual disabilities and an awareness of the need to acknowledge and promote their human dignity is created.

The school, as an institution, became better equipped to deal with the transition of young adolescents with severe intellectual disability into adult life. An awareness was created of the need to incorporate transition goals into the learners' individual support plans and the curriculum.

4.5 CHAPTER SUMMARY

Research methodology is just a vehicle for the action itself, which, in this study, is research aimed at learning and change. The results were brought about by means of the collaborative work of a small group of people, immersed in the context of special needs education in South Africa. This chapter gave an overview of the working parts of the 'vehicle', the methodology utilised in this study. The next three chapters, chapters 5, 6 and 7, provide accounts of the action taken, the findings that emerged and the learning gained from cycles 1, 2 and 3 of the study.

CHAPTER 5: DISCUSSION OF CYCLE 1: WHAT ARE THE CHALLENGES AND RESULTING SUPPORT NEEDS OF YOUNG ADOLESCENTS WITH SID ABOUT TO TRANSITION INTO ADULTHOOD?

5.1 INTRODUCTION

The previous chapter provided a detailed account of the methodological issues central to this study. This includes the study's philosophical approach (critical realism), its research design (PALAR) and research methods, as well as ethical considerations and trustworthiness measures. This chapter is taking a step into the realm of real life. It is the first of the chapters that will show how the collaborative approach of this study facilitated action that brought about change, not only in the lives of learners with SID, but also in the lives of their social ecologies – families, the school under study and community stakeholders. PALAR, the research design that I utilised, is cyclical and collaborative in nature. This chapter represents an account of the findings of Cycle 1 of the research. During this cycle, the aim of the ALS was to answer the first sub-question of the main question: *What are the challenges and resulting support needs of adolescents with severe intellectual disability regarding transition to life after school?* Three themes regarding the challenges and support needs of young adolescents with SID emerged from the data:

1. Challenges and support needs related to the *dignity* of learners with SID
2. Challenges and support needs related to *empowerment*
3. Challenges and support needs related to *inclusion*

The results show that the challenges related to the three themes could compromise the quality of life of individuals with severe intellectual disability, but, on the other hand, that the implementation of appropriate support measures could overcome these challenges and lead to a good quality of life.

5.2 THE THREE THEMES IN RELATION TO THE CONSTRUCT 'QUALITY OF LIFE'

It is important to distinguish between the *general* concept of a quality life, and the concept 'quality of life' utilised in this study. Both terms refer to a good and enjoyable life, but 'quality of life' is widely used in the field of intellectual disability as a conceptual framework for planning support programmes. I refer to Chapter 2, where this was discussed in detail.

Schalock et al. (2010) identified eight quality-of-life domains: personal development, self-determination, interpersonal relations, social inclusion, rights, emotional wellbeing, physical wellbeing and material wellbeing. The theme 'dignity' links with emotional and physical wellbeing and rights; the theme 'empowerment' links with self-determination and material wellbeing; and the theme 'inclusion' links with interpersonal relations and social inclusion. Figure 5.1 shows how dignity, empowerment and inclusion could be stepping stones towards a good quality of life, whereas indignity, disempowerment and exclusion could lead to a poor quality of life.

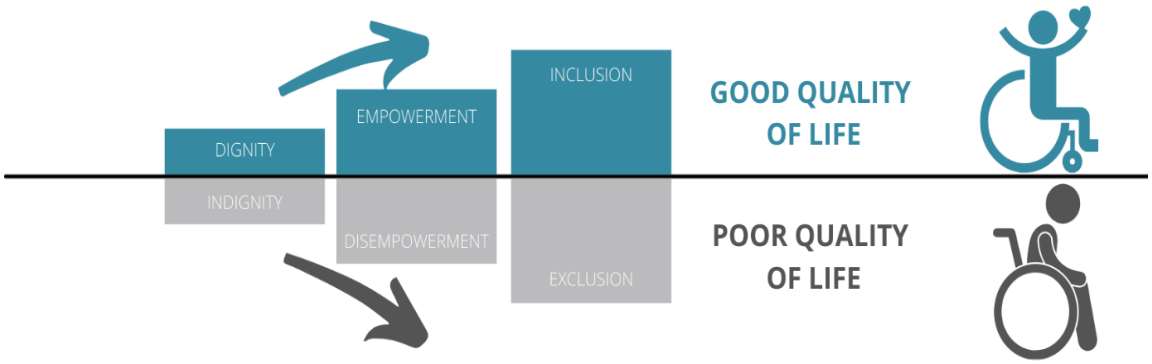


Figure 5.1: Stepping stones towards a good or poor quality of life

While working on the individual transition plans of our selected learners, we needed to strive more and more *towards* the fulfilment of our selected learners' unique needs by ensuring that support measures are in place to facilitate satisfactory transition and ensure a good quality of life for these individuals. Conversely, we needed to work *against* the challenges or transition threats in the lives of these learners that might ultimately result in unsatisfactory transition and poor quality of life. The themes will be presented by first referring to each theme's underlying challenges, after which I will discuss the supports needed to bridge these challenges to attain quality of life after school.

5.3 THEME 1: CHALLENGES AND SUPPORT NEEDS RELATED TO THE DIGNITY OF LEARNERS WITH SID

It is necessary to reflect on the meaning of the concept 'dignity' for a moment before discussing the challenges that threaten to undermine the dignity of young people with SID. Dignity is widely viewed as a basic human right. In Chapter 2 of the South African Constitution, the Bill of Rights (section 10), it is stated that "everyone has inherent dignity and the right to have their dignity respected and protected" (South Africa, 1996a, p. 6). Barclay (2018) contends that one of the core things to which the concept 'dignity' may refer is the value of a human being's life. Reaume (2013, p. 673) puts it like this:

> Dignity is ascribed to human beings independently of their particular accomplishments or merits of praiseworthiness. It refers to a kind of worth that is not contingent on being useful, or attractive, or pleasant or otherwise serving the ends of others."

This means that, before one can even start planning a transition programme for learners with intellectual disability, all stakeholders need to agree that people with disabilities are *people*, humans who have a right to dignity, just like any other human *without* a disability.

Regrettably, based on the data collected in this study, it still seems that some people view a person with an intellectual disability as someone who is *less* entitled to dignified treatment than others with a typical cognitive ability. Participants recounted how young individuals with intellectual disability were stigmatised and bullied, due to cultural, religious and peer group-related bias. Because these young people seldom have the ability to voice their opinions, express dissatisfaction or convey their needs, caregivers may neglect them or provide unacceptable care. Instances of the sexual harassment or exploitation of young people with SID in workplaces were also reported.

In Figure 5.2, the bricks in the wall depict the above challenges as barriers that may prevent the person with SID being treated with dignity and may then prevent them from transitioning to a quality life. The bridge represents the supports required to overcome these barriers. These are support measures that participants thought might facilitate youths with SID to transition to a quality life. I will now discuss the challenges and support needs related to each of these sub-themes in the following sections.

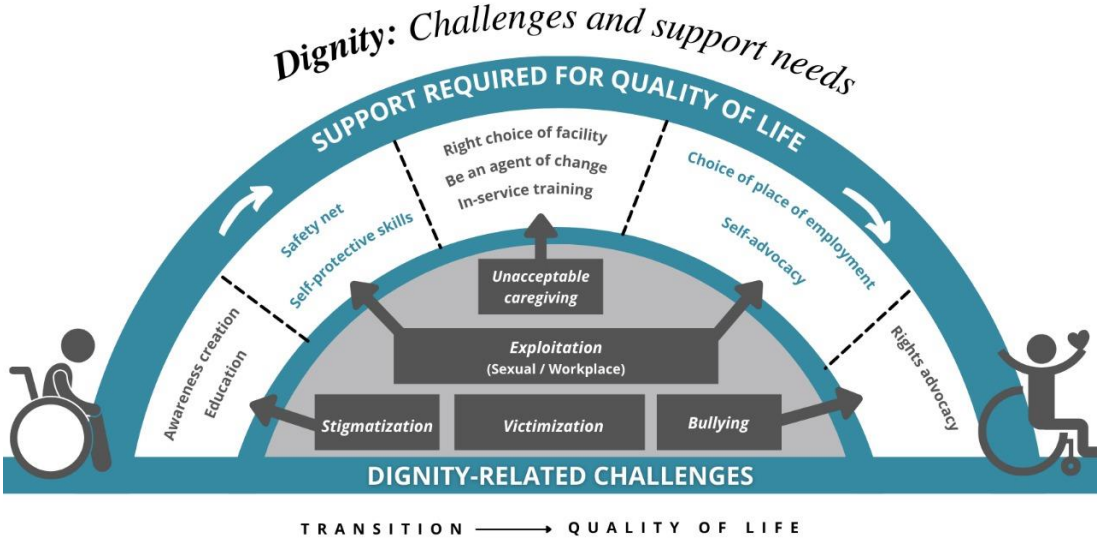


Figure 5.2: Challenges leading to disregard for dignity and supports needed to bridge these challenges to attain quality of life

5.3.1 Dignity-related Challenge 1: Stigmatisation, victimisation and bullying

The mother of one of the selected learners of the study reported how she and her son were rejected and their dignity compromised. This woman fled from an abusive husband, just to experience stigmatisation and victimisation in her own mother's home, due to the cultural and religious bias of her family members.

> *… life there was not easy, he was so abusive for 20 years. And then – 2013 – I decided to move out of the house, and then I moved out – aaah – I went to my mom's home, and my mom is that person who believes in ancestors, I don't believe in the ancestors, she wanted to do some rituals in the – her – place, and I didn't agree with her, until she throw me out of her house. After she chased me away of the house, I took my son to the shelter at MG, and I was sleeping in ehhh in my changeroom at work. I was waiting for everybody to go, and then I will go and hide myself in the changeroom, until the next morning, and I'll do as if I'm coming from home, where else I was sleeping there for six months* (M2, reported by P4).

The belief that the forefather spirits are bringing bad luck or punishment (such as a child with a disability) to the living is still firmly held in some South African communities:

> *On the point of belief in the forefathers – uhm – many people believe that your soul continues existing after your body is dead. And then this soul or spirit can direct and counsel about life matters to those still living. And then – eh – the spirit can bring good or bad luck to those still living. Eh – number three – that the spirit can even reprimand and punish if necessary* (P6).

Studies by African researchers have found, especially in African communities, that people with disabilities are still treated with disdain, or may even be abused or killed without consequence. The word 'bokooa' in Sesotho refers to something dreaded, undesirable and wished away in the community (Sefotho & Leshoto, 2020). Traditional Zimbabwean culture positions disability a result of witchcraft, the displeasure of ancestors, or the promiscuity of the mother – thus it is a shameful thing to have a child with a disability (Chataika, 2012). A South African study conducted by Sibanyoni (2018) in special schools in the Eastern Cape situated in impoverished rural communities found that most of the children under study who had physical disabilities experienced various forms of abuse such as rape, physical and emotional abuse, bullying, neglect and sexual assault.

Stigma is not only confined to situations where religion or culture determines attitudes. Participants reported that bullying by peers was rampant as well. Some of the learners in the school under study were active on social media (as far as their writing abilities would allow) – just to be bullied and called 'dumb' by other adolescent social media users with typical intellectual abilities:

There are bullies – cyberbullies – who say, for instance, don't ever contact this girl, she's in a dumb school… (P5).

They were embarrassed to be part of a school that catered for the intellectually disabled, they felt that they were stigmatised, they didn't use that word, but that was the essence of it, ahm –- teased, and bullied, as they said, in the community, because of the school that they attended (D1).

Bullying of vulnerable employees with SID occurs in workplaces as well. D1 said that young adolescents with SID were victimised by employees of workplaces. For example, the permanent employees of a car wash would rob the young individuals with SID of the tips that they were supposed to receive:

We also found that, in some cases, like at the car wash, when customers gave tips, ahm – the regular people – the people who were employed, at the actual car wash, were particularly unkind to our learners and then they would take the tips away from them. Soooo – our learners were bullied (D1).

A parent, F6, shared his experiences of his daughter when she started working at a vegetable shop:

She then started at Fruit and Veg and worked on – on a tip basis where they tip for packaging and such things – like helping the passengers at the till. Unfortunately, we found out that – at the end of the day, when she had her coins cashed, that her money was stolen, and – because of her eyesight, she never picked it up (F6).

According to Reiter and Lapidot-Lefler (2007), 83% of learners attending special needs schools have experienced bullying. Bullying behaviour included being laughed at, being told rude things, being beaten, being sworn at, being threatened, kicked or pinched, being forced to do things against their will, being inappropriately touched without consent and having property stolen. It is evident that these vulnerable young people need help to eradicate victimisation against them.

5.3.2 Support needs related to Challenge 1: Combating stigmatisation, victimisation and bullying by means of awareness creation and education

Already at the start-up meeting of the ALS, participant P8 stressed that the social ecologies of the young adolescent with intellectual disability carry the responsibility to educate people in communities and create awareness:

I think in terms of what we are doing here, we have an educational responsibility towards society, so that we can sensitise society …

Responding to the story of the parent who suffered from cultural and religious bias towards her son, the ALS discussed ways to create awareness and educate communities. An important point was the involvement of community leaders to bridge biased attitudes:

> *If you look from a cultural perspective, where somebody's children come from, from a village, or smaller groupings of – of informal settlements even, to what extent are we pulling in the – the community leader? The traditional leader – in that area. Because, if you can catch that person's heart and interest, then you are – I think – are going to influence the community greater to open up…* (P8).

> *Yes, definitely, I want to add on to that. Our parents – some – not everyone – hide their children. Now we want to put them into an employment in the community. And definitely, there your community leaders can play a proactive role…* (P5).

If quality of life is to be the end goal of a transition programme, all stakeholders need to examine the way they treat, talk to and work with young adults with SID. Communities and workplaces need to realise that the lives of people with disabilities have value "simply because they are persons" (Kittay, 2005, p. 102).

Adolescents with intellectual disability often need advocates to speak up against bullies on their behalf. Participant P4 reported that this was the case with L2, a young boy with cerebral palsy. When his mother realised that some of the community children were victimising him, she enlisted the help of a social worker and managed to resolve the situation:

> *Those children, they were teasing him. And then I ended up calling the social worker from school, to go and talk to those children, and explain to them, ehhh – why R is like this, how they can play with him, and then – she talked with them, and then they understood, and even ended up loving him* (M2).

In this case, the social worker was an advocate for the human rights of L2. Advocacy for people with intellectual disability is a vital support need to ensure that young adults with intellectual disability are treated with dignity in communities and in workplaces. South Africa is party to the UNCRPD of 2006, which means that the country accepts all requirements imposed by this international agreement. Section 11(b) of this Convention aims "to combat stereotypes, prejudices and harmful practices relating to persons with disabilities, including those based on sex and age, in all areas of life" (United Nations, 2006). Based on this agreement, family members and educators of people with disabilities have an obligation to combat prejudice and harmful conduct such as bullying.

5.3.3 Dignity-related Challenge 2: Exploitation of individuals with SID

Participants reported that permanent employees sometimes exploited young individuals with SID in places of employment. For example, S1 reported that the permanent employees in a business situated in a shopping centre would send a vulnerable young girl with SID around in the large, busy mall to carry out mundane tasks for their personal gain. Another example was the exploitation of an adolescent with SID (still in school) who was doing job sampling at a bakery.

This employer enlisted the young boy for cheap labour extremely early in the morning. The school staff only realised that something was amiss when the boy became extremely tired and eventually owned up to what was happening:

> *A second challenge was ahm – in the, in the bakery. Our learner that was placed there, was tremendously overworked. So, he would spend the three hours on Mondays and Tuesdays there, but unbeknownst to us, the business owner had asked him if he would be willing to work on a different shift, so like 04:00 in the morning, for the early bakery shift, and this was before school. So, he didn't tell us about it, because it was – the owner had promised to remunerate him. And – so he would go there, to the bakery, ahm, he'd leave home at 03:30 in the morning, and he would walk ahm, past the hostels, ahmm – to get to the bakery, which was entirely unsafe, and he would be at the bakery at 04:00, he would work there for the three hours, until seven, and then be ready at the bus stop for the school bus to collect him, so we didn't know what was going on, and we were wondering why was he so tired* (D1).

Opini (2010) warns against the exploitation of people with intellectual disability as cheap labour and specifically refers to some sheltered workshops, where these individuals are spending their days in vocational-like settings. Instead of a place of societal liberation where the individual learns vocational skills, such a workshop might, in fact, use them as an army of workers that are committed to lifelong servitude to the institution, while receiving meagre wages. In the case of the boy working at the bakery, the bakery owner not only exploited the young adolescent's cheap labour, he also caused him to suffer from a lack of sleep and put him in danger by making him walk to work in an unsafe area.

The exploitation of vulnerable people in the workplace may also occur in another alarming manner: sexual exploitation by neurotypical co-workers. Participants reported worrying instances where young female adolescents doing job sampling in workplaces experienced unwanted attention from male employees:

> *The male employees were just a little bit forward with them, and this made the girls really uncomfortable, so we chose to then have our girls in the office, at school, ahm, and they would do things like photocopying, ahm – and carrying*

> *things, you know, distributing things to staff members, filing, covering files, like office administrative type of tasks* (D1).
>
> *In the case of one place of employment, a learner's parent phoned the school to report an incident, we investigated the allegations immediately, the employer removed the person from service at once, he apologised profusely. That case is still ongoing – so, unfortunately, that was a bad experience for us* (S1).

South Africa is notorious for having an alarming rate of gender-based violence and women (or girls) with disabilities, being more vulnerable, experience gender-based violence more often than neurotypical women (Humphrey, 2016). Persons with intellectual disability may be manipulated into abusive relationships by means of rewards or flattery and, at the same time, may have difficulty reporting the abuse (Muswera & Kasiram, 2019). Prevention is, in this instance, infinitely better than cure. If young people with SID are to be afforded dignified treatment, they need an appropriate work environment where they will be treated with empathy and respect, and where support measures exist to prevent workplace exploitation.

5.3.4 Support needs related to Challenge 2: Prevention of workplace exploitation

Participant 3 stressed that an individual with intellectual disability cannot simply be dropped off at a place of employment without any support. She mentioned three important support measures: the presence of a person very familiar with the young individual at the workplace to observe challenges and be a 'safety net', at least for a period of time; the choice of a place of employment, where someone who is empathic to the individual (such as a close family friend or family member) can play a supportive role; and a set of guidelines provided by the school when first enlisting the place of employment as a job sampling site:

> *About the challenges in the workplace, it's very, very important that you have like a safety net for those kids, so they know what to do in a difficult situation. That was why it was important for me and P5 to go with the child, to know the child well, to go with her, just to be available, even though the employer said, 'no, you can leave her', we said to A we will be there for her for at least the first month. And then, in the past I've seen it's usually a friend of the family that offers an opportunity for a – ahm – job shadowing opportunity – ahm – and when job sampling, it's always good to have the school approach the employer. Because we've got paperwork in place, and ahm – still have the parents on board, but the first step must be the school* (P3).

These points were supported by FM 2, who cited a workplace success by a young man with Down Syndrome. This boy had the support of his family, a family friend who owned an engineering company who was prepared to accommodate him and a good job coach, who ensured that he acquired the skills needed to be successful:

> *He works in a ahm – engineering company – he's their technical assistant, and he's been there for 11 years.… his mom was a huge support in helping – in helping him to settle into school, and after school, helped and worked towards independence, uhm – I think she – she knew the owner, and then, he did have a job coach, who went in and did job task analysis, and then went and followed up when there was – uhm – you know, if there was any challenges, or just – popped in to support, he hasn't had support in a long time* (FM 2).

Although the social ecologies around the individual with SID are central to their workplace support and the prevention of exploitation, this is not enough. The young adolescent needs to be prepared to advocate for themselves. This is especially true for young ladies with SID, who need to be taught self-protective skills to counter sexual harassment. Participant D1 reported how she included sexual education in her programme:

> *We also had to prepare them for the fact that, regardless of where you go, the threat of harassment is very real, and so we spent quite a bit of time with them on life skills – ahm – and protective behaviours. Learning to say no, how to say no, how to have a network of social support, who to report to, when to report, and what was acceptable and unacceptable behaviour* (D1).

Despite the vulnerability of adolescents with SID, sexual health education is often conspicuously absent from transition programmes due to disability stigma. In a study conducted among Western Cape residential facilities for people with SID, McKenzie et al. (2013) report that some facility managers believed that any sexual activity for people with intellectual disability was immoral, or that their residents were not capable of having such relationships. This attitude is typical of the medicalised view that the bodies of people with disabilities are non-functional – either devoid of sexuality or hypersexual – and that they are unable to control their urges (Van der Heijden et al., 2019). Treacy et al. (2018) call for action regarding sexual health education for young people with disabilities. Their lack of preparedness for abusive situations due to the faulty view that they will not understand sexual education, do not need it or that the education will, in fact, awaken uncontrollable urges, puts them more at risk of abuse, exploitation, unwanted pregnancies and sexually transmitted diseases (Treacy et al., 2018). The attitude of the residential care facility managers as described above points towards another challenge: the plight of those young adolescents with SID whose disabilities prevent them from working in an open labour market setting and who are dependent on caregivers throughout adulthood.

5.3.5 Dignity-related Challenge 3: Unacceptable caregiving of young SID adolescents with multiple disabilities

Participant 4 reported on the predicament of a mother of one of the chosen learners of the study, M1. The mother needed to go to Limpopo every week to take care of her elderly

mother, leaving the 16-year-old non-verbal girl with cerebral palsy and intellectual disability in the care of her two sisters. The mother feared that the two elder daughters sometimes left their sister in the house without supervision when, for instance, taking trips to the shop. She expressed her concern about the situation:

> *You can – leave A here, and maybe go to the shop – and come back and can find someone maybe raping her – and that stuff. She's no more safe to stay in the house – even if I'm here – but – I can go here and there, and then, leave her with her sisters, or with my granddaughter, maybe they leave A – you can't know* (M1).

Since A (L1) was approaching the end of her school career, the mother realised that L1 needed a safe place where she could be taken care of, possibly a residential facility. There was such a facility close to their home, but its residential care was expensive (about twice the amount of L1's disability grant) and the centre offered unacceptable care. L1 attended the facility in the afternoons after school until her father could pick her up after work. Her dignity was compromised by the neglect that she was subjected to while having to wait there:

> *Like even, like there, at the centre – when coming back from centre sometime, she's wet, or she has – soiled herself for long time, and they did not change her – that is only the biggest challenge.*

The centre did not offer any stimulating activities for the residents:

> *And the one thing is, they totally don't do anything with the disabled children, they just sleep – they don't go anywhere.*

McKenzie et al. (2014) conducted a survey at 37 non-governmental South African care facilities in South Africa. They found that the facilities were constantly struggling with funding and were far from realising the human rights of the residents, who were isolated from the community and did not receive vocational or life skills development. This situation compromised the quality of life of the residents. Young adolescents with multiple disabilities often have no other options available in low- to middle-income countries such as South Africa (McKenzie et al., 2014). The question may well be asked whether it is even possible to plan for a better future while transitioning them from school to adult life.

5.3.6 Support needs related to Challenge 3: Making the best care choices and facilitating change

The right choice of a care facility could be critical to the quality of life of the individual with SID and multiple disabilities. Parents and learners should be facilitated towards the choice of a facility that offers dignified physical care, as well as appropriate emotional and

cognitive support. One of the care facility managers, FM 5, said the following about this important matter:

> *Parents need as much information as possible about the different places early on. Young people could attend a week or two on a probational basis – to see whether the young person is going to adapt well and feel happy, to see whether or not it's going to work. If the decision is then made to bring the young person to the facility, it will be easier to adapt* (FM 5).

De Geus-Neelen et al. (2019) view parents as advocates, information seekers, spokespersons and providers of social support due to their lifelong connection to their children, which stretches right through school into adulthood. During the transition period, parents and school staff alike could act as agents of change, according to the opinion of the manager of a post-school facility for young adults with SID. She believed that changing the current facilities over time was possible:

> *To transform such a facility – it's a process. It starts with an individual. It starts with the manager. First, the individuals need to look inward, what motivates them, what is the reason for them doing what they do, why do they do it.* (F1).

One of the therapists interviewed, T1, recommended that the expertise of school staff could be utilised for the in-service training of care facility staff:

> *Another suggestion, an aspect I think occupational therapists and other educational experts can assist with, is training. We need to train the staff of the care centres, teaching them to handle our young adults with intellectual disabilities in a more therapeutic manner, and ahm – possibly also work on support groups for the parents or primary caregivers. Through training sessions or support groups, they could be guided towards better understanding and be equipped with better skills to support our young adults better and enable them to live with dignity* (T1).

Bigby and Beadle-Brown (2018) identified factors promoting quality of life in care centres, such as good management practices, an enabling and motivating culture, recruitment of staff with the right values, adequate resources and small, homelike settings. These are goals towards which all stakeholders should work tirelessly, regardless of the amount of time and patience it may require.

The ALS concluded that the need to treat individuals with intellectual disability with dignity, not only in care centres, but also in places of employment and schools, where a foundation for their futures is laid, is non-negotiable. The human dignity of people with SID should be an existential and philosophical cornerstone for any kind of transition programme

(Reaume, 2013). Still, the reality is that people with intellectual and physical disabilities often remain dependent on others to some extent for the rest of their lives.

Capri and Swartz (2018) point out that power is inherently relational. Invariably, the attitudes of actors in the lives of young adults with SID (parents, caregivers, siblings, neurotypical peers, teachers and other community members) cause young people with SID to perceive themselves as powerless. These power relations render people with SID unable to engage in self-advocacy (Capri & Swartz, 2018). The second theme illustrates how relations with people around the adolescent with SID can be either disempowering or empowering.

5.4 THEME 2: CHALLENGES AND SUPPORT NEEDS RELATED TO THE EMPOWERMENT OF LEARNERS WITH SID

Moran et al. (2017, p. 19) define 'empowerment' as "the process of giving power or control over one's own life to an individual or group that has traditionally been marginalised". For these authors, empowerment goes beyond rights – it provides the structure, resources and supports for the individual to *realise* these rights, demonstrate their abilities and exercise control over their life.

Zimmerman (1995), one of the founders of empowerment theory, distinguishes psychological empowerment from community or organisational empowerment. Psychological empowerment is about the belief that goals can be achieved despite barriers (Zimmerman, 1995). Zimmerman (1995) distinguished between empowering *processes* and empowered *outcomes*. Data in this study has pointed towards three empowerment categories: attitudes, processes and outcomes. These categories can be either empowering or disempowering. In Figure 5.3, the bricks in the wall represent the empowerment challenges, consisting of disempowering attitudes, processes and outcomes. These may make the individual feel powerless to change or control anything in their life and may rob them of any desire or motivation to be striving towards self-determination and to transition to a quality life. The bridge represents the support required to combat disempowerment. This support involves empowering attitudes, processes and outcomes that promote the belief of the young adult (and those supporting them) that they *do* have the ability to succeed, that there *is* hope and that life goals *can* be set and reached. As shown in Figure 5.1, empowerment is the second of the three stepping stones (dignity, empowerment and inclusion) towards quality of life.

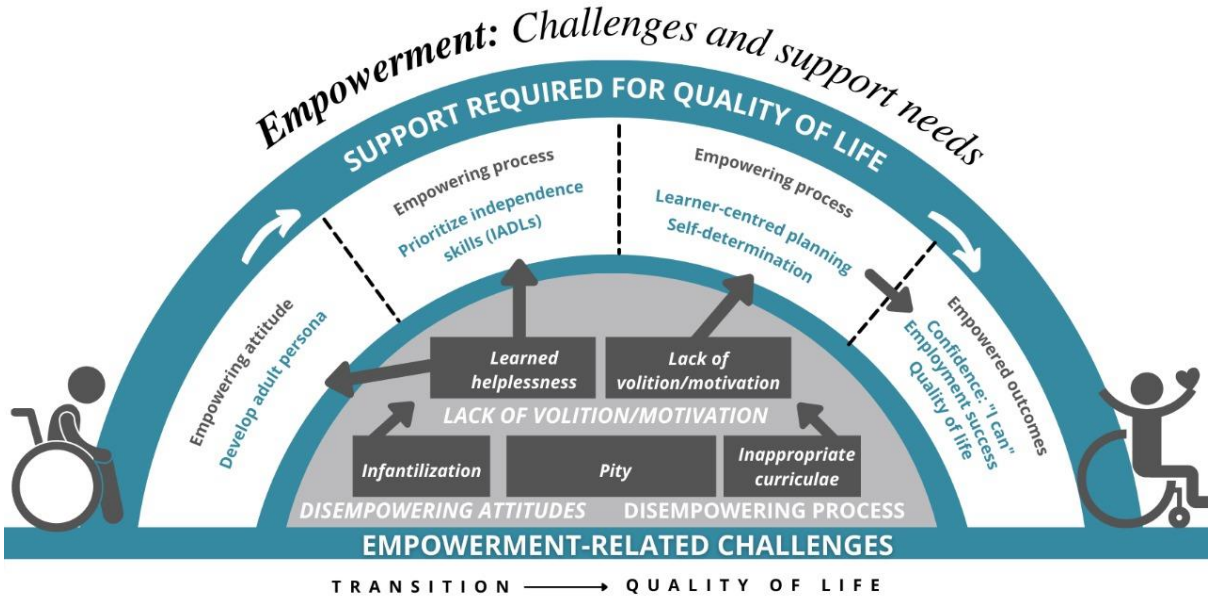


Figure 5.3: Challenges that may lead to disempowerment and needed supports to bridge these challenges and attain quality of life.

5.4.1 Empowerment-related Challenge 1: Disempowering attitudes: infantilisation and misplaced pity

According to the Oxford Dictionary (2021), the meaning of the term 'infantilise' is "to treat someone as a child or in a way which denies their maturity in age or experience" (Oxford Dictionary, 2021). In essence, this definition means that some human beings are robbed of the rightful power that their age or experience should afford them, and they are thus disempowered. According to Capri and Swartz (2018), the infantilisation of people with intellectual disabilities is a form of maternal overprotection, which becomes an endless cycle of disempowerment, perpetuated in care facilities and other social circles. This results in the development of an infantile personality in the disempowered individual. In a country such as South Africa, where advocacy for disability rights has not yet gained as much momentum as in other Western countries, infantilisation is still a widely accepted norm by which people with SID are treated (Capri & Swartz, 2018). A facilitator, FM 1, reported that multiple-challenged young people with SID were very likely to be infantilised:

> *One needs to be vigilant, because facilitators tend to handle them like babies, that type of thing. Facilitators need to maintain age-appropriateness.*

However, not only adolescents with multiple disabilities get treated like children. D1 taught fully verbal and mobile learners with SID. Yet, she reports:

> *The major thing that the learners said in their one-on-one interviews – was that – nobody treated them like an adult* (D1).

Capri and Swartz (2018) found that, in South Africa, caregivers were reverting to infantilising communication, the use of debasing nicknames, patronising reprimands and childlike décor. These individuals did not enjoy adult status, much less the privilege of autonomy or choice. In our discussions in the ALS, the complexity of choosing a 'just right' attitude towards adolescents with SID became evident. Although the participants agreed that adolescents with SID should *not* be infantilised, most ALS members believed that the level of functioning of the young individual should dictate which responsibilities could be assigned to them:

> *I say we approach them as adults, and we give them responsibility, but still, within their abilities. So, meaning, we can communicate with them as adults, and respect them as adults, but still protect them, and talk to them in a very concrete and basic way that they can understand* (P5).

> *I feel the same way as A. Our young adults can have responsibilities, but within their capabilities. It's a show, teach, practice – uhm – approach, so that they can help themselves – also in independent living. If you – uhm – know the individual – you know his or her abilities and challenges, it's easier to – to choose uhm – 'I can' responsibilities for him* (P3).

'I can', as a frame of mind, is impossible if one is an object of pity. Pity, just like infantilisation, is a dangerously disempowering attitude (Van Aswegen, 2020). Yet, some participants regarded it as a natural reaction to the challenges of these individuals. One parent, P7, acknowledged that he himself often fell into the trap of being over-sympathetic towards his daughter with SID.

> *I myself have fallen into this trap many times in my life with M, I must admit, ja – it's one of those things… (laughs)* (P7).

Another participant, P2, thought that pity displayed by community stakeholders was difficult to avoid and that one should even embrace it in a certain sense to get them involved.

> *I think we will never get away from the – pity for the disabled person – because that is the way people are, because they see you as different, they feel you as different, they – they – even though they don't look different, once they speak to them… I feel, it's fine, let them start – I'm talking about everybody else outside, not us – let them start by feeling pity, because that's the first emotion, you have to start somewhere* (P2).

Conversely, P4 shared a response from a facilitator, FM 1, who believed passionately that a paradigm shift should take place, away from regarding people with intellectual disabilities

with pity (she called it the 'bleeding heart syndrome') and towards empowerment ('greatness'). She said:

> *It comes from a space of bleeding heart, pity, where, you know, that whole notion is just wrong, it's rubbish. We all learn differently, we are all differently abled. We are all under construction, you can teach me some things, I can teach you some things, even though I may be cognitively higher functioning. Thinking back, I learnt so much from each individual I had worked with. My life is so much richer because of that. It was an equal exchange of – humanity – I suppose. I think that my greater vision for the world would be working against the bleeding heart mentality, but towards moving them ahead, towards their greatness. Just like we want to move towards our greatness* (FM 1).

The so-called 'bleeding heart mentality' (pity) is a driving force for the often religion-based charity model of disability, where the person with a disability is viewed as vulnerable, passive and dependent on the goodwill of others to provide assistance in the form of charity or welfare (Neille & Penn, 2017). Van Aswegen (2020) warns that this approach, although mostly well intentioned, has the potential to have long-term negative social consequences for those that it aims to assist. The well-meaning donors often have more of a desire for moral recognition than a genuine concern for the rights and a regard for the abilities and dreams of those receiving the 'charity'. They do not realise that their efforts result in a loss of dignity and disempowerment of the very people they are trying to assist (Van Aswegen, 2020).

In countries such as South Africa, where the medical and charity models of disability are still rampant, governments tend to believe that the needs of people with disabilities can be tackled if they have resources left over after members of the broader population have been attended to (Groce & Kett, 2013).

Ironically, South Africa is a signatory to the UNCRPD (United Nations, 2006), which marks a paradigm shift in the attitude to persons with a disability – from 'objects' of charity or medical treatment, to 'subjects' with rights and responsibilities, who are capable of being active members of society and who are entitled to make decisions about their own lives (Groce & Kett, 2013).

5.4.2 Support needs related to Empowerment Challenge 1: An attitude change – teaching young adolescents with SID that they are emerging adults, not eternal children

Participant P4 reported that the first aim of D1, who taught at a school for SID learners, was to develop the persona of an adult in each of her group of young adolescents. To do

this, she took a few simple steps: First, she turned her classroom into a microcosm of the world of work. She established a work-like routine with work-like rules and responsibilities, like those an adult would adhere to in the real world:

> *They had to report to the classroom at 08:00, ahm – sign in a register, so we – we hadn't even been talking about work. We just made this about our daily classroom routine. Self-discipline was also extremely important. Ahm – and then, in October of that year, once we had established routines, we had ahm – you know – in – in a way helped them develop the persona of an adult person* (D1).

In addition, she made the learners 'look the part' by having them wear a different uniform to the rest of the learners to reinforce a sense of them being adults:

> *What we tried to do, and this was a suggestion from them, was that they wore a different uniform from the rest of the learners. And that would commence in January of the following year. We then ahm – informed their families – ahm – that this would be the case, because all that happened was that – the rest of the school would wear a yellow shirt with grey pants, and what they did was, they wore a white shirt. So, when they came back in January of the following year, they came back essentially as the matric graduating class of that school. Ahm – that sense of wearing a different uniform – with a tie – which was their own thing that they threw in there – and shiny shoes – ahm – gave them a sense of being the adults. So first they needed to embody what it was like to be an adult in the working world before they could actually transition into anything* (D1).

Participants thought that the paradigm shift away from infantilisation and towards adult-like treatment needed to be perpetuated in the homes of adolescents with SID. Not only the young adults, but also their parents and caregivers needed to understand that these young individuals were no longer children, but adults:

> *I realised that, as soon as you embarked on the path towards the facilitation of a paradigm shift, to have them view themselves as adults instead of children – and to let them understand that more would be expected of them – you needed to have the parents on the same page. If not, the whole effort would be a disaster. You would teach them about their rights, about their responsibilities, but at home they would still be treated like children* (P4).

Participant 4 reported several facilitators stating adamantly that an attitude of 'I can' had to be instilled, combatting prevalent passive, helpless attitudes in these individuals. This was even more important than teaching any skill. A facilitator who managed a coffee shop employing only individuals with SID, said:

> *…we always try to, first and foremost, teach them that they can do something. They are worthy* (FM 3).

Another facilitator built 'I cans' by giving attainable goals and 'just right' challenges, so that the individuals would experience success and build confidence:

> *…to slowly build 'I cans' in the workshop, by means of a 'just right' challenge … so you know, you start small, with small challenges, and then, as they progress, you give them more and more challenges, until you find the 'just right' challenge for that person* (FM 1).

The same facilitator described how N, a Down Syndrome girl who hid whenever she had to do something work-related, became more confident as the group celebrated her 'I can' moments:

> *… you know, to teach her to take pride in what she did we gave lots of positive feedback on every tiny thing she accomplished, almost a celebration of every 'I can' moment. And so, as she received more positive feedback, her motivation to try things increased* (FM 1).

5.4.3 Empowerment-related Challenge 2: Curricula for SID learners in South Africa: a disempowering process?

The challenge of having a just-right curriculum that addresses the needs of learners with intellectual disability in preparation for transition became all too apparent in the responses of participants. In South Africa, the post-apartheid Department of Education (DoE) had a vision of an inclusive education system where all children would learn together, with a system of support that would address not only disability, but also a range of barriers to learning such as poverty, inequality and other social conditions (DoE, 2001). Yet, a post-school facilitator and a therapist reported that some young individuals with SID suffered adverse psychological effects due to having constantly experienced failure in a one-size-fits-all school system.

> *I think they are in a space of 'I can't' because some of them experienced constant failure in the school system, where all was focused on IQ, and whether or not you can read and write, so because they couldn't keep up, they are already in a space of 'I can't' (*FM 1*).*

> *They compare themselves with friends in terms of scholastic abilities, they say 'I can't read, I can't write – I can't get a job, I can't be a doctor.' So, they start to reject themselves and fall into depression. It's difficult for our children to understand the concept of 'I'm different, and that's OK'* (P5).

According to McKenzie (2020), the ideal of one curriculum for all in South African schools stemmed from the country's apartheid history. This politically motivated goal had the unintended consequence that, in many schools, a one-size-fits-all approach was followed, with little regard for the special education needs of learners with barriers to learning.

However, the decision was recently made to develop three separate curricula aimed at the needs of children with intellectual disability. Yet, in one of the pilot schools that first implemented the D-Caps curriculum (for learners with SID), a therapist, S3, believed that the curriculum content often does not speak to the cognition level of the learners.

> *Our lesson presentation is not always on the level where our learners are. The content of the curriculum is often – on a level – higher than where our learners are. Looking at intrinsic motivation, looking at what drives learners with intellectual disability to participate in something or to learn a new skill – the way we present the curriculum does not speak to that* (S3).

On the other hand, expectations of young individuals with *multiple* disabilities may be *too low*. Since the assumption is often made that they cannot do anything, choices are continually being made *for* them. Participant P4 referred to S3, a therapist, who stressed that a feeling of autonomy may make a world of difference when working with these individuals:

> *They can't necessarily choose what centre they will be going to, what they would like to eat, or even what they would like to do that day. They are being put on the bus, go to school, are being put on the bus back home. But those tiny choices of – would you like a bite of meat now, or rather a bite of pap? That autonomy, to be able to choose, that's important…* (S3).

This school therapist thought that the curriculum content for SID learners was too academically inclined and that the goal setting was not transition-focused. Independence skills need to carry a much higher priority, since these skills are much-needed post-school competencies:

> *For instance, we need to say, this is this child's home circumstances, he needs to help with food preparations, or he needs to assist with cleaning his home, then we need to focus on that. It will reduce the burden of care on the side of the caregiver, it's going to increase the confidence of the young adult, he will feel more autonomy* (S3).

Participants were also concerned about the fact that too little priority was assigned to teaching methods that are aimed at the unique educational needs of learners with SID. S3 stressed the use of small steps and fixed procedures and pointed out that individuals with SID needed to be taught how to carry over skills or behaviours in other settings:

> *I would say that what our learners find challenging are activities with many steps to master, and that learners with intellectual disabilities struggle to carry over skills from one situation to the other. So, even though we try to teach them skills in an environment as close as possible to the environment where they are going to need the skill, if anything in the environment where they need to apply these skills changes, it will be a challenge, since they rely so heavily on procedure, and on small steps. Practising every skill in a hundred different ways, in different*

> *settings, and learning from different people (parents, teachers, employers, therapists, family…) is the only way to have them learn appropriate behaviour or responses* (S3).

As a therapist, her professional opinion was that basic skills should be prioritised, reinforced by frequent practice and systematically built upon. She stressed that trying to teach too much at once can be counterproductive.

> *We need to drill in those basic skills, starting with one, or two, or three, and build upon those, instead of trying to teach them too much, making them anxious, making them feel that they are always failing, that they are not good enough. We need to focus on those things within their reach and go from there* (S3).

Disempowering educational practices may have a profound effect on the intrinsic motivation of young people with SID during the crucial transition period and into adult life, as became clear in the accounts of the participants to be discussed next.

Ryan and Deci (2017) define motivation as an energy and an intention to act. To the contrary, amotivation, or a lack of motivation, results in passivity. There is no intention to act because the person perceives themself as incompetent. Participants reported that amotivation or poor motivation was prevalent among young people with intellectual disability. A facilitator shared the challenges of a post-school facilitator to motivate some of her students:

> *Something we all see in individuals with special needs is – the volition, the motivation is a huge problem. I think to a great extent the reason for this is that so little is expected of them* (FM 1).

Participant S1, who managed a post-school employment programme at a school for learners with SID, reported the same challenge. Learners started the job sampling programme eagerly, but then could not sustain their intrinsic motivation:

> *Of course, they are unbelievably eager to start working in the open labour market. Learners were hugely motivated to display good behaviour at school so that they could qualify for placement. But then, after about one term, the eagerness started to wane. Some of them started to develop 'illnesses', such as a tummy ache, a headache or a runny stomach* (S1).

Referring to a specific case of a learner who developed such psychosomatic symptoms while doing job sampling, S3 pointed out that the learner's lack of motivation could be related to stress because the places of employment were not suited to her individual needs and preferences. Her intrinsic motivation improved dramatically the moment she could work in the setting that she preferred:

> *The first six months she did very well at her workplace, a pre-school. There was no problem, she went there every day with a big smile. The second six months of*

> *her first year she went to work – but she fell ill regularly, or she had a seizure, or we had to go and fetch her – it was at a busy doggy parlour where many clients were constantly entering and leaving. During the next six months, she was placed at – uhm – a vegetable shop, which was even busier, and she had to work in the front of the shop, between the shelves – lots of human contact – in the end she only went to work once or twice during those six months. Then we decided – for a variety of reasons – to place her at the pre-school again – and suddenly, all problems disappeared! The bottom line is, she was so anxious about working at the other places that she would have a seizure or would fall ill – her emotional state manifested to such an extent in physical symptoms that she was just not able to go to work* (S3).

Morningstar and Mazzotti (2014) found that self-determined transition programmes resulted in high levels of psychological empowerment, locus of control and hope. Ryan and Deci (2017) link self-determination to autonomous or intrinsic motivation, which means that the individual is driven to act intentionally and volitionally, resulting in interest, persistence and task engagement.

This brings us to the discussion of an important support measure for empowerment: self-determined, learner-centred decision-making regarding after-school outcomes.

5.4.4 Support needs related to Empowerment-related Challenge 2: Learner-centred planning and self-determination

"Nothing about us without us!" This was a rallying cry among Eastern European labour organisers years ago and it has now become a slogan of the disability rights movement (Franits, 2005). Self-determination has been defined as a skill set, including problem solving, self-awareness and decision making (Shogren et al., 2017). To return to the slogan, no decisions about persons with SID should be made without them. They need to be facilitated towards self-awareness and towards skills development in the areas of problem solving and decision making. Participants in the study agreed that the first step in transition planning should be to determine the needs and preferences of each individual learner. S3 said:

> *I think it's really important to work individually – to have a really deep knowledge of what drives our learners. Not only how they learn, but what matters for them as a person, to tap into that, to focus on that* (S3).

A facilitator agreed with this principle, stressing that she observed the young adults closely to find out what their passion was:

> *You begin to see what their passion is, what they like doing, what they find really interesting* (FM 1).

Participant D1 and her team ensured that, during their job sampling programme, learners were placed according to their interests:

> *In our one-on-one interviews, learners told us what they were interested in. Ahm – so – our learner for example who was placed at the panel beater, he just had a natural affinity for fixing things in general, not necessarily cars, not necessarily panel beating, he just loved to fix things. So, he was quite happy getting his hands dirty, and – and you know, seeing the finished product at the end of it all* (D1).

Shogren et al. (2018) set out to determine whether the self-determined learning model of instruction would make a difference in the self-determination scores of transition-aged learners with severe intellectual disabilities. Teachers were trained to implement the programme, prioritising three phases of instruction: Phase 1: Set a goal; Phase 2: Take action; Phase 3: Adjust the goal or plan. Significant changes in student self-determination were reported. Self-determination and independence, also termed self-management by some, are closely related (Sandjojo et al., 2018). Participants have indicated that independence skills are an important priority and support measure for empowerment.

5.4.5 Empowerment-related Challenge 3: Learned helplessness

Young people with disabilities who are infantilised by well-meaning caregivers tend to develop learned helplessness (Sandjojo et al., 2018). Participants of this study reported a dissonance between the efforts of therapists, who worked towards age-appropriateness and better independence, and the attitude of parents or carers, who often found it more practical to simply do things *for* the young person with an intellectual disability. A therapist voiced her frustration about this challenge:

> *I think it is very important for parents to make a mindshift, and as therapist, this often frustrates me deeply. That – I can teach your child a hundred times to fasten his shoelaces, but if he doesn't do it at home, he won't learn. In the literature, it's called 'acquired helplessness' – simply because we just do so many things* for *leaners with disabilities, later on they don't want to learn how to help themselves anymore* (S3)*.*

Participants' experiences showed that acquired helplessness may lead to poor daily living skills, which will then just compound the young adult's powerlessness. A post-school facilitator, FM 2, expressed her concern about young adults with SID who had not yet mastered basic self-care and other daily living skills:

> *Many have not been given the skills to be able to – ahm – do simple tasks in the kitchen, like making sandwiches, making tea, making coffee, making drinks, washing dishes, ahmm – interpersonal skills, like – making sure that they eat correctly, wash their face correctly, after eating, to make sure their face is clean before they go out, brush your teeth, ahm – these are all areas that I have found*

that – they hadn't mastered these skills. Something like buttening – simply buttening – doing belts, ahm – you know general – getting dressed, tying shoelaces – these are all areas where many of the students – persons with Down Syndrome that I have interacted with, adults, have not mastered these skills (FM 2).

Learned helplessness, dependency and passivity can be reduced by implementing person-centred active support, an approach that promotes active engagement in meaningful activities. Instead of taking over, staff should empower individuals with SID by expanding their abilities (Sandjojo et al., 2018).

5.4.6 Support needs related to Empowerment-related Challenge 3: Prioritising independence skills

Participants felt that teaching post-school independence skills needed to be central to transition planning. For example, D1 decided to prioritise budgeting skills as a transition skill:

> *We did not want them to be in a – in a transition period where they would then be part of the working world, earning money, but not being able to manage that money. So, we started off by, in the mathematics class – ah class time – drawing up a class budget. The class agreed on an amount of R20 per month that went into the class budget. So that money was then used for the purpose of tea bags, coffee, sugar and milk, just for the exclusive use of the class. Ahm – I bought a kettle, and we set up a little tea and coffee station at the back of the classroom.*

Shopping was another instrumental activity of daily living, prioritised by an experienced teacher:

> *The learners and I usually went to Spar every two weeks to buy all our ingredients for the baking. We prepared with our recipes and advertisements of Spar. We then took those advertisements, and those that could, their calculators. Then we composed our shopping list. If a product was R27,00, we said, OK, we'll need R30, and we then set up our list, and the amounts, and had a total in the end, so that we could know how much money we needed, and also, uhm, if we needed change. And then, at our arrival at the mall, each got a part of the shopping list, a basket, and off we went* (P3).

A therapist, S3, stressed the prioritisation of self-care activities for learners with multiple disabilities:

> *Realistically spoken, they will need lifelong support. But to what extent can we reduce the amount of support that they need? Even if I just hold the toothpaste while my mom brushes my teeth, I'm more part of the process, a human being, not just an object that needs care. Because I think, often that is what happens to our severely intellectually disabled learners – they become this person that needs to be kept alive. And the only aim is to keep this child alive. And then they lose their human dignity; lose human interaction. To me it's about human dignity and autonomy – to be able to do something independently* (S3).

Sandjojo et al. (2018) evaluated the effectiveness of self-management training for people with SID, aimed at enhancing independent functioning in daily life.

The results showed that the training contributed to the attainment of self-management goals and a reduction in support needs (Sandjojo et al., 2018). Empowering self-management skills such as the ability to do shopping independently may lead to better social inclusion and a sense of belonging (Wilton et al., 2018). Social inclusion, as a quality-of-life goal (Schalock et al., 2018), will be under discussion next.

5.5 CHALLENGES AND SUPPORT NEEDS RELATED TO INCLUSION

The Oxford Dictionary (2021) defines the term 'inclusion' as "the practice or policy of providing equal access to opportunities and resources for people who might otherwise be excluded or marginalised, such as those having physical or mental disabilities or belonging to other minority groups" (Oxford Dictionary, 2021). Article 19 of the UNCRPD requires governments to "recognise the equal right of all persons with disabilities to live in the community, with choices equal to others" and to ensure that they enjoy "full inclusion and participation in the community" (United Nations, 2006). Social inclusion is one of the quality-of-life domains (Schalock et al., 2010), but is a vague term, which can have many different connotations (Gooding et al., 2017). Amado et al. (2013) noted that, even though people with SID may physically live in a community or participate in community activities, they may experience little sense of belonging and have very few meaningful relationships with neurotypical community members. To compound the complexity of the term 'social inclusion', Amado et al. (2013) point out that the experiences of relatedness, belonging and community membership are subjective and will differ from person to person. This thesis will not attempt to go into all the complexities of social inclusion and belonging. Rather, challenges that may lead to the social exclusion of young adults with SID that emerged from the data have been identified, as well as supports that may assist these individuals to overcome those challenges, as illustrated in Figure 5.4.

Figure 5.4: Challenges that may lead to exclusion and needed supports to bridge these challenges, leading to quality of life

5.5.1 Challenges that may lead to social exclusion

5.5.1.1 Multiple disabilities

A significant portion of the learners in the school under study have multiple challenges over and above their intellectual disability, such as physical disabilities, autistic features, sensory issues and behavioural challenges. After home visits and parental interviews, P4, P5 and P6 reported that the learners with the most profound social inclusion challenges were the two learners that lived with multiple disabilities. Participant L1, a 16-year-old girl with SID and cerebral palsy, is a wheelchair user, has only one functional hand, wears diapers and is non-verbal. Due to her having outgrown her wheelchair, she never accompanied family members to the shops, did not visit friends or neighbours and did not accompany the family to church. School was the only place where she went. Participant L3, an 18-year-old fully verbal girl, has spina bifida. She has fully functional hands, but multiple health challenges, such as chronic bladder infections, ongoing treatment for kidney failure, high blood pressure and an ulcer. This girl was sturdily built and very heavy. Her mother nearly always left her at home when she went somewhere due to the effort it took to get her into and out of a vehicle. They never visited friends and only occasionally went to visit close family members. Santino (2020) points out that approximately 50% of parents who have a child with a disability report that their child has no friends, or only one friend. Often, this

is due to concomitant disabilities such as a combination of physical, cognitive and sensory impairments, which may lead to social isolation and loneliness (Santino, 2020).

Support required to facilitate inclusion for young adults with multiple disabilities

Participants revealed that they achieved better inclusion by putting individuals with intellectual disability 'out there' in communities. Exposure to public spaces serves to work against the tendency to isolate these individuals and withdraw them from public scrutiny. A facilitator reported how she included *all* her students, notwithstanding the gravity of their disabilities, when going on outings. These outings included shopping trips, trips to restaurants and even a camping trip. She also enabled them to 'dress the part' while doing so. Talking about her wheelchair users with multiple disabilities, she said:

> *They wanted to be included. Emotionally, they were on a type of teenage level, although they were already in their late twenties or early thirties. So, they wanted to wear bling, they wanted funky wheelchairs, you know, they needed space to live out who they were and what they wanted. They wanted to go out to the shops, to do window shopping, like a girl's day out, to be pampered, have their nails painted, and you know – girly type of stuff* (F1).

The first vital support to get individuals with multiple disabilities 'out there' is to provide them with the assistive devices and/or transport to do so. In the case of the selected learners whose challenges I have described above, L1 needed a wheelchair to have any chance of getting into public spaces. L3's parents owned a bus with a ramp, without which it was near impossible for one person to get her into a vehicle. However, the bus broke down constantly and this challenge effectively confined the girl to the house. McConkey and Collins (2010), in their study, arrived at three strategies for promoting social inclusion. Firstly, to *engage* the person in social and community activities; secondly, to *seek out opportunities* for inclusion in social, work, leisure and educational opportunities; and thirdly, to recruit *new members to their social networks*. These strategies are the direct opposite to isolation and withdrawal from social exposure. However, people with SID will not benefit from social exposure if they are unable to interact with others. Participants pointed out some of the communication challenges of young individuals with SID.

5.5.1.2 Communication barriers

The selected learners that were assessed for this study displayed challenges with language and communication. These challenges vary from an inability to speak to a lack of eye contact, inappropriate and 'random' utterances, difficulty understanding figures of speech, an inability to counter verbal attacks during conflict situations, challenges with expressing

emotional experiences and difficulty remembering instructions or difficult names (auditory memory). The mother of one of the selected learners observed that her son's lacking conversational skills caused him to become socially alienated:

> *Sometimes his conversation is not right, it's not the – the one that people understand. Sometimes they think he is crazy, ahm – just like – eh – asking simple questions that – eh – the answer is obvious. People, they just take him as if he is crazy or what. Just like ah – talking senseless things that doesn't entertain other people. So that worries me, how is he going to be when he – he is an adult* (M2).

According to P5, people with SID find it very challenging to verbalise emotional experiences, which may cause misunderstandings and further alienation:

> *Complicated emotions are difficult to verbalise – for example, feelings such as 'I don't want to socialise today' or 'I'm feeling moody' are just verbalised in a generalised manner, for example by saying 'I'm angry'. They find it extremely difficult to understand or explain their own emotions* (P5).

To young adolescents with SID, language containing abstract concepts or figures of speech are very challenging to interpret, leading once more to misunderstandings:

> *They struggle to grasp abstract figures of speech such as 'money doesn't grow on trees'. This confuses them and creates inner conflict* (P5).

Auditory memory issues may cause challenges in the workplace, since individuals with intellectual disability may struggle to remember difficult names or intricate instructions:

> *The lingo that they use in the business – those terms – is so important, because for example, in the nursery, the plant names are a – a big challenge. So, if they tell her to get the ferrozas, will she know which ones are ferrozas? Because it sounds like freezias – or whatever – so we think sometimes it's easy sometimes for our children, because they can do the physical work, but there's a lot of challenges that we don't think of as – as school staff, but the employer thinks, this – this child will never be able to learn that* (P5).

The research site, although a school for learners with SID, accommodates a number of learners whose cognitive functioning falls more within the range of mild to moderate intellectual disability, and others who function within the severe to profound range of intellectual disability. Communicative abilities vary accordingly. Chew et al. (2009) pointed out that those with mild intellectual disabilities are most likely to have better verbal abilities and to communicate with speech, whereas those with moderate intellectual disabilities may have more limited language abilities (such as using incomplete sentences). Those with severe to profound intellectual disabilities are likely to have severe communication

limitations and may need to rely on vocalisations, facial expressions and body language to indicate their wants and needs (Chew et al., 2009). It is important to note, however, that not all people who have communication barriers have cognitive impairments. Stephen Hawking, who suffered of motor neuron disease, is a case in point. His illness caused his muscles to atrophy, but left his mind unaffected (Lehman, 2011).

Without the means to communicate effectively, young adolescents with complex communication needs have serious challenges to express their needs, develop social relationships and exchange information with others (Blackstone et al., 2007). This may negatively influence the individual's ability to function in the open labour market. Bryen et al. (2007) found that most employers emphasised the importance of having good communication skills for employment success and to 'fit in' in the workplace. A good core vocabulary, as well as a worksite-specific vocabulary, is essential to function effectively and establish relationships in the workplace (McNaughton & Arnold, 2010). Communicative competence is essential for the quality of life of young individuals with communication barriers, since it provides a pathway towards personal, social, educational and vocational goals (Light & McNaughton, 2014).

Support required to overcome communication challenges

P5 shared how L1, who is non-verbal, flourished when she was introduced to a communication device. She responded very well to it and understood how to make choices and request things. However, the communication device is the property of the school and when L1 transitions into adult life, the device will have to stay behind. Therefore, L1's ITP includes the provision of a communication device of her own.

People who are unable to use speech as their sole means of communication need to make use of alternative and augmentative communication (AAC), which could include pictures, gestures, picture exchange communication systems (PECS) and speech-generating devices (Muller, 2014). AAC can be a game-changer in that it enables a person with severe disabilities to communicate and participate in a wide range of environments (Light & McNaughton, 2014). An AAC user puts it as follows: "AAC is my bridge to the world, and a window for the world to see the real me. It supported me in moving from frustration to communication, and from isolation to relationships with others" (McNaughon et al., 2019, p. 1). The importance of arming the individual with SID *and* complex communication needs with AAC during transition preparation cannot be over-emphasised. In fact, during an ALS discussion, P5 stressed that mastery of an AAC system or device should happen much earlier in their school career:

> *…a child like L1 – one of our severely disabled children – it's important that we start young, so that they get comfortable with a system, because starting to teach them at a 16-year-old age on an AAC system for the first time is late…*

Challenges with communication are intrapersonal – challenges within the person themself. Intrapersonal challenges include issues such as communication disabilities, epilepsy or challenging behaviours (Abbott & McConkey, 2006). However, *inter*personal challenges such as social and behavioural challenges may cause social exclusion as well.

5.5.1.3 Challenges with interactive skills in social circles

People with intellectual disabilities are among those most vulnerable to social exclusion (Owuor et al., 2017). Amado et al. (2013) have found that people with intellectual disabilities have few friends and that their social circles are made up of family members, paid staff members and others with disabilities. The data obtained in this study pointed towards challenges in different social circles, such as peer groups, public spaces and places of employment.

Challenges with peer group acceptance

A facilitator related that individuals with SID attending her transition programme found it difficult to make and keep friends:

> *They don't necessarily know how to – or – they struggle with making and keeping friends* (FM 2)*.*

During conflict situations, individuals with SID often do not have the social judgement to act appropriately. Participant P5 found that agitated reactions during conflicts could be scary enough to be the cause of social exclusion:

> *Our children have real difficulties with conflict management. Often, they are very rigid, very concrete, it's black or white, right or wrong. They may become extremely anxious or agitated and that may cause them to be excluded* (P5).

Participant 5 related that some of the higher functioning adolescents with SID wanted to be active on social media, but since they had limited reading abilities, they soon felt excluded from a peer group that included neurotypical peers:

> *What typically happens, is, he can recognise his name, he has a Facebook account, he sees that his name has been posted a few times with laughing emoticons, so he assumes that the others are making fun of him and that they are all laughing at him. But, actually they wrote something completely different.*

Participant 5 reported that one of the selected learners of the study tried to become part of such a peer group. Her need to be socially accepted was such that she pretended for months that she was in a mainstream school, taking subjects similar to those in the group – until she had to come clean one day and tell them that, in fact, she was in a special school.

> *I was, like, lying about me, saying that I was in this grade, and then I'm not, 'cause I was afraid that I would go out – that they would leave me alone – just like that …* (L5).

To their credit, the group did not reject her after this revelation. Another boy of the selected group lied to friends about his cerebral palsy in an attempt to appear more socially acceptable. His mother said:

> *Sometimes, he's lying about his disability. The friends, they'll ask him: What happened, why are you walking like this? And then he will say, I got in a car accident* (M2).

Some learners with intellectual disability have such a great need to be accepted in a peer group that they end up being exploited.

> *Our learners often experience emotional rejection, so often they have a great need for acceptance and then become part of a peer group for ulterior reasons – without them realising what those reasons are. For instance, an intellectually disabled adolescent may be used as a drug mule, or a girl may be sexually attractive and get exploited in that respect. So, peers may seemingly accept them into a group, but for dubious reasons* (P5).

Woodgate et al. (2020) found that, despite efforts to promote social inclusion, children with disabilities continue to report feeling lonely and excluded. According to this study, some of the barriers to inclusion are a lack of social competence and a lack of common interests with neurotypical peer groups. Participant 5 reported how a young boy who had been included in a mainstream school's athletic team due to his running ability felt socially excluded:

> *You know, he is a runner, he's physically normal, he competes against normal athletes, but it's very, very difficult for him to socialise with those learners. He'll tell me, ma'am, they are talking about things that I don't understand. So, whether they are discussing their academic tests or games that they play or whatever, he can't join the conversation, he can't socialise on their level, then he'll isolate himself, so it's really difficult for him.*

Participants of the study felt that one way to overcome peer rejection is by the facilitation of social inclusion interventions by stakeholders close to the individual with intellectual disability.

Social inclusion interventions as a support tool to facilitate peer group acceptance

The mother of one of the selected learners went the extra mile to facilitate his social inclusion in a peer group. She bought a soccer ball, gave it to the community boys and told them they could have the ball if her son could be included in their games. As time went by, the boys developed empathy for the boy and took trouble to involve him in the game:

> *They allow him to join in, and he enjoys it. Before we came here, we are a month staying here, we were staying at the hub there, and there were four kids there. I got a ball, and I gave them, he was just running with them, and they were just helping him, they will just leave the ball in front of his foot, so that he will just kick – sometimes he will just use his crutch!* (M2).

The mother of this learner instinctively chose a sport activity as an intervention measure to facilitate her son's social inclusion. Research confirms that sport is an effective social inclusion support measure. Scifo et al. (2019) reviewed 12 articles to determine the beneficial effects of sport intervention programmes for people with intellectual disabilities. The authors found that sport programmes positively affect a range of aspects such as quality of life, community participation, dignity, rights, choice and control.

More opportunities for social interactions and more frequent outings were reported for those individuals who were part of sport programmes than their sedentary peers (Scifo et al., 2019). These opportunities for social interactions may facilitate the acquisition of better social skills, preventing inappropriate behaviour that may cause challenges in public spaces.

5.5.1.4 Challenges with socially inappropriate public behaviour

Participants reported that adolescents with intellectual disability tend to have poor impulse control and will sometimes act in a manner that is not within socially acceptable norms. The mother of a young boy with SID expressed her fear that her son's awakening sexual awareness would cause him to expose himself inappropriately in a public space, causing others to be repulsed and reject him:

> *And another thing, he is struggling from masturbation. That is my big, big, big worry. If he goes to the boarding school – I was thinking, if he goes to the boarding school, and he will expose himself to other people…* (M2).

Data indicated that poor impulse control and a lack of understanding of moral codes may even lead to more serious social blunders, such as theft. To her embarrassment, S1 occasionally received phone calls from employers who complained that learners involved in the job sampling programme had taken desired items at work:

> *Our other challenge was that some of them would pinch things in the workplace from time to time – very few learners did this. We then immediately contacted*

the workplace – mostly they contacted us first – the occupational therapist apologised on behalf of the school and immediately offered to pay for the stolen item (S1).

Behaviour deemed as socially inappropriate may even alienate parents from family members and isolate them socially. P8 reported how a lack of insight on the part of family and community members caused her family to avoid social contact:

> *But then, also, in a social setting, where you – like a restaurant – or when you visit family or friends – there are some people who think your child is just naughty, or just needs a good hiding … That – that is a challenge, hey. It isolates – because you can only visit with certain people that understand this child. You cannot go to any type of restaurant, M – we like doing fine dining, we like to take the children with, to expose them, M hates it, because she needs to sit still and be quiet. So, first thing she'll ask you: Is it a sit-still-and-be-quiet restaurant? And then its awkward, and then – you know what, then you don't do it. You don't do it.*

Social challenges may surface at places of employment, which may cause the employer to second-guess the employability of the individual with SID.

5.5.1.5 Challenges with employability skills

Employability skills are social and cognitive skills that adults normally need to function effectively in a workplace (Case-Smith & O'Brien, 2013), as described by one of the facility care managers:

> *…the simple things when you go to a job, you know, ahh – the hygiene, being on time, letting someone know if you're – if you're sick – you know, always be polite. Uhh – those type of things* (FM 3).

Young individuals with SID may have a limited short-term memory and may struggle to plan daily activities. This became clear in P4's account of a selected learner's first workday:

> *L5 was told to wipe down the cots where the little ones slept. After having been given the instruction, she asked where the mop was. The employer was a little puzzled, but gave her the mop, thinking that she probably wanted to wash the floor after having wiped down the cots. However, L5 started to wash the floor diligently and never wiped the cots. The employer wasn't sure whether L5 misunderstood, or whether she simply forgot the instruction. The therapist and the employer agreed that L5 would need a visual schedule where the tasks for the day would be set out clearly in order to ensure that she knew what exactly was expected of her every day* (Research diary).

Employers require some basic self-organisational abilities when hiring an employee. Wennberg and Kjellberg (2010) refer to Kylén (1997), who points out that people with

intellectual disabilities find it challenging to order information, to organise their own thought processes, find alternative solutions to new problems and comprehend symbolism. It is evident that these individuals need support to bridge these challenges.

Support required to develop socially appropriate interaction and employability skills

It cannot be assumed that young adolescents with SID will automatically pick up social and employability skills. They need to be coached constantly, as reported by a teacher:

> *We teach them work ethics, skills you need to be able to work. You know, things like task completion, punctuality, respect for each other – all those things they need to learn, so this needs to be reinforced at home too. Time – they have to work from a certain time up to a certain time. They have to take a break. They need to have pride. Uh – they need to be motivated* (S2).

A facilitator, FM 1, used the workshops at her post-school facility to teach employability skills, after which she exposed the young individuals to 'less sheltered environments' to see how they would cope; a process that she called 'work hardening':

> *They started in the workshops, which is where they learnt employability skills. The work hardening was when they had to transfer the employability skills that they had learnt in the workshop to a less sheltered environment, for example, the men went to work in a factory, and the girls went to work at that dress-me-please place*. (F1).

Another teacher, D1, worked a whole year on only employability skills:

> *We spent an entire year focusing on skills such as routine, time management, self-discipline – ahm – and the management of the class. So, we tried to create a microcosm of society and of the working world within the class itself.*

She prevented petty theft from taking place by teaching specific steps to ensure honesty and integrity:

> *We even had to focus on a simple thing like, saying, if you find anything in the car, ah, while you were cleaning, like money, or a pen, or whatever, we explained in detail where those things needed to be placed in the front of the car, so the owner could see it. We explained that that was establishing trust and that they were not supposed to take anything. So, honesty and integrity were a huge part of coaching these learners in this particular transition programme* (D1).

According to Abbott and McConkey (2006), research has shown that higher social competence is a predictor of greater social inclusion. All participants who had managed transition programmes before stressed the need for constant coaching to enhance life skills and employability skills.

5.6 CHAPTER SUMMARY

True to the principle of learner-centredness, this chapter looked at the needs of and required support to the young individual with intellectual disability. These needs must be central to transition planning in order to combat the ever-present challenges or threats, especially in the South African context. Human dignity, empowerment and inclusion are all principles very central to the South African Constitution and other disability policy documents, but noticeably absent in the realm of real life, where societal behaviour patterns such as stigmatisation, infantilisation and exclusion from community activities are still very much part of the daily lives of young people with intellectual disability and their parents. In the next chapter, I discuss Cycle 2 of the study, which addressed the utilisation of family-school-community partnerships as support measures for the successful transition of young adults with SID into adult life.

CHAPTER 6: DISCUSSION OF CYCLE 2: UTILISING FAMILY-SCHOOL-COMMUNITY PARTNERSHIPS TO MEET LEARNER NEEDS

6.1 INTRODUCTION

The previous chapter was an account of Cycle 1 of the research – an investigation into the challenges and support needs of the young adolescent with SID about to transition into adult life. Chapter 6 reports on Cycle 2 of the research, which was aimed at answering the second critical question: *How can family-school-community partnerships better meet the support needs of adolescents with intellectual disability before and during transition?* In Chapter 5, I discussed possible ways to address challenges regarding the support needs of learners with SID. Therefore, the focus of Chapter 6 will be more on building partnerships as a support measure to meet the needs of these young adolescents before and during transition. Following an ecological approach (based on the work of Bronfenbrenner, 1979), the ALS investigated the different support networks in the lives of young individuals with SID and how these connect or fail to connect to each other to form successful or less successful partnerships. Since I adopted critical realism as the philosophical paradigm, the analysis was very much concerned with causal mechanisms and endeavoured to identify *reasons* for challenges that prevented stakeholders from building partnerships that work. The analysis provided answers to three core questions regarding family-school-community partnerships:

- *What* are the challenges experienced in this partnership?
- *Why* are these challenges experienced in this partnership?
- *How* can the partners do better to improve this partnership and thus enhance the transition process?

Small et al. (2013) stress the importance of utilising a whole-system approach during transition planning. Since the young individual with SID is going to lose the positive presence of the school, including teachers, friends and extra-curricular activities, they are at risk of being isolated within their familial microsystem, which may be increasingly vulnerable as the parents age. Transition planning needs to root these young people in "a viable and varied mesosystem", including work, leisure and social inclusion in the neighbourhood (Small et al., 2013, p. 286). To facilitate this, it is vitally important to foster transition partnerships (Pallisera et al., 2014). Many of these partnerships are built on or start out from a sound *family-school partnership*, which needs to be central throughout the learner's school career (Okeke, 2014).

I will thus proceed to discuss the important, but complicated family-school partnership, framing the discussion with the 'what', 'why' and 'how' questions shown above. Thereafter, I will proceed to the various *family-school-community partnerships*, looking once more at challenges and ways to address them.

6.2 THE FAMILY-SCHOOL PARTNERSHIP

Members of the ALS, especially P5 and P7, highlighted the fact that the family, more specifically the parents, are key stakeholders in the family-school partnership during transition:

> *There cannot, or will not, be a process without their involvement, and they should know this. It's not that – if you want, you can be part of the process – you* have *to be part of this kind of a process, to make it successful, and eventually, it's in the interest of the young disabled adult* (P7).

> *They are the most important partner in this whole setup. Also, after 18, the child goes out of school, but they stay a partner in the transition process for years to come, we are not there anymore, they will always be there – until they're not there anymore* (P5).

Yet, is this 'most important partner' in the partnership actively participating in transition planning? Looking at the challenges experienced in the partnership, it does not seem so.

6.2.1 What are the challenges experienced in this partnership?

From the school's side, participants highlighted perceptions about parents, such as that they are 'not serious enough' about the future of their children, that they are waiting passively for the school to act and 'wake up' too late, that they do not keep documents containing important information, are not interested in doing home tasks with the learners, are late for parents' meetings or do not turn up at all, are non-involved in general and do not attend workshops. These perceptions are based on the day-to-day experiences of staff members. One of the interviewees, a school staff member of another school, made the following remarks:

> *The parents don't always realise the gravity of this matter during the year in which the child turns 14. They are inclined to wait until the child turns 17, and mostly only when he turns 18, before they wake up and start making enquiries at the school* (S1).

> *They don't remember the information that we provide. At the information session, we state clearly that the children leave school at the end of the year when they turn 18. And every year we have one or two parents that contact us during the last term saying: "Surely my kid can stay in school until he turns 21?" So, they don't remember the information* (S1).

> *We also include a list of protected workshops. Parents don't keep those lists. Often, at the age of 18, or 19/20 years, when the child has already left school, the parents say: "You never told us where the child could possibly work – what is a protected workshop?"* (S1).

Gerdes et al. (2020) explored the family-school partnership in a secondary school context. Although the context is different from the special needs education context of this study, important similarities were found in the challenges experienced while trying to make the partnership work. These authors found that a transfer of information is no guarantee of adequate action on the side of the parents. Information can be confusing, misunderstood or ignored altogether, especially if the parents are continuously at the receiving end of a one-way stream of information (Gerdes et al., 2020). This study found that parents' meetings were often not perceived to be very useful by the parents and that most parents perceived the school as a distant, impersonal entity, creating an us-them situation. Parents sometimes had trust issues related to school staff and felt that their voices were not heard when it came to decision making (Gerdes et al., 2020). Echoing this observation, P5, one of the ALS members, confirmed that parents tend to develop trust issues towards service providers, including schools. Unfortunate experiences in the context of the long-term treatment of their child with SID contributes to this mistrust:

> *It's difficult for our parents to trust. Even if we talk to them, even if we walk with them – ahm – during this transition plan, it's difficult for them to trust. Because – they have a looong background of disappointments, of hearing worst-case scenarios, and then things turning out differently. They've been talking to professionals from when their kid was young, where the doctor would, for example, say that – your child will never even walk, and then the child starts walking. Then, ahm, you get to therapists, teachers being harsh, negative about – ahm – your hopes, the parent's hopes and dreams, you get a lot of inconsistent information throughout the years, as the child develops. And that makes it difficult for parents to trust.*

Participant 5 also warned that relationship issues with individuals on the staff could colour the parent-school partnership:

> *The parents might like Teacher X in the Stimulation Phase, but then have a very difficult year in, for instance, the Intermediate Phase, or Grade 2 or Grade 3. They may really struggle with those teachers. And then – the next year might be great, so – they go through very inconsistent phases with their kids.*

The trust issue is an indication that the family-school relationship, as foundation for a successful partnership, is a sensitive and complicated one. In the South African context, there seems to be an array of reasons for the challenges experienced in this partnership.

6.2.2 *Why* are these challenges experienced in this partnership?

Participant 6, who stays in a rural settlement himself, had several answers to the 'why' question, based on years of experience and interactions with parents of learners with SID living in South African townships or rural settlements. Since the challenges of these parents, who are the vast majority in the school under study, often remain unheard and unseen, I decided to highlight these specific issues in this discussion. Participant 6 identified factors within the microsystem (the family itself), the mesosystem (where interactions between the family and the school take place), the exosystem (where societal influences play a role) and the macrosystem (where beliefs, values and norms influence the actions of the family).

With regard to the familial microsystem, P6 identified the breakdown of familial structures and resulting single parenthood as an important reason for parental non-involvement in school matters:

> *These parents have limited time or no time at all to take part in schooling matters. They are the only breadwinners in the house, mostly they commute long hours to and from their place of work, some are hostel dwellers and some stay in their place of work. So, there is no immediate contact with their children or their caregivers. And then – information and communication are always broken*.

Psychological issues prove to be another inter-familial factor at the root of parental non-involvement. Participant P7 reported a tendency in parents to lose hope and therefore fail to see the sense of participation in any transition planning:

> *Some parents reach a state of hopelessness due to the future prospects of a SID learner.*

To this observation, P5 added that all parents of learners with SID need to work through the cycles of grief continuously:

> *Our parents go through a grief cycle continuously, whether they are in denial, angry, feeling depressed or helpless, or they are at a place of acceptance. And – uhm – this is truly an ongoing process. Because every time something negative happens, they – uh – a new milestone is supposed to be reached, they go through the whole grief cycle again. And it's such an ongoing, difficult process, that we must work with our parents with understanding.*

Fernández-Ávalos et al. (2020) conducted a study about feelings of loss and grief in parent-caregivers of adults with intellectual disability. These authors found that the grief process was complicated by the workload and stress of the constant caregiving. This affects their physical, social and emotional wellbeing.

Fears about the future of their children can be so severe that they avoid thinking about it and do not search for solutions (Fernández-Ávalos et al., 2020). This avoidance, which may be a form of denial, may be the reason for parents not wanting to face the prospect of their children having to leave school and enter adult life, a tendency that several participants thought to be irresponsible carelessness.

In the family-school mesosystem, P6 identified several reasons for the apparent non-participation or passivity of parents, one being that children in poverty-stricken households may seldom see their parents, as men and women work away from home in cities, on mines, in factories or as domestic workers, an observation confirmed by Ebersöhn (2017). These children are often in the care of grandparents, who have low levels of education and are functionally illiterate. Grandparents (or parents) who cannot read well, feel confused and overwhelmed when they receive school communication or home tasks that they cannot comprehend. They prefer to opt out of situations where they are required to participate in decisions about the learner's education:

> *Less educated parents feel comfortable to depend on those they perceive better off than themselves, due to social and occupational class. These parents opt to shy away, opt not to participate…* (P6)

Language barriers may also stand in the way of effective communication, participation in school meetings or retention of information shared at such meetings:

> *It's difficult to express your views or feelings in a language other than your own* (P6)*.*

Participant 6 correctly observed that the roots of the challenges within the micro- and family-school mesosystems often lie much deeper, or should one say wider – in the exosystem or surrounding community. The very social fabric of rural or impoverished communities may become compromised due the many associated challenges of poverty. Dashiff et al. (2009) found that poor neighbourhoods are characterised by inadequate housing, substandard schools, social disorganisation and high rates of adult unemployment. This is no different in South Africa. Ebersöhn (2017) described challenges in remote impoverished settings, such as a lack of essential public services (water and electricity), excessive distances to schools and health services, expensive public transport and poorly maintained gravel roads. Taverns become places where substance abuse and violence co-exist (Ebersöhn, 2017). Participant 6 cited substance abuse as a reason for the deterioration of family structures and the diminished ability of parents to conduct responsible parenting:

Due to high levels of addiction to alcohol, some parents can't cope with the demands of building stable family and schooling systems around the challenged learner.

Participant 6 was critical of young parents who, according to his observations, tended to break away from the traditional communal structures and have become dependent on 'handouts':

The young crop of parents in rural communities are most compromised here. They've quickly developed a dependency syndrome to the government's social grant system or handouts. Therefore, they fail to participate in collaborative structures among the community.

The macrosystem, which refers to the system of values and beliefs surrounding the individual, may have a profound influence on the family and its ability to participate fully in the family-school mesosystem. The experiences of the mother of one of the selected learners, M2, is a case in point. She was chased away from her mother's home, where she fled in the first place to escape an abusive husband. The reason for this is that she refused to participate in rituals that the extended family wanted to execute to appease the forefathers, since they believed that her son's disability was a form of punishment that would bring bad luck to the rest of the family. Participant 6 could name three direct consequences of this belief system: breakdown of the family support system, lack of proper medical treatment and hopelessness or depression:

And then, on how this belief stands as a barrier to parents with a disabled child, I've got three points here. It alienates families. A disabled child needs a broad support structure of immediate and extended family members and various community structures. So, if there is this belief you find that those structures are broken down, so the immediate caregiver of the disabled learner is so alienated. Number two, it delays the researched medical or therapeutic interventions because it may take a long time before the required process of treatment is followed due to faulty ritual processes that the family chooses to follow. And then, number three, it brings despondency. Families and stakeholders participating in such rituals may conclude that there is no life for a disabled child because of the power of curses or spells cast on the child before birth, or after birth.

Figure 6.1 summarises the breakdown of the family-school partnership due to a range of challenges. The inner circle represents the view that the school often holds of parents that do not participate well in school matters, as opposed to the parental perceptions and emotions on the other hand. These stakeholders do not see the challenges represented in the next layer of the figure, which cause the behaviour or attitudes observed in the inner circle. The third layer of the figure refers to deeper causal factors, such as societal ills on the part of the parents and the role of the DBE that influence the actions of school staff.

The outer layer of the figure represents system failures and religious and cultural bias in the exosystem that may have an influence on either the parents or the school.

BREAKDOWN OF THE FAMILY-SCHOOL PARTNERSHIP

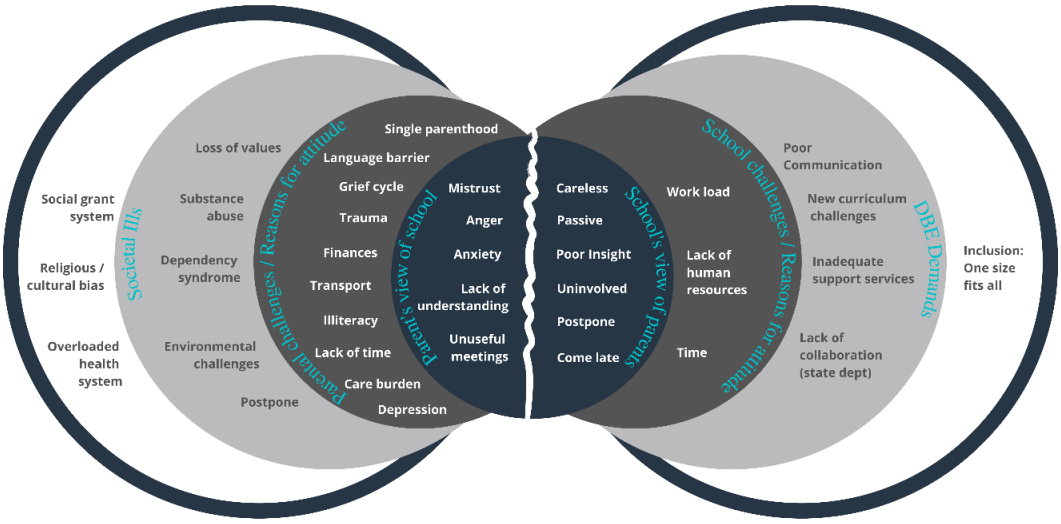


Figure 6.1: Breakdown of the family-school partnership: Causal layers

Since critical realism is the philosophical paradigm of this study, this figure attempts to depict the stratified reality of challenges in the family-school partnership. The empirical level represents objects or events that can be observed or experienced, such as those in the inner circle of the figure. The ideas or opinions of stakeholders are part of this level. The actual level are events that occur that we do not necessarily observe, such as those events in the second layers of the figure. The school does not observe the challenges in the parents' lives that cause their behaviour attitudes and vice versa. The last two levels represent the realm of the real, where causal mechanisms are represented (Fletcher, 2017).

Having identified challenges in the family-school partnership in the South African context, and reasons for these, it is vital to use this knowledge to look for solutions to make the partnership work better, since parental involvement is one predictor of post-school success (Morningstar & Mazzotti, 2014). Parental involvement is crucial in all aspects of the transition process: decision making, the provision of support, attendance of meetings and advocating for their child (Rowe et al., 2013). It can thus be argued that the school, as a facilitator in this partnership, needs to not only know the child and their challenges and support needs, but should also be sensitive to the challenges and needs of the family. Staff members need to go the extra mile to ensure parental involvement. Therefore, the next point under discussion will be the 'how' question: How the school partner could do better to make the family-school partnership work during transition.

6.2.3 How can the school better facilitate the family-school partnership?

Data of this study has shown that the family-school partnership is a challenging one where learners with SID are involved. If there is mistrust, a power imbalance and a lack of respect, any efforts from the school's side to facilitate partnerships with community stakeholders are doomed to failure since the parents will not be driven to take the process forward. The notion of parental empowerment requires a paradigm shift on the side of most schools. School staff often work hard and try their utmost to involve parents, but in the process, may not realise what implicit messages they send with the way they conduct parent meetings. Here is how S1's efficiently organised transition interviews with parents went down:

> *We ran four groups simultaneously. This year – last year – we did it in the hall. We prepared tables in four different corners of the hall for the different groups where parents could have conversations with us, the secretary manned the entrance hall, where the parents who came a little early could wait, and then they would immediately tell us if a next group had arrived. Uhm – the interviews usually took about 20 to 30 minutes, with a 15-minute period in between where one could quickly check what we had typed, check the language, and in case some parents talked a little longer, it wouldn't keep up the next interview* (S1).

The ALS discussed the scenario, and had the following points of concern:

- There was no real privacy, since four groups met simultaneously in one setting.
- The time (about 20 minutes) was too short for the parents to share anything important. It is much more likely that the interviews turned out to be a one-way information-sharing session from the staff's side.
- Parents were probably intimidated by the setting and manner of organisation and made to feel overwhelmed by the amount of information shared in a short time.

This kind of parent meeting may contribute to the power imbalance experienced by many parents, some already feeling unsure (being illiterate and possibly not so fluent in English). As P7 put it:

> *I think parents often think they cannot contribute, they sometimes think the – the school and everybody should do everything and they know everything…*

Participant P6 stressed that an attitude change should be the starting point:

> *I think, mostly the changing of mindset. Mutual respect is number one, encourage participation is number two, provide decision-making opportunity is number three.*

Piškur et al. (2012) stress the need for family-centred services, where the family is seen as an expert on the child's abilities and needs, and the professionals work in partnership with the family. What is needed is an attitude change where the two partners regard each other with respect, make joint decisions to the benefit of the young adult and participate equally well in the execution of the plans that have been decided upon.

Equality, positive communication, respect and trust are four of the aspects present in a partnership, according to Summers (2005). To be co-workers or partners in a partnership, a certain level of equality is needed, yet clearly a parent who is, for instance, illiterate, will not have the professional knowledge or expertise of a trained teacher. Gerdes et al. (2020) identified three levels of equality in the family-school partnership: equal access to resources, recognition of expertise and acknowledgement of authority. *Equal access to resources* refers to the fact that the parent needs to have all the available information to make an informed decision. This means that the teacher needs to go the extra mile to explain the relevant information in a way that the parent understands (have a translator if needed or ensure that a literate family member is present who can keep the necessary documentation safe). *Recognition of expertise* means that each party (the parent and the teacher) needs to recognise the other party's knowledge of, and experience with the learner under discussion. The third aspect of equality, according to Gerdes et al. (2020), is the *acknowledgement of authority*. This means that there should be shared authority to make decisions about the learner's future path, in this case, the transition plan (Gerdes et al., 2020).

Participant 6 put the issue of parental expertise regarding their child as follows:

> *I think they should be made aware of the fact that they have a lot of expertise as parents themselves, and – like somebody also said, nobody knows the child better than the parent.*

He stressed the issues of shared goal setting, decision making and teamwork as follows:

> *…we must all just be better aligned, aligning ourselves to the goal, but these goals – it's not a goal from the school, it's a goal from a team of people – uhm – that drives this transition process, otherwise they're gonna think they must just fall into what the school, or whatever committee that they're not part of, are gonna decide, and they may not uhm – be very – uhm – extremely anxious to be part of it. We should persuade them that – that teamwork is the only option that can make the dream work, kind of thing* (P6).

Participant 6 was passionate about the fact that the power imbalance should be addressed by making the parents feel valued, not glossed over or treated like minors:

> *No matter who they are, where they work, what their education level is, what their background is, this is really, really important. So, they must feel – also they must feel ah – they are highly valued at the end of the day, and they must also know that we all learn from one another, so I think for me, the transition process will be a work in progress, it's gonna be a dynamic thing.*

Participant 5 stressed the need for individual, unhurried parental interviews, where a safe space is created for parents to share sensitive information and personal fears.

> *Sometimes parents feel safer to speak on a one-on-one basis. I mean, our children sometimes struggle with sensitive issues, whether it be parents hiding the child because of inappropriate acts of a sexual nature – they won't ever bring out these things, or these – their concerns in a group – no parent will do that. And ah – I think there's a place for group discussions, and I think there's a place for individual interviews.*

Participant 5 believed that it is during such individual support sessions that trust is built, which is again a good basis for collaboration in a family-school partnership. The ALS concluded that the equality principle has some similarities with the dignity theme (Chapter 5), acknowledging the parent's dignity as an equal partner, and may enhance the parent's emotional capacity to advocate for the young adolescent with SID, to share their challenges and needs so that better decisions may be made in their best interest.

During ALS discussions, P7 continually stressed the need to empower parents, to enable them to play their rightful role in the decision-making process regarding their child with SID:

> *We should focus on – to empower the parents with knowledge and skills. I think parents can be really empowered and even motivated through workshops and information sessions and stuff like that – uhm – they can – I don't think it should just be a meeting where people are told 'this is the process', uhm, the process must be developed with their inputs, not just inputs, involvement, physical, direct involvement of the parents.*

Participant 7 viewed parental empowerment as a venture going beyond individual families and their needs. He believed that parents should be involved in "the platform, or a committee, or a body, or whatever you will call it, that drives this transition process" and that strong, dynamic parent members should be the drivers of some organisational issues regarding the school's transition planning:

> *I think champion parents – driver parents – must be identified, you must first identify parents like this and get their support, and I think, to inspire them, they must also be trained, ahm – and then they can influence and convince other parents.*

Despite the fact that school staff ALS members were a little sceptical of parents' attendance of such workshops and their capacity to take the lead in transition planning, P6 insisted that parents *do* need to take ownership of the process, even on a managerial level, that the workshops should be different in the sense that they should not only be one-way information sessions, but that parents should be inspired and motivated and that all parents needed to feel included:

> *…if you can get an expert that can talk to the parents, and really give them some technicalities around this thing, and sort of almost like, also, a motivational talk to get them involved, and really geared up for the thing. It's not a one fits all and one person knows all, kind of thing, uhm – the transition team is really, really a partnership, what will recognise the interest of the different participants, not I'm specifically talking about the parents. And – relating to their background, their language, their socio-economic background, their levels of education, their race, and so forth. So, they should really feel included. Maybe one thing that you need to promote, is to highlight to parents, and to other partners, the success stories of these other institutions or schools …*

In this context, Nachshen (2005) cites the Cornell Empowerment Group (1989, p. 2), who define empowerment as "an intentional, ongoing process through which people lacking an equal share of valued resources gain greater access to and control over those resources". Nachshen (2005) explains that empowerment takes place at three levels. Community empowerment is the broadest level, and involves the actions taken by a group of people to improve life (in this case, the life of young adults with SID) in a community. Organisational empowerment, the second level, involves goal-directed actions by members of an organisation (such as the transition forum P7 would like to see). At the individual level, psychological empowerment results in better control over one's environment (the immediate physical and social environment of the family) through proactive action or advocacy (Nachshen, 2005). Again, the ALS deduced that parental empowerment seems to have the potential to lead to the empowerment of the young adolescent with SID, since being better armed with knowledge and skills and being more in control of the transition process can only enhance the parent's ability to empower their young adolescent with SID during the transition process.

6.3 FOSTERING LINKAGES WITH COMMUNITY STAKEHOLDERS TO CREATE FAMILY-SCHOOL-COMMUNITY PARTNERSHIPS

The transition period can be described as the developmental period that bridges the end of adolescence and the beginning of young adulthood (Lowe & Dotterer, 2018).

It is a multidimensional process that includes seeking employment, establishing adult relationship, working towards social and community participation, and gaining more independence (Pallisera et al., 2014). At the same time, it is a traumatic period for the young adult, as well as the family, since transition inevitably results in the loss of friendships, known support systems and valued relationships (Pallisera et al., 2014). The best way to reduce the trauma and facilitate inclusion in the relevant new ecological system is through coordinated support at different levels, which requires partnering with different professionals and other community stakeholders, the links having been fostered by means of teamwork between the school and the family during the transition period (Pallisera et al., 2014). Fostering such partnerships in a social ecology, where a lot of bias still exists regarding individuals with intellectual disability, is no easy task. As I did before when focusing on the family-school partnership, I will focus on the 'what', 'why' and 'how' questions to frame the discussion. Because it is difficult to separate the 'what' and 'why' questions in this discussion, I will combine them, after which I will address the 'how' question.

6.3.1 What are the challenges experienced in fostering post-school partnerships with community stakeholders in the South African ecology and why are these challenges experienced?

The ALS identified four core challenges in the South African ecology that are barriers to sustainable job placement, social inclusion, service provision to individuals with multiple disabilities and quality of life.

These are the following:

- The post-school support gap
- Challenges with public disability awareness and stigma
- Challenges with policy implementation and government departments
- Inadequate, but expensive service rendered by some workshops

The support gap after school is partly due to the difficulties parents experience to render sustained support after school and partly to insufficient availability of vocational rehabilitation specialists. This challenge will be discussed first.

6.3.1.1 The post-school support gap

The ALS found that parents, who are expected to continue to build partnerships with stakeholders with which the school has linked them, seldom have the capacity to do so.

FM 1 observed that parental interactions with employers may even harm the partnership in some cases:

> *I must say, many of the places did not want anything to do with the parents. I can understand that, because here and there, parents tended to create a bit of drama, you know – it was just – it was not healthy or good for anyone. Also, the other problem was, as soon as some parents became involved, the young adults would revert back to that childish mode.*

Yet, the school staff needs to withdraw from the after-school support since they need to prioritise the school's learners. Participant 1 reported that, where the school-employer partnership ended, the parents were often unable to follow through:

> *The thing is – the follow-up, support afterwards. Uhm – we had one occupational therapist. Our teacher could not zoom in all the time after the learner had left school. So, it depended a lot on the parents, parents had to zoom in and stay in contact with the employer on their own, and that was the problem, many of the excellent job opportunities we found for the children were lost; fell flat. There was insufficient manpower from the school's side to keep things running, because the school had to zoom in on its learners* (P1).

Participant 5 warned that expecting the school therapists to manage the transition planning and execution may be a challenge, since these therapists have other duties as well:

> *For me as a therapist to get to real in-depth preparation for them to leave school, and then, working with all the other children – uhm – that have behaviour issues, that have medication to sort – different things, that we still do every day to help the teacher cope – whatever our role entails. We need to be realistic, it's not as if the government will be giving us ten more therapists because we are developing a transition plan.*

It is clear, therefore, that the first major challenge is a post-school support gap. According to the participants of this study (such as P1), sustained employment for people with SID is only viable with sustained support. Wehman et al. (2012, p. 139) quote the definition of supported employment, as viewed in the United States, as follows: "Competitive employment in an integrated setting with ongoing support services for individuals with the most severe disabilities". This means that an individual with SID is placed in the open labour market according to their work preferences and strengths and then supported for as long as is needed to transition to independence in the workplace.

Wehman et al. (2012) view this approach as superior to the attendance of protected workshops in terms of outcomes and cost. However, workplaces are public spaces where individuals with SID are exposed to members of the public who may not be very comfortable with these 'different' young people.

6.3.1.2 Challenges with inadequate public disability awareness and stigma

Participants of this study experienced that community stakeholders, such as members of the public in public spaces, are often uninformed about young adolescents with intellectual disability and tend to display biased attitudes. F3, who had to put up with the bias of the public towards the employees of her coffee shop, who were all individuals with disabilities, said:

> *…there's* so *many stigmas – people think for instance that – ah – all autistic kids hit stuff, or scream, or drool, or that type of stuff.*

Since intellectual disability is often 'invisible' – not necessarily noticeable in the person's physical features – people did not realise that these people had challenges to overcome. Clients of the coffee shop would display impatience, and were even rude at times:

> *They for instance only looked, oh – OK, that person's got Down Syndrome, so probably the only person that has a disability. They didn't think of autism, they didn't think of foetal alcohol syndrome, they didn't think of – just – people having learning disabilities or low IQs, because a lot of times you can't really see that on the outside, so then according to them, they don't have a disability – ahm – and then they would treat them differently than young adults with Down Syndrome for instance, because, with them you can actually see that there is a disability. So, in the beginning that was, that was really hard – that people didn't understand, or didn't want to understand – ahhhm – I mean, we've had customers ah – walking in, and then saying, oh, why is your service so slow – ahm – even though it's not slow, ahm, not slow at all* (F3).

Mitter and Scior (2018) define 'stigma' as a type of social disgrace in which the individual is discredited based on certain attributes, for example disability or drug use. These authors identify four forms of stigma: public stigma, which refers to the attitudes held by society about the individual; institutional stigma, which involves policies that reduce the choice of the person; self-stigma, which takes place when the person not only accepts, but also internalises the public stigma; and family stigma or associated stigma, where family members or caregivers internalise the stigma. With stigma rife in the South African community, this is a serious barrier towards forging community partnerships.

Even though public stigma still exists, one could reason that at least the country has good disability policies that could be utilised as a framework for solid community partnerships. However, the ALS found challenges with policies and government departments, which will be discussed next.

6.3.1.3 Challenges with policy implementation and government departments

Participant 7 made it his mission, as an ALS member, to study all the policy documentation currently in use in South Africa, and this was his conclusion:

> *There's a lot focused on, say, blind people, deaf people and autism, and it's great, I think it should be there, but there's very little focus – uhmm – and policy implementation, things driven for the – the intellectually disabled, I think there's a lot of room for improvement there. They just don't feature remotely where they should feature in terms of being supported and being part of a system.*

Having looked for possible support from government departments, participants found that each government department was focused on a different aspect of the post-school needs of the person with an intellectual disability and that more collaboration was needed for a coordinated support effort. S3 observed challenges regarding post-school support from government departments:

> *And the problem is going to be, who takes responsibility? Because actually, it should be the Department of Social Development. And – it's a good idea to say, let's use a community service occupational therapist. But – they work for the Department of Health. And (laughs) they don't like to work across departments. I think social workers can also make good case workers, but then – that transition from the Department of Education to the Department of Social Development – I think that – that's the flop. That's where we drop the baton. Because before 18, everybody says – sorry – it's the Department of Education's problem. After 18 – sorry – Department of Social Development. Can't – sorry. And so – we have young people without assistive devices, young people who haven't been placed appropriately, because there's a lack of collaboration.*

Abdullah et al. (2015) described inter-agency collaboration as the development, coordination and implementation of a transition programme by a team consisting of different stakeholders, such as parents, school representatives and representatives of agencies outside the school. These authors found that an absence of inter-agency collaboration is an important reason for support gaps. It is clear then, that a lot of work is still needed in the realm of supported employment in the open labour market. However, workshops, which are still viewed as ideal transition destinations in the South African context, have been around for decades. The ALS investigated the quality of service and prices of some of these workshops and found some disappointing results.

6.3.1.4 Workshops that render inadequate but expensive service

Protected workshops, some of which are, in effect, care centres, with little evidence of meaningful work being done, are to a great extent the only transition destination of most

young adults with SID (Wehman et al., 2012). This is no different in South Africa. Two of the ALS members, P5 and P3, visited a workshop that caters exclusively for young adults with autism spectrum disorders. Since one of the selected learners in the study has autism, the team needed to investigate the possibility of referring his parents to this workshop. This is what P5 reported afterwards:

> *I felt that the place and programme were working with a 'one size fits all' approach, which is entirely inappropriate with such unique individuals. Everybody was busy with the same thing (they were paging through magazines). It looked more like they were being 'kept busy', not like goal-directed and meaningful work. There were no adaptations for communication, no visual schedules or daily programmes. Nothing that gave the place a homey feel, such as photos or something pretty against the wall. No resident was busy with an individualised programme. It did not seem as if the residents were grouped according to ability. The areas were not adapted to accommodate autism or any other disability, for example the kitchen was small and cramped, no signs that it was being used, except for the basin. Areas weren't clearly marked. There were stairways inside and uneven surfaces outside that could be dangerous for older individuals or individuals with physical disabilities. I felt that the cost (R6 500 per month) was far too high for what they seem to offer.*

Foskett (2014) provides a comprehensive history of the care provision for people with intellectual disability in South Africa. This author reports that, in 2012, the Department of Social Development subsidised 293 protective workshops across the country. The aim was to work on skills development and entrepreneurship. Some of these protective workshops have partnerships with private companies (Foskett, 2014). These are good developments, but the country still has a long way to go. Some protected workshops, such as the one described by the ALS members above, end up being places of safety where attendees are 'kept busy', as P5 reported. Residential facilities in South Africa are situated in isolated locations, housing the residents away from the community in which they grew up. This is contrary to international best practice, which advocates for social inclusion (Foskett, 2013). A study by McKenzie et al. in 2012 (McKenzie et al., 2014) investigated 37 residential care facilities in the Western Cape and found that many of these homes provide little in the way of education and training. There was little emphasis on developing the residents' competence and improving their quality of life.

For example, residents did not undertake any housekeeping chores and did not integrate into the community (McKenzie et al., 2013). This situation is contrary to all three themes identified in this study: dignity, empowerment and inclusion. The ALS wished to see the learners of the school under study transition to a better quality of life.

The next point under discussion, then, is the 'how' question: How can we do better in terms of parent-school-community partnerships and, in doing that, better support our young adolescents with intellectual disabilities?

6.3.2 How can parent-school-community partnerships be improved to provide better transition support for young adults with intellectual disability?

Since the school needs to withdraw from the partnership at some point after the transition process, it is important to facilitate the family towards support measures that can make the transition outcomes realistically sustainable. In this section, some of the potential support measures that emerged from the ALS discussions will be covered.

These are the following:

- Parental support, in the shape of community support nets
- The role of the job coach in supported employment
- Suggestions on how to work on awareness creation and inclusivity in public spaces
- The need to prioritise independence skills and participation
- The utilisation of disability policies and legislation while remaining realistic about government's ability to make a practical difference.

6.3.2.1 Facilitating parent support nets

In the family circle, the microsystem where the primary support of the learner with SID needs to originate, there is a host of challenges that may threaten family wellness, as pointed out by P6. Family wellness should be prioritised to ensure that the parent is empowered to act as a strong and responsible partner in all transition partnerships (Kim & Turnbull, 2004). To this end, a deep understanding of the challenges and needs of the family surrounding the learner with SID could contribute to better support of these parents and thereby enable the participation of adolescents with SID (Piškur et al., 2012).

Participant 5 suggested that, during individual interviews, parents should be encouraged to link up with friends and family to build a support net that could render support with matters such as transport, respite care, emotional support and practical help during medical emergencies.

These measures could lighten the load of the parent, relieve their stress, and give them hope. Some of the parents of the selected learners reported how valuable such support measures were:

> *For example, if I have to go to town, I can't take A with me, our bus has broken down. So, I can't take A, then she says, 'Don't worry, I'll look after her'* (M1).

> *She's very caring, if I tell her, come and see A's foot, she will enquire every day, asking 'How is she today? Is there anything I can do?'* (M1).

> *My younger sister is having a car. When he has a seizure, I call my younger sister, and then she will come and pick us up* (M2).

Participant 6 suggested that a good place to start would be to facilitate parent support groups:

> *Partnerships and collaboration should be encouraged to start in small trickles. For example, parents in the same age, or parents of children with the same condition forming support buddies.*

Van der Mark et al. (2019) conducted a study about the daily realities of mothers of children with disabilities in a South African urban settlement, Khayalitsha. They found that these mothers tended to bear the responsibility of care alone and would become quite isolated in their own small world. They suggested that the first step would be to build a trusting relationship with such a parent and then one should convince them to become involved in peer support groups, as well as community and professional services. Phasha et al. (2017, p. 5) refer to inclusion as meaning that "we all belong" and that every citizen should ensure "that mutual interdependence is respected as an ideal and a virtue". These authors suggest that opportunities should be created for parents, families and cultural custodians to complement the work of professionally trained educators. Social interdependence and community support are principles that tie in with the concept of Ubuntu, which literally means 'humanness' and refers to the African value of respect for others and communal interdependence: "A person is a person through other persons" (Eide & Ingstadt, 2011, p. 102).

It is through making use of linkages suggested by people in the family's extended family or circle of close friends that one often manages to secure sustainable employment for these individuals, since such an employer is usually prepared to go the extra mile. Participant 3 shared the following story:

> *In my experience, it's usually someone the family knows that is prepared to give the young adult a chance, it rarely happens that an employer will just take on an unknown person with a disability. For example: Learner A went for horse-riding lessons, and she loved spending extra hours there on Saturdays. The parents then went to speak to the stable owner and asked whether she could work there daily. They arranged that the parents would provide her Sassa grant as a 'salary', just for her to gain experience. The stable owner was fine with that.*

Making use of an employer close to where the family lives is also much more practical. Participant 1 shared how, at his previous school, they used to help hostel dwellers to find employment in their hometown:

> *There were many learners in the hostel – a child from a remote town, we contacted the parents, asked them for the number of the Spar owner, or the number of a panel beater, or a car dealer, or whatever, in that community, then we contacted them from the school's side. It took a lot of effort from that staff member, but she was very dedicated. We still have – I still know of learners who work at panel beaters in their hometown. So, it was vital to support the parents – to help them do job hunting in the hometown.*

Finding a job with the help of the school, family and friends is only half of the challenge. The most important challenge is to *keep* the job. Sustained after-school support seems to be a key issue. Wehman et al. (2012) stresses that job placement successes can be directly attributed to the day-to-day support and help of job coaches and other employment specialists.

6.3.2.2 Utilising a job coach to fill the support gap

Participant FM 3, who ran a post-school programme, reported that one young man with Down Syndrome managed to find and keep a job. The main factor in his success was good support, not only from his parents, but also from a job coach:

> *He works in an – ahm – engineering company, he's their technical assistant, and he's been there for 11 years. His mom was a huge support in helping him – after school, helped and worked towards independence, uhm – I think she – she knew the owner, and then, he did have a job coach, who went in and did job task analysis, and then went and followed up when there were any challenges.*

An important step in job placement is to link up with the employer, who might be hesitant to take a person with intellectual disability into service. Foskett (2014) cites some reasons for employer hesitancy to employ people with SID. They have no skills to manage them, think that people with disabilities cannot do what others can do, think that people with disabilities may injure themselves or others, and think that it is costly to employ them (Foskett, 2014). A workplace visit is therefore essential before placement. Not only is it necessary to assess the work environment to see whether it is suitable for the specific person one has in mind, but the school representative also needs to put the employer's mind at ease. Participant F1 explained how to reach out to the employer:

> *You first need to explain the process, how it's going to work, indemnity form and so on – you make them feel very comfortable. And you try to explain what an incredible opportunity this would be. That it won't cost them anything. That a facilitator will accompany the individual in the beginning – you know, until they*

feel comfortable. Just to ensure that you don't cause extra stress for them and that they are in a space of 'I can'. So that they really feel they are making a huge difference in that individual's life.

Regular follow-up is essential after job placement. This became evident after two of the selected learners had been placed in potential workplaces.

Some of the issues that needed to be solved early on were the following:

- Social blunders that learners made, such as failing to greet clients appropriately
- Work-related skills, such as remembering and executing tasks
- The need to set up visual supports, such as a visual schedule
- Dressing appropriately
- Being productive and thorough enough when carrying out tasks
- Challenges with emotional regulation: Having had an emotionally distressing day, one young adult was unable to function in the workplace the next day. The employer could contact the therapist who acted as job coach. She could sort out the cause of the distress by talking to the parents (P4, research diary).

Wehman et al. (2012) recommend the use of a professional vocational rehabilitation specialist as a job coach. These authors describe an array of supports that such a specialist typically provides, ranging from job seeking (the identification of the person's abilities, vocational interests and preferences), job development services and linking up with employers to seek appropriate positions. A job coach also commits to long-term support services. Once the young adult has become stabilised on the job, the specialist continues to provide regular contacts to provide support (Wehman et al., 2012). In South Africa, however, it is a challenge to find a sustainable and affordable solution for the need to have post-school job coaches other than school staff. Participant 4 investigated possible stakeholders that could provide trained job coaches for people with SID, but could not find any formal service providers in the private sector who offered such services in the city in which the school was situated, nor was the funding of job coaches a support measure that the Department of Labour was able to provide. The ALS discussed several possible solutions, such as making use of retired staff members, who will then be signed up for vocational rehabilitation training. Making use of occupational therapy students from the local university was another possible solution that could be pursued.

6.3.2.3 Promoting more inclusive public attitudes and enhancing community living and independence skills during and after transition

The ALS members agreed that they would like to witness our communities becoming more inclusive. However, several participants stressed that isolation leads to social exclusion. Participants stressed that people working in or attending public spaces can only learn to act in a more appropriate and inclusive manner if they *meet* people with intellectual disabilities and their families, and receive guidance by stakeholders in the field, such as the families themselves, or school staff. To this end, schools and families need to break the isolation and take young people with SID into public spaces. Participant 3 suggested outings to public spaces to enhance community living skills. She gave several examples, for instance fitting on clothes in a retail clothing store, doing grocery shopping for the weekly baking, taking a trip on the Gautrain and going to a fast-food restaurant. I cite her example of a visit to the fast-food restaurant:

> *We also liked going to Wimpy to eat a Wimpy breakfast. The learner was expected to indicate independently how they would like the eggs, if he would like white or brown bread, coffee or juice and so on. We requested the parents to do something similar, maybe once a month. I sometimes took them to McDonald's, each learner ordered their own milkshake. Those that weren't verbal, or who had speech difficulties, made use of PECS – a picture exchange communication system, where the learner indicates his choice by means of a picture or a sentence strip. I went to the place beforehand, to explain to the staff that I was going to come with the learners, and that some of them were non-verbal, and that they just needed to be patient and look carefully what the learner indicated.*

Exposure to and participation in community activities in public spaces enhance social inclusion (Pišcur et al., 2012). Wilton et al. (2016) found that shopping as a social practice presented the individual with an intellectual disability with an opportunity to feel more socially connected. Choosing shopping items and paying for them is an enactment of autonomy (Wilton et al., 2016). Autonomy can be enhanced by learning appropriate independence skills during the transition period. Piškur et al. (2012, p. 139) cite the International Coaching Federation (ICF), who define the concept 'participation' as "a person's involvement in life situations". This may include everyday community-based activities such as shopping, leisure activities, household activities and social engagements in different contexts. According to Piškur et al. (2012), participation relates to wellbeing and quality of life. The ALS studied the current Life Skills curriculum prescribed for learners with SID at the school under study. Examples of independence skills in the curriculum that need to be acquired with the collaboration of the parents are doing laundry, serving simple meals, dressing appropriately,

drawing up a simple budget and using a bank card. The ALS members agreed that these skills need to be prioritised and practiced in real-life settings during the transition period.

However, what purpose would it serve to do all this work on social participation and independence if a young adolescent is going to spend their days in the secluded setting of a protected workshop? The ALS members agreed that they needed to take a good look at the skills set and approach of some of the protected workshops. A possible antidote for the current challenges in protected workshop settings, as discussed earlier, could be the notion of active support. Active support is a practice designed to promote the quality of life of people with intellectual disabilities through engagement in meaningful activity and social relationships (Flynn et al., 2018).

The approach promotes opportunities for people with an intellectual disability to experience a life as close as possible to the life of people without an intellectual disability. According to Flynn et al. (2018), staff members need to make an attitude change from perceiving their role as a caregiver to someone who supports people to lead their own lives. It includes, for instance, identifying an everyday activity, such as making a cup of tea, and training staff to provide just enough assistance to enable the person to participate in the activity. This approach has proved beneficial for care home residents in that their participation improves and depression is diminished (Stancliffe et al., 2011). The person becomes an active participant instead of a passive observer. The approach includes community living skills and exposure to real-life settings.

Coping in real-life settings is much easier if community stakeholders are prepared to go the extra mile to become more disability friendly. Some of the participants felt that public spaces could be guided to prepare better adaptations for people with an intellectual disability:

> *The norm for restaurants and public spaces is usually wheelchair accessibility, adaptations in bathrooms and so forth. But for our population with intellectual disability that is unable to read, no adaptations are available. In my professional opinion as an occupational therapist, I feel that it is important that people with intellectual disabilities should be enabled to order their own food, so I think adapted menus could be a good way to facilitate that. One could adapt menu boards and posters with simple numbers next to the photos so that the person can see that he would like to have number 1, number 2 or number 3, or so that he can point to it* (T1).

Simplican et al. (2015) propose an ecological model of social inclusion that includes individual, interpersonal, organisational, community and socio-political factors. Where public attitudes often still display bias, the ALS proceeded to look at policy and legislation

that govern public spaces and places of employment to see whether government departments could act as transition partners in the transition process.

6.3.2.4 Knowing disability legislation and rights but avoiding over-dependence on government

At face value, the South African government seems to have made adequate provision for the protection of disability rights by means of legislation and policies. Neille (2020) calls the South African Constitution (South Africa, 1996a) one of the most inclusive constitutions in the world. The South African Bill of Rights mandates the right to non-discrimination, education, information, safety and housing. In addition, the South African government has established a Ministry on Women, Children and People with Disabilities. Furthermore, it has adopted a White Paper on an Integrated National Disability Strategy (Office of the Deputy President, 1997). People with disabilities are eligible for monthly disability grants, provided they have proof of South African citizenship and undergo various medical assessments, according to the Social Assistance Act (South Africa, 2004). Knowledge of these policies and the rights of people with disabilities under the Constitution may be of infinite value when advocating for social inclusion. However, although these laws and policies are based on sound principles, many of them refer to people with disabilities as a homogenous group (Nuwugaba & Rule, 2015). This is creating implementation challenges, with continuous tensions between policy and legislation on the one hand, and practice and resource allocation on the other (Neille, 2020). Participant 7 warned against over-dependence on state departments and stressed that stakeholders in the field of intellectual disability should instead take the initiative to take transition goals forward:

> *We need – we need to find a way where one would depend much less on the state, the state is not going to drive this. The bottom line is, the white papers are there, but they don't even make their targets remotely, so, we need to come with a new proposal, a new system, we need a kind of a forum, where occupational therapists, teachers, employers, all are involved.*

MacLachlan et al. (2017) propose the utilisation of forums of civil society, consisting of women's rights movements and other networks of associations (such as non-profit organisations), which can meet to work on a specific theme, after which they could lobby to be included in meetings and committees of government departments to represent the interests of people with disabilities. Participant 7's suggestion points to something similar: Stakeholders such as disability organisations, therapists, teachers, parents, employers and workshop facilitators could all meet in the spirit of Ubuntu and work together to contribute to more effective transition planning and execution. From there, doors could open to

government departments to work towards better policy implementation and inclusive strategies. This, in turn, should lead to improved quality of life for adults with SID.

6.4 CHAPTER SUMMARY

In this chapter, I report on the investigation conducted by the ALS into ways in which family-school-community partnerships could better meet the needs of young adolescents with severe intellectual disability. The data revealed that an array of challenges may complicate the family-school partnership. These challenges need to be understood and addressed before a viable partnership, based on equality, respect and trust, is possible. Parental empowerment is needed, and parents need to realise that their role in transition planning is vitally important. The school's interactions with parents need to be inclusive and emphatic and should not only consist of one-size-fits-all information sessions. Regarding linkages with community stakeholders, the study concluded that it is particularly important to break parental isolation and facilitate support nets to alleviate parental stress.

The school should initiate partnerships with employers and protected workshops. School staff and other professionals could provide much-needed guidance to employers and workshop facilitators to bring about better participation and employment success. The after-school support gap is an important challenge. Whereas parental support could be extremely valuable, it is rarely sustainable. Expert support in the shape of job coaching is needed. This is a service that is not yet readily available in South Africa.

The aim is to turn the person with SID into an employee that is not just tolerated by the employer, but is pulling their weight to become an asset in the workplace. In public spaces, better awareness creation can be achieved by taking learners with SID on outings that facilitate more frequent public exposure. Such outings would also constitute real-life learning experiences for the acquisition of independence and social skills. Protected work settings need to work towards better independence and social exposure as well, and the active support approach seems to be a good choice.

Public spaces should be encouraged to implement measures to become more disability friendly, a step that could have good marketing value for the business owner and may improve participation and quality of life for people with SID. On the policy front, it seems that the needs of people with intellectual disability are under-represented in policy documents. Various challenges have been found with collaboration between government stakeholders. The chapter concluded with a suggestion of one of the participants to work towards the creation of community-based forums to address sustainable transition planning.

The next chapter is an account of the way in which the ALS worked on the actual transition plans of the five selected learners. These plans were based on the principles that emerged from the data of Cycle 1 and Cycle 2.

CHAPTER 7: DISCUSSION OF CYCLE THREE: IMPLEMENTATION OF THE LEARNER-CENTRED TRANSITION PLANNING: WHAT WORKED, OR DID NOT WORK, AND WHY?

7.1 INTRODUCTION

The previous two chapters provided an account of the research conducted by the ALS to discover the underlying principles that should govern the complicated process of transitioning young adolescents with SID into adult life. In Chapter 5 (a discussion of Cycle 1), I reported on the challenges and resulting support needs of young learners with SID. Three themes emerged: dignity, empowerment and inclusion. In Chapter 6 (a discussion of Cycle 2), I discussed family-school-community partnerships as transition support means and identified various partnership challenges specific to the relevant South African setting that emerged from our enquiry. Possible solutions that emerged from the data were suggested. In Chapter 7, I report on the implementation of the findings of the first two cycles to address the third critical question: *How can the knowledge created by this team enhance sustainable learner-centred transition planning for learners with severe intellectual disability?* The chapter is structured around the following sub-questions related to the critical question:

- What role did learner-centredness play in the attainment of the quality-of-life outcomes in the case studies of the five selected learners?
- What did we learn regarding the roles of different partners in family-school-community partnerships in the context of learner-centred transition planning?
- What would a blueprint for a transition process designed to facilitate maximum learner growth towards adulthood look like?
- What paradigm shifts (if any) have been observed in the minds and actions of key stakeholders regarding transition planning for learners with SID?
- What threats to the sustainability of transition planning have been observed, and how could these threats possibly be addressed?

Due to lack of space, the full case descriptions of the actions with the five selected learners could not be included in this chapter, but are given in Appendix 4.3. It is recommended that the stories be read *first* as an important backdrop to the findings of this chapter.

7.2 THE ROLE OF LEARNER-CENTREDNESS IN THE ATTAINMENT OF QUALITY-OF-LIFE OUTCOMES IN THE CASE STUDIES OF THE FIVE SELECTED LEARNERS

In learner-centred planning, the learner is in the centre of the planning process and their strengths, interests and dreams are central in the determination of the goals of the transition planning (Kotten, 2018). That is why the actions taken in the five case studies were based on each learner's ITP (see the example shown in Appendix 4.2). This plan was based on an individual conversation with the learner. An informal, one-on-one conversation between the therapist and the learner was structured around a picture-based career interest questionnaire, which guided the learner to indicate their preferred choices and interests for adult life. The results of this informal person-centred assessment were complemented by an individual parent interview, after which some of the challenges or support needs of the learner that needed to be addressed came to light. Person-centred planning is closely aligned to the construct of self-determination, which is all about personal choice and self-directedness (cf. section 2.2) and which, in turn, has been shown to enhance quality of life (Wu & Chu, 2012). Collaborative support is key to the facilitation of the learner towards their goals in life (Small et al., 2013). This support should be rendered via the ecologies surrounding the young person with intellectual disability (Epstein, 2019); ecologies where the attitudes of the different stakeholders regarding people with SID might be a major stumbling block (Ambuj & Anna, 2017). During the case studies of the five learners, a balance had to be struck between all the factors mentioned above: self-directed goals, individual challenges, support needs, family-school-community partnerships as support means and goal-directed actions that needed to be undertaken despite attitudinal and other practical barriers.

Table 7.1 illustrates the challenges of the five learners (see section 4.5), the actions taken based on each learner's ITP, collaborative support rendered and outcomes related to quality-of-life theory.

Table 7.1: The five case studies: Challenges, actions taken, collaborative support and outcomes

Code and description of learner	Challenges experienced and reasons for challenges	Core supportive actions (guided by learner-centred ITP)	Collaboration to provide support	Quality-of-life outcomes
L1: Non-verbal female learner with cerebral palsy, wheelchair user, one functional hand	**Disempowerment:** Attitude of 'she can't' on the side of the class teacher and other staff members	**Intervention:** Initiate the making of key holders by utilising her strengths (use of one hand)	P4, class teacher of L1	**Personal development:** Better personal competence; empowered attitude of 'I can'

Code and description of learner	Challenges experienced and reasons for challenges	Core supportive actions (guided by learner-centred ITP)	Collaboration to provide support	Quality-of-life outcomes
				Attitude change on the side of the staff
	Disempowerment: Infantilisation: wearing a bib that was meant for an infant at 16 years of age	**Development of adult persona:** Wearing age-appropriate scarves instead of bibs	Scarves bought by P4, collaborated with mother, sister, class assistant and teacher to substitute bibs with scarves	**Emotional wellbeing:** Improved self-concept, dignity
	Exclusion: Inability to communicate verbally	**Provision of communication device**: Include her in daily activities, empower her to express her needs and wishes	P4 collaborated with class teacher and P5 (therapist) to provide an assistive device from the school's side. P5 still in process of acquiring a device to use at home.	**Interpersonal relationships:** Ability to convey needs. **Self-determination:** Can convey choices
	Exclusion: Isolation: Always stays home due to lack of appropriate wheelchair	**Provision of mobility aid:** School therapists requested state hospital close to learner's home to provide wheelchair	P5, physiotherapist, state hospital staff, parents	**Physical wellbeing:** Comfort; better mobility
	Disempowerment: Infantilisation: Learner kept in diapers due to the belief that she is unable to be toilet trained	**Prioritise independence skill:** Toilet training via accessible commode	Collaboration between physiotherapist who ordered the commode, sponsor, P4 and mother who commenced with toilet training	**Self-determination, rights:** Dignity; self-determination
	Exclusion: Does not go on shopping trips. **Disempowerment:** Has never handled her own money.	**Social exposure:** Spending own money in supermarket	P4, class teacher, mother, family member who provided transport	Community integration and participation
L2: Male learner with cerebral palsy (diplegia).	**Disempowerment:** Lack of employability skills.	**Prioritise skills development:** Gardening project: Plant and grow seeds;	Sponsor (business community) for pots, seeds, watering can	**Personal development:** Competence in gardening skills

Code and description of learner	Challenges experienced and reasons for challenges	Core supportive actions (guided by learner-centred ITP)	Collaboration to provide support	Quality-of-life outcomes
Walks with difficulty; fully verbal		harvest vegetables to consume or sell	and potting soil. Collaboration between P4 and P6 (for translation) and mother	
		Prioritise skills development: Car wash project: Wash staff cars for payment, budget for shopping and spend money according to budget	Collaboration between school staff members: class teacher, P3 (departmental head), one of the groundsmen (to teach car washing skill)	**Personal development:** Competence in car washing skills **Emotional wellbeing:** Positive self-concept **Interpersonal relations:** Interaction with support staff teaching him
	Disempowerment: Unable to read recipes to prepare own meals or bake for leisure.	**Prioritise independence skill:** Utilising a picture-based recipe book	P5 and P3 (consumer skills teacher and departmental head of the Senior Phase) collaborate to make a recipe book	**Personal development:** Competence in home living skills
	Disempowerment: Limited time concept	**Prioritise independence skill:** Reading a picture- and photo-based calendar	Collaboration between parent, P5 and school secretary	**Personal development:** Time concept
	Exclusion: Difficulties to access public life or employment due to severe recurrent epileptic seizures	**Intervention**: Provision of health advice to parent	Collaboration between school sister, parent and public hospital staff	Health and healthcare
L3: Female learner with spina bifida, lower half of body paralysed, but upper body functional; fully verbal;	**Exclusion:** Isolation at home Unreliable transport. Little to no exposure to public spaces. Challenges with consistent daily	**Interventions:** Employment Placement at charity shop. Coaching regarding social employability skills.	Collaboration between parent, P4, P5, P6 and employer.	Better community integration and participation. **Personal development:** Improved work-related skills.

Code and description of learner	Challenges experienced and reasons for challenges	Core supportive actions (guided by learner-centred ITP)	Collaboration to provide support	Quality-of-life outcomes
health challenges	workplace attendance due to health challenges. **Disempowerment:** Limited employability skills.	Communication with employer. Negotiated continued employment after management change. Mitigated health challenges by having her work only one or two times a week.		**Material wellbeing:** Ability to earn money.
	Disempowerment: Lacking insight in making marketable beads	**Skills development:** Coaching, provision of examples	Collaboration between P4, sponsor, parent and other parent competent in making wooden jewellery	**Personal development:** Competence in beading
	Disempowerment: Unable to read recipes to prepare own meals or bake for leisure. Family owns only a gas stove, which is dangerous for the learner.	**Skills development:** Reading picture-based recipe book. **Intervention:** Purchase mini oven via sponsor.	Collaboration between P4, P3 and business owner.	**Personal development:** Competence in home living skills.
	Disempowerment: Infantilisation: **Personal appearance:** Learner does not dress in an age-appropriate manner; does not own any make-up. (Also relates to **dignity**.)	**Attainment of adult personal skills development:** Makeover session for first workday. **Intervention:** Donated make-up kit.	Collaboration between P4, class teacher and parent Make-up kit obtained from leftover concert stock.	Self-concept; dignity.
L4: Male learner, on the autism spectrum Communication difficulties, no behaviour challenges Sensitive to noises and unknown places	**Disempowerment:** Lack of employability skills.	**Skills development:** Baking lessons.	Collaboration between parent, owner of company presenting baking lessons, P4, P5 and P3.	**Personal development:** Improved baking skills **Material wellbeing:** Possibility to earn money.
	Disempowerment: Limited time concept.	**Prioritise independence skill:** Reading a picture- and	Collaboration between parent, P5 and school secretary.	**Personal development:** Time concept.

Code and description of learner	Challenges experienced and reasons for challenges	Core supportive actions (guided by learner-centred ITP)	Collaboration to provide support	Quality-of-life outcomes
		photo-based calendar.		
	Disempowerment: Inability to read recipes and distinguish between measuring cups.	Provide picture-based recipe book, including the makuku recipe, colour-coded measuring cups.	Collaboration between parent, P5, owner of the baking company and P3.	**Personal development:** Ability to read a recipe and do measurements.
L5: Female learner, appearance of a normal adolescent, fully mobile and verbal, but visual memory and literacy challenges	**Exclusion:** No exposure to job-related opportunities.	**Intervention:** Employment placement at a pre-school.	Collaboration between P4, job coach, parent and employer.	**Material wellbeing:** Opportunity to earn money.
	Disempowerment: Lack of employability skills, e.g. rendering quality cleaning service.	**Skills development:** Coaching in cleaning skills.	Collaboration between job coach and parents.	**Personal development:** Mastering cleaning tasks.
	Exclusion: Auditory memory challenge, inability to remember tasks.	**AAC:** Use of visual supports to bridge challenge and include her in the work environment.	Collaboration between employer, job coach and P5.	**Personal development:** Remembering daily tasks.
	Disempowerment: Limited time concept.	**Prioritise independence skill:** Reading a picture- and photo-based calendar.	Collaboration between parent, P5 and school secretary.	**Personal development:** Time concept; ability to plan week.
	Disempowerment: Unable to read recipes to prepare own meals or bake for leisure.	**Prioritise independence skill:** Utilising picture-based recipe book.	P5 and P3 (consumer skills teacher and departmental head of the Senior Phase) collaborate to make recipe book.	**Personal development:** Competence in home living skill.

In the headings of Table 7.1, I distinguish between ‘challenges’ and ‘supportive actions’, terms that correspond to the terms ‘challenges’ and ‘support needs’ illustrated in figures 5.2, 5.3 and 5.4. Challenges, in this sense, refer to the barriers to successful transition into adult life that could negatively influence the individual’s quality of life.

The challenges are, in most instances, a combination between the physical and cognitive challenges of the individual, and the attitudes and resulting actions of stakeholders surrounding the individual. This corresponds to the more holistic socio-ecological view of the construct intellectual disability. Buntinx and Schalock (2010, p. 284) put it as follows:

> Intellectual disability has come to be seen as not just a significant limitation in intelligence and adaptive skills; rather, it is viewed as a problem of the whole person in his or her life situation that impacts health, community participation, and the roles that the person plays in society.

The ALS discussions led to a decision to group the challenges into three categories: challenges that respectively relate to dignity, empowerment and inclusion (cf. Chapter 5). These three categories are value-laden and relate to disability rights and the need to change the frames of reference of stakeholders in the disability field in a developing country such as South Africa, where a dissonance exists between the attitudes and beliefs of the public and the official disability policies of the country.

Supportive actions, in this study, are viewed as enabling actions that should be taken to bridge an individual's unique challenges. The supports paradigm that originated in the mid-1980s brought person-centred planning, personal growth, community inclusion and empowerment together (Luckasson et al., 2002). Schalock et al. (2010, p, 175) define 'supports' as "resources and strategies that aim to promote the development, education, interests and personal wellbeing of an individual and that enhance human functioning". The Supports Intensity Scale of Thompson et al. (2004) is an instrument that can be utilised to assess the pattern and intensity of the supports needed by an individual in seven life activity areas: home living, community living, lifelong learning, employment, health and safety, social relations and protection and advocacy (Thompson et al., 2004). These life activity areas correspond with the domains of the quality-of-life model. In this study, I designed the ITPs according to these life activity areas.

The goal is to facilitate each individual learner's learning towards post-transition quality of life. I preferred quality of life as a guiding theory above other disability models such as those presented by the American Association on Intellectual and Development Disabilities and the International Classification of Functioning, Disability and Health. These two models are based on functional limitations and the mitigation of these limitations. However, within the context of education, much more than just 'fixing' limitations is at play. The context of a person's personal life involves experiences, perceptions and preferences that cannot be expressed in such terms.

Planning for a person's future needs to take that person's personal preferences, as well as available resources, into account (Buntinx & Schalock, 2010, p. 284). These authors typify quality of life as the guiding theory, "a vehicle through which individually referenced equity, empowerment and life satisfaction can be understood and enhanced".

Based on the results of this study, I found that quality of life, as an end goal, is only possible if collaborative partnerships are forged to provide the individual with the required support.

In the next section I discuss in what way the ALS viewed the different roles of the partners in the partnerships and the way these partnerships could enhance post-transition outcomes.

7.3 THE ROLES OF DIFFERENT PARTNERS IN FAMILY-SCHOOL-COMMUNITY PARTNERSHIPS IN THE CONTEXT OF LEARNER-CENTRED TRANSITION PLANNING

After implementing the transition plans with each of the five learners, each ALS member was provided with one case study to analyse and comment on, after which we had a reflective group discussion about the results emanating from each transition plan. In terms of facilitating partnerships for transition, the ALS concluded that each partner had a unique role to play to not just facilitate, but also sustain the transition outcomes. Figure 7.1 and the subsequent discussion reflect the conclusions the ALS reached regarding the roles of the different partners.

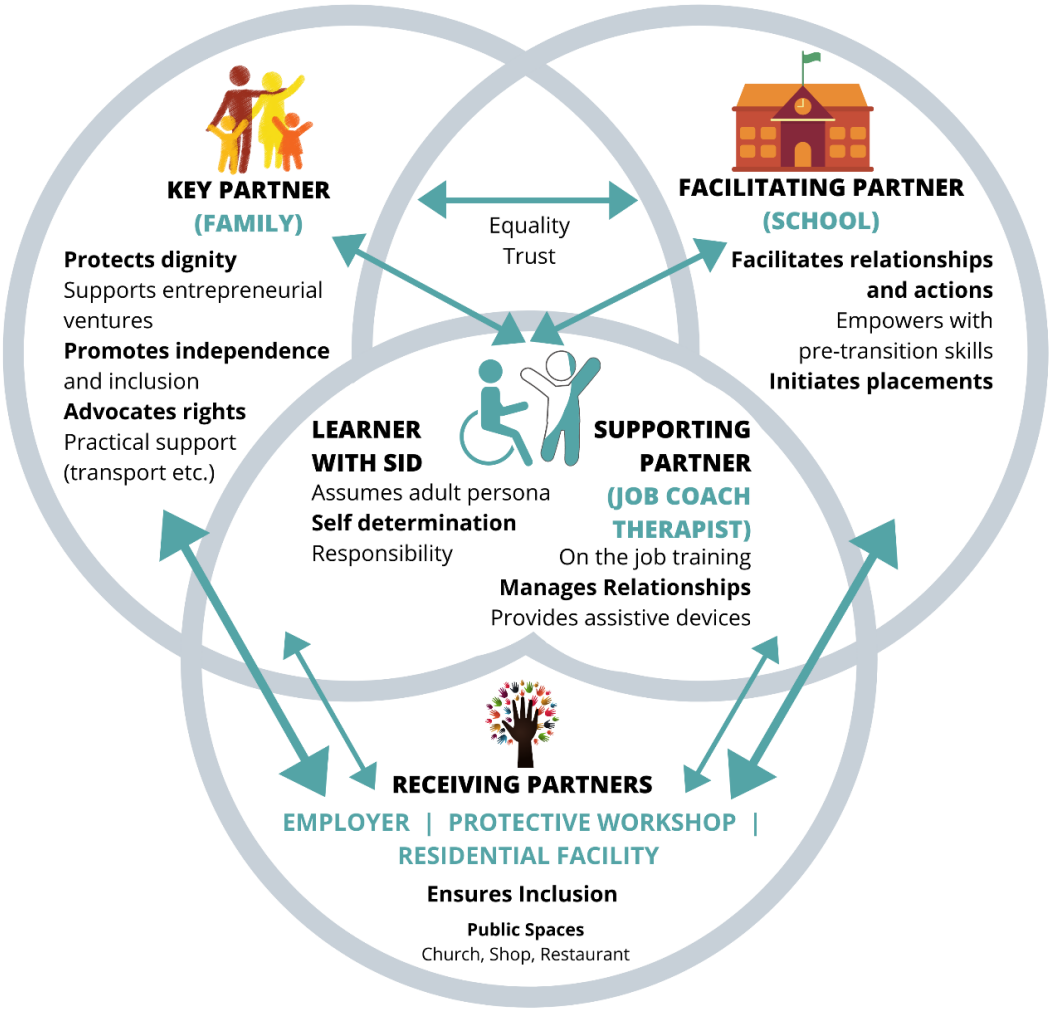


Figure 7.1: Roles of the different partners in supportive partnerships

The group concluded that the school is the facilitating partner. In the case descriptions, the school-based partners (the transition manager, the class teacher and the therapists) reached out to other relevant partners (parents, employers and service providers) and facilitated them towards the needed action. The facilitating partner *initiates* the action. Without the action of the facilitating partner, the transition process cannot even start.

P7 put it like this:

> *It took teamwork between the school, which was the driver, the parent and the community … most of the initiatives and interventions came from the school's side.*

The school had to initiate action in most cases, such as to source aids for learners. Its role was thus key to the success of the transition plan. For instance, L1's parents could not access a wheelchair for their daughter on their own and did not have the knowledge or capacity to address her communication needs. Participant L5 needed a visual schedule as a crucial employment support measure, which was very easy to set up from the school's side.

The parent or parents (family) are the key partners. *They* know their child the best; *they* give key information regarding their child's dreams, wishes and abilities; as guardians of vulnerable individuals, *they* make key decisions; and they need to grow into informed and empowered drivers of their child's future when the school withdraws. This was clearly illustrated in the case of L4, whose whole transition project ground to a halt because of a breach of trust between myself and the learner's father. Participant 7 made the following observation in this respect:

> *This is a particular case where it shows if somebody – ah – if a parent is not involved, and somebody else doesn't get involved, then probably, in most cases, nothing is going to happen.*

Although very much aware of time constraints and practical challenges in the school environment to perpetuate something as labour- and time-intensive as home visits, the group agreed that home visits were extremely helpful in building a partnership with the parents. These visits enabled valuable information about the learner to come to light. For example, in her home environment, L1 demonstrated abilities that had not been apparent to the school staff. Home visits also enabled a clear picture of the practical and financial challenges of the parents (e.g. L2, who lived in a single room and whose mother had no access to transport to hospitalise him when he had a serious seizure). These insights enabled the ALS members tasked to work on the transition plans to mould the learners' ITPs to their individual challenges.

After the ALS members had read the case studies, the comments of the group participants revealed how important it was to empower and involve the parents. However, there was also evidence that it was not always possible for parents to transcend their daily challenges with their children and could find it challenging to successfully plan, execute and maintain the process of their children's transition into adulthood *all alone*. Thus, although the parent is a *key* partner, they really need the other partners to improve the prospects of the young adult.

> *…we are so inside a problem that we don't always look from the outside, what you can maybe do differently to make things better.* (P7)

The parent, as a key partner, is best positioned to advocate for their child's rights and to ensure that they are treated with dignity. For instance, L1's mother refused to place her in a care centre where the attendees were 'just sitting'. Another example is L2's mother, who successfully advocated for her son's inclusion in the local soccer team. Other measures of support that no one else will likely be able to render are support for entrepreneurial ventures and practical support, such as transport.

Participant L2's mother kept an eye on his vegetable garden and gave directions on when the seedlings needed to be transplanted and watered. Participant L3's mother facilitated her beading by providing her with a special beading table and keeping an eye on the colour combinations she chose. Participant L3 would not have been able to hold a job at the charity shop if her mother had not transported her there.

Sponsors, government departments and other service providers are supportive partners. Of these, the job coach, depicted in the illustration as placed right next to the learner in the centre, renders *crucially* important support, linking the parent, the employer, the school and the learner in a continuous supporting cycle until employment success is achieved.

> *But look what L5 was able to do with coaching, with visual aids, with the right type of – of help – the challenges in the workplace just underline the need for the intervention of a job coach, so eh – the role of a job coach I think is really crucial…* (P8)

L5 would not have been able to bridge all the challenges presented by her new job if it had not been for the job coach. The job coach anticipated some of the challenges, prepared the learner and the employer for employment placement and kept in contact with the employer to address any challenges that came up. She also guided the different stakeholders to further steps as the process unfolded.

The employer or the care centre is the receiving partner. Therefore, an important question that needs to be asked before placing a learner with SID in a particular environment would be: *How will this employer and this environment receive this particular person with these unique challenges and abilities? Is this a good fit?* In both the cases where our adolescents were successfully employed, the employers were warm, accommodating people and the environment was friendly – and the two learners blossomed. Yet, the fact that the place of employment is a good fit does not mean that the employer needs to compromise the quality of the work they expect from the employee. That is why the job coach needs to guide the employer and the employee alike to grow into a working relationship that is to the benefit of both.

> *… just because somebody is disabled, this doesn't mean the employer is going to turn a blind eye to anything that he or she is doing wrong, or not perfectly well – ahm, and also obviously regarding their conduct towards clients…* (P8)

P5 stressed the need for an activity analysis at the workplace.

> *What exactly will be required for each type of activity? Will the learner be able to do it or not? Another important factor would be the accessibility of the workplace, transport. What type of transport will be utilised to get to work? Has the young SID*

person been trained to use public transport? In L3's case, her parents could do the transport. Other aspects of activity analysis are: What work speed is required? In a corporate environment, the quantity and quality of work would have been much more demanding than what is required of L3. We also need to look at the type of interactions the person will have – co-workers, clients and so on.

She stressed the need to direct the employer to create structure and boundaries right from the start, to feel free to coach the young person with SID at the moment when it is necessary:

I think, often employers don't feel confident, or competent enough to communicate honestly with a person with SID. Maybe they don't want to hurt their feelings. But it is much better to handle things that come up in the moment.

Haines et al. (2015) stress that reciprocity that amounts to a win-win situation, where both partners receive mutual benefits, is essential. This became evident in relation to our receiving partners, the employers, who found that they *could* gain from employing our learners with SID.

If all these supportive partnerships are in place, the person in the centre, the young adolescent with SID, will be empowered to realise their dreams and to gradually assume an adult persona, the persona of a valued and fully functioning member of society.

Wishing to generate practical guidelines for real-life transition planning and execution, the ALS analysed the findings from an operational angle to see how we could possibly develop a practice-based blueprint for transition planning. This is covered in the next section.

7.4 A PROCESS MODEL FOR TRANSITION PLANNING: FACILITATING GROWTH TOWARDS ADULTHOOD

The analysis of the combined data sets pointed to a need for three distinct stages in transition planning for learners with SID: The pre-transition stage (transition preparation), the transition stage (the actual steps taken to transition adolescents into adult life) and the post-transition stage (putting measures in place to ensure the sustainability of the results achieved). These are explained in detail below.

7.4.1 Pre-transition stage (ages 15 to 16)

During this stage, the importance of the Life Skills curriculum cannot be underestimated. The focus here is on empowerment (see figure 5.2**)**. This is the stage where the learners need to work hard on their daily living skills, or instrumental activities of daily living (IADL), which S3, an occupational therapist, explained as follows:

> *…it's mostly activities of daily living, in occupational therapy we refer to these skills as instrumental activities of daily living or IADLs, these are higher cognitive functions than only self-care, these skills are needed to function from day to day in the community and in your own environment. Examples are cooking, shopping, cleaning the house, safety and emergency response.*

Case-Smith and O'Brien (2013, p. 520) provide a comprehensive summary of instrumental activities of daily living and community participation skills that older adolescents with SID need to acquire. These include the following:

- Meal preparations and clean-up
- Community mobility (e.g. the use of public transport)
- Health management and maintenance (e.g. knowledge of own medication)
- Household maintenance and management (e.g. to change a lightbulb)
- Clothing management (washing or mending clothes)
- Use of communication devices (e.g. a cell phone)
- Shopping and money management
- Safety and emergency response (e.g. how to call emergency services)
- Community participation and performance skills (e.g. to take responsibility for own routines)

It is extremely important that, in the beginning of this period, parents, as key partners, are informed of the work that will be done during this stage, since they, too, need to work on independence skills at home. Failure to partner with the parents in this regard may cause a dissonance between the aims of the school and the approach of the parents. If the parent continues to do things for the learner, this may lead to learned helplessness (see section 5.4.3). Another aspect that emerged from the case studies is the issue of appropriate dress (L1, L3, L5). Both learners who were placed in employment environments needed guidance regarding appropriate dress, and their parents needed to be made tactfully aware of the need to attend to this matter (L3 and L5, Appendix 4.3).

7.4.2 Transition stage (ages 17 to 18)

During this stage, the focus shifts to post-school preparation. This relates to empowerment (see Figure 5.3), but overlaps with the emotional wellbeing quality-of-life domain, which refers to self-concept and dignity. D1 believed that the learners need to be empowered with the relevant skills to assume 'the persona of an adult person'.

> *They had to report to the classroom at eight o'clock, ahm – sign in a register, so we – we hadn't even been talking about work. We just made this about our daily*

classroom routine. Self-discipline was also extremely important. Ahm – and then, in October of that year, once we had established routines, we had – you know – in – in a way helped them develop the persona of an adult person.

To make a visual statement of their growth into adulthood, these learners need to dress in a different manner than the rest of the school. For example, they could wear a different, more formal school shirt with a special tie. Workplace simulation should be prioritised. Classes where practical skills are taught (such as consumer skills, where food preparation is taught, or agriculture, where gardening skills are taught) should be organised like workplaces, where the learner needs to sign in and out. Workplace rules should be set, and appropriate employee behaviour needs to be practised. Learners need to learn how to assume responsibility for tasks and develop pride in a job well done (see section 5.4.4).

Another priority is to assess the learners' interests and abilities individually. There was agreement that a good transition plan would need to start with the intensity of each learner's support needs, and that learners should be classified into three groups. The first group consists of those learners who have high support needs (such as L1 in this study). These learners will be assessed to determine communication and mobility support needs, and to enhance self-determination, independence, quality of care and social inclusion. Their abilities also need to be assessed individually to determine what kind of craft they could possibly be taught, for example, L1 in this study was able to use her functional hand to paint and decorate simple key holders. Since these learners are more vulnerable than the other groups of learners, any dignity-related challenges they might experience (such as infantilisation) need to be addressed. The second group would be those learners who are verbal and have good hand function, but have other high physical support needs (for example the health and mobility challenges experienced by L2 and L3). These learners might be able to find employment in the open labour market, but might have challenges related to their physical endurance. They could possibly benefit from a hybrid transition plan, which could include part-time employment in a disability-friendly environment (once or twice a week), supplemented by attendance of a protected workshop on the other weekdays. The learners in this group could also benefit from an entrepreneurial skill (such as planting and selling vegetables (L2), baking and selling scones (L4) or making and selling beads (L3). The third group would be those learners with functional verbal and physical capabilities, and cognition bordering on the mild to moderate intellectual disability range (such as L5 in this study). These learners could benefit from appropriate work placement in the open labour market, but would need appropriate employment support, even after school. It is important to note that these groupings are not watertight, and that a holistic and individualised assessment of an individual's abilities and support needs is required.

For example, one might find that a learner with high physical support needs, but a high level of motivation and good cognitive functioning, could, with adaptations, do well in employment. On the other hand, one might have a learner who has no physical support needs, but who is unable to carry out instructions appropriately, or a physically fit, and fully verbal young person with severe behaviour challenges, who might disrupt a work environment in the open labour market.

In order to adhere to the principle of learner-centredness, an individual interview should be conducted with each learner who might benefit from job placement, like the therapist did during this study. The main purpose of this interview will be to complete a career interest questionnaire. This step is followed up soon afterwards with an individual parent interview, where the results of the questionnaire and other assessments are discussed with the parents and an ITP is drawn up. In this study, the ITP was based on the headings of the Supports Intensity Scale of Thompson et al. (2004) (see Table 2.4). Guided by this framework, the young person's support needs, potential and interests should be discussed during the parent interview. Possible links to potential employment within the family circle or among close family friends should be explored. For learners with high support needs, the conversation will revolve more around dignity-related issues and quality-of-life needs. An important part of the discussion is the question of social inclusion. Parents need to be made aware of the importance of the exposure of their young adult to public spaces and social settings such as shops, restaurants, churches and social visits. Other issues such as health, fitness and leisure should be touched on as well, since these are important points related to quality of life. It is important that the interview should be conducted in an unhurried and relaxed manner and that the parents' trust should be won. The interviewer should not act in a condescending manner, but should establish an atmosphere that is conducive to partnership, and which pre-supposes equality.

The job coach then needs to look for appropriate job placement sites for those learners that could be eligible for employment. The preferences, abilities and challenges of the learners should be kept in mind and the sites carefully chosen in terms of factors such as accessibility and workplace climate. A pre-placement conversation with the employer is needed, where the employer is prepared for the job sampling period and the potential tasks of the learner are discussed. During job sampling, the learner does not receive any payment and is accompanied by a job coach. The job coach should ideally be someone who is not a school staff member, such as a retired special needs teacher, since the job coaching will continue for some time after the learner has left school.

Before a new job placement is finalised, the job coach should be in possession of a task analysis, set up before the job sampling, so that they know exactly what is expected of the learner. Based on the task analysis, they closely observe how the learner is coping, and conduct on-the-job training. At school, the job sampling days are followed by job-specific off-site coaching. For example, if the learner is working at a car wash, they might be allowed to wash cars at school to practise job-related skills. Specific coaching sessions for social skills that seem to be lacking should be undertaken as well, for example greeting customers and appropriate interaction with fellow employees, as was the case with L3 in this study. Aids and adaptations could be prepared to assist the learner to bridge some gaps, as was the case with L5, who needed a visual schedule to remember her daily tasks. When the learner is about to leave school, issues such as transport to work and the relationship between the employer, the job coach and the parent should be thrashed out. The way forward regarding future paid employment and the amount of support still needed by the job coach should also be discussed.

Parallel to the job sampling efforts, the parents of those learners who are to attend protected workshops or residential care centres after school should be coached on the choices they have during a meeting where relevant school staff members who have gathered sufficient knowledge about these facilities are present. These choices would be dependent on the financial capacity of the parents and their requirements for the care of their young adult. If need be, they should be taken to the facility for a walkabout, to meet the management and to receive the required documentation. The adolescent may even be allowed to attend the facility for a few days to see how things go. Those learners who are to work on entrepreneurial skills should be provided with a support person from the family's side (a buddy such as a young unemployed family friend or sister), who will be able to conduct quality control and handle money matters. These learners will also need a sponsor who will be able to support the small business financially.

7.4.3 Post-transition period (after leaving school)

During the post-transition period, the school needs to gradually withdraw its support for those learners who have been placed in employment, handing over the responsibility for the support to the job coach, who can report the progress, or lack thereof, to the school from time to time. This feedback is important for the improvement of the school-based transition programme. It is hoped that, after this process, the young adults might become well integrated into society, like L5 did:

> *Look how she has grown as a human being, as a – as a young lady, who can contribute to society*… (P8, on L5's case).

In order to present the process explained above in a more concise manner, the ALS compiled a tabulated illustration of a transition process model, based on the research conducted during this study, as depicted in chapters 5 and 6:

Table 7.2: A transition process model

PRE-TRANSITION STAGE (AGES 14 TO 16)		
ACTIVITIES	**ROLE PLAYER(S)**	**ENVISAGED OUTCOME(S)**
Parent group meeting(s)/workshops	School-based multi-disciplinary team	**Parental empowerment**: Inform parents of transition programme Have group discussions Identify leader parents
Learner activities: **Role play** – appropriate social interaction **Home living skills:** Make own bed, make own meals, wash and fold own laundry, etc. **Community living skills:** Budgeting, shopping, how to use a bank card, wayfinding, using public transport Real-life experiences by means of outings **Communication**: AAC communication measures appropriate for after school use; cell phone use; phone etiquette; safety measures in public spaces, handling emergencies	Life Skills teachers/class teachers and support staff involved in outings Parents	**Empowerment:** Improved social skills Improved independence skills Improved community living skills **Dignity:** Age-appropriate image **Inclusion:** Exposure to public spaces Awareness-building in public spaces **Communication support:** Improved ability to keep safe and handle emergencies
TRANSITION STAGE (AGES 17 TO 18)		
ACTIVITIES	**ROLE PLAYER(S)**	**ENVISAGED OUTCOME(S)**
Parent group meeting(s)/workshops	School-based multi-disciplinary team	**Parental empowerment:** Inform parents of aims and activities of the Transition Phase Have group discussions Identify leader parents
Learners in last school year wear different attire Workplace simulation sites within the school environment	School management team Parents	**Dignity:** Paradigm shift – learners need to adopt an adult persona
Assessment (can be conducted at the end of the previous year) Career interest questionnaire	Therapist(s) Learners	**Learner empowerment:** Learners' preferences and strengths are identified Learners with multiple disabilities: of quality-of-life improvement needs identified

ACTIVITIES	ROLE PLAYER(S)	ENVISAGED OUTCOME(S)
Learners divided into competence groups	Therapist	Learners with similar competencies or ITP aims are grouped together to simplify planning
Individual parent interview (to be followed up as needed with telephonic conversations or more interviews)	Relevant stakeholders at school, e.g. class teacher, therapist	**Parental empowerment:** Share and confirm findings of assessments Fill in gaps needed for ITP Ensure that parents understand aims and envisaged activities Build good rapport and trust of parents Recognise parent as expert
Set up ITP for learner Provide ITP to parent and discuss it with parent	Multi-disciplinary team, including class teacher and therapist	Holistic plan with attainable aims for learner's transition
Initiate actions needed for the execution of learners' transition plans: Identify and visit job placement sites, make choices according to criteria set by therapist Manage logistics of job placements (e.g. transport) Facilitate making or acquisition of aids for ITPs Facilitate the linking of parents to post-school public services (e.g. social grant application) Recruit and train job coaches	School staff member tasked with job placements	Put supports in place for identified needs Adjustments to ITP where needed Continuous communication with all relevant stakeholders
Job task analyses of learners' jobs	Therapist(s)	Provision of job-related guide for job coach's instruction
Employer interviews	Therapist or appointed staff member	Provision of guidance to employer Inquiry into requirements of the job
Job placements	Staff member tasked with job placements	Practice employability skills in real-life situations Job hardening (becoming work-fit)
On-the-job training	Job coach	**Empowerment:** Support learner, act as intermediary stakeholder between employer, parents and school, resolve potential challenges on the spot
Off-site skills training (at school)	School staff (e.g. Life Skills teacher or class teacher) Social skills: Therapist facilitates resolution of challenges (e.g. role play)	**Empowerment:** Learner practices skills they find challenging at work

ACTIVITIES	ROLE PLAYER(S)	ENVISAGED OUTCOME(S)
Visits to care centres, protected workshops and residential centres	Transition manager or senior staff member Parent Learner	**Parental empowerment:** Seek an appropriate facility in a timeous manner, book space
Seek sponsorships for start-up kits and continued financial support for small entrepreneurs	Relevant staff member or parent	Facilitate support for entrepreneurial projects
POST-TRANSITION STAGE		
ACTIVITIES	**ROLE PLAYER(S)**	**ENVISAGED OUTCOME(S)**
Continued support: Job coach continues support until no longer needed	Job coach Parents	**Inclusion:** Sustained job placement Continued participation in social roles, shopping, etc.
Feedback obtained from parents and job coach	Staff member tasked with job placements	Improvement of school's transition planning

Table 7.2 is a summary of the process to be followed during the different stages of transition planning and execution. However, for these actions to be carried out, one would need staff members who are motivated to participate in the facilitation of the transition process. The next two questions that will be addressed are whether the efforts of the team contributed to positive change in the attitudes of school staff members and parents, and if so, what may have caused these changes. I will also reflect on the sustainability of these attitude changes.

7.4 PARADIGM SHIFTS OR ATTITUDE CHANGES IN THE MINDS OF KEY STAKEHOLDERS

Since the stakeholders within the different ecologies (family, school and community) surrounding the person with SID play such an important role in realising the goals and dreams of the young adolescent and in facilitating them towards a quality adult life (Small et al., 2013), the ALS had a discussion around changing attitudes that often proved to be biased or limiting. Working with different stakeholders during transition preparation is an extremely complicated venture with many possible variables playing out in various contexts. One cannot expect to arrive at a singular explanation for attitudinal change (Fullan, 1993). However, based on data generated in the group, I have attempted to tabulate the different attitude changes in participants, the ways in which these changes manifested, as well as possible explanations for these changes, in line with the critical realist data analysis framework, which aims to identify causal mechanisms or explanations for change (Wynn & Williams, 2012).

Table 7.3: Attitude change observed in participants

Attitude change observed	Manifestation of these changes in participants	Possible explanation for the changes
Paradigm shift in adult participants: Recognition of potential of people with SID as opposed to 'dumbing them down', in P8's words.	**Parents:** More hopeful, positive, even excited	Intensive engagement; relationship and trust building by ALS team Parents witnessing positive changes in real time
	Teacher (L1): Changed focus of teaching Tendency to infantilise learners was diminished (class teacher and assistant) of L1)	Staff members witnessing real-life results of transition planning; learning from taking action; class teacher and therapists motivated to perpetuate positive change
	ALS, therapists: Different view of prospects and needs of learners (e.g. L1)	
	Employer: From guarded or over-indulgent to constructively critical, but kind (L5 and L4)	Coaching by job coach First-hand experience of SID person as a human being

One of the parent members of the ALS was highly impressed with L5's growth towards adulthood. L5's employment success caused a paradigm shift in her own view about her daughter's ability to find employment. Her comment reflected on the fact that stakeholders working with adolescents with SID tend to 'expect the worst' of them

> *…I must say: Wow! Wow, wow, wow! How L5 was described in the beginning, and how her parents described her in the end – it's two different people. So – what I would like to stress here – if you expect the worst from people, they will usually deliver. And sometimes, sometimes I get the feeling that – uhm – we want to dumb our children down, because they are mentally challenged, so we don't expect much from them* (P8).

School staff witnessed the change in L1 that L7 described in the following manner:

> *… it gave her joy, and a feeling of being in power, having a purpose in life, being appreciated, and even being admired by the community. I think we often discover potential in these young people when they are challenged with something, or put to the test, if I can put it that way. We assume way too often that – that they cannot do many things.*

Her class teacher, touched deeply by the way our joint efforts enhanced L1's quality of life, decided to shift the focus of her curriculum presentation completely towards transition-focused activities. Therapists became involved in the project, assisting with getting her the needed aids to enhance her participation and improve her independence (see L1's case study narrative in Appendix 4.3).

Participant 7 commented on the knock-on effect that the projects had on the collaboration between different staff members who had not even been part of the original project:

> *…the snowball effect it can have, ah – if people talk to one another, and take hands, and they support, and then they come up with solutions together, and just – it's about teamwork. And it's about teachers and therapists and the parents. They should talk more…*

What emerges from all this is that the changes that had taken place happened through action. As the participants observed and lived through the actions taken, they started to shift their paradigms, change their minds. Learning, growth and development took place *during* and *after* the action. Fullan (1993) believed that, when trying to facilitate a major reform in an organisation such as a school, the sequence 'ready, fire, aim' is better than the traditional 'ready, aim, fire'. 'Ready', according to him, is important, since some notion of direction is needed, but then action and inquiry ('fire') should be next in line. Only after that, can one 'aim', which refers to reflection, and the formulation of new beliefs, and mission and vision statements, leading to more structured planning.

I quote P8:

> *We must really remember that success breeds success. And we should use projects, and what we learn from projects and examples like this, to really inspire others to become involved, and to become part of developing and supporting the growth of these youths…*

But before the euphoria of success blinds us to the stark realities of life, we need to reflect on another crucial question: Are these changes *sustainable*? Has the learning been enough to effect some long-term changes?

7.5 SUSTAINABILITY OF CHANGES: THREATS AND HOW TO ADDRESS THEM

The response of P6, the Setswana teacher, to the L2 project pointed to some challenges or threats related to the sustainability of paradigm changes. He reasoned that, even if it had been possible to find employment for L2 (which he did not believe would be the case), he would not be able to use public transport safely. Even if he did, what would community members say when witnessing a boy like that boarding or disembarking from a taxi? Participant 6 thought that it would be best for L2 to be admitted to a care centre where he could be safe and where his interests could be pursued in a protected environment. Another problematic experience was a meeting I held with some of the teachers of the Senior Phase learners.

The project was still in its initial phase, and when I shared that I was working on finding job placements for L3 and L5, most of the teachers reacted with vehement scepticism. I was showered with accounts of the learners' flaws and inabilities, and warned that I was giving the parents false hope. I could see that the view that these learners cannot really amount to anything was deeply ingrained in staff members' minds. Participant 6, the Setswana teacher, possibly grew up in a culture where religious and cultural bias towards people with disabilities was rife. Change was a challenge. Table 7.4 provides a summary of the threats to the sustainability of change and learning experienced in the project, as well as possible reasons for these threats.

Table 7.4: Sustainability threats and reasons for threats

Sustainability threats	Possible reasons for threats
General public: Deeply entrenched bias regarding abilities and prospects of learners with disability	Embedded cultural and religious beliefs Society is still leaning towards the medical model of disability
Staff: Resistance to change, need for a 'comfort zone'. Scepticism about job placement efforts (P6, P3 and senior teachers) Concerns about the labour-intensiveness of job seeking and support efforts in the context of limited human resources (P5) Prioritisation of pressing day-to-day management issues above research and long-term planning (P1)	The nature of educational institutions – tend to be resistant to change (Fullan, 1993). Remnants of thought paradigms related to the medical model (stemming from previous school culture) No sense of urgency regarding the prioritisation of transition-focused education; subsequently, the re-assignment of duties is not considered The Department of Education is not yet prioritising transition-related activities in its policy guidelines and staff assignment, consequently transition is also not prioritised by school management
Parents: Withdraw, may discontinue what you have started (M3 and F4)	Emotionally and practically over-taxed, not able to see outside the situation, will always tend to revert to the safest and most comfortable option (M1, M3 and M4) Financial challenges (M1, M2 and M3) Practical challenges – e.g. transport (M1, M2 and M3) Trust breach or poor communication (F4)
Learners: May not sustain motivation and drive felt initially (L3; accounts of S1) Practical challenges (e.g. how to get to work) may become overwhelming (M2 and M3) Exploitation danger (L5) Being infantilised and just 'looked after' in a care centre (L1)	Job hardening ('work fitness') needed (L2, L3 and L5), physical and health challenges (L2 and L5) Poor community living skills, such as using public transport (L2), budgeting (L2, L3 and L5), and using a bank card (L2, L3 and L5) Employers may see an opportunity for cheap labour (L5) Vulnerability of people with SID (L1) Entrenched views of people with SID in the South African community (P6)

Since the school has been found to be the facilitating partner in the transition process, it would make sense to start breaking the cycle of transition failure and to address the threats by facilitating change in the school environment first. However, Fullan (1993) described the core challenge of effecting change in a school environment as follows:

> …we have an educational system which is fundamentally conservative. The way that teachers are trained, the way that schools are organised, the way that the educational hierarchy operates, and the way that education is treated by political decision makers, results in a system that is more likely to retain the status quo than to change. When change is attempted under such circumstances it results in defensiveness, superficiality or at best short-lived pockets of success (p. 14).

In another humorous quote, he writes that change is like "a planned journey into uncharted waters in a leaky boat with a mutinous crew" (Fullan, 1993, p. 35). Fullan (1993) was of the opinion that the starting point of effecting change is to awaken the already present moral purpose of teachers. He sees moral purpose as a change force. Their moral purpose, the reason for them choosing to become teachers in the first place – to make a difference in the lives of children – should become "more prominent, more active, more visible, more problematic" (Fullan, 1993, p. 93). During the practical leg of the study, I saw this moral purpose being awakened in some staff members when witnessing the joy and excitement of the participating learners accomplishing feats not thought possible before. Moral purpose is the driving force for solving challenges such as transport, lack of finances and biased employers. As Fullan (1993) puts it:

> Schools may not be able to cure all social ills, but to succeed at all in their task of educating the next generation, they must find ways of minimising the negative impact of such problems on the teaching and learning process. To do this, they must find new allies and build new kinds of connections to the communities of which they are a part (p. 105).

Kitchenham (2008) conducted a detailed study of the evolution of John Mezirow's transformative learning theory (Mezirow, 1978). I found this study very helpful to grasp the aspects of transformative learning theory that became evident during the learning and growth, not only of the ALS, but also other staff members and even parents. As part of his discussion of Mezirow's evolving theory, Kitchenham (2008, p. 117) refers to an adult person's frame of reference. A frame of reference is the way in which people make meaning, and includes 'habits of mind' (Kitchenham, 2008, p. 118). Habits of mind are ingrained beliefs, attitudes, expectations and judgements that people hold (Kitchenham, 2008). In this study, it became clear that the 'habits of mind' of the school staff, members of society and even parents still strongly gravitate towards the medical model and towards the notion that most,

if not all, these learners are unable to obtain or hold a job and that they should just be 'cared for' in a segregated facility. Again, in the words of P8: "We want to dumb our children down". This belief then becomes a self-fulfilling prophecy. A learner like L1 remains in diapers, wears a bib, and is immobilised in a wheelchair designed for people with little or no mobility, while she is, in fact, quite mobile. Later, her stiffening muscles *will* worsen her physical challenges, and if no one expects her to try, she will *indeed* never learn how to use a toilet.

The first step leading to a changed frame of mind, according to Mezirow (1978), is a 'disorienting dilemma' (Kitchenham, 2008 p. 105), an event that disrupts the neatly organised frame of reference that the person had held up to the moment of the 'dilemma'. There were numerous examples of such 'disorienting dilemmas' that triggered participants to reflect on and reconsider their past 'habits of mind'.

Examples are the following:

- L1's teacher, who witnessed that she could actually make a product that was marketable, whereas he previously expected very little of her.
- P8, who, as a mother, was blown over by the fact that L5 could be successfully employed. She herself has a daughter with similar abilities to L5 and had not previously thought it possible.
- M1, L1's mother, who had previously thought that people in the community would find the sight of L1 offensive or repulsive – yet L1 was welcomed warmly in the shop where they went to spend L1's money (earned after selling her products).

This kind of learning, according to the theory of Mezirow (1994) is "learning through meaning transformation" (Kitchenham, 2008, p. 110). The person observes an anomaly that conflicts with their current meaning scheme or frame of reference. They then start to reflect critically on what they had previously believed and start to reorganise their meaning and transform their frame of reference (Kitchenham, 2008). A person who has, through self-reflective transformative learning, adopted a new frame of reference, can then potentially turn into a change agent himself (Fullan, 1993). Figure 7.2 illustrates the transformative learning process, based on the transformative learning model (Mezirow, 1994). Transformative learning, such as has been observed on a very small scale in this study, may ultimately lead to sustained change, driven by change agents who may, in turn, transform the habits of mind of other stakeholders surrounding the young adult with SID (see Figure 7.2).

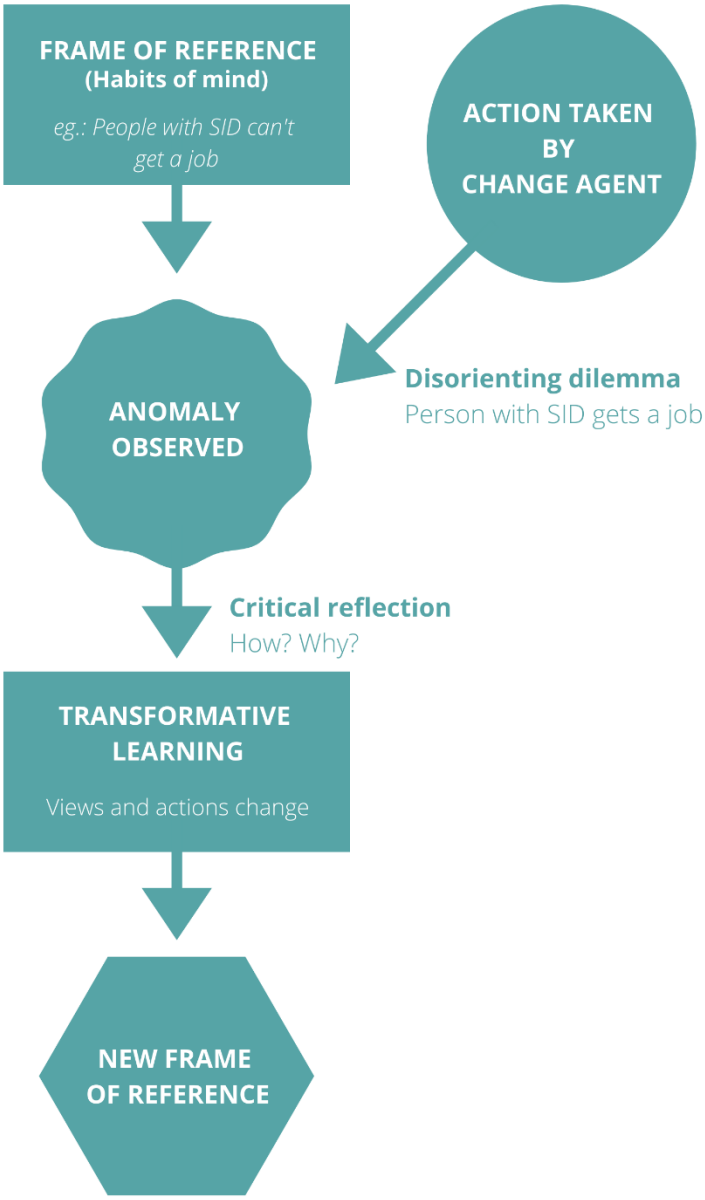


Figure 7.2: The process of changing habits of minds through actions (disorienting dilemma) Based on a simplified version of the revised transformative learning theory of Mezirow (2000)

Figure 7.2 illustrates how a person with a fixed idea about people with SID (that they will never be able to obtain employment) may change their mind when witnessing an anomaly (a person with SID who is indeed successfully employed because of actions taken by a change agent). This observation is then a disorienting dilemma, which causes the person to reflect critically on their previous views to ultimately arrive at a new frame of reference.

7.6 FINAL REFLECTION ON FINDINGS

A favourite quote of Zuber-Skerritt (2011), who first conceptualised PALAR, is a sixth-century saying by Heroclitus: “Learning does not mean to fill a barrel, but to ignite a flame” (Zuber-Skerritt, 2011, p. 5). Nearing the completion of this study, I believe the core causal factor of successful transition planning is the utilisation of change agents; individual impassioned people who need to ignite flames; who are determined to make transition work and who have it in their hearts and minds to go many extra miles to solve challenges. I quote Fullan (1993) once more:

> If teachers and other educators want to make a difference, and this is what drives the best of them, moral purpose by itself is not good enough. Moral purpose needs an engine, and that engine is individual, skilled change agents pushing for changes around them, intersecting with other like-minded individuals and groups to form the critical mass necessary to bring about continuous improvements (p. 51).

However, working in isolation may hamper the best of the change agent’s efforts.

> Isolation is a problem because it imposes a ceiling effect on inquiry and learning. Solutions are limited to the experiences of the individual. For complex change, you need many people working insightfully on the solution and committing themselves to concentrated action together (p. 45).

Fullan (1993) stresses that, although it may seem contradictory, collaboration and individualism are equally important in the learning process, since groupthink may become a barrier to learning:

> Many saying that black is white agree that among one's most shameful memories are of saying that black is white because other people are saying it (p. 45).

Having had the privilege to utilise PALAR to guide this study, I can attest to both sides of the coin: Not only did the group’s contributions enhance my own learning, but I also woke up to the realisation that I, as an individual, had a moral duty and compulsion to be a change agent to ignite flames, not only in my work environment, but also in society at large.

7.7 CHAPTER SUMMARY

In this chapter, I gave an account of the outcomes of the third cycle of the study. The chapter started with a tabulated summary of the actions taken and outcomes reached during the five case studies. This demonstrated how we applied the knowledge of the data collected in Chapter 5.

The summary was followed by a discussion about the insights of the ALS on partnership roles (as observed in the five cases). These insights were reflected in a figure drawn up by the group, which demonstrated how we applied the knowledge gained in Chapter 6. Following that, the ALS endeavoured to synthesise all the findings by drawing up a process model for transition planning, consisting of three different phases: the pre-transition phase, the transition phase and the post-transition phase. The process model was based on the data of all three cycles. Utilising a critical realist approach, the ALS then identified causal mechanisms for the changes (or lack thereof) that took place in the lives of the participants. The group found that attitudinal changes and the awakening of moral purpose in the facilitating partner – the school – was key. Moral purpose, however, should be the driving force of action, and action should be properly managed and planned. From a managerial perspective, it would be ideal for the school to appoint a person who could take full responsibility from the school's side to facilitate the transition programme, since it is a labour-intensive venture, involving partnership building, employment placement, visiting care facilities and coordinating learner-centred activities such as assessments, skills building and outings. Such a person, fulfilling the role of a transition manager, would play a vitally important role and could act as a change agent. However, this person would absolutely need the support and creative problem-solving abilities of a transition team. In the next, and final chapter, a final overview of the study will be provided and aspects such as limitations and recommendations addressed.

CHAPTER 8: SUMMARY, REFLECTIONS, SUGGESTIONS AND CONCLUSIONS

8.1 INTRODUCTION

Chapters 5, 6 and 7 were accounts of cycles 1, 2 and 3 of the research, respectively, discussing the challenges and needed supports of adolescents with SID, the supportive role of partnerships, and changes observed in the actual cases of five learners after having participated in the transition programme. Chapter 8 will provide an overview of the whole study and will reflect on the answers to the research questions in relation to the research. Limitations and further questions for research and practice will be discussed. Lastly, I will reflect on the contribution the study may make to the existing body of knowledge.

8.2 SUMMARY OF THE STUDY AND OVERVIEW OF FINDINGS

In this section, I will simultaneously summarise the content covered in the chapters and provide an overview of the findings in relation to the research questions.

8.2.1 Chapters 1–4: Framing the study with guiding theories and methodology

In Chapter 1, I set the scene for the study, covering core concepts, theories and guiding principles. The rationale for the study emanated from my personal and professional experience as a parent of two young adults with severe physical and intellectual disabilities and as a teacher in the field in South Africa. There seems to be a dire need for researched solutions to the post-school challenges these young adults face due to the lack of adequate transition planning and execution in the country. The questions that would frame the study were set as follows:

Main question:

How can family-school-community partnerships be promoted to foster learner-centred transition to adult life for youth with intellectual disabilities?

Sub-questions:

- What are the challenges and resulting support needs of adolescents with intellectual disability regarding transition to life after school?
- How can family-school-community partnerships better meet the support needs of adolescents with intellectual disability before and during transition?

- How can the knowledge created by this team enhance sustainable learner-centred transition planning for learners with severe intellectual disability?

In Chapter 2, the need for learner-centredness in transition programming was one of the core arguments. The chapter opened by benchmarking good practices apparent from salient transition studies in the field. Following the discussion of these sources, I proceeded to review literature on the concepts of self-determination and person-centred planning. Since a holistic framework for the study was essential, quality of life as an end goal for transition planning was covered in detail. To set the scene for the fact that the study is being conducted in a South African setting, I conducted a critical discussion of a South African transition study in the last part of the chapter.

In Chapter 3, the discussion revolved around those who surround the learner, reviewing literature on partnerships as a support measure for young adults with SID who are transitioning into adulthood. The discussion was conducted against the backdrop of Bronfenbrenner's ecological systems theory and included references to concepts related to social ecology, such as social inclusion, ecomaps and social capital. Some relevant South African socio-ecological challenges, such as poverty, as well as religious-cultural bias, were briefly discussed. I closed the chapter by referring to Ubuntu as a socially cohesive African viewpoint.

Chapter 4 justified the methodological choices of the study, covering the philosophical framework (critical realism), as well as other methodological issues such as the research design (PALAR), the selection of participants, data collection and data analysis methods, ethical issues and trustworthiness.

8.2.2 Chapters 5–7: Addressing each critical question

Chapters 5, 6 and 7 presented the findings of cycles 1, 2 and 3, respectively, conducted in a collaborative manner by the Action Learning Set, a group of seven people (myself included), in which, as facilitator, I initiated the discussions, organised the meetings and took the lead in ethically sensitive data collection measures such as individual interviews.

Chapter 5 presented the findings related to the first critical question: *What are the challenges and resulting support needs of adolescents with severe intellectual disability regarding transition to life after school?* Three sets of challenges and support needs were discussed, revolving around the themes of dignity, empowerment and inclusion. These themes related strongly to quality-of-life theory. Findings suggested that adolescents with

SID needed appropriate supports for them to be able to bridge the challenges around dignity, empowerment and inclusion, the end goal being to transition into a full and satisfying adult life.

Chapter 6 reported on Cycle 2 of the research, endeavouring to answer the second critical question: *How can family-school-community partnerships better meet the support needs of adolescents with intellectual disability before and during transition?* Following an ecological approach, the ALS investigated the different partnerships that could be utilised as support measures for the transition of young adolescents with SID. Data analysis showed that the key partnership in transition preparation, the partnership between the school and the family (more specifically the parents), was far from ideal, and that serious barriers existed. The ALS stressed the need to bridge challenges by reaching out to parents and families to make this partnership work, since parental expertise regarding their child's unique abilities and challenges is a crucial cornerstone of any kind of sustainable transition plan.

Regarding community partnerships, the ALS found that, when leaving school, a post-school support gap exists, especially regarding job coaches for young adults that have been placed in employment. The group identified the ideal roles and responsibilities of each partner (see Figure 7.1). Another post-school challenge was inadequate public disability rights awareness in South African society, resulting in people in public spaces having a skewed and biased outlook on the behaviour and abilities of people with SID. In the public service domain, the group found a disconnect between different government departments that are tasked to provide post-school support for people with SID.

Chapter 7 covered the third cycle, during which transition-related actions were undertaken with the five selected learners, based on the data collected during the first two cycles. The chapter was aimed at answering the third critical question: *How can the knowledge created by this team enhance sustainable learner-centred transition planning for learners with severe intellectual disability?* Individual transition plans were developed for the five learners and implemented by myself and various members of the ALS as required. The ALS then analysed these case studies to set up a transition planning process model, using a critical realist data analysis framework. The sustainability of the model was then interrogated, and challenges raised, as discussed below.

8.3 CHALLENGES BASED ON FINDINGS AND RESULTING IMPLICATIONS FOR PRACTICE

During the ALS discussions, various practical challenges were brought to the fore, such as the time and human resources to implement the process model, the need to allocate more time for life skills in the daily roster, the post-school support gap, the lack of education policies that could provide guidelines for transition planning and implementation, and dignity-related challenges at residential care centres and workshops. These challenges will now be discussed in turn.

8.3.1 Implementation challenges related to time and human resources

Based on the amount of time and human resources needed to implement the process model, the ALS suggested that the school might have to re-think the roles and responsibilities of some staff members. To fully implement a working transition programme, a transition manager, solely focused on the facilitation of all the activities related to transition, would be key to success. A transition team, consisting of educators *and* parents, would ideally be central to the collaborative planning and implementation of transition-related activities. Such activities would include visits to post-school facilities, the facilitation of parent information sessions, individual parent meetings and the implementation of the actions dictated by the individual transition plans of school leavers. Actions such as job sampling placements, the training of job coaches, engagements with employers and setting up a variety of transition supports for learners according to their individual needs would be part of the whole effort.

8.3.2 Implementation challenges related to curriculum focus

The ALS agreed that independence skills, home living skills, employability skills and community living skills, collectively referred to as instrumental activities of daily living, are of vital importance in transition-focused education. These skills are addressed in the subject Life Skills, but due to the full curriculum and the number of subjects that have to be covered, Life Skills has thus far been assigned too little time on the daily roster. This has the unintended consequence that the learners may leave school unable to apply basic skills such as telling the time, using a bank card, planning basic expenses, using public transport and shopping for basic resources. Practical measures might have to be put in place to rectify this skewed focus. This may include assigning more time to the subject, presenting in-service training to educators to empower them to plan in a transition-focused manner and facilitating regular real-life exposure to public settings.

Excursions to public spaces such as shops, restaurants and banks, and actions such as drawing money or boarding a bus or taxi are examples of such learning opportunities. Enough time should be allocated for senior learners to do job sampling and off-site job skills acquisition, since this is the only way for the learner to get exposure to the real-life demands of employment settings and to have the opportunity to assume adult roles and responsibilities.

8.3.3 Challenges related to employment support

The ALS identified a post-school support gap that is a serious barrier to sustained employment. Data emerging from the case studies showed that the role of job coaches was an indispensable post-school support measure. The cases of the two school leavers showed that employment support is needed way after the young adult with SID has left school. A job coach builds and maintains relationships between key partners and supports not only the learner in the acquisition of the needed skills, but also the employer, who might not feel comfortable to engage the parents of the person with SID regarding challenges experienced in the workplace. One of the suggestions of the ALS was that retired teachers with experience in teaching learners with SID could be appointed as job coaches since they already have the appropriate skills to play such a role.

8.3.4 Challenges related to transition-focused education policies and procedures

Thus far, education authorities in South Africa have viewed inclusion as a school-level challenge, prioritising policies related to the inclusion of learners with disabilities in mainstream schools. However, the ALS believes that this viewpoint should be expanded to the facilitation of *after-school inclusion into society*, including places of employment. Towards that aim, research-based policy guidance to schools is needed, providing a blueprint for the process to be followed before, during and after transition. Re-allocation of staff duties might be part of such a blueprint, since a transition manager who is tasked with the facilitation of the transition programme has been found to be central to the success of such an effort. Another seemingly small matter that needs to be addressed is the simplification of the process to apply for permission to undertake educational excursions related to job placements and the acquisition of community living skills. The current process, which involves the completion of a lengthy document a month before each trip, is more appropriate for occasional outings and difficult to sustain when taking learners out on a regular basis. Lastly, as part of its inclusive focus, the DBE might consider reaching out to other government departments to address some transition-related challenges, for example the acquisition of communication and mobility aids for after-school use, and the remuneration of job coaches.

8.3.5 Challenges related to residential centres and protected workshops

Since residential care centres and protected workshops are the post-transition destination of many of our learners, it is important to address potential threats to the dignity and human rights of young adults with SID attending these facilities. The Department of Social Development needs to provide clear practical and ethical guidelines to such facilities to ensure that practices that infantilise adults with SID or infringe on their human rights come to an end. Staff at these facilities mostly have good intentions and are unaware that something as simple as the way a person is addressed may lead to the perpetuation of disempowering attitudes. For example, the manager of one of the facilities we visited spoke of the adult residents as 'children'. Another facility prohibited the residents from having any money in their possession. A private facility that we visited required prospective attendees to be 'sterilised'! I found it astonishing that a facility could have such a sensitive, contentious and highly personal decision as an admission requirement! I am also of the opinion that these facilities need to find ways to integrate their attendees with society more. The places we visited were completely segregated and residents had little to no contact with the outside world. If it has not yet been done, the Department of Social Development could also liaise with the Department of Health about the placement of occupational therapy students that could help to work on more varied, stimulating daily programmes for these individuals, especially those with more physical challenges who are unable to work in workshops.

Another set of challenges and gains will now be discussed: Those related to the use of PALAR as research design.

8.4 REFLECTION ON PALAR AS THE DESIGN OF THIS STUDY: GAINS, CHALLENGES AND NEW INSIGHTS

Looking back, I feel I need to reflect on the different degrees of participation that I observed in the ALS members, as well as the role of these group members in the actions that were undertaken. The ALS members knew each other quite well, on a first-name basis, so this was a sound foundation for conducting productive group discussions. Still, since each member had their own priorities and daily tasks, the degree and quality of the participation of members varied from meeting to meeting and from action to action. Some members had skills that were needed at specific times. For example, the therapist conducted the individual sessions with the learners, and the Setswana teacher and I conducted most of the parent visits together. Others, like the principal and vice-principal, had management duties that often took their focus away from scheduled meetings.

This required me, as the PALAR facilitator, to keep looking for ways to engage and consult all members as we went along. In hindsight, I now believe that it would have been better to only involve the top management members in an advisory capacity and rather recruit members that were able to be more actively involved in meetings and other actions. The emotional support, honest varied viewpoints and constructive criticism of all ALS members were a great gain. It motivated me to press ahead when I was feeling fatigued and discouraged, since I had to have some new actions to report on by the time the next meeting was due.

Another insight that I gained from my experience with PALAR was that, in a participatory study, coordination is as important as participation. The group needed someone to coordinate the actions, blend the different people together and utilise their unique skills, making them see that they could all contribute to the ultimate result. An action group still needs an *individual* who can undertake the coordination of the effort.

During this study, I learnt that an action resulting in observable success is the most important trigger for learning, and that this learning, in turn, prompts change. When observing success resulting from an action undertaken, people start reflecting about what they have observed, asking questions, such as: Why did that work? How did that happen? Can we repeat that success? How can we repeat it? This is part of the iterative cycle of reflection and action, resulting in learning, that constitutes PALAR, which I had the privilege of experiencing first-hand. Even though the principal was unable to attend all the meetings, the successes that he observed prompted him to start a small-scale transition programme for the higher-functioning school leavers, offering them to stay at school a year longer and creating internal work placements in the school environment. Although this effort is not yet speaking to the need for social inclusion, self-determination and paid employment in the open labour market, the principal's suggestion is a start, and represents a willingness to facilitate positive change. The *sustainability* of change is another question. I believe that the actions undertaken in the study were a start, but that much more is needed to overcome the resistance to change displayed by staff members that were not in the ALS. This is even more true if one thinks of the wider context of the South African educational environment and the South African public opinion about people with SID.

The last gain of PALAR that I would like to discuss is related to the R at the end of the acronym: Research. Most members of the ALS are educators, practitioners who work with children in classrooms, who have never been involved in academic research before. Yet, their efforts have now resulted in researched results that contribute meaningfully to the body of knowledge on transition planning for learners with SID.

The PALAR design opens the door to people in real-life situations to contribute to research in a down-to-earth manner. This ensures that research does not result in impractical musings sitting on shelves, gathering dust, but that a real difference can be made in spaces and communities where it is sorely needed. Since they participated in the actions and the learning, they can take ownership of the results and take pride in the accomplishments of the group. PALAR is about learning how to find real-life answers to real-life challenges and about real-life actions to improve the lives of real-life people.

After having worked tirelessly on finding answers to my research questions, I have found that ever-emerging new questions vastly outnumber the answers already arrived at. I therefore wish to list some questions that arose from the study; questions that might warrant investigations by future researchers.

8.5 QUESTIONS ARISING FROM THE STUDY THAT MIGHT LEAD TO FUTURE RESEARCH

This study brought some themes to the fore that need further exploration. Some of the possible topics for future research could be the following:

- How can the principles of Ubuntu enhance social inclusion for people with SID in African communities?
- What are the experiences of employers regarding the role of a job coach in the workplace inclusion of a person with SID?
- How can parents of adolescents with SID be empowered to address religious, cultural and peer bias in communities?
- How can schools and after-school facilities partner to protect the dignity of young adults with SID?
- What actions can be taken to enhance the school-parent partnership at schools for learners with SID?
- How can parents of children with SID be empowered to set up community support nets that may lighten their burden of care?
- How can schools partner with public spaces to enhance the social inclusion of people with SID?

I believe that, while searching for answers to questions, the knowledge generated in the ALS contributed meaningfully to the current body of knowledge. These contributions will be discussed next.

8.6 CONTRIBUTIONS TO THE CURRENT BODY OF KNOWLEDGE AND TO THE GROWTH OF PARTICIPANTS

Three categories of contributions will be discussed: Theoretical contributions, methodological contributions and contributions towards the growth and learning of participants.

8.6.1 Theoretical contributions

The three themes discussed in Chapter 5 – dignity, empowerment and inclusion – are themes that are relevant in the South African context and may be relevant in other settings where some groupings in communities have not yet made the needed paradigm shifts regarding the recognition of the basic human needs of people with a disability. Using these three criteria, schools and other stakeholders catering for people with SID should weigh the actions they take to ensure that they are *really* working towards the quality of life of these individuals. If the school is using their most challenged children's photographs on promotional material that they send to sponsors, are they not compromising the dignity of these learners for financial gain? If class assistants do tasks *for* learners that are too 'slow', are they empowering these learners, or are they promoting learned helplessness? If learners with special needs are always either at school or at home, never in shops, churches or other public spaces because it is too inconvenient, are we working towards inclusion, or are we promoting exclusion? If the school's transition programme consists of handing lists of care centres to parents a month or two before the learners need to leave school, are they empowering learners and parents, are they working towards inclusion, or are they contributing to the notion that people with SID have only one possible post-school destination that involves being segregated from their community? These are questions that need to be raised continuously while we work with stakeholders in the field of disability.

In Chapter 6, the challenges that are underlying causes of the breakdown of the relationship of trust between parents and school staff, which prevent the two parties from forging a working partnership for the benefit of learners with SID, came to the fore. These are challenges that are very much present in the South African context, but could also be present in other similar contexts. School staff members need to take note of these challenges and show commitment and empathy in their efforts to reach out to parents. If there is no partnership between the school and the family, any efforts from the school's side to transition young adolescents into adulthood, including places of employment, will almost certainly be doomed to fail. In fact, the admission from another school's deputy principal that most of their transition efforts fail since parents do not continue what had been started, sparked my interest in the issue of partnerships in the first place.

The role of the job coach in employment success is another key factor that emerged in this study. Although it is still unclear how the appointment and remuneration of job coaches would be managed, continued after-school job coaching by a third party (neither the school nor the parent) seems to be indispensable.

In Chapter 7, the question of the sustainability of changes effected by this PALAR study came up. The conclusion was that action precedes learning, which leads to change, but that sustainable change needs the continued work of one impassioned individual, supported by a transition action group. An action learning group is an excellent way to effect learning and change, but it still needs an action leader to coordinate and direct the effort.

Lastly, it is hoped that the transition process model, compiled from the data collected in this study, might be a blueprint for any school teaching learners with SID who wants to work on its transition programming. Although it is far from perfect, it is a guideline based not only on literature, but also on the experiences of stakeholders in the field who have the interests of people with SID at heart.

8.6.2 Methodological contributions

Although it was not through choice, but through necessity, spurred by the challenges of the Coronavirus pandemic, the use of voice notes as data collection measure was found to be a surprisingly effective method to collect rich data and even to prompt group discussion. I believe this method could be of use in circumstances where face-to-face interviews and meetings are not possible.

I was not familiar with PALAR before I commenced with this study, but even though I think my efforts were far from perfect, I believe that my explanation of and reflection on the PALAR process contributes to the body of knowledge around PALAR. It is hoped that future researchers may be able to gain from my experiences. Conducting a PALAR study benefitted my personal growth as well, since I am introverted by nature and prefer to do things on my own. Having to facilitate communication and collaboration in the group opened my eyes to the value of multiple voices and points of view while working towards a common goal.

8.6.3 Contributions towards the growth and learning of participants

The case studies are evidence that the primary and secondary participants all benefitted from the research. The learners benefitted in that their self-image improved, having accomplished feats such as holding a job, making and selling a product or rendering a paid service.

The parents benefitted in that they were facilitated towards actively building the future of their young adult with SID. The ALS members benefitted in that they experienced growth and contributed towards the improvement of their own school's transition planning.

Despite making contributions to the field, some limitations of the study need to be acknowledged.

8.7 LIMITATIONS

COVID-19 was a limiting factor, since many people were working from home and the country was under lockdown, which meant that phone calls and emails to possible interviewees, especially in government departments, often went unanswered. The lockdown levels restricted our ability to proceed with our planned actions and we had to repeatedly adjust our action plans. During the third cycle of the study, we had a very short period to try and accomplish some goals with the two 18-year-olds between the period when the schools re-opened after the lockdown period and their last day of school. The next year was characterised by school disruptions once more and learners attended school on a rotational basis. One of the five learners took a long time to return to school, due to parental fears regarding the virus. Due to this, we could not bring all the projects to completion before it was time to end the formal data collection. Still, the cases yielded enough data until they were reported for data analysis. We decided to continue working on the completion of the projects as part of the school's own transition research, even though the formal research and data analysis had been concluded.

Since this was a small-scale qualitative study, conducted in a South African context with a specific set of participants, findings may not be generalisable to other settings that do not resemble the context of the study.

8.8 CONCLUSION

In conclusion, I would like to refer to the main question: *How can family-school-community partnerships foster learner-centred transition to adult life for youth with intellectual disabilities?* The collaborative nature of the research design has been instrumental in setting up partnerships to support youths with SID before, during and after transition into adulthood, as has been demonstrated in the five cases. Each partner plays a unique and indispensable role in the journey of the young adult with SID during their transition towards adulthood (see Figure 7.1).

The study showed that people with SID need to be enabled to voice their own dreams and preferences – therefore learner-centredness and self-determination are non-negotiable

principles. The therapist who was part of the ALS ensured that the adolescents were enabled to make career-related choices through a picture-based career interest questionnaire.

All transition-related actions were carried out according to an individualised, but holistic Individual Transition Plan based on the learner's unique preferences and needs, as well as the parents' information and valued opinion.

For young people with SID, transition cannot happen within a few months. These adolescents need several years to acquire the skill set they need to be fully functional adults who are ready to play a productive role in society. This includes not only employability skills, but also self-care skills, social skills, home living skills and community living skills, which should be worked on long before the learner leaves school. The ALS found that these skills need to be prioritised in transition-focused education (ideally mandated by appropriate DBE policies).

It is my sincere wish that the results of the study may contribute towards a much-needed paradigm shift in South African communities regarding the rights, needs and potential of people with SID and that collaborative partnerships will continue to be instrumental in empowering these young individuals towards a dignified, quality life, and inclusion in a society where all people are viewed as humans in their own right, regardless of their needs or challenges.

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ANNEXURES

APPENDIX 1: ETHICS APPROVAL

APPENDIX 1.1: COMBER SCIENTIFIC COMMITTEE APPROVAL

Faculty Education:
Research & Innovation - M&D Administration

Private Bag X1290, Potchefstroom
South Africa 2520

Tel: 018 299 4770 / 018 285 2101
Email: 20505957@nwu.ac.za

Web: http://www.nwu.ac.za

27 May 2019

To Whom It May Concern

RE: Student name: **Ms MJ Malan;** Student number: **10341447**
(PhD – Educational Psychology)

I hereby confirm that the research proposal of the above-mentioned student was approved by the COMBER Scientific Committee meeting of **22 May 2019.**

The Research title referred to Research and Innovation committee for approval is as follows:

Promoting family-school-community partnerships to foster learner-centred transition into adult life for youth with severe intellectual disability

Should you have further enquiries in this regard, you are welcome to contact Ms Ronélle van Staden at 018 285 2101 or by email at 20505957@nwu.ac.za, alternatively you may contact Prof L Wood at 018 299 4770 or by email at Lesley.Wood@nwu.ac.za.

Yours sincerely

COMBER Scientific Committee

Original details: (20505957) C:\Users\20505957\NWUNextcloud\SNTO(X)\Faculty of Education\Letters\2019\Proposals\COMBER\Confirmation of Proposal Approval.docm
27 May 2019

File reference: 9.4

APPENDIX 1.2: ETHICAL CLEARANCE LETTER

Private Bag X1290, Potchefstroom
South Africa 2520

Tel: 086 016 9698
Web: http://www.nwu.ac.za/

North-West University Education, Management and Economic Sciences, Law. Theology, Engineering and Natural Sciences Research Ethics Office (NWU-EMELTEN-REC)

Tel: +2718 299 4707
Email: lukas.meyer@nwu.ac.za

14 January 2020

ETHICS APPROVAL LETTER OF STUDY

Based on approval by the North-West University Education, Management and Economic Sciences, Law. Theology, Engineering and Natural Sciences Research Ethics Committee (NWU-NWU-EMELTEN-REC) on 18/11/2019, the NWU-EMELTEN-REC hereby approves your study as indicated below. This implies that the NWU-EMELTEN-REC grants its permission that, provided the general and specific conditions specified below are met and pending any other authorisation that may be necessary, the study may be initiated, using the ethics number below.

Study title: Promoting family-school-community partnership to foster learner-centered transition into adult life for youth with severe intellectual disability
Principal Investigator/Study Supervisor/Researcher: Prof L Wood
Student: Mrs. M Malan

Ethics number:

N	W	U	-	0	0	5	3	7	-	1	9	-	A	2
Institution				Study Number						Year			Status	

Status: S = Submission; R = Re-Submission; P = Provisional Authorisation; A = Authorisation

Application Type: Single Study
Commencement date: **14/01/2020**
Expiry date: 14/01/2021

Risk: Greater than minimal but provides the prospect of direct benefit.

Approval of the study is provided for a year, after which continuation of the study is dependent on receipt and review of annual monitoring report and the concomitant issuing of a letter of continuation.

General conditions:

While this ethics approval is subject to all declarations, undertakings and agreements incorporated and signed in the application form, the following general terms and conditions will apply:

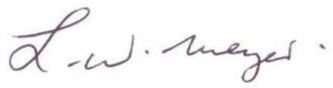
- *The principal investigator/study supervisor/researcher must report in the prescribed format to the NWU-EMELTEN-REC:*
  - *Annually on the monitoring of the study, whereby a letter of continuation will be provided annually, and upon completion of the study; and*
  - *without any delay in case of any adverse event or incident (or any matter that interrupts sound ethical principles) during the course of the study.*
- *The approval applies strictly to the proposal as stipulated in the application form. Should any amendments to the proposal be deemed necessary during the course of the study, the principal investigator/study supervisor/researcher must apply for approval of these amendments at the NWU-EMELTEN-REC, prior to implementation. Should there be any deviations from the study proposal without the necessary approval of such amendments, the ethics approval is immediately and automatically forfeited.*

- *Annually a number of studies may be randomly selected for active monitoring.*
- *The date of approval indicates the first date that the study may be started.*
- *In the interest of ethical responsibility, the NWU-EMELTEN-REC reserves the right to:*
  - *request access to any information or data at any time during the course or after completion of the study;*
  - *to ask further questions, seek additional information, require further modification or monitor the conduct of your research or the informed consent process;*
  - *withdraw or postpone approval if:*
    - *any unethical principles or practices of the study are revealed or suspected;*
    - *it becomes apparent that any relevant information was withheld from the NWU-EMELTEN-REC or that information has been false or misrepresented;*
    - *submission of the annual monitoring report, the required amendments, or reporting of adverse events or incidents was not done in a timely manner and accurately; and/or*
    - *new institutional rules, national legislation or international conventions deem it necessary.*
- *NWU-EMELTEN-REC can be contacted for further information via Ethics-EMELTEN-apply@nwu.ac.za or 018 299 4707*

The NWU-EMELTEN-REC would like to remain at your service and wishes you well with your study.

Please do not hesitate to contact the NWU-EMELTEN-REC for any further enquiries or requests for assistance.

Yours sincerely,



Prof Lukas Meyer
Chairperson NWU-EMELTEN-REC

Current details:(23239522) G:\My Drive\9. Research and Postgraduate Education\9.1.5.4 Templates\9.1.5.4.2_NWU-HREC_EAL.docm
20 August 2019

File Reference: 9.1.5.4.2

APPENDIX 1.3: REQUEST TO CONDUCT RESEARCH

Private Bag X1290, Potchefstroom
South Africa 2520
Tel: +2718 299-1111/2222
Fax: +2718 299-4910
Web: http://www.nwu.ac.za

The Faculty of Health Sciences Ethics Office of the North-West University is acknowledged for the use of their document with minor adjustments made by the North-West University Education, Management and Economic Sciences, Law, Theology, Engineering and Natural Sciences Research Ethics Committee (NWU-EMELTEN-REC).

NWU-EMELTEN-REC STAMP

REQUEST TO CONDUCT RESEARCH AT ALMA SCHOOL (TSHWANE NORTH DISTRICT)

TITLE OF THE RESEARCH STUDY:

Promoting family-school-community partnerships to foster learner-centred transition into adult life for youth with severe intellectual disability.

ETHICS REFERENCE NUMBERS:

PRINCIPAL INVESTIGATOR: Prof Lesley Wood

POST GRADUATE STUDENT: Marietha Malan

ADDRESS:

CONTACT NUMBER:

Your permission is requested to conduct an **action research project (PALAR project)** that forms part of a doctoral study. This study has been approved by the North-West University Education, Management and Economic Sciences, Law, Theology, Engineering and Natural Sciences Research Ethics Committee (NWU.....) and will be conducted according to the ethical guidelines and principles of Ethics in Health Research: Principles,

Processes and Structures (DoH, 2015) and other international ethical guidelines applicable to this study.

1.1 WHAT IS THIS RESEARCH STUDY ABOUT?

Transitioning young adolescents with intellectual disability from school to adult life remains a challenge, particularly in contexts of social and economic disadvantage.

- *We plan to investigate how partnerships between the family, the school and the community may support the adolescent with intellectual disability to transition successfully into adult life.*
- *The research will take place by means of participatory action research. A core group of staff members, parents and community stakeholders will act as co-researchers in order to arrive at an end result that is practical and sustainable. Group sessions will take place at Alma School at a time convenient for all participants. Experienced researchers trained in participatory action research (PALAR) will be included in this study.*
- *A group of learners will be selected, with parental permission, to participate in the study. With the help of a school therapist, they will be evaluated in order to establish what their support needs and strong points are. Because the study is learner-centred, the learners will be given the opportunity to share their future vision and preferences with regard to adult life. The ultimate aim is for the learners to lead a quality adult life.*
- *The parents of the selected learners will be interviewed in order to obtain a holistic picture of the learners' transition challenges. Parents will be actively involved in their children's transition planning.*
- *Partnerships with community stakeholders will be fostered in order to bridge the gap between school and adult life.*
- *Learners who have the potential to be employed, will be exposed to different job opportunities with the support of staff members.*
- *After data collection, the study will result in the development of a transition planning methodology that could benefit not only the learners of the specific school where the study was conducted, but also learners attending other LSEN or full service schools.*

1.2 ARE THERE RISKS INVOLVED IN THE STUDY AND WHAT WILL BE DONE TO PREVENT THEM?

- *Working with vulnerable participants such as learners with intellectual disability always carries a measure of risk. Learners may not understand what is expected of them and may become anxious or feel pressurized to take part in the study even though they do not want to. To address this, the therapist who works with them on a daily basis will take the lead in all interactions with them. Questionnaires will be presented by means of picture communication symbols, which all learners should understand quite well (example included).*
- *When taking the learners out to do job sampling, all the normal precautions will be taken as is usually the case for educational outings. This involves the permission*

of the Department, the permission of the parents and the use of experienced and trained drivers and official school vehicles. Support staff will accompany the learners at all times and no learner will be exposed to any potential dangerous work situation.

1.3 HOW WILL WE PROTECT CONFIDENTIALITY AND WHO WILL SEE THE FINDINGS?

- *Participation will be anonymous. Participants' names will never be used when reporting the findings. Instead, the participants will be numbered and, for example, referred to as ALS member 1. We respect participants' privacy, so we will ensure that no unwanted persons have access to sensitive or personal information. All hard copies of documents will be locked up and electronic data password protected. T device and electronically saved, where it will be password protected. Data will be stored for a period of 15 years.*
- *All participants, including the learners, will be informed of what the study entails and no participant will be involved in the study unless he/she has given informed consent. Participation is entirely voluntary and any participant may withdraw whenever he or she feels the need to do so.*

What will happen with the findings or samples and how will you know about the results of this research?

- *The findings of this project are only intended for this specific study. If any decision is taken to use the findings for future studies, those studies will first have to be approved by the ethical committee of the university and the data will again be handled in a confidential manner according to set standards.*
- *As soon as the results of the research are known, the Action Learning Group will present them to all stakeholders, including a representative or representatives of the Tshwane North District and the governing body of the school.*

Is there anything else that you should know or do?

- You can contact Marietha Malan at 0744930479 if you have any further questions, or you may contact Prof. Lesley Wood at Lesley.wood@nwu.ac.za.
- You can also contact the North-West University Education, Management and Economic Sciences, Law, Theology, Engineering and Natural Sciences Research Ethics Committee via Mrs Marlize Bisschoff at 018 299 4707 or marlize.bisschoff@nwu.ac.za if you have any concerns that were not answered about the research or if you have complaints about the research.

I hereby request your permission to conduct this research project, as I sincerely believe that it could really make a difference in the lives of learners with severe intellectual disability.

Thank you for your kind consideration.

Friendly regards,
Marietha Malan

APPENDIX 1.4: RESEARCH APPROVAL LETTER (GAUTENG DEPARTMENT OF EDUCATION)

GAUTENG PROVINCE
Department: Education
REPUBLIC OF SOUTH AFRICA

8/4/4/1/2

GDE RESEARCH APPROVAL LETTER

Date:	**22 January 2020**
Validity of Research Approval:	**04 February 2020 – 30 September 2020** **2019/372**
Name of Researcher:	**Malan M.J**
Address of Researcher:	**1216B Dickenson Avenue**
	Waverley
``	**Pretoria, 0186**
Telephone Number:	**012 335 0252/ 074 493 0479**
Email address:	**mariethamalan0@gmail.com**
Research Topic:	**Promoting family-school-community partnerships to foster learner-centred transition into adult life for youth with severe intellectual disability.**
Type of qualification	**PhD**
Number and type of schools:	**One LSEN School**
District/s/HO	**Tshwane North**

Re: Approval in Respect of Request to Conduct Research

This letter serves to indicate that approval is hereby granted to the above-mentioned researcher to proceed with research in respect of the study indicated above. The onus rests with the researcher to negotiate appropriate and relevant time schedules with the school/s and/or offices involved to conduct the research. A separate copy of this letter must be presented to both the School (both Principal and SGB) and the District/Head Office Senior Manager confirming that permission has been granted for the research to be conducted.

The following conditions apply to GDE research. The researcher may proceed with the above study subject to the conditions listed below being met. Approval may be withdrawn should any of the conditions listed below be flouted:

22/01/2020

1

Making education a societal priority

Office of the Director: Education Research and Knowledge Management
7th Floor, 17 Simmonds Street, Johannesburg, 2001
Tel: (011) 355 0488
Email: Faith.Tshabalala@gauteng.gov.za
Website: www.education.gpg.gov.za

1. *Letter that would indicate that the said researcher/s has/have been granted permission from the Gauteng Department of Education to conduct the research study.*
2. *The District/Head Office Senior Manager/s must be approached separately, and in writing, for permission to involve District/Head Office Officials in the project.*
3. *A copy of this letter must be forwarded to the school principal and the chairperson of the School Governing Body (SGB) that would indicate that the researcher/s have been granted permission from the Gauteng Department of Education to conduct the research study.*
4. *A letter / document that outline the purpose of the research and the anticipated outcomes of such research must be made available to the principals, SGBs and District/Head Office Senior Managers of the schools and districts/offices concerned, respectively.*
5. *The Researcher will make every effort obtain the goodwill and co-operation of all the GDE officials, principals, and chairpersons of the SGBs, teachers and learners involved. Persons who offer their co-operation will not receive additional remuneration from the Department while those that opt not to participate will not be penalised in any way.*
6. *Research may only be conducted after school hours so that the normal school programme is not interrupted. The Principal (if at a school) and/or Director (if at a district/head office) must be consulted about an appropriate time when the researcher/s may carry out their research at the sites that they manage.*
7. *Research may only commence from the second week of February and must be concluded before the beginning of the last quarter of the academic year. If incomplete, an amended Research Approval letter may be requested to conduct research in the following year.*
8. *Items 6 and 7 will not apply to any research effort being undertaken on behalf of the GDE. Such research will have been commissioned and be paid for by the Gauteng Department of Education.*
9. *It is the researcher's responsibility to obtain written parental consent of all learners that are expected to participate in the study.*
10. *The researcher is responsible for supplying and utilising his/her own research resources, such as stationery, photocopies, transport, faxes and telephones and should not depend on the goodwill of the institutions and/or the offices visited for supplying such resources.*
11. *The names of the GDE officials, schools, principals, parents, teachers and learners that participate in the study may not appear in the research report without the written consent of each of these individuals and/or organisations.*
12. *On completion of the study the researcher/s must supply the Director: Knowledge Management & Research with one Hard Cover bound and an electronic copy of the research.*
13. *The researcher may be expected to provide short presentations on the purpose, findings and recommendations of his/her research to both GDE officials and the schools concerned.*
14. *Should the researcher have been involved with research at a school and/or a district/head office level, the Director concerned must also be supplied with a brief summary of the purpose, findings and recommendations of the research study.*

The Gauteng Department of Education wishes you well in this important undertaking and looks forward to examining the findings of your research study.

Kind regards

.....

Mrs Faith Tshabalala
Acting Director: Education Research and Knowledge Management

DATE: 22/01/2020

Office of the Director: Education Research and Knowledge Management
7th Floor, 17 Simmonds Street, Johannesburg, 2001
Tel: (011) 355 0488
Email: Faith.Tshabalala@gauteng.gov.za
Website: www.education.gpg.gov.za

APPENDIX 1.5: PERMISSION LETTER (DISTRICT OFFICE)

GAUTENG PROVINCE
EDUCATION
REPUBLIC OF SOUTH AFRICA

Enquiries: A DAWOOD/ A JOOSTE
Sub-Directorate: ISSP
Office Number: 124
Tel: 012 543 4315/16
Email: Ashraf.Dawood@gauteng.gov.za / Ann.Jooste@gauteng.gov.za
Ref: 31/08/18

TO	:	**THE PRINCIPAL** **ALMA SCHOOL**
FROM	:	**MS THEA COETSER** **DISTRICT DIRECTOR: TSHWANE NORTH**
DATE	:	**30 JANUARY 2020**
SUBJECT	:	**PERMISSION GRANTED TO CONDUCT RESEARCH**

Dear colleagues

It is our pleasure to inform you that the District Office grants Ms M Malan permission to conduct research at your school on the topic: **'Promoting family-school-community partnerships to foster learner-centred transition into adult life for youth with severe intellectual disability'.**

She may only conduct the research **after contact time** to protect teaching and learning activities. The principal must be consulted regarding an appropriate time to conduct the research.

She is personally responsible for providing and utilizing her own research resources. Participants names must not appear in the research report and all appropriate ethical measures must be implemented to protect them.

Tshwane North District expects her to submit, upon completion, a summary of her research findings as stipulated in **Clause No. 14 of the GDE letter of approval she received.**

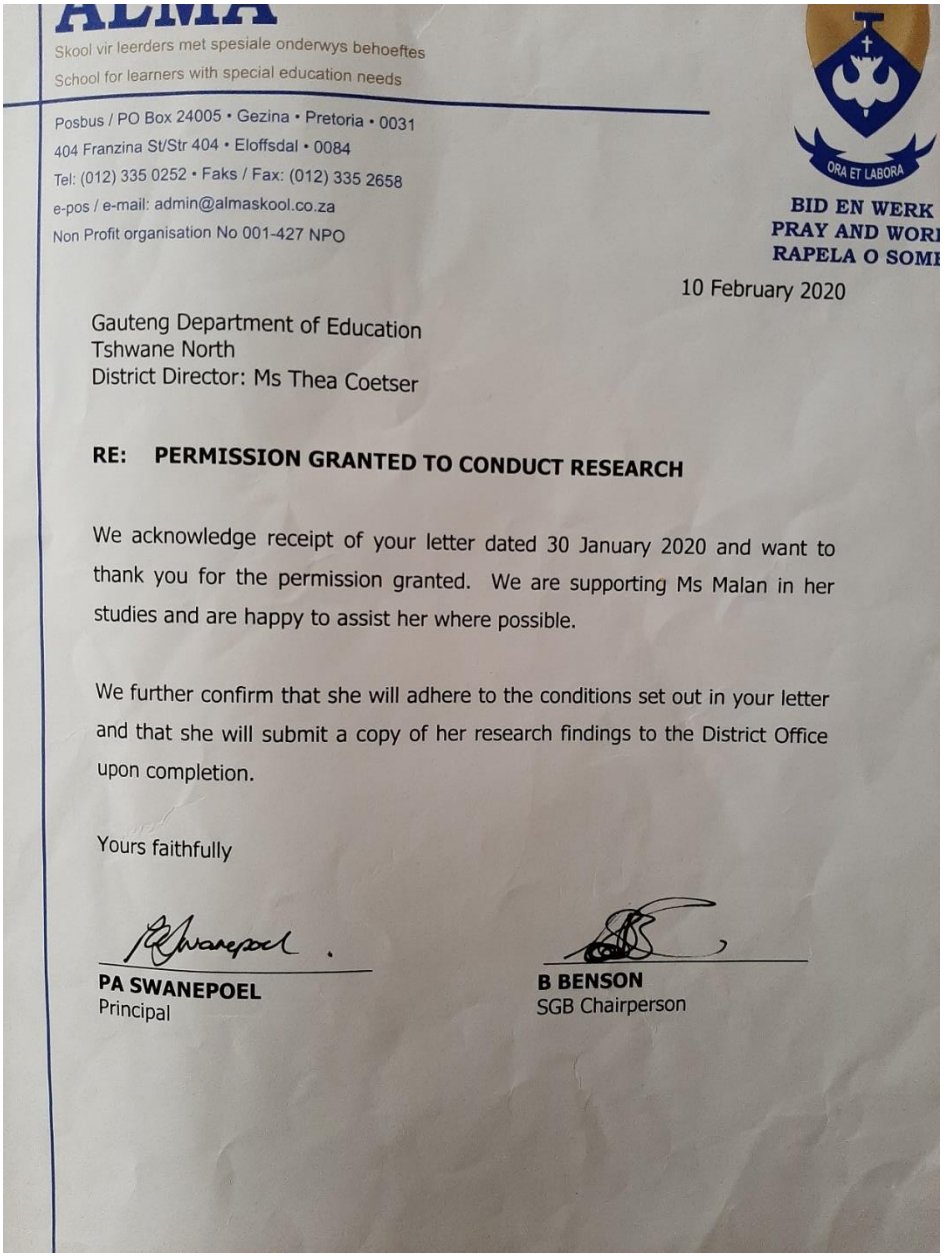
The District appreciates your contribution towards the enhancement of education in the province and District.

Regards

MS THEA COETSER
DISTRICT DIRECTOR: TSHWANE NORTH
04/02/2020

MS THEA COETSER
DISTRICT DIRECTOR: TSHWANE NORTH
Tel: (012) 543 4302, Cell: 083 346 6963, Fax: 086 633 4568 | Email: Thea.Coetser@gauteng.gov.za
Wonderboom Junction Mall, 1st Floor, Corner Lavender & Lavender West Road,
Wonderboom, 0066, Private Bag X945, Pretoria, 0001
www.education.gpg.gov.za | Call Centre: 0800 005 175

APPENDIX 1.6: LETTER FROM THE SCHOOL



ALMA

Skool vir leerders met spesiale onderwys behoeftes
School for learners with special education needs

Posbus / PO Box 24005 • Gezina • Pretoria • 0031
404 Franzina St/Str 404 • Eloffsdal • 0084
Tel: (012) 335 0252 • Faks / Fax: (012) 335 2658
e-pos / e-mail: admin@almaskool.co.za
Non Profit organisation No 001-427 NPO

ORA ET LABORA

BID EN WERK
PRAY AND WORK
RAPELA O SOMA

10 February 2020

Gauteng Department of Education
Tshwane North
District Director: Ms Thea Coetser

RE: PERMISSION GRANTED TO CONDUCT RESEARCH

We acknowledge receipt of your letter dated 30 January 2020 and want to thank you for the permission granted. We are supporting Ms Malan in her studies and are happy to assist her where possible.

We further confirm that she will adhere to the conditions set out in your letter and that she will submit a copy of her research findings to the District Office upon completion.

Yours faithfully

PA SWANEPOEL
Principal

B BENSON
SGB Chairperson

APPENDIX 1.7: SAMPLE OF ACTION LEARNING SET CONSENT FORM

Private Bag X1290, Potchefstroom
South Africa 2520
Tel: +2718 299-1111/2222
Fax: +2718 299-4910
Web: http://www.nwu.ac.za

The Faculty of Health Sciences Ethics Office of the North-West University is acknowledged for the use of their document with minor adjustments made by the North-West University Education, Management and Economic Sciences, Law, Theology, Engineering and Natural Sciences Research Ethics Committee (NWU-EMELTEN-REC).

NWU-EMELTEN-REC Stamp

INFORMED CONSENT DOCUMENTATION FOR MEMBERS OF THE ACTION LEARNING GROUP

TITLE OF THE RESEARCH STUDY:

Fostering family-school-community partnerships to enhance learner-centred transition support for adolescents with intellectual disability

ETHICS REFERENCE NUMBERS:

PRINCIPAL INVESTIGATOR: Prof Lesley Wood

POST GRADUATE STUDENT: Marietha Malan

ADDRESS: Prof L. Wood: 11 Hoffman St, Potchefstroom
M.J. Malan: 1216B Dickenson Ave, Waverley, Pretoria

CONTACT NUMBER: Prof. L. Wood: 018 299 4770
M.J. Malan: 0744930479

You are being invited to take part in an **action research project (PALAR project)** that forms part of a doctoral study. Please take some time to read the information presented here, which will explain the details of this study. Please ask the researcher or person explaining the research to you any questions about any part of this study that you do not fully understand. It is very important that you are fully satisfied that you clearly understand

what this research is about and how you might be involved. Also, your participation is **entirely voluntary** and you are free to say no to participate. If you say no, this will not

affect you negatively in any way whatsoever. You are also free to withdraw from the study at any point, even if you do agree to take part now.

This study has been approved by the **North-West University Education, Management and Economic Sciences, Law, Theology, Engineering and Natural Sciences Research Ethics Committee (NWU.....)** and will be conducted according to the ethical guidelines and principles of Ethics in Health Research: Principles, Processes and Structures (DoH, 2015) and other international ethical guidelines applicable to this study. It might be necessary for the research ethics committee members or other relevant people to inspect the research records.

What is this research study all about?

- *We plan to investigate how partnerships between the family, the school and the community may support the adolescent with intellectual disability to transition successfully into adult life. A learner-centred transition plan will be developed for the selected learners. The ultimate aim is for the learners to lead a quality adult life.*

- *This study will be conducted in Pretoria. Group sessions will take place at the school at a time convenient for all participants. Experienced researchers trained in participatory action research (PALAR) will be included in this study.*

Why have you been invited to participate?

- *You have been invited to be part of this research because you are a stakeholder that can make a valuable contribution in this study and because you have indicated interest in addressing the issue of transition. The group will consist of staff members of the school (Post level 1, 2 and 3 teachers and a therapist) and parents. During this study, we will work on a transition plan for up to 6 selected learners in order to prepare them for transition into adult life. The group will be collaborating actively in the process, acting as co-researchers. The reason for this is that we wish the results of the study to be of practical value in real life, more specifically in the actual school setting where the study is conducted and in the actual communities of the learners that are involved.*

What will be expected of you?

- *You will be expected to take part in a group session once a month where we will do some planning and will reflect on what we have learnt.*
- *Your help may also be needed when interviews with participants are conducted. In such cases your role will be discussed in detail before the interview.*
- *The occupational therapist will be involved in the evaluation of the learners and their personal interviews.*
- *We may involve members of the group or other staff members when taking learners out for work placement.*

Will you gain anything from taking part in this research?

- *The gains of this study are more altruistic than personal You will contribute to an improved transition plan for the school and will experience the satisfaction of seeing our learners have a better quality of life after school.*

- *The study will also create a better community awareness of the challenges and strong points of people with disabilities.*

Are there risks involved in you taking part in this research and what will be done to prevent them?

- *No risks to you yourself are foreseen for your participation in the research.*

How will we protect your confidentiality and who will see your findings?

- *Your participation will be anonymous. That means that your name will never be used when reporting the findings, unless you wish to be specifically mentioned for your contribution. Instead, the participants will be numbered and, for example, referred to as ALS member 1. We respect your privacy, so we will ensure that no unwanted persons have access to sensitive or personal information. All hard copies of documents will be locked up and electronic data password protected. As soon as data has been transcribed, it will be deleted from the recording device and electronically saved, where it will be password protected. Data will be stored for a period of 15 years.*

What will happen with the findings or samples?

- *The findings of this project are only intended for this specific study. If any decision is taken to use the findings for future studies, those studies will first have to be approved by the ethical committee of the university and the data will again be handled in a confidential manner according to set standards,*

How will you know about the results of this research?
Will you be paid to take part in this study and are there any costs for you?

There will be no costs involved for you, if you do take part in this study, except for the travel expenses of the two parent members, which will be attended to. However, snacks will be available at group sessions.

Is there anything else that you should know or do?

- You can contact Marietha Malan at 0744930479 if you have any further questions or have any problems, or you may contact Prof. Lesley Wood at Lesley.wood@nwu.ac.za.
- You can also contact the North-West University Education, Management and Economic Sciences, Law, Theology, Engineering and Natural Sciences Research Ethics Committee via Mrs Marlize Bisschoff at 018 299 4707 or marlize.bisschoff@nwu.ac.za if you have any concerns that were not answered about the research or if you have complaints about the research.
- You will receive a copy of this information and consent form for your own purposes.

Declaration by participant

By signing below, I …… agree to take part in the research study titled:

Fostering family-school-community partnerships to enhance learner-centred transition support for adolescents with intellectual disability

I declare that:

- I have read this information/it was explained to me by a trusted person in a language with which I am fluent and comfortable.
- The research was clearly explained to me.
- I have had a chance to ask questions to both the person getting the consent from me, as well as the researcher and all my questions have been answered.
- I understand that taking part in this study is **voluntary** and I have not been pressurised to take part.
- I may choose to leave the study at any time and will not be handled in a negative way if I do so.
- I may be asked to leave the study before it has finished, if the researcher feels it is in the best interest, or if I do not follow the study plan, as agreed to.

Signed at (*place*) ..... on (*date*) …… 20....

....

Signature of participant **Signature of witness**

Declaration by person obtaining consent

I *(name)* …… declare that:

- I clearly and in detail explained the information in this document to

  ……

- I did/did not use an interpreter.
- I encouraged him/her to ask questions and took adequate time to answer them.
- I am satisfied that he/she adequately understands all aspects of the research, as discussed above
- I gave him/her time to discuss it with others if he/she wished to do so.

Signed at (*place*) ..... on (*date*) …… 20....

.....
Signature of person obtaining consent

Declaration by researcher

I *(name)* …… declare that:

- I explained the information in this document to ……..
- I did/did not use an interpreter
- I encouraged him/her to ask questions and took adequate time to answer them
- The informed consent was obtained by an independent person.
- I am satisfied that he/she adequately understands all aspects of the research, as described above.
- I am satisfied that he/she had time to discuss it with others if he/she wished to do so.

Signed at (*place*) ..... on (*date*) …… 20....

.....
Signature of researcher

APPENDIX 1.8: ASSENT FORM (SEVERE INTELLECTUAL DISABILITY LEARNER)

Private Bag X1290, Potchefstroom
South Africa 2520
Tel: +2718 299-1111/2222
Fax: +2718 299-4910
Web: http://www.nwu.ac.za

The Faculty of Health Sciences Ethics Office of the North-West University is acknowledged for the use of their document with minor adjustments made by the North-West University Education, Management and Economic Sciences, Law, Theology, Engineering and Natural Sciences Research Ethics Committee (NWU-EMELTEN-REC).

NWU-EMELTEN-REC Stamp

ASSENT DOCUMENTATION FOR ADOLESCENTS WITH INTELLECTUAL DISABILITY

TITLE OF THE RESEARCH STUDY:

Fostering family-school-community partnerships to enhance learner-centred transition support for adolescents with intellectual disability

ETHICS REFERENCE NUMBERS:

PRINCIPAL INVESTIGATOR: Prof Lesley Wood

POST GRADUATE STUDENT: Marietha Malan

ADDRESS:

CONTACT NUMBER:

PLEASE READ THE FOLLOWING LETTER TO THE LEARNER:

You are being invited to take part in a **research project.** This letter is explaining what the study is about. Please ask the person explaining the research to you any questions about anything in the letter that you do not understand. You may decide whether or not you want to take part. You are free to say no to participate. If you say no, no one will be angry at you. You are also free to stop taking part in the study any time, even if you do agree to take part now.

What is this research study all about?

- *We want to find out how we can help our learners to have a good life when they leave school. We would like you to be ready for the world outside, make new friends, be as independent as possible and to do things you love. To be able to do this, we have to make good plans long before you leave school. We will need your help to find out what you like and what your strong points are.*

What will be expected of you?

- *Your therapist will ask you some questions and do some activities and games with you to find out what your talents are and what you would like to do one day.*
  We will also be talking to your parents and other people who may be able to help you to reach your goals by the time you leave school.

Can something bad happen to me if I do this?

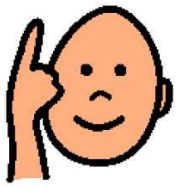
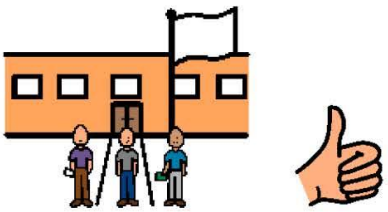
- *The teachers and therapist of the school will be very careful and will make sure that you are always very safe. We may visit some work places, but just like any other outing, one of our bus drivers, who can drive very well, will drive the bus and a teacher and assistant will go with us to help and make sure that you are safe.*
- *We will also talk to your parents and find out if they are fine with it if you take part in the study.*

Will you tell anyone else what I have told you?

- *No one else will know what you have been telling us. When we write down our notes, we will make sure that we do not use your name. Someone who reads the research will not know that we have written something about you.*

Is there anything else that you should know or do?

- *You can ask teacher Marietha Malan if you have any further questions or have any problems.*
- *Please answer the questions on the letter below to give your permission to take part in the research*:

	Did anyone read the letter to you? ✓ Yes ✗ No
	Did you understand you can choose to do this? ✓ Yes ✗ No
	Did you understand you can stop if you want? ✓ Yes ✗ No
	Do you have any questions? ✓ Yes ✗ No
	Do you understand the questions asked? ✓ Yes ✗ No
	Do you want to help us to think about what you want to do after school? ✓ Yes ✗ No

Signature: _____Signature of witness: _____

Date: _____

Declaration by person obtaining assent

I *(name)* …… declare that:

- I clearly and in detail explained the information in this document to

  ……

- I did/did not use an interpreter.
- I encouraged him/her to ask questions and took adequate time to answer them.
- I am satisfied that he/she adequately understands all aspects of the research, as discussed above
- I gave him/her time to discuss it with others if he/she wished to do so.

Signed at (*place*) ..... on (*date*) …… 20....

.....
Signature of person obtaining consent

Declaration by researcher

I *(name)* …… declare that:

- I explained the information in this document to ……..
- I did/did not use an interpreter
- I encouraged him/her to ask questions and took adequate time to answer them
- The informed consent was obtained by an independent person.
- I am satisfied that he/she adequately understands all aspects of the research, as described above.
- I am satisfied that he/she had time to discuss it with others if he/she wished to do so.

Signed at (*place*) ..... on (*date*) ……..…… 20....

.....
Signature of researcher

APPENDIX 2: DATA GATHERING

APPENDIX 2.1: EXTRACT FROM VOICE NOTE DISCUSSION (ATTITUDE)

EXTRACT: ALS VOICE NOTE DISCUSSION NO 1: ATTITUDE TOWARDS LEARNERS

Researcher: What is your view about 'I can', the 'bleeding heart' mentality, to what extent should we expect our learners to grow more towards being independent adults than remaining dependent children, and how can we facilitate that? Please send your views via voice note.

RESPONSES

P5 (Therapist):

My answer to the first question is, definitely - uhm – approaching them as adults. But – uhm – reducing the demands to them as adults in a concrete, basic way, so it only matches their abilities, for instance, ahm – we will guide them on adulthood ways expected – if you go to a workplace, you must be clean, you must be courteous towards your boss, you must – ahm – be able to be on time – those kind of things are all adult work skills, so that is why I say we approach them in as adults, and we give them responsibility, but still, within their abilities. And then, also, we as people and employers also have to adapt to them. So, meaning, we can communicate to them as adults, and respect them as adults, but still protect them, and talk to them in a very concrete and basic way that they can understand. So, we just also have to adapt. Uhm – so in terms of attitude, I think we will treat them as adults, but within their capabilities, bearing that in mind.

P4 (Departmental head, senior phase):

I feel the same way as A (P5). Our young adults *can* have responsibilities, but within their capabilities. It's a show, teach, practice – uhm – approach, so that they can help themselves – also in independent living. If you – uhm – know the individual – you know his or her abilities and challenges, it's easier to – to choose uhm – 'I can' responsibilities for him. It's important for parents to be on board, it's also important. It's also important that the team knows the expectations of the job sampling employers, to prepare the young adult. There will be hiccups, but it can be – ironed out. Yes – the bleeding heart mentality – that is a big problem. To pity is not the way to go – rather support – be supportive – and be aware – awareness of the type of young adult that is going to be job sampling – rather be supportive – mentality, not pity.

P7: (Male parent, has a daughter with SID)

I've been digesting all the comments and inputs you've made, and would like to make some inputs myself, maybe to start with the rationale behind my input is, that we need to recognize diversity – ahm – amongst our disabled children, or young adults. There's to my mind no – no one size fits all recipe, and that's my approach, also when I make this input, when you come to the attitude, uhm – I think we should treat them as adults – or – well, should we treat them as adults or children, it's a mix in my mind, as some of you have also stated, and it also depends on the level of disability. Some cannot use money, like M (his daughter), she's got no idea what's the difference between 50 bucks and – and ten bucks, others cannot speak properly, uh – don't know what 2 plus 2 is, like M again, some again, can read books, buy their own sweets, making use of money, so I really think we should be guided by the level of disability.

P5 (Therapist):

So much insight, B (P7)! I am going to get you to talk to our school leaver's parents! It is sometimes difficult for parents to relate to what teachers/therapists are saying because we do not live with their kids. But you as a parent, having gone through a LOAD of ups and downs and having moved up and down on the grief cycle… YOU guys are the experts that our parents need!

APPENDIX 2.2: EXTRACT FROM RESEARCH DIARY

REFLECTION ON ALS DISCUSSION HELD BETWEEN 20 AND 21 MAY

I have had a whole series of voice note interviews during the lockdown period, which I have found to work much better than anticipated. Participants listened to the questions and responded with rich, focused answers, because they have time to think and compose a response, even making some notes. These interviews were conducted with non-ALS members – parents, therapists, and teachers outside the ALS circle.

So now I decided to see how we could have ALS discussions about the points that emerged from these interviews. Not knowing whether this could work at all, I posted a series of voice notes on our WhatsApp group. It was a kind of a summary of comments of participants. The first point was about the views of participants on the duality that you find in people with intellectual disabilities: That they often conduct themselves like children, but they have adult bodies. So how are you to approach them? This is a very important question, because it involves a baseline attitude that I personally believe can make the difference between success and failure in a transition programme. Do you believe they CAN, or they CANNOT? And what can they really do? Do you approach such an individual as an adult, or as a child? Especially one of the participants had very strong views about this, saying that you can't treat adults like children, you need to create a sense of 'I can', you need to have 'just right challenges' and you need to push back against the 'bleeding heart mentality', which is pitying and over-protecting them.

I posted the comments, and then threw in the question: What is a proper and balanced attitude in this regard? The response was fantastic. Almost everybody in the group shared their views, and their views were well-weighed and contained really good food for thought. What was nice, was to see how the views of the therapist, the teachers and the parents complement each other. Two new questions emerged from the discussion: How do we address the gap between school support and after-school support during transition, and how do we heighten community awareness and facilitate adaptations in public spaces specifically for people with SID? Because if we work on independence during our transition programme, and the person (for example) cannot read the menu in a restaurant and thus will find it difficult to order a meal, we have a problem.

So today those are the topics for discussion. I searched for all the comments of participants that I have already collected that have a bearing on the above topics and threw new questions in.

The only one that was completely quiet was Mnr. A. I messaged him personally and asked that, if and when he has data and a proper signal, he should please enlighten us on similar challenges

from the perspective of African parents or community members in townships or remote areas. Because he is the only one that can provide that perspective. I'm a little afraid that he might be overwhelmed with everyone's responses (which were really excellent) and that he might feel that he does not want to stick his neck out since he does not have anything to add. But he does have a unique contribution to give.

So, I'm waiting anxiously again for the responses. It's hugely interesting. What is good, is everybody can respond in their own time. We lack the dynamics of a face-to-face group discussion, but in a way that keeps us more focused.

I have a lot of work now, transcribing all yesterday's material, but I can't wait to do it.

APPENDIX 2.3: EXTRACT FROM CONVERGENT VOICE NOTE INTERVIEW

Hi G, the first thing I would like to ask you is, tell me a bit more about yourself, your life with R, but just what you feel comfortable with, I just want to have some background.

Hi M, aaaah – my life, I have two sons, I was married to MK, and thenn – the life there was not easy, he was so abusive for twenty years. And then – 2013 I've decided to move out of the house, and then I moved out – aaah – I went to my mom's home, and my mom is that person who believes in ancestors, I don't believe in the ancestors, she wanted to do some rituals in the – her – place, and I didn't agree with her, until she throw me out of her house. So, I went to look for a place, I found a place in W, now I have a place there in W, ahhm – after he chased me away of the house, I took R to the shelter at MG, and I was sleeping in ehhh in my changeroom at room at work. I was waiting for everybody to go, and then I will go and hide myself in the changeroom, until the next morning, and I'll do as if I'm coming from home, where else I was sleeping there for 6 months. And R was at the shelter that time, and the life there at the shelter was not easy, he was not enjoying anything, it was so difficult in his life. Ahm - Then I – decided – I knew that can't afford a room – to rent a room – but I decided to take that advantage – that chances to look for a room, I found a room at C5, Mamelodi West, we stayed there for two years. And then – there was a little bit problems there – then the landlord asked me to move out so that eh – she can take care of ahh - of - her dad – her elderly dad – her dad is 94 years old – he keep on missing and we must lock the gate and - we have seen that is not fair for R to - for us to lock the gates, because R likes to play, soo we decided that I must move out to look for a place where R will be free. And then I find a place at T6, and then we are live at T6, I rented a room again there. Even now, the life is not easy. I'm living with R and my sister's child. I took my sister's child so that my sister can help us to buy food, so that he can help me in life – she can help me in life. Because she's working, she's going to work early- early in the morning, and she lea – she was leaving her daughter alone to take care of herself until she goes to school, and then I've decided, no, she can bring the child to me so that I can take care of her. Ahh – we are near the school, we are near her school, I'm working at a Christian school and eh – my sister's daughter is there. So – for now we are there – M, if this it's not enough, this is not enough, you can ask me anything, I'll answer, because I think this will help me, and help my son in future. Feel free to ask me anything, I'll answer.

APPENDIX 3: DATA ANALYSIS

APPENDIX 3.1: AGENDA OF VIRTUAL MEETING

REMINDER AND AGENDA:

VIRTUAL MEETING OF ALMA TRANSITION A-TEAM

This is a reminder of our VIRTUAL meeting, which we hope to have Wednesday 10 February.

Time: 12h00 – 12h45

AGENDA

1. Cycle 1: Learner challenges and support needs – themes.
2. Progress with learners.
3. Possible steps to consider taking with the school leavers.
4. Community stakeholder links.
5. Closure: Reflection.

APPENDIX 3.2: RESULTS OF INITIAL ALS DISCUSSION (THEMES FOR CYCLE 1)

INCLUSION	EXCLUSION
Being part of a peer group Going shopping Going to church Being socially acceptable - In the workplace - In relationships Adhering to societal norms	Being hidden/isolated Going to extremes to be accepted Being unaware of societal norms Part of a fractured family Poverty Societal ills

DIGNITY	STIGMATISATION/VICTIMISATION
Unconditional acceptance Choice Autonomy Sense of purpose Predictability Control Safety	Cultural bias Peer bullying Exploitation Neglect Anxiety Psychological pathology

EMPOWERMENT	DISEMPOWERMENT
Being viewed as an adult Working towards independence Mastering of daily living skills Motivation Confidence ('I can') Participation in sport School – realistic goal setting Appropriate school support Set up for success Able to communicate	Being viewed as a child Infantilization Pity (bleeding heart syndrome) Learned helpnessness Poor daily living skills Poor motivation, passivity Lack of assistive devices Set up for repeated failures Unable to communicate

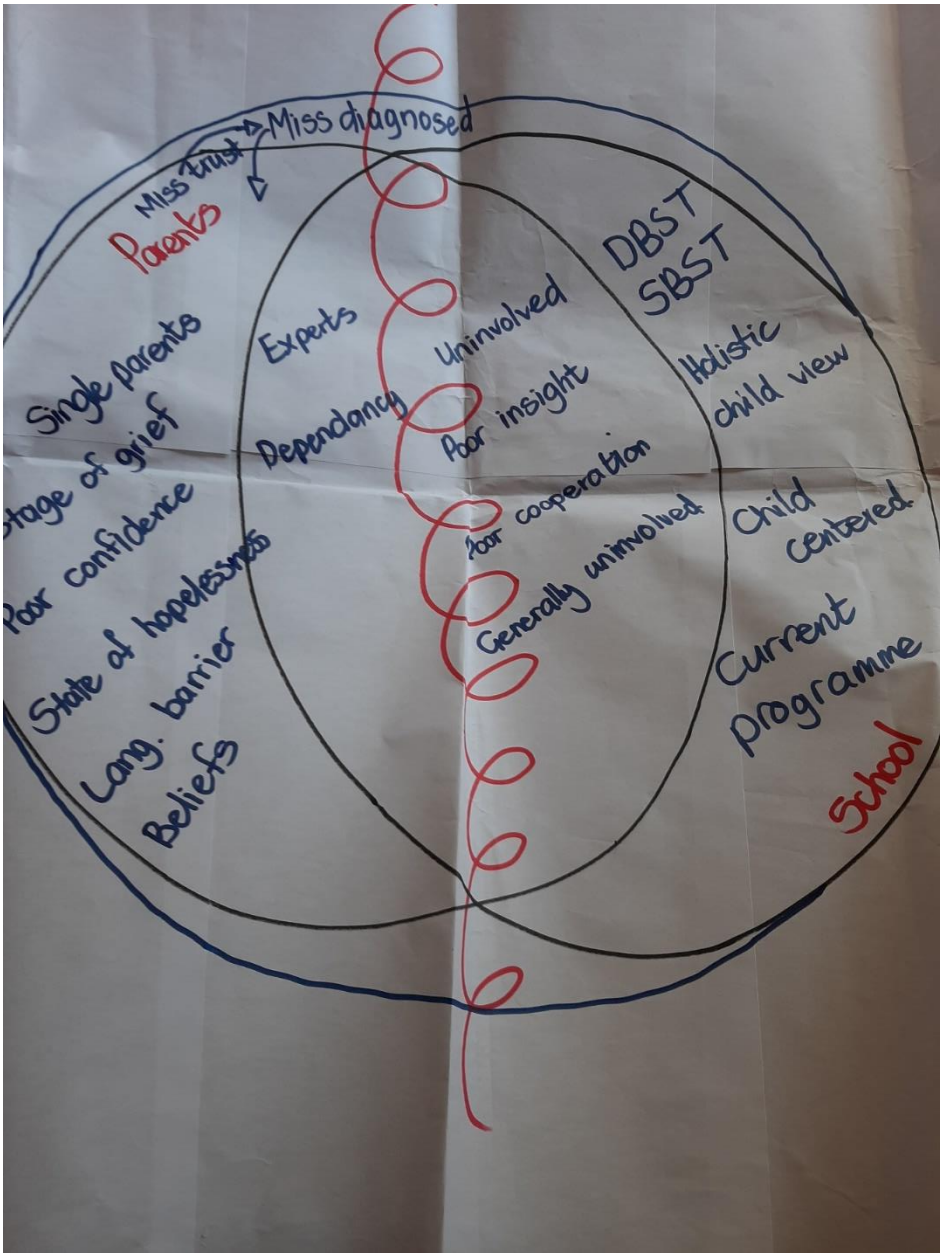
EMPATHY/WARMTH	SCORN
Patience Emphatic guidance Meeting the person on an appropriate level Gathering knowledge for improved understanding Boost self-image	Impatience Ridicule Talking over the person's head Lack of knowledge, poor disability awareness Unfavourable comparison Lack of acceptance Leads to lack of self-acceptance, poor identity formation

APPENDIX 3.3: CODING (PARENTS)

DATA ANALYSIS: PARENTS

DATA SEGMENT	CODE
PARENTAL CHALLENGES	
MOTHER R I was married to X, and thenn – the life there was not easy, he was so abusive for twenty years.	Marital dischord
And then – 2013 I've decided to move out of the house, and then I moved out – aaah – I went to my mom's home, and my mom is that person who believes in ancestors, I don't believe in the ancestors, she wanted to do some rituals in the – her – place, and I didn't agree with her, until she throw me out of her house.	Cultural beliefs (linked to community) Bias against children with disabilities/fear/lack of education
After he [she – the mother] chased me away of the house, I took R to the shelter at MG, and I was sleeping in - ehhh - in my changeroom at room at work. I was waiting for everybody to go, and then I will go and hide myself in the changeroom, until the next morning, and I'll do as if I'm coming from home, where else I was sleeping there for 6 months. And R was at the shelter that time, and the life there at the shelter was not easy, he was not enjoying anything, it was so difficult in his life.	Hardship – Resilience
ALS THERAPIST our parents go continuously through a grief cycle, whether they are in denial, angry, feeling depressed or helpless, or they are at a place of acceptance. And – uhm – this is truly and ongoing process. Because every time something negative happens, they – uh – a new milestone is supposed to be reached, they go through the whole grief cycle again.	Grief cycle
MOTHER R I've been alone thinking about him, but I don't get a conclusion.	Isolation
MOTHER R: …the people they just take him as if he is crazy or what. Just like ah - talking senseless things that doesn"t entertain other people. So that worries me, how is he going to be when he-he is an adult.	Stress about social integration
FATHER M: I try to get him a disability grant, but it was in vain, but I will try it again.	Challenges – public services

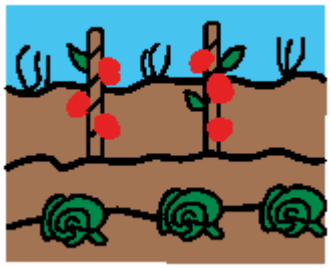
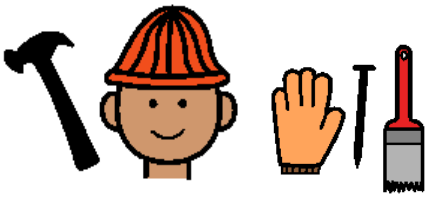
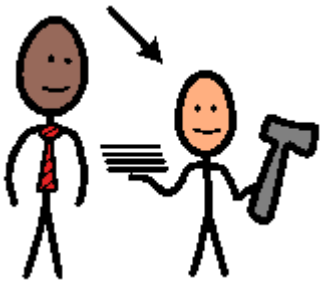
APPENDIX 3.4: ILLUSTRATION GENERATED BY THE ACTION LEARNING SET



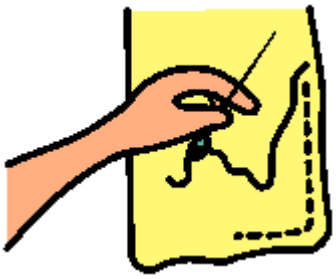
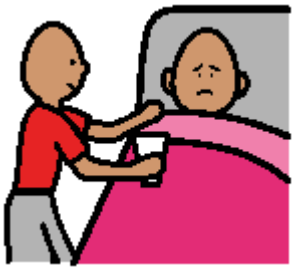
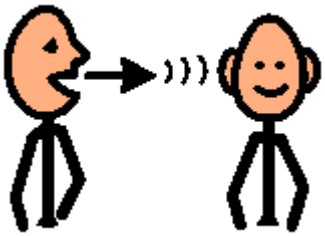
APPENDIX 4: CASE STUDIES OF FIVE LEARNERS (CYCLE 3)

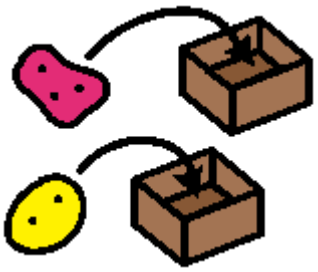
APPENDIX 4.1: CAREER INTEREST QUESTIONNAIRE

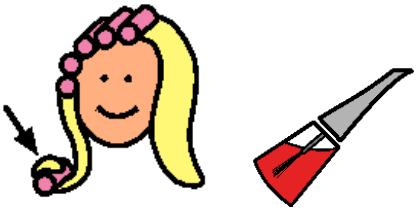
WHAT KIND OF JOB WOULD YOU LIKE VERY MUCH?

 Gardening	✓	✗
 Building and fixing things	✓	✗
 Office work	✓	✗
 Working with a computer	✓	✗

 **Bake or cook**	✓	✗
 **Selling things or working in a shop**	✓	✗
 **Fixing or washing cars**	✓	✗
 **Singing or making music**	✓	✗

 **Doing needlework**	✓	✗
 **Caring for sick people**	✓	✗
 **Working with/talking to people**	✓	✗
 **Making jewellery**	✓	✗

 **Making crafts**	✓	✗
 **Working with children**	✓	✗
 **Sorting and packing things**	✓	✗
 **Helping people in some way**	✓	✗

 **Cleaning places or things**	✓	✗
 **Working at a hairdresser or beauty salon**	✓	✗
 **Working with animals**	✓	✗

APPENDIX 4.2: EXAMPLE OF INDIVIDUALISED TRANSITION PLAN

INDIVIDUALIZED TRANSITION PLAN

BACKGROUND

Name of learner: L3

Date of birth: 2002-06-08

Age: 18

Diagnosis: SID/PD (Spina bifida)

Relevant medical information: Was born at 8 months with spina bifida and hydrocephaly. Developed kidney failure, has high blood pressure and an ulcer. Has chronic bladder infection, takes antibiotics permanently. Kidney failure and infection now under control, but feet still swollen. She has no bladder control; uses adult diapers or catheterization. Upper body tends to sag when getting tired. Wheelchair user – strong pusher. No medical aid – state patient. Receives grant, receives meds and nappies from state hospital. Nappies not enough. Difficult to handle – she is very heavy. Mom very grateful for hoist that was bought after a fundraiser.

Medication: Diuretics, antibiotics, meds for high blood pressure and ulcer etc.
Family background: Mom divorced after an abusive marriage, has another life partner now, he is the father of a young adult with SID as well. The family has challenges with regard to their vehicle, which is constantly failing them – without the vehicle L3 is unable to go anywhere. The mother is currently unemployed and takes care of both young adults. There are conflicts with the father's ex-wife. The mother does not have a good relationship with her own family but gets good support from her partner's family. Her partner's mom resides with them. They don't go out very often. L3 is mostly home-bound. She rarely goes shopping and has never had her own pocket money.

LEARNER PREFERENCES (AS DESCRIBED IN DREAM SHEET)

Work-related interests/preferences: Sorting/folding clothing, likes animals, likes crafts, cooking and baking, likes gardening.

Leisure activity/activities: Listening to music, colouring, making jewellery.

Social circles: Only family.

HOME LIVING SKILLS

Strengths	Support needs
Can operate common kitchen tools such as a knife, measuring cups, grater and microwave. Can prepare basic meals such as breakfast cereal and two minute-noodles. Knows the contents of packaged foods. Can cut vegetables such as green beans. Can make coffee.	Safety concerns about using the gas stove. Suggestion: To get her her own two-plate electrical hot plate, placed on a height suitable for her wheelchair. Provide at least one surface at a suitable height for her wheelchair for food preparation. Needs to learn how to use a washing machine. Needs to learn how to use a can opener.

Sets the table, puts away leftovers, can do the dishes and sweep the floor. Puts dirty clothes in hamper. Puts order in own bedroom. Can sort and fold clothes, puts in closet. Helps with gardening outside.	Needs an adapted picture-based recipe book to follow recipes.
Goal(s): Learn to use washing machine, can opener. Make a recipe book with microwave recipes, picture based. Attend to height of work surface. Possibly buy a hotplate. **Timeline**: Before the end of the year. **Support coach**: Mom (can opener, washing machine), Teacher Marna (recipe book)	
COMMUNITY LIVING SKILLS	
Strengths	**Support needs**
Is verbal, able to express needs. Can ask for help.	Needs own pocket money Needs to shop for own toiletries. Needs to get the opportunity to get to know a specific shopping centre. Laminated shopping list with preferred toiletries and snacks to tick off monthly
Goal(s): Get own pocket money, go shopping. Make shopping list – teacher Marna. **Timeline:** Monthly **Support coach**: Stepdad and/or mom	
PERSONAL DEVELOPMENT (Including functional academic and problem-solving skills)	
Strengths	**Support needs**
Handles self-care and grooming well Able to choose own outfits to wear Interacts with family members and prepares meals for Hannes	Finer touches with regard to grooming – make-up, hair, nails and work outfits. Needs to own and use a cell phone Needs to know how to call emergency numbers. Needs to understand basic budgeting principles. Needs to learn to follow a calendar with important events. Practice basic sight reading of brand names/names of shops – teacher Marna has laminated sheets with these on.
Goal(s): Work make-over, cell phone usage instruction & emergency numbers, budgeting, calendar use. **Timeline:** **Support coach:** Teacher M to make calendar, budgeting – stepdad. Makeover in preparation of first workday – teacher J. Laminated sheets with brand names – teacher M.	

EMPLOYMENT-RELATED SKILLS	
Strengths	**Support needs**
Is doing well with beading Can sort and fold clothing	Needs good quality resources to make beads that are marketable. Possibly to attend a market once monthly to sell goods. To assist weekly at Solidarity's second hand charity shop.
Goal(s): Make a beading kit with the help of the craft teacher (teacher Marinda) and look for a sponsor via teacher Corinne (vice principal). Job coaching at Solidarity's shop (sorting donated clothing and toys) **Timeline:** Before the end of the year **Support coaches:** Teacher M, A (OT), teacher C – sponsor?	
HEALTH AND SAFETY SKILLS	
Strengths	**Support needs**
Can answer basic questions posed by a health official	Needs to understand and explain own disability in her own words. Needs to know more about her medication regime (times, broadly which pills she takes etc.) Medication list to be printed, laminated and pasted in her cupboard door, available to emergency caregiver, should something happen.
Goal(s): Better understanding and verbalisation of disability, health and medication **Timeline:** No timeline – long-term goal **Support coach:** Mom? Printing and lamination of meds list – teacher M	
SOCIO-EMOTIONAL AND LEISURE SKILLS	
Strengths	**Support needs**
Sociable Likes music, singing, wheelchair dancing Plays golf, karate	Needs company – M care centre attendance at least twice per week (family's financial position is such that more than that is a challenge) Can continue to do karate at school. Already discussed with sports coach, who does not mind.
Goals(s): Attend 'sokkies' presented by Alma School. Attend Mondays at M Care Centre – singing day. Arrange specific day of attendance of school karate sessions. **Timeline:** **Support coaches:** Mnr. S, Alma School, care centre – teacher M links up.	
Signature of learner: Signature of parent(s): Signature of other ITP meeting attendees: Follow-up dates for this meeting:	

APPENDIX 4.3: CASE DESCRIPTIONS OF THE FIVE LEARNERS (CYCLE 3)

CASE DESCRIPTIONS OF 5 LEARNERS: CYCLE 3

1. Case 1: L1, a sixteen-year-old female learner with multiple disabilities

L1 has cerebral palsy (spastic quadriplegia). She is a wheelchair user, wears diapers, is fully care-dependent and non-verbal. Her one hand is dysfunctional, curled in a tight fist, but she can use the other one. P5, the therapist, recommended that we choose her as an example of a learner with multiple disabilities who will not be able to obtain a job in the open labour market. Our aim was to see how we could improve her quality of life. It was agreed that P6, who is a Tswana speaker, would accompany me to her home, which was in a township.

When P6 and I arrived at L1's home in the township, I was surprised to observe L1 walking towards us on her knees. I had been under the impression that the extent of her disability was such that she was unable to move on her own. At school she is using a well-supported wheelchair which is tilted backwards with raised sides and a supportive head rest We were warmly received by the mother, a friendly middle-aged woman. The home was small, but neat. There were neat couches, a television set, and a kitchen counter in the front room. The mother shared her fears about L1's care and her need to find a safe place of care for her. The centre where she currently went after school provided substandard care and did not offer anything in terms of meaningful activities to the residents. The mom went to a neighbouring town every week to look after her elderly mother, while L1 was under the care of her two sisters. Although L1 was non-verbal, she understood instructions and questions, could indicate answers, and could make her needs and preferences known. The family did not take L1 to shopping trips or to church. It was difficult, since she did not have a wheelchair (she had outgrown the old one). The mother did not see her way open to ask someone other than close family members to take care of L1, since she thought that it was too much to expect from other people to change the diaper of a sixteen-year-old. She did think that L1 would have the potential to be toilet trained, but L1 could not manage to get on to the toilet, so that was a challenge.

Photo 7.1 P6 (an ALS member) in front of the house Photo 7.2 The inside of L1's house with Mom right.

Back at school that Monday, I spoke to the two physiotherapists at school about the wheelchair problem. They arranged with the physiotherapists at the nearby state hospital to provide a brand-new wheelchair for L1. Since I had shared the need for L1 to learn how to use an AAC device, the one physiotherapist took initiative and obtained a device from the occupational therapists. The class teacher was surprised to see how well she did with the device and sent me a photo.

Photo 7.3 A new wheelchair!

Photo 7.4 Communication aid

I discussed her appearance with P3. It bothered us that L1 was still wearing a bib meant for an infant at the age of sixteen. She did drool a lot, but we thought that having multiple scarves could work well too. I bought some scarves and asked the teacher if he would start to use them to see whether it worked. They did so, and although the class assistant needed some guidance to fold the scarf in such a manner that it was functional and decorative at the same time, it worked very well, and we sent some scarves for use at home, too.

P5 recommended an appropriate possible residential care home for L1, which I then visited. The place was neat, and it seemed that good care was taken of the residents. However, residents with very low cognitive abilities or those with multiple disabilities merely sat in the TV room, some staring blankly ahead, one young man lying on a mattress on the floor, his face turned to the wall. The people who had good hand function and were higher functioning cognitively were much better off. They were stringing beads in a workshop and looked busy and happy. I realized that L1's chance to end up in that TV room was high, unless one could teach her a skill that the workshop would find usable.

In collaboration with her teacher, we embarked on operation key holder, to see if L1 could make very simple key holders as an entrepreneurial venture, or as a workshop product in the residential

care centre where she would inevitably end up. She did very well, painting the key holders completely on her own and pasting the decorations in the middle of the wooden key holders with only a little help and direction by the teacher. The teacher drilled holes in the key holders and fixed key rings in the holes. We then took L1 around the school to sell her key holders. They were so popular that some teachers even ordered more. We decided to let L1 keep the proceeds of the day. The expression on her face when the money was placed in her school bag was priceless. The mother came home from Polokwane specially to take L1 to the shop. It was a great adventure. L1 was beside herself with joy and bought everything she had always wanted so much: A new doll, a chocolate, some yoghurt – and a new bib! Obviously, the family did not yet see any sense in replacing the bibs with scarves.

Photo 7.6: L1 painting on her own.

Photo 7.7: Painting is done

Photo 7.8: Decorations stuck on.

Photo 7.9: Holes and keyrings.

Photo 7.10: Selling her products.

Photo 7.11: Shopping!

Photo 7.12: Sheer joy!

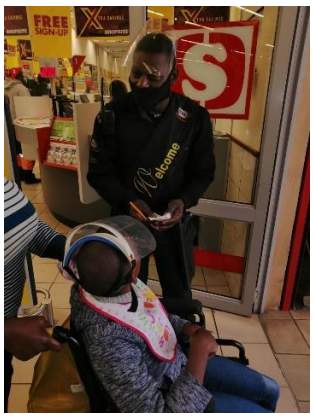


Photo 7.13: Paying by herself

Photo 7.14: Social inclusion

Back at school, the teacher was greatly impressed with the result of our venture. He decided to teach his whole class to make key holders as a long-term project and to make sure that the learners themselves received the money for the key holders they sold.

2. **Case 2: A sixteen-year-old male learner with cerebral palsy (diplegia)**

L2 has cerebral palsy and is a diplegic, which means that the lower half of his body is most affected. He walks with difficulty, using a walker to get around at school, but shows good understanding and is fully verbal. P5 conducted an individual session with him, using our career interest questionnaire. He indicated that he would love to do something connected with cars. He also loved gardening. During the interview, his mother confirmed that he had these interests. L2 and his mom stayed in a single room where they shared a toilet with the other tenants on the premises. When P6 and I visited them, we were treated to cooldrink and snacks outside the room. This mother has been through extreme hardships after an abusive marriage and after having been rejected by her own family due to cultural and religious prejudice regarding her son's disability. During our interview she also shared what challenges she faced to seek help when he had epileptic seizures, since she had no transport.

Photo 7.15 Living in a single room.

Photo 7.16 Hospitality!

Our first action was to facilitate the young boy to grow his own potted garden, since there was no space on the premises to plant something. However, at our next visit, I was surprised and overjoyed to learn that the mother and son now lived in a much better home. It so happened that L2's father, who had been an abusive husband, fell seriously ill. The mother, despite having left him years ago, then went to care for him until he eventually passed away, leaving the house to her and his son. This house did have small portions of soil where something could be planted. We nevertheless left the containers that we brought, but L2 preferred to transplant all the plants into the soil, where they flourished.

Photo 7.17 Seedlings, seeds and pots

Photo 7.18 His own garden!

During this visit, L2 told me that he would really love to wash cars. We then started to do skills building at school, allowing him to wash cars on the school premises – for payment. L2 loved this. He really did an excellent job and the cars shone when he was done. He took a lot of pride in the fruits of his labour. However, he was very tired after having finished and the next day he had muscle aches due to the effort it took to do such a physically taxing job. This I learnt from P5, the therapist, since L2, when I asked him, vehemently denied that he felt tired! The therapist hoped that L2's ability to keep up physically would improve with practice (a process, which is referred to as 'work hardening' in occupational therapy). In the meantime, P5 told me about a service provider who provided free training to young men with disabilities to become panel beaters. I visited the place and they promised to let us know when the next take-in would be so that L2 could be included on a trial basis, mainly to see whether he would be physically up to the job. Once more, the coronavirus wave halted our project, since it would be too risky to expose the young man to possible infection in a work environment outside the school.

Photo 7.19 Hard work!

Photo 7.20 Pride!

Photo 7.21 Another client!

3. **Case 3: L3, an eighteen-year-old young lady with spina bifida**

L3 was in her final school year when we started her project. She is fully verbal. Since she has spina bifida, she is incontinent and suffers from health challenges, such as chronic kidney infections and needs constant treatment to prevent kidney failure. However, she can push herself and has good home living and independence skills. P5 and I visited L3's home together. We decided that P5 would have the individual session with L3, discussing the career interest questionnaire with her, while I would, at the same time, have an interview with the mother. All went well, except for the fact that P5 had a hard time conducting L3's session in a meaningful way, since she kept indicating that she liked every field of interest! Luckily, with the mother's input, we could establish that L3 did beading as a hobby, liked baking a lot and showed an affinity for sorting and packing things.

Photos 7.22 – 7.25 Making jewellery as a hobby

Back at school, P5, P3 and I discussed L3's transition plan. Regarding a work opportunity, P3 knew about a charity organization that received clothing donations and thought that L3 could assist them to sort and fold clothing. However, it turned out that the management of that organization did not react to P3's attempts to establish a job sampling opportunity for L3. I knew of a similar charity organization that received any kinds of donations after which they sorted and re-packed them to be

sold. One afternoon I stopped there, met the management, and discussed the possibility of having L3 there for job sampling. To my joy, the manager was very kind and was willing to give it a try!

L3 and her mother were overjoyed when they heard the news. We agreed that her class teacher would treat her to a makeover to prepare her for her first workday. All was set but then, rain poured down on the big day. It was a challenge to get L3 into the car without getting soaked, so the decision was made to postpone the occasion. She was extremely disappointed. However, our makeover inspired the mother to go the extra mile that Friday, when the school leavers' farewell took place. L3's teacher donated the makeup set that was used for the makeover to L3 and her mother really did an excellent job. L3 looked beautiful!

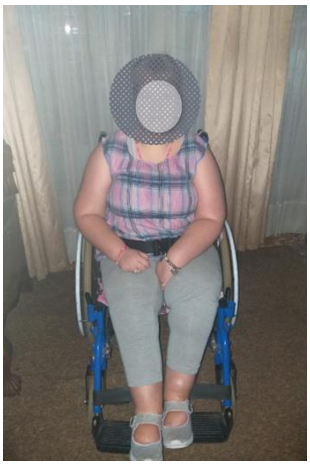



Photo 7.26 Disappointment! Photo 7.27 Looking truly beautiful.

The second workday went without a hitch. L3 started going to work once per week.


Photos 7.28 – 7.29 The joy of having a real job.

I went to talk to the employer to find out how things were really going. She was happy about L3's progress, but there were a few social skills challenges. L3 tended to ignore customers who entered the shop, even when they greeted her first in a friendly manner. The employer found this embarrassing. Moreover, she had made a derogatory remark with racist undertones towards a black

fellow employee, which was completely unacceptable. I was horrified and promised that we would address these issues immediately. P5 had an individual session about workplace social skills with L3, which had an immediate positive outcome. The arrangement now went down excellently. The employer was great, the setting was safe and welcoming and L3 counted the sleeps to the next workday. Some days her mother even had a hard time to convince her that it was time to go home! However, although the employer went out of her way to accommodate L3, she did mention that L3's work speed decreased as the day went along and that her productivity was not all that great. We hoped that she would gradually become more 'work-fit'.

L3's transition plan was aimed at a holistic quality-of-life experience. We therefore worked on aspects other than job placement as well, such as her time management skill (reading a picture-based calendar), hobbies for productive leisure time utilization (beading and baking). To facilitate these hobbies, we provided her with a sponsored beading kit and a two-plate stove with an oven, as well as a picture-based recipe book. For social interaction, we arranged for her to attend a nearby care facility twice per week and for health and exercise, the school's sports coach agreed that she could still attend karate lessons.

I checked in regularly to see if things were still running smoothly at the workplace, and got extremely positive feedback from both sides, employer and parent. However, one day, while checking in with the mother, she gave me the upsetting news that the charity shop was being sold to another owner. The mom was hesitant about this change, saying that she did not think it would be wise to leave L3 with an unknown person. I went to the shop and met the new owner, who was extremely friendly and more than willing to continue the arrangement with L3. After the mother had met the new owner, she became more positive and willing to allow L3 to continue doing the job that she so loved. However, before she could start getting used to the new employer, disaster struck: L3 contracted Covid-19 at the after-care centre where her mom had since started working. Having serious co-morbidities, such as chronic treatment for kidney failure, she was soon suffering from low oxygen levels and other complications and had to be admitted to hospital in a serious condition. Defeating the odds, she beat the virus and, at the time of writing this, she is still recuperating at home.

Photo 7.31 Resting after an ordeal in hospital.

4. Case 4: L4, a sixteen-year-old male learner on the autism spectrum

L4, a learner who is on the autism spectrum, has no physical disability. He is always groomed well and dressed immaculately. Although L4 is very introverted and speaks very little, he has a good receptive language ability. No challenging behaviour has been reported.

After the lockdown, some weeks passed before L4 started coming to school again. When he did, P5 conducted a personal interview with him to complete the career interest questionnaire. L4 mostly gave non-verbal responses, such as nodding or shaking his head or pointing to pictures. He indicated preferences such as cooking, baking and crafts and had an affinity for music. P6 and I travelled to the rural town where L4 stayed with his grandmother. We conducted an interview with the father, who was mostly busy with work engagements during the week. The grandmother was the primary caregiver. She seemed like a warm and caring person. The father came across as strict, intelligent, and business-like.

L4's grandmother welcoming us in front of their house.

The father and mother were separated. There was some animosity apparent between the mother and father (F4), something that emerged during my work with the family. L4 visited either the mother or the maternal grandmother every second weekend or during holidays. The father stressed that L4 was very fond of baking and cooking and that he could see him make a career of that. When I communicated with the mother, she confirmed this and sent some photos of L4's cooking. During the interview, the father remarked that he knew someone in their church who owned a bakery, where he thought L4 could possibly do job sampling. L4 had very good home living and independence skills and, according to the father, he did well in social settings where he knew the people. He did not enjoy being in unfamiliar settings with unfamiliar people.

I started by making L4 a calendar to promote his time management skills. Here I encountered a challenge. I required some family photos to insert into the calendar for L4 to be able to know when family members were having their birthdays. The father sent only about three photos without including the dates of birth. When I requested more photos and dates of birth, he referred me to the mother. I contacted the mother, who reacted very well and sent me a whole lot of photos, which I put into the calendar. However, I only managed to earn the ire of the father with the calendar, who was enraged to find that the mother's boyfriend was included in the calendar! Of course, I had no idea that the person was the mother's boyfriend and much less that I was going to tread seriously on toes by including the photo. I apologized profusely, but from there, all communication with the father was met with a stony silence! I tried to reach out to the mother, but she ignored me as well.

I made L4 a picture-based recipe book as well and hoped to soften the father by letting him know that I had made the recipe book and was sending it home with L4. At the same time, I asked him for the contact details of the bakery so that I could contact the bakery to plan for job sampling, possibly during weekends. However, the father let me know that the bakery had closed due to

Covid-19-related financial challenges. After thinking long and hard about next steps to take, I hit on the idea to look for someone that presented baking classes. If L4 could upskill himself, it would be much easier to place him somewhere. I discussed this idea with P8, who recommended a lady presenting baking classes and I contacted her. She turned out to be very friendly and accommodating. She offered to present individual lessons to L4 at a very reasonable price. We agreed that she would prioritize the making of Makuku scones, a traditional African snack often served at occasions such as funerals and weddings. A good Makuku baker would be able to earn decent money. I typed a long message to the father, explaining all that I had found out. His demeanour changed instantly. He was extremely excited and positive and quite prepared to pay for the lessons. We agreed that he would bring L4 to the lessons and that I would ensure that there is a facilitator to accompany him. However, as the date drew closer, the third Coronavirus wave hit the country. A level 4 lockdown was announced, and all gatherings were prohibited. Although the lessons could not really be viewed as gatherings, I was apprehensive at the thought of L4 being exposed to the virus, which was by that time spreading like wildfire. I discussed this with the father, and he agreed that it would be wiser to postpone. At the time of writing this, we are waiting for the coronavirus wave to pass.

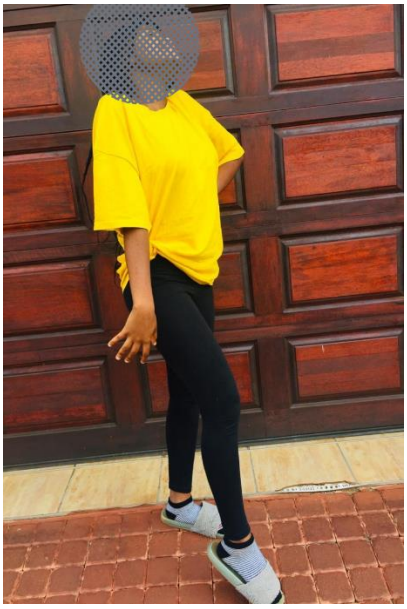
5. Case 5: L5, an eighteen-year-old female with SID, functioning more towards MID, no physical disabilities.

L5, a school leaver at the time when we started her project, appeared like a typical teenager, maintaining a modern hairstyle, dressing appropriately for her age, having a cell phone, interested in the opposite sex – on face value one would never have suspected that she has any disability. However, listening to the interview between P5 and the therapist, I realized that she did have some expressive language issues. She had challenges with vocabulary and word finding, but of course, English was not her first language. During the first conversation with her father, he reported how she fell behind irrevocably in the mainstream schools and how they went from pillar to post to try and address her learning disability until she ended up in a special school. She was literate, but only on a basic level. The parents are high-functioning people – the father a university lecturer, the mother a speech therapist. They are well resourced financially and stay in a security complex.

During her interview with P5, L5 indicated several areas of interest, of which nails and beauty and several care-related careers stood out (caring for sick people, working with small children). P5 thought that nails, beauty, or hairdressing were good options, but during my interview with the father (the mother works in another town and was not present) he thought that working with small children was the best choice. We called L5 in after the interview with the father and she confirmed this. We therefore agreed that we were going to attempt a placement at a preschool facility. During the interview, the father told me that L5 helped to maintain the household while the mother was in another town. She helped to take care of her younger brother, did the laundry and cooked meals. Her home living skills were well developed, but community level skills (such as working with a bank card, budgeting, and using public transport independently) still had room for improvement. I spoke to an occupational therapist known to P5, who lived in the same neighbourhood as L5, to find out whether she knew of any preschools that I could approach for L5's job placement. She offered to speak to the owner of the preschool that her son used to attend. She had a good relationship with the lady, who turned out to have a warm, accommodating personality. The therapist and I went to speak to her to explain the purpose of the research and the value of the opportunity for L5. The therapist then offered to act as a job coach. We agreed that she would see L5 and the parents for a few sessions to do job placement preparation, after which L5 would start a training period at the preschool. The owner of the preschool could not afford a helper after Covid, so she was grateful for an extra pair of hands.

During the job placement preparation, the job coach worked on issues such as employability skills and appropriate dress. She had a discussion with L5 about dressing appropriately for the job, stressing that high-heeled shoes would not work for a job like a pre-school helper – youneeded comfortable shoes. L5 then had some home tasks: She had to dress up as if it were thefirst day of work, and she had to send videos of her doing some cleaning and preparing breakfast cereal. The feedback was proof that job coaching is essential! L5's cleaning video looked good, but in the video about preparing breakfast, she used traditional African 'mieliepap', adding sugar and milk and

mixing all of it with her hands! Of course, in African culture handling food and eating with the fingers is completely appropriate, but in the much more formal setting of a preschool, this would be totally unacceptable! She sent a photo of herself posing in her work clothes, but to our surprise, she was dressed in slippers!



L5, dressed for work… in slippers!

The therapist followed up with another session to set straight some of the issues that L5 had misunderstood. We then agreed with the employer on a first workday, and all was set! Below is L5 on her first workday:

The job coach stayed in contact with the employer and sent me her feedback, while I shared this with the ALS – on our whatsapp group. The area where the preschool was (and where L5 lived) was quite far from the school, so it would be impractical for the school therapist to do the job

coaching. Moreover, since our earlier research showed that a job coach not connected to the school would be a good idea for after-school support, the group agreed that including such a person in the project would be an appropriate measure.

The employer was quite happy with L5, saying that she instantly connected with the children and took initiative to keep them busy and play games with them. Regarding the cleaning, however, there were some challenges. L5 had difficulties to understand and remember instructions. For instance, the employer would instruct her to wipe the cots and mop the floor, and L5 would only mop the floor. She also cleaned speedily, but not thoroughly. The job coach then asked the parents to bring L5 to her home one Saturday, where she asked her domestic worker to allow L5 to work alongside her and teach her all the important things to attend to while cleaning. I asked the employer to send photos that represent the different tasks L5 was expected to do every day. These I used to make a visual schedule for L5 to refer to so that she could remember her daily tasks. We also printed the names and photos of all the children in the preschool so that we could mark the baskets where their lunchboxes were kept. This made it easier for L5 to distinguish between the lunchboxes and to remember who brought which food.

After having implemented all these measures, things started going much more smoothly. The employer reported that L5 did not even need the visual schedule anymore, since she now knew the daily schedule and could remember her tasks on her own. After a few months, the job coach and I had a discussion on the way forward with L5. Things were going well, but L5 needed to progress to the next stage of the project. She could not work for free for ever. That would amount to exploitation. The job coach then approached the employer and asked whether she would like to write a resumé for L5, since we would like to apply for paid employment for her. The employer responded by saying that she would not want to lose L5's help, and that, even though she could not afford full payment, she would start to pay L5 a stipend until her financial situation improved. We called the parents in and explained the situation to them. They were very happy to accept the arrangement. We agreed that they would sit down with L5 and draw up a budget, so that she could learn how to spend her money wisely and appropriately. I also asked the parents to send me feedback on their experience of L5's development, which they did:

> *You know, there has been massive improvements in terms of the programme that eh – you – you decided on running. She – she has developed massively in terms of – uh – cleaning, in terms of taking care of the household – you know, making sure that whatever she does, she completes. Eh – moreover, in terms of – eh – taking care of the little brother – doing things thoroughly, as opposed to what she used to do, you know, rush job, but these days, since she was on your program, she has really improved, and we are quite impressed with how she's doing things now. Looking at her siblings at home, she also calls them to order, if they're really, not doing as they were supposed to do* (F5, L5's father).