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Families' perspectives in career transition planning for adolescents with Down Syndrome in the underserved Sizwe community

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Abstract

This study examined families' perspectives and lived experiences regarding career transition planning for adolescents with Down Syndrome (DS) in an underserved Sizwe community in Soweto, South Africa. Using a phenomenological design, this qualitative study employed purposive sampling to select ten families of adolescents with DS and four Community-Based Organisations (CBOs). Semi-structured telephone interviews with participants were conducted between May and June 2025. Survey data from CBOs complemented family perspectives. Thematic analysis was used to analyse data. Ethical considerations were prioritised. Four themes emerged: families demonstrated limited awareness of systematic career transition planning, relying on faith-based coping and external agents; financial constraints emerged as the primary barrier to accessing services and saving for children's futures; families recognised children's strengths but lacked resources to develop these into career pathways; and families perceived schools as primarily responsible for career transition planning, reflecting uncertainty about their own role. CBOs offered general support but lacked specialised career transition planning programs for families and individuals with DS. Faith-based affirmations substitute seeking practical resources to nurture and develop specific skills or creating career transition plans that would actively prepare adolescents for independence in post-school settings. Recommendations include specific national policy guidelines that promote the post-school transition of special school graduates and collaborative partnerships in career transition planning among families, schools, and CBOs. The study is limited to the perspectives of one community, which may not reflect experiences and perspectives on the subject under study in other underserved communities.

Keywords: *adolescents, Down Syndrome, developmental disabilities, families, career-transition planning, underserved communities*

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1. Introduction

The transition from adolescence to adulthood marks a crucial developmental milestone, which can be particularly complex for adolescents with developmental conditions such as Down Syndrome (DS) due to the diverse nature of the condition and its associated medical and social challenges. While individuals with DS historically rarely lived beyond childhood, significant advances in medical care and social support have increased their life expectancy to approximately sixty years, making effective transition planning essential for achieving successful outcomes (Snyder et al., 2020; Esbensen et al., 2024; McGlinchey et al., 2025).

Although families play a pivotal role in career transition planning by providing unique insights into their children's strengths, preferences, and needs, those in underserved communities often face substantial barriers, including limited resources, inadequate support services, and restricted knowledge and awareness for effectively supporting their children (Aleman-Tovar & Burke, 2022; McConkey et al., 2024).

This research explores the perspectives of families regarding their involvement in career transition planning for adolescents with DS in an underserved Sizwe community in Soweto, South Africa. This urban community is characterized by socio-economic challenges, including high unemployment, limited infrastructure, and restricted access to specialized career development and transition support services, conditions that significantly influence families' capacity to engage in systematic career transition planning.

A qualitative phenomenological research design was employed to capture the perspectives of nine parents and one guardian of adolescents with DS between May and June 2025. To ensure cultural sensitivity and authentic expression, all interviews were conducted in participants' preferred language, IsiZulu, and subsequently translated into English for analysis. Additionally, perspectives from four community-based organizations supporting families with developmental challenges were gathered through an online questionnaire to provide a broader contextual understanding of available support structures. This methodological approach enabled an in-depth exploration of family perspectives within their sociocultural context.

2. Literature Review

2.1 Down Syndrome: Medical understanding

DS is a genetic condition caused by an extra full or partial copy of chromosome 21 (Karkera, 2021). This chromosomal change leads to a unique set of physical and cognitive traits. These include intellectual disability, delayed speech and language skills, low muscle tone (hypotonia), and specific facial features like a flat nasal bridge, upward-slanting eyes, and a single palmar crease (van Gameren-Oosterom et al., 2011). There are three types of DS: Trisomy 21, which is the most common form and makes up about 95% of cases; translocation DS, where part of chromosome 21 links to another chromosome; and mosaic DS, in which some cells have the extra chromosome while others do not (Karkera, 2021).

The condition was first described by British physician John Langdon Down in 1866. However, its genetic cause was not discovered until 1959 when Jérôme Lejeune found the chromosomal basis of the syndrome (Kamat, 2024; Karkera, 2021). The first reliable documentation on the prevalence of DS in Africa resulted from a study by Adeyokunnu in 1982. The study sought to establish the incidence of DS over nine years at the academic hospital in Ibadan, Nigeria, documenting an incidence rate of 1 to 16 per 1000 live births (Christianson, 1996).

2.2 Life Expectancy Improvements, Trends, and Inequalities

Significant advances in medical care, early intervention, and inclusive education have significantly increased life expectancy and quality of life for individuals with DS globally. Life expectancy for individuals with DS has risen significantly over the past century, especially in high-income countries. Studies from Europe, the USA, Australia, and the UK show a median age at death of 53-60 years for people with DS (Motegi et al., 2021). This marks a notable rise from historical data: life expectancy was just 9 years in 1900, 12 years by 1951, 28 years in 1984, and about 60 years today (Esbensen et al., 2024). Similar trends can be seen in other developed countries, with research from Japan indicating that one in three individuals with DS now lives past age 60 (Motegi et al., 2021). Glasson et al. (2016) note that, while live birth of DS has remained relatively stable in many developed countries, survival rates have been improved due to advances in cardiac surgery, treatment of respiratory infections and comprehensive early intervention programs.

However, these findings predominantly reflect high-income contexts with advanced healthcare infrastructure, early intervention programs and inclusive education systems, as information on life expectancy, transition to adulthood, ageing experiences, and age-related conditions in individuals with DS is limited in low and middle-income countries, such as African contexts (McGlinchey et al., 2025). This highlights significant disparities in understanding developmental trajectories across socioeconomic and healthcare systems. Factors such as inadequate infrastructure, cultural barriers and limited resources severely limit health data collection (Musa et al., 2023). McGlinchey et al. (2025) further explain a critical lack of epidemiological, cognitive and biomarker data on adults with DS in Africa, seriously affecting diagnosis, care planning, support and inclusion in global research efforts.

Despite the ongoing systemic challenges across African healthcare systems, pockets of success exist where individuals with DS receive good care, and their families find specialised support. However, these services are mainly found in private facilities and in some urban areas, making them mostly accessible to those with better economic means (Adeniyi & Adeniyi, 2020). In Nigeria, the Centre for Early Development, Learning and Care in Ibadan offers various services for children with developmental challenges, including DS. In Ethiopia, research on prenatal diagnosis shows that while diagnostic services for managing DS exist, they are found mainly in private hospitals, posing challenges for low-income families (Sium et al., 2023). In South Africa, even though the National Health System intends to ensure everyone has access to quality healthcare, many face obstacles to good services. These barriers include affordability, availability and physical accessibility (Van Biljon et al., 2022).

The inequality in service access creates a two-tiered reality: elite and middle-class families with financial resources can access private multidisciplinary care that matches services in high-income countries. In contrast, most families in underserved communities lack access to multidisciplinary support and care. Therefore, this disparity raises critical questions about whether life expectancy and quality of life documented in Western literature represent universal trends or remain privileges of economically advantaged contexts, both globally and within selected African social classes. Understanding this reality is very important for contextualising the focus of the study. The study seeks to examine the experiences and perspectives of families in an underserved urban community, where proximity to urban centres with private facilities does not ensure accessibility when financial challenges are overwhelming.

2.3 Understanding Down Syndrome in Social Contexts

Beyond medical knowledge, how society views DS greatly impacts the lives of individuals and their families. These views change significantly depending on the context: culture, access to services and family well-being. A meta-review by Zhang et al. (2025) shows that many societies still have a low level of acceptance for conditions like DS. As a result, affected individuals and their families face rejection and stigma from community members, neighbours, relatives and even strangers in daily interactions. This leads to feelings of inferiority and social disadvantage for both individuals with DS and their families. Although the effects of stigma vary by context, they demonstrate concerning consistency. In Ethiopia, parents face different types of stigmas. They deal with public stigma aimed at their children, courtesy stigma that affects them because of their child, where they adopt negative views and distance themselves and their children from social situations (Tekola et al., 2020). In Brazil, parents of children with DS in rural areas encounter considerable social stigma, which leads to feelings of being ignored and inferior. This stigma directly impacts their access to health services and overall well-being (Amorim & Shimizu, 2022). In Saudi Arabia, despite efforts to raise public awareness and reduce stigma through media and educational programs, social views still create significant obstacles for the full integration of individuals with DS into community life (Parveen et al., 2024).

The societal perceptions interact with other factors, making career transition planning and adult outcomes more difficult. Parental perceptions and societal expectations significantly impact career transition planning and outcomes. They often limit how parents see their children's futures and view them as realistic possibilities (Long et al., 2024). The introduction of prenatal testing for DS has added to this complex situation. Testing practices often reflect and strengthen mixed societal opinions about the value and potential of individuals with the condition, leading to challenging emotions for prospective parents (Bell & Hutchinson, 2025). In light of these challenging social realities, many parents turn to religious coping methods to handle stress, find meaning in their experiences and push back against negative societal narratives (Çaksen, 2025). This suggests that spirituality plays important roles when formal support systems are inadequate or when families feel isolated by stigma.

2.4 The Transition to Adulthood: Universal Challenges and Disability-Specific Complexities

At the age of 18, individuals in most countries assume adult legal rights and responsibilities, including the legal right to make independent decisions regarding medical, mental health, educational, and financial matters (Turchi et al. 2024). Adolescence, therefore, serves as a crucial preparatory period for developing the skills, knowledge and support networks necessary for successful adult functioning (Moons et al. 2021). While the transition to adulthood presents challenges and complexities for neurotypical individuals, it is more complicated and stressful for individuals with developmental disabilities like DS (Tadesse et al., 2024).

Globally, individuals with DS have less access to education and job opportunities than neurotypical individuals (McGlinchey et al., 2025; Carter et al., 2021). Even with significant research and services available in Global North countries (McGlinchey et al., 2025), there is limited research on the post-secondary outcomes for individuals with DS (Channell & Loveall, 2018; Loveall et al., 2022). This trend also applies to transition-age youth with developmental disabilities, who often find it hard to get jobs and enter postsecondary education (Taylor et al., 2022; Carter et al., 2021). This study argues that high unemployment rates and post-school challenges among individuals with DS and other developmental disabilities are mainly due to the absence or delayed career transition planning.

2.5 Conceptualising Career Transition Planning and Family Involvement

Transition planning involves outlining clear steps to reach set goals, helping individuals move smoothly from one stage of life to another, particularly from adolescence to adulthood (Moons et al., 2021). Research on best practices in transition planning underscores several essential elements for a successful process, and omitting any of these elements can result in poor outcomes after school: child involvement, family involvement, relationships between families and schools, a meaningful curriculum, and child-oriented, outcome-based goals (Hetherington et al., 2010). Almalki et al. (2021) also posit that, to help adolescents transition smoothly from school to adulthood and assume a productive role in society, there is a need to identify transition goals, link post goals with those of Individual Education Plans (IEP), align transition and IEP goals, and provide opportunities to teach skills and evaluate progress.

Family involvement is active in all these processes. Thus, their engagement in career transition planning correlates with enhanced post-school results for adolescents with DS (Schutz et al., 2022). They provide important insights into the career and employment preparations as they understand their children's interests, preferences, strengths, and needs in ways other service providers, such as educators, educational psychologists, occupational therapists, or nurses, may not. Therefore, family-child relationships are among the most important social connections in career transition planning. However, the dynamics of this relationship during the career transition to young adulthood have not received much attention, especially for adolescents with developmental disabilities (Fang et al., 2021).

While research on the role of families in career transition planning for individuals with developmental disabilities is emerging worldwide, studies focused specifically on adolescents with DS are still scarce. Recent studies include Codd and Hewitt's (2021) research examining parental views on preparing children with intellectual disabilities for adulthood in the UK, and Almalki et al.'s (2021) study focusing on challenges to parental involvement in transition planning for children with intellectual disabilities from an educational viewpoint in Saudi Arabia. Only two studies have examined parental roles and experiences in career transition planning for individuals with DS. Long et al. (2024) explored parental perceptions of adulthood for emerging adults with DS in the USA. They revealed that parents had mixed feelings about their children reaching adulthood, with their definitions of adulthood closely related to skills gained. A scoping review by Washington-Nortey et al. (2025) investigated parental expectations for children with developmental disabilities. Of the 58 studies that met the criteria, only four focused on DS. Most of the studies were conducted in the USA, primarily addressing autism spectrum disorders. Parents expressed various expectations beyond academic success, including outcomes in employment, relationships, and daily living skills. This research area remains unexplored in African contexts, with no published studies examining family roles and perspectives in career transition planning for adolescents with developmental disabilities such as DS.

2.6 South African Context for Transition Planning

Comprehending the distinct challenges families encounter in career transition planning for adolescents with DS requires examining South Africa’s policy environment, service delivery structures and the nature of the specific community context relevant to this research.

Policy landscape. Despite South Africa’s developed inclusive legislation and educational and transitional policies, post-school opportunities for individuals with disabilities such as Down syndrome persist. The Constitution of South Africa (1996) enshrines the rights of persons with disabilities, while in 2001, the government launched Education white paper 6, a 20-year plan to address the shortcomings in the education system, such as inadequate opportunities for school-to-work linkages (Ellman et al., 2020). However, post-school opportunities for individuals with disabilities remain limited (Bam et al., 2023).

This policy gap becomes evident when comparing South Africa to countries with more comprehensive transition legislation. Unlike countries such as the United States with the Individual with Disabilities Education Act and Australia's Disability Standards for Education, South Africa lacks a comprehensive legislation addressing post-school transition planning and support for individuals with developmental conditions (Ellman et al., 2020). Current post-school transition support programs primarily cater to mainstream school graduates, leaving learners from special schools without systematic transition support (Dzhugudzha et al., 2025).

Service delivery system. The fragmented nature of South Africa's disability support system reflects the country's complex socio-economic landscape and historical inequalities. Research on inequality in South Africa shows how the country's apartheid-era economic development created enduring forms of structural disadvantage that continue to shape access to services and opportunities (McKeever, 2024). These support systems predominantly focus on individuals with disabilities from underserved communities and households, where multiple intersecting challenges create additional barriers to effective transition planning. Within this context, the Sizwe community represents a miniature of broader challenges facing underserved populations. Kotzé (2010) describes residents of the Sizwe community as mostly poor, uneducated and unemployed. The government has set up a social security system by investing in social wages, which comprise education, health services and social development programs (Gadisi et al., 2020). The system also aims to lower living costs for disadvantaged households and individuals through different types of social assistance, such as old-age grants, child support, and disability grants.

However, government services alone cannot address the complex needs of families navigating life challenges. Community-based organisations (CBOs) have been established nationwide to help families in underserved communities. These organisations tackle various needs, focusing on reducing poverty, improving health systems and providing specialised support for families with physical, sensory and developmental disabilities. They play an important role in society by filling gaps that the corporate or government sectors do not adequately address (Choto et al., 2020), although their capacity is often limited by resource constraints such as funding.

Policy gaps present significant challenges for families and adolescents residing in underserved communities. In the absence of structured transition support within special school curricula, families are compelled to navigate post-school planning on their own, facing limited information, financial difficulties and disjointed services. International studies reveal stress, uncertainty and barriers that families face during transitions (Codd & Hewitt, 2021; Peters et al., 2022), yet there is insufficient knowledge about how the limitations of South Africa's policies influence everyday experiences of families in the career transition planning for adolescents with DS.

Recent South African scholarship sheds light on these systemic shortcomings. Botha et al. (2023) present a detailed critique of South Africa's skills development programs, demonstrating that despite the existence of legislative frameworks intended to encourage inclusion, the practical execution is lacking, which results in individuals with disabilities being marginalised from mainstream development opportunities. Their analysis highlights that existing programs are mainly designed for typically developing individuals. Dzhugudzha et al. (2025) reinforce this critique, arguing that existing post-school transition support programs, such as learnerships, predominantly serve graduates from mainstream schools, systematically excluding graduates from special schools. These studies reveal critical systemic exclusion for families of adolescents with DS in special schools with limited resources. This policy-practice gap translates to navigating post-school planning without mandated transition support plans like those in the United States. Access to support depends on the individual schools, teacher awareness or family advocacy, leading to unequal outcomes. This disconnect between policy and reality necessitates urgent attention, particularly in understanding how families in underserved communities navigate these systemic barriers. This study sought to fill this gap by documenting family experiences within their sociocultural and economic contexts to guide policy and service enhancements.

2.7 Conceptual Framework

Given the complexity of the interplay of individual, family, community and systemic factors that influence career transition planning, this study employs a dual conceptual framework, combining Bronfenbrenner's ecological systems theory with the neurodiversity approach to disability. This conceptual framework offers a broad view for understanding the perceptions of families managing career transition planning for adolescents with DS. Bronfenbrenner's Ecological Systems Theory (EST) offers a practical way to understand how individuals interact with the different layers in their environment (Amali et al., 2023). Bronfenbrenner (1994) argue that human development is influenced by systems ranging from immediate to wider societal settings. At the core is the microsystem, which includes the adolescent's direct surroundings, such as home, school and community, where daily interactions happen. This system plays a crucial role in shaping an adolescent's attitudes, expectations and readiness to adulthood. The mesosystem includes the connections between the microsystems, such as partnerships among families, schools, and CBOs (Crawford, 2020). Such connections are vital for effective career transition planning. The exosystem refers to systems that indirectly affect adolescents, such as healthcare facilities, social services and local employment agencies. Although adolescents may not interact with these systems daily, they influence access to information, resources, and support for a smooth transition to adulthood. The macrosystem involves larger cultural, social and policy contexts (Crawford, 2020). This includes attitudes towards disability, inclusive education, inclusive policies and employment of individuals with developmental disabilities. This system determines support available to families in underserved communities. Lastly, the chronosystem adds the dimension of time; it considers life changes, shifts in family situations and changing societal perspectives.

The neurodiversity approach to disability challenges the medical model of disability that views developmental disabilities as medical problems that need fixing. Instead, cognitive and neurological differences are viewed as part of natural human variation (Dwyer, 2022; Chapman, 2020). Judy Singer (2016), who introduced the term "neurodiversity" into the academic sphere, stresses that individuals with developmental disabilities should not be seen as dysfunctional. They have unique strengths and ways of engaging in the world. This perspective suggests that disability is not just found in the individual but results from the interactions between the individual and the environment, which fail to accommodate them (Chapman, 2020). This view emphasises social inclusion, self-determination and respect for individuals with developmental disabilities.

Bronfenbrenner's ecological systems theory, along with the neurodiversity approach to disability, highlights the importance of families as primary advocates for their adolescents with DS. They operate within interconnected systems to support, nurture and develop their children's unique strengths and skills in preparation for independent living after school. This framework shows that effective career transition planning requires families to navigate and mobilise support across all systems, including family, schools, community, and CBOs.

2.8 The Significance of the Study

The theoretical framework reveals significant gaps in current research and practice. While international research explores family perspectives on transition planning, this study area remains limited in African contexts. To the authors' knowledge, no studies have examined family experiences and perspectives in career transition planning for adolescents in South African contexts, despite the unique challenges and opportunities present in the context. Current South African DS literature is limited to clinical reviews (Christianson, 1996), educational interventions (Reyneke & Hoosain, 2020; Brynard, 2014), family and caregiver experiences (Barr et al. 2016), and post-school and employment experiences (Tod, 2013; McGlinchey et al. 2025). Although Muvua et al. (2008) examined how schools in the Cape Metropole prepare adolescent learners with DS for work, this school-focused study did not explore family roles, experiences and perspectives in career transition planning processes. This gap is significant given the ecological systems theory's emphasis on family-school-community collaborations and the neurodiversity approach's focus on strength-based transition planning.

3. Methodology

3.1 Research Design

This study employed a phenomenology research design to explore the perspectives and lived experiences of families of adolescents with Down syndrome. This approach was the most appropriate as it aligned with the study's aims and conceptual framework. Given that family roles and experiences in career transition planning remain limited in South African contexts, a qualitative approach was essential to generate in-depth, contextually rich data.

3.2 Participants of the Study

Purposive sampling was used to recruit ten primary participants: nine parents and one guardian of adolescents (ages 11 -16) with DS residing in the Sizwe community of Soweto, South Africa. This sample was determined based on principles of qualitative research and the specific characteristics of the study population and context. The first author physically recruited participants through outreach efforts at one of the community service points frequently used by families with children with DS in the community. Rapport was established by explaining the nature of the project to gain trust before the data collection process.

The sample of primary participants consisted of nine parents and a guardian aged between 36 and 56 years. Most were females (n=7), and three (n=3) were males. Regarding marital status, six participants were single and four were married. Educational levels varied: seven participants completed Grade 10, two completed Grade 12, and one completed Grade 12 with several certificates. Employment status was predominantly marked by unemployment (n=6), with two participants employed on a part-time basis and two on a full-time basis. Monthly household income ranged from R500 to R5300, with most participants depending on government social grants, including disability and child support grants. Only one participant received R8000 monthly. This purposive sampling provided a contextually rich understanding of families' perspectives on transition planning for adolescents with DS in underserved communities.

Ten CBOs specifically focusing on developmental disabilities were identified through purposive sampling and contacted via email and telephone. The sampling frame was developed through consultation with disability advocacy networks and existing research contacts. Despite follow-up efforts, four CBOs agreed to participate in the study. Including CBOs as secondary participants enabled multiple data sources, strengthening qualitative research credibility by providing different perspectives on the same issue under study. CBOs represent important mesosystem and exosystem influences in Bronfenbrenner's theory; they provide crucial services to families in underserved communities, making their perspectives important.

The first CBO was established in 1976. The organisation is well established with structured programs and reaching 400 families, predominantly from underserved communities around the Western Cape. Another CBO was established in 2015, reaching out to 500 predominantly black families from diverse socioeconomic backgrounds across the Gauteng province and beyond. The third CBO is a newly formed one still developing its services. The organisation currently has 117 families, of all races, from mixed socioeconomic backgrounds in Gauteng province. The last CBO was established in 2005, focusing on 50 families, predominantly black from low-income backgrounds across multiple provinces.

3.3 Instrumentation and Data Gathering Process

A semi-structured interview schedule was developed to collect data on primary participants. Interviews were conducted via telephone between May and June 2025. This modality was selected as it accommodated the participants' work schedules and family responsibilities. It also enabled participants to engage from familiar environments. Each interview lasted 30-50 minutes and was conducted in the participants' preferred language, IsiZulu. All interviews were audio-recorded with participants’ consent. The first author, fluent in IsiZulu and English, transcribed all interviews verbatim in IsiZulu immediately following data collection to preserve linguistic nuances and contextual meanings. Transcripts were then systematically translated into English by the first author, adhering to translation principles for qualitative research (Squires, 2009). This translation process ensured that the essence of participants’ experiences and perspectives was accurately presented in the English language analysis and reporting. However, some linguistic and cultural nuances may be complex to capture across languages.

An online open-ended survey tool was developed and distributed using Google Forms to gather information about the CBOs' services, challenges and perspectives on family transition planning support. The survey complemented interview data by providing a broader context about available services and organisational perspectives on family roles in career transition planning.

3.4 Data Analysis

Data was analysed using Braun and Clarke’s (2006) six-phase thematic approach. Audio recordings were transcribed. The analysis process involved familiarisation with the data from interviews. Initial codes were generated by systematically identifying meaningful data units, followed by collating codes into broader categories. These categories were reviewed to ensure they accurately reflected the coded data and the overall dataset. CBO survey responses were analysed using descriptive analysis. Finally, themes were defined and named to capture their essence.

3.5 Research Ethics

Ethical clearance for the research was obtained from the University of Johannesburg’s Research Ethics Committee. This approval facilitated access to families and CBOs involved in the study. All participants provided voluntary informed consent before data collection commenced. Participants were informed of their right to withdraw from the study at any time. Strict confidentiality measures were implemented to protect the identity of the community and participants. The actual name of the participating community has been replaced with the pseudonym "Sizwe" to protect the community from potential stigmatisation. Individual participants and organisations are identified only through numerical codes.

3.6. Study Limitations

While this study provides rich, contextually grounded insights into families' perspectives on career transition planning, several methodological limitations should be acknowledged. First, the small sample size of ten families, while appropriate and sufficient for a phenomenological research design focused on depth rather than breadth, limits the transferability of findings to other contexts, communities or family set-ups. Thus, the study had limitations; the focus on one community in Soweto may not reflect experiences and perspectives of the selected ten families in the Sizwe community, which may not represent the diverse experiences across South Africa's varied geographic, cultural and socio-economic contexts.

The limited response rate from CBOs may not fully represent the range of organisational perspectives and services on family support needs. In addition, reliance on self-reported data indicates that subjective interpretations shape the participants' perspectives, readiness to disclose information and memory abilities. Participants might fail to remember or disclose all the information important to this study.

Furthermore, the study gathered perspectives at a single time (May- June 2025), which may not capture the fluid and evolving nature of families' career transition planning experience over time. Additionally, although telephone interviews offered accessibility and convenience for participants balancing work and family obligations, they do not allow for the observation of non-verbal communication. They may have limited the discussion of sensitive issues that participants may have preferred to address in face-to-face interactions. Finally, the limited response rate from CBOs (four out of ten contacted) may not fully reflect the diversity of organisational viewpoints, service models and support capabilities available in the country. CBOs that decided not to participate may have different traits, challenges, or service philosophies not included in the study.

4. Findings

During the second phase of the analysis process, initial coding identified distinct codes across the dataset. These codes captured specific concepts expressed by the participants, such as “waiting for government support”; recognition of children’s cooking skills; “trust in teacher expertise”; “transportation costs as a barrier”; “inability to save money”; faith-based copying, and “reliance on divine intervention”. These initial codes were systematically organised into broader categories in the third phase based on their conceptual relationship and patterns. For instance, codes related to “faith-based copying”, “waiting for God’s plan; “hoping for divine help”, and “leaving the future to God” were grouped into a category reflecting passive, spirituality-oriented approaches to planning. So, through interactive review and refinement in analysis phases four and five, these categories were developed into four overarching themes that captured the essence of families’ experiences. Each theme was verified against the original data to ensure accuracy and coherence. For example, theme 1 (passive coping as a substitute for practical planning) merged from the convergence of codes showing families’ reliance on external agents (God, government, schools) without actively developing concrete transition strategies. This pattern was illustrated by statements like “only God knows what will happen” (P1); “I have never thought about it” (P10), and descriptions of “just living a normal life” without specific preparation activities.

The final phase involved defining and naming these themes to capture their essence. Throughout the analysis, attention was paid to explicit meanings and underlying assumptions and conceptualisations, ensuring themes reflected what participants said explicitly and the more profound implications of their perspectives. The following section presents four themes from the data: passive copying as a substitute for practical planning; financial and resource constraints as primary barriers; recognition of the child’s strength despite limited systematic development; and the school as the primary career transition agent.

Theme 1: Passive Coping as a Substitute for Practical Planning

Most families showed limited awareness of transition planning for their children and access to career transition planning services and support from CBOs. They gave general descriptions of their current efforts in raising their children, as indicated by one parent as “*just living a normal life*”. One parent was hoping for continued government support. Some parents believed that divine intervention would guide their children’s futures. Such faith-based affirmations substitute seeking practical resources, developing specific skills or creating career transition plans that would actively prepare their children for independence in post-school settings. This is shown in the following captions:

> *"I do not know what will happen to him…I always ask myself that question, you know…If God could help her….I am not doing anything…I have never thought of doing anything to prepare her as such"* (P3)
>
> *"He will manage; his problem is in writing and speaking, but he listens when you correct him"* (P6)
>
> *"I tried saving for him, but I failed. I hope the government will continue supporting him"* (P7)
>
> *"I do not know, only God knows"* (P1)
>
> *"I have no idea, but I see other parents with children with DS. I do not see much; most of them do not do anything in life. I know of two individuals, one is 29 and the other 24, they are seated at home"* (P2)
>
> *"She will grow just like other children"* (P5)
>
> *"I always wonder what will happen to my child when I die"* (P9)
>
> *"I have never thought about it; you know"* (P10)

The service delivery patterns of CBOs highlighted a massive gap in supporting families of children with developmental disabilities with career transition planning. Most provided general disability support programs such as counselling, food parcels, general life skills on caring for a child with developmental disability, social networking events, direct work placement initiatives, educational webinars and workshops. Only one CBO also focused on raising awareness about post-school preparations. The following captions from CBOs outline specific skills and knowledge they impart to families.

> *"The ability to be able to communicate with their children, to be able to manage difficult behaviour and know what strategies to employ. To educate them about their children's condition and various stages of development. To support the emotional, psychological and physical well-being through including social activities where they network, share information, engage in physical activities and get coaching and counselling on self-care"* (CBO1)
>
> *"Work hand in hand with other parents to create an environment where our kids can flourish"* (CBO2)
>
> *"Awareness about post-school, importance of having a plan in place. Assisting with grant applications and placement info regarding workshops and after-school programs"* (CBO3)
>
> *"Disability awareness, support, caring techniques, food parcels… Offer information on where to find specific support and care"* (CBO4)
>
> "*We had a support group at XXX, we used to talk about so many issues, however, we no longer meet…I do not know why. We last met last November… but we have*

> *never talked about how to prepare our children for life after school, you know"* (P7)

This theme focuses family perspectives regarding career transition planning, and the barriers to family involvement. The results reveal that families have a limited understanding of transition planning as a formal process that requires their engagement. Their passive strategies, such as relying on faith, government support or external institutions, reflect gaps in knowledge and constraints like uncertainty, inadequate access to information and lack of systemic guarantee. Although spiritual beliefs provide solace, replacing practical preparation with faith impedes adolescents' readiness for life after school. The lack of career-focused programming from CBOs reinforces families' unawareness and passive role in the transition process.

Theme 2: Financial and Resource Constraints as Primary Barriers

Financial and resource constraints surfaced as the primary barrier to career transition planning. Most families frequently conveyed their inability to set aside funds for their children's future or to enrol in paid programs to prepare them for independent life after school. These constraints obstructed them from accessing fee-based services or building financial security for their children.

> *"Okwamanje kusanzima, (for now it is difficult) Uma wakhe waphelelwa ngumsebenzi (her mother lost her job) wabulela emakhaya (she went back to the rural areas) ngiyazama ukubabekela imali (I am trying to save, but am failing) …."* (P4)
> *"She is not getting the disability grant…her mother failed to complete the processes"* (P4)
> *"I would like to do that, but I do not have enough. The money is not enough even for basics"* (P5)
> *"The money I have is for basic survival needs"* (P7)
> *"It is a challenge to raise a child as a single parent; I have to do everything"* (P6)
> *"I am saving 500 rands every month for all my children"* (P10)

CBOs substantiated these financial barriers, recognising transport costs, limited reach across diverse communities and family financial restrictions as significant impediments to accessing services. One CBO pointed out that families who require the most support cannot participate in some programs due to transport challenges. The only organisation that offered vocational training to adolescents and youths with developmental disabilities charged R1000 monthly, a fee that exceeds the financial capabilities of most families, given their reported household income of R500 to R5300.

CBOs also encounter funding challenges, as reliance on unstable funding sources restricts their capacity to deliver comprehensive services or to subsidise some services to families who cannot afford them. CBOs found it challenging to consistently engage with underserved populations, as geographical isolation posed further obstacles to service provision. The inconsistent funding and disruptions in service provision experienced by grant-dependent CBOs meant that the institutional support families depend on is often unreliable.

The CBOs highlighted the following challenges:

> *"Most of the time, the parents who need most support cannot attend our events or activities due to transport or financial issues. Our group is split around Gauteng, making it hard to have a common and central place suitable for everyone. Our programs are not funded. Making it expensive to render some of our services"* (CBO1)
>
> *"Finances and availability of the team, as most are either unemployed with no finances to move from one place to another to provide service, or they work in an environment which does not allow them enough time to execute the mandate"* (CBO2)
>
> *"Logistical barriers, Funding barriers, Resources, Social grants"* (CBO3)
>
> *"Commitment from parents. Direct financial support expectations"* (CBO4)

This theme focuses on the barriers to family involvement, and the socio-economic factors that influence transition planning. Financial constraints have been identified as the most widespread barrier, with household income ranging from R500 to R5300 and dependence on social grants leading families to prioritise immediate survival over future planning. Limited resources restrict access to paid vocational programs, activities offered by CBOs or savings for post-school pathways. CBOs face funding challenges that limit their availability to provide subsidised or specialised support. This convergence of financial barriers for both families and CBOs results in a systemic gap, where those most in need of transition planning support are the least able to access it, reinforcing cycles of disadvantage.

Theme 3: Recognition of the Child’s Strength Despite Limited Systematic Development

Despite the absence of extensive formal career transition planning, most families understood the children’s skills and preferences. The majority pointed out particular strengths and interests: “*He enjoys cooking, he helps out though it can be messy*”, *He has an interest in mechanics and metal objects*”, “*she loves singing and dancing*”, “*you know maybe if God can help him perfect his soccer skills*”, “*he can fix anything on the phone*”. Parents recognise their children’s interests as opportunities, but lack the knowledge and resources to nurture these skills into practical career options systematically.

Although CBOs offer a range of support services, the disparity between acknowledging individual strengths and nurturing them into career pathways is evident in their programming. CBOs delivered general support services but lacked the specific focus necessary to turn individual interests and capabilities into structured career development opportunities, thus highlighting challenges families are facing in accessing skill development support and information.

This theme focuses on family perspectives and barriers and facilitators. Families’ understanding of their children’s interests and abilities is crucial, consistent with neurodiversity approaches focusing on strengths. However, the deficiency in knowledge, resources and support necessary to transform these observations into systematic skill development constitutes a significant barrier. On the other hand, CBOs tend to offer general disability support rather than tailored services that build upon recognised strengths. This disconnect between family awareness and strength-based career development support available highlights a significant shortcoming in the current service delivery.

Theme 4: The School as the Primary Career-Transition Agent

Parents and guardians perceived educational institutions as key agents in career-transition planning. This indicates a transfer of responsibility from the family to the education system, with parents and guardians seeing themselves as passive and secondary agents rather than active participants in the transition process. This also reflects their uncertainty about their role in planning for the transition. While schools play a crucial role in career transition planning, relying solely on them may limit the comprehensive, personalised preparation resulting from collaborative partnerships between parents and schools.

> *"Since I am taking them to their school for children with Down Syndrome, they know better Uyabo… I am not even clued up about what they learn, I have faith that whatever they do is for my child's benefit"* (P6)
> *"The school is doing a good job in preparing him for life after school"* (P4)
> *"The school is doing a good job, and they learn a lot"* (P8)
> *"Teachers are qualified to help our children make it in life; it is up to the child to listen or not"* (P3)
> *"His teacher knows him better, you know, she says a lot during consultations. I am happy with the school"* (P7)
> *"I have not identified my child's skill. I am waiting for the schools to introduce vocational and skills subjects to them sometime next year, then I will have an idea"* (P9)

Two CBO representatives share their observations about families of individuals with developmental disabilities.

> *"It is often found in the lower-income groups that parents are reluctant to let their child work as they are worried about losing the grant. Parents often think it is OK for their school-leaving child to sit at home. We want parents to understand the importance of purpose. All skills learned in the previous 12 years of going to school need to be maintained…parents need to understand the young adult's expectations within the reality of the family's situation, and we promote informed shared decision making"* (CBO3)
> *"Many parents are very much aware of how to look after their children, but the challenge is when to let go once their children are older, being open to receiving help and adjusting to living their lives outside being a primary caregiver for their child"* (CBO4)

This theme focuses on family perspectives, barriers and socioeconomic factors. Families regard schools as essential for career transitions, indicating a lack of knowledge and resources, trust in professional expertise and uncertainty about their roles. Although valuing the involvement of schools is a positive aspect, excessive delegation can impede the collaborative partnerships that have been demonstrated internationally to facilitate effective transition planning.

5. Discussion

Career transition planning assists adolescents with DS and their families to prepare for a life process that can otherwise be stressful (Ellman et al., 2020). This study explored families' perspectives and experiences in career transition planning for adolescents with DS in an underserved community, highlighting significant gaps between parental aspirations and the practical solutions and support systems available. The findings illuminate how systemic barriers, limited resources, and deficiencies in service delivery create complex challenges for families as they manage their children's transition into adulthood. A key discovery is the impact of limited awareness and knowledge on families' understanding of their roles in career transition planning, often leading to passive coping and overdependence on external institutions. Four emerging themes emphasise the complex nature of families' experiences in this context.

Spirituality has been examined as a resource to manage potentially stressful circumstances (Duarte et al., 2022). Families with children diagnosed with DS may have spiritual needs related to this challenging situation that involves family roles, parenting, and health. The significant reliance on faith-based coping strategies among families under study demonstrates a typical response to the uncertainty and stress involved in raising children with DS. A research study by Ellman et al. (2020) also reveals challenges faced by parents of individuals with developmental disability during transitions from special school to post-school life settings. Thus, spirituality offers moral support to help them adapt to life circumstances (Karaca & Şener, 2021). However, spiritual beliefs can serve as a coping mechanism and a potential barrier to effective engagement in career transition planning. In this study, families entrusted their children's future to divine intervention, the government and educational institutions, replacing their practical and active role in career transition planning. Research indicates that individuals with DS and their parents often face challenges, such as limited information and transparency, when transitioning to adulthood (Peters et al., 2022). The limited programmes from CBOs focusing on career transition planning further exacerbate this situation.

Navigating the transition to adulthood can be particularly challenging for individuals with developmental disabilities due to barriers such as limited access to resources, inadequate support systems, and varying levels of family involvement (Test et al., 2009). Economic struggles have also emerged as primary obstacles to effective career transition planning among families in their quests to prepare their adolescents for an independent life, and to the CBOs who provide support. Results of the study indicate that most parents struggle to meet basic needs, much less to invest in specialised services or future-oriented strategies. This observation aligns with research by Carroll et al. (2022), who indicated that poor economic status, particularly in marginalised families, significantly restricts access to post-school opportunities for individuals with disabilities. The involvement of parents in career transition planning has been linked to positive outcomes (Schutz et al., 2022); however, financial and resource limitations often confine parents to passive roles. The restricted access to specific programs due to transportation issues, limited access to transition planning support, and paid programs for vocational training exceed their financial means. Unstable funding of CBOs further worsens these constraints, establishing a cycle where the most in need of assistance are the least able to access it.

Parents demonstrated recognition of their children's interests and abilities, a crucial initial step in career planning (Wehman, 2013), indicating potential for strength-based strategies in career development. However, the gap between recognising abilities and practically developing them into career pathways reveals a significant challenge in planning. Therefore, without nurturing, guidance, and systematic support, these strengths largely remain unexploited. The families' difficulty turning recognition into skill development highlights a disconnect between informal parental knowledge and formal career development processes. Hence, study results indicate families' lack of information on career transition planning, and the current support system fails to connect identified strengths with vocational preparation. These findings align with Schutz et al. (2022) on pre-employment transition services, job preparation, obstacles, and knowledge of local resources in the USA. The study concluded that most parents were unaware of the available transition resources. As recent advances in medical care have increased life expectancy and improved the quality of life for individuals with DS (Motegi, 2021), employment and independent living preparation are essential skills to impart to adolescents with DS. Conversely, most CBOs offer general disability support programmes such as counselling, food parcels, basic life skills for caring for a child with developmental disabilities, social networking events, direct work placement initiatives, educational webinars, and workshops. Most of these support services lack specialised programmes to empower families to actively participate in career transition planning and programmes that could convert individual talents into employable skills or vocational pathways. This misalignment raises concerns, as Niemiec and Tomasulo (2023) emphasise the need for strength-based, positive psychology, and well-being approaches to assist individuals with disabilities.

The success of the planning process largely depends on family involvement, as parents of children with developmental disabilities have deep hopes for their children's futures that extend beyond academic success to include their overall development (Er-rida et al., 2024). However, the study results indicate that families mainly perceive schools as the primary agents of career transition planning. Based on Education White Paper 6, special schools must offer comprehensive education programs with life skills training and programme-to-work linkages (Ellman et al., 2020). So, when families transfer career transition planning responsibilities to educational institutions, it reflects both families' recognition of their limitations in knowledge and their search for professional guidance and support. This reliance may also reveal parents' uncertainty about their involvement in transition planning. These findings differ from Sujarwo et al (2021)'s finding that parents rely on schools for their children's education, development, and future planning because they prioritise earning an income to meet family needs.

However, uncritically depending on a system can cause serious setbacks. Unlike countries like the USA and Canada, which have policies to guide smooth transition planning for individuals with disabilities, South Africa does not have legislation to address post-school transition (Ellman et al, 2020). While the Department of Education refers to an individual learning plan as a valuable option to help learners who face obstacles to learning, the transition from school to post-school is not adequately addressed. In the same view, Dzhugudzha et al. (2025) argue that countries like Australia have established transition planning programmes for individuals in special schools; however, South Africa has yet to implement such programmes. Current school-to-work transition support programmes do not cater to learners from special schools, as they follow a "district curriculum accommodation plan," which differs from the academic curriculum in mainstream schools.

These findings demonstrate that families possess a limited understanding of their role is career transition planning, tend to rely on passive coping mechanisms, and frequently assign responsibility to external institutions instead of viewing themselves as active collaborators. The identified obstacles to family engagement are complex, encompassing financial difficulties, restricted access to transition planning-specific information and services, an absence of systematic support frameworks, and ambiguity regarding their role. CBOs provide valuable services, with their capacity constrained by unstable funding and limited geographic reach. Similarly, socioeconomic factors influence all facets of the transition planning experience, from prioritising survival needs over future planning to transport barriers and grant dependency impacting service access and employment aspirations.

These findings carry significant implications for policy and practice in South Africa. Firstly, there is a necessity for specific national legislation regarding post-school transition planning for individuals with developmental disabilities, who are primarily in special schools, akin to the mandates observed in the United States and Australia. Existing policies tend to prioritise mainstream learners, leaving families of special school graduates without structured support and defined roles. Furthermore, this legislation must be accompanied by effective implementation plans: capacity-building efforts to enable families to engage actively; sustainable funding for CBOs and schools to offer specialised services; financial support through subsidised or free transition programs and transport assistance or mobile models to serve underserved communities. There is a need for increased funding for CBOs to provide sustained and specialised transition support services to families. Partnerships with private companies should be used to promote such social investments, supplementing government funding for disability support organisations. This can be achieved by creating tax incentives for businesses that fund transition planning programmes or by developing corporate mentorship schemes that connect employers with individuals with developmental disabilities.

Service delivery models must evolve from general disability support to strength-based, personalised career development strategies. While counselling, food parcels and social networking fulfil essential roles, they do not adequately address the specific requirement for systematic career transition planning. CBOs, schools, and disability support services require training, resources and frameworks to implement strength-based strategies that assist families in identifying, nurturing and developing their children’s unique abilities into viable career pathways. This transition necessitates a departure from deficit-oriented interventions towards neurodiversity-informed practices that acknowledge individuals with DS as having valuable strengths and potential contributions to society.

Addressing passive coping involves addressing its fundamental causes: limited information, absence of visible success models and systemic obstacles that hinder proactive planning. Peer support networks can provide practical knowledge and instil hope, while mentorship programs that link adolescents with DS to employed adults with DS can make career opportunities more tangible. Documenting and sharing success stories is vital to counteract narratives of inevitability and dependency. Most importantly, society addresses post-school outcomes for individuals with developmental disabilities early, rather than waiting for adulthood. Comprehensive transition planning is vital and should start during adolescence, as this developmental phase offers an ideal window for preparing individuals for post-school independence and community integration.

6. Conclusion

The study unveils significant gaps between family aspirations for their adolescents with DS and the practical support system available. The predominant reliance on passive coping strategies has substituted for practical career transition planning actions. Families perceive the school as the leading primary career transition agent, reflecting their recognition of their limitations in knowledge and their quest for professional guidance and support in career transition planning. Financial constraints also emerge as a systemic barrier, affecting families' ability to access services and CBOs' capacity to deliver comprehensive support. These factors automatically confine families to passive roles in the career transition planning process. The study contributes to the limited literature on the family's roles and experiences in career transition planning for individuals with developmental disabilities in African contexts.

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References

Adeniyi, Y. C., & Adeniyi, A. F. (2020). Development of a community-based, one-stop service centre for children with developmental disorders: Changing the narrative of developmental disorders in sub-Saharan Africa. *Pan African Medical Journal, 36*(1). https://doi.org/10.11604/pamj.2020.36.1.23071

Aleman-Tovar, J., & Burke, M. (2022). A literature review about transition planning experiences among culturally and linguistically diverse families of youth with disabilities in the United States. *International Review of Research in Developmental Disabilities, 63,* 51–102. https://doi.org/10.1016/bs.irrdd.2022.03.001

Almalki, S., Alqabbani, A., & Alnahdi, G. (2021). Challenges to parental involvement in transition planning for children with intellectual disabilities: The perspective of special education teachers in Saudi Arabia. *Research in Developmental Disabilities, 111,* 103872. https://doi.org/10.1016/j.ridd.2021.103872

Amali, N. K., Ridzuan, M. M., Rahmat, N. H., Seng, H. Z., & Mustafa, N. C. (2023). Exploring learning environment through Bronfenbrenner's ecological systems theory. *Journal of Academic Research in Progressive Education and Development, 12*(2), 144–162. https://doi.org/10.6007/JARPED/v12-i2/17324

Amorim, B. Y. F. d., & Shimizu, H. E. (2022). Stigma, caregivers and the child with Down syndrome: A bioethical analysis. *Revista Bioética, 30,* 72–81. https://doi.org/10.1590/1983-804220223021

Barr, M. D., Govender, P., & Rencken, G. (2016). Raising a child with Down's syndrome: Perspectives from South African urban caregivers. *African Health Sciences, 16,* 929–935. https://doi.org/10.4314/ahs.v16i4.14

Bell, C. B., & Hutchinson, N. (2025). Parents of individuals with Down syndrome: Opinions and experience of prenatal testing. *Journal of Intellectual Disabilities.* Advance online publication. https://doi.org/10.1177/17446295251343689

Botha, M., Fischer Mogensen, K., Ebrahim, A., & Brand, D. (2023). In search of a landing place for persons with disabilities: A critique of South Africa's skills development programme. *International Journal of Discrimination and the Law, 23*(1–2), 163–180. https://doi.org/10.1177/13582291231100123

Bronfenbrenner, U. (1994). Ecological models of human development. In *International Encyclopedia of Education* (3rd ed., Vol. 2, pp. 37–43). Elsevier.

Brynard, S. T. (2014). Educating learners with Down syndrome successfully: A narrative journey. *Mediterranean Journal of Social Sciences, 5*(20), 1888–1900. https://doi.org/10.5901/mjss.2014.v5n20p1888

Carroll, E., McCoy, S., & Mihut, G. (2022). Exploring cumulative disadvantage in early school leaving and planned post-school pathways among those identified with special educational needs in Irish primary schools. *British Educational Research Journal, 48*(6), 1065–1082. https://doi.org/10.1002/berj.3815

Carter, E. W., Awsumb, J. M., Schutz, M. A., & McMillan, E. D. (2021). Preparing youth for the world of work: Educator perspectives on pre-employment transition services. *Career Development and Transition for Exceptional Individuals, 44*(3), 161–173. https://doi.org/10.1177/2165143420938663

Channell, M. M., & Loveall, S. J. (2018). Post-high school transition for individuals with Down syndrome. In *International Review of Research in Developmental Disabilities, 54,* 105–135. Elsevier. https://doi.org/10.1016/bs.irrdd.2018.08.003

Chapman, R. (2020). Neurodiversity, disability, wellbeing. In *Neurodiversity Studies* (pp. 57–72). Routledge. https://doi.org/10.4324/9780429322297-7

Choto, P., Iwu, C. G., & Tengeh, R. K. (2020). Non-profit organisations and socio-economic development in South Africa: A literature analysis. *Humanities & Social Sciences Reviews*. https://www.researchgate.net/publication/340737174

Christianson, A. L. (1996). Down syndrome in Sub-Saharan Africa. *Journal of Medical Genetics, 33*(2), 89. https://doi.org/10.1136/jmg.33.2.89

Codd, J., & Hewitt, O. (2021). Having a son or daughter with an intellectual disability: Transition to adulthood—a parental perspective. *British Journal of Learning Disabilities*, *49*(1), 39–51. https://doi.org/10.1111/bld.12327

Crawford, M. (2020). Ecological systems theory: Exploring the development of the theoretical framework as conceived by Bronfenbrenner. *Journal of Public Health Issues and Practice, 4*(2), 170. https://doi.org/10.24105/jphip.2020.4.2.170

Duarte, E. D., Braga, P. P., Guimarães, B. R., da Silva, J. B., & Caldeira, S. (2022). A qualitative study of the spiritual aspects of parenting a child with Down syndrome. *Healthcare, 10,* 546. https://doi.org/10.3390/healthcare10040546

Dwyer, P. (2022). The neurodiversity approach(es): What are they and what do they mean for researchers? *Human Development, 66*(2), 73–92. https://doi.org/10.1159/000521337

Dzhugudzha, N. T., Uys, C. J. E., & Ramano, E. (2025). Current practices influencing school-to-work transition for learners with mild intellectual disability: A scoping review. *South African Journal of Education, 45*(2), 1–16. https://doi.org/10.15700/saje.v45n2a2502

Ellman, E., Sonday, A., & Buchanan, H. (2020). Transition from special school to post-school life in youths with severe intellectual disability: Parents' experiences. *South African Journal of Education, 40,* S1–S9. https://doi.org/10.15700/saje.v40ns1a1881

Er-rida, S., Zaidouni, A., Mafhoum, M., Oubibi, M., Alami, M. H., & Mdaghri Alaoui, A. (2024). Inclusive education: Exploring parental aspirations for children with Down syndrome in regular schools. *The Open Psychology Journal*, *17*(1). https://openpsychologyjournal.com/VOLUME/17/ELOCATOR/e18743501311174/FULLTEXT/

Esbensen, A. J., Schworer, E. K., & Hartley, S. L. (2024). Down syndrome. In M. G. Valdovinos (Ed.), *Intellectual and developmental disabilities* (pp. 279–302). Springer Nature. https://doi.org/10.1007/978-3-031-66932-3_13

Fang, S., Galambos, N. L., & Johnson, M. D. (2021). Parent–child contact, closeness, and conflict across the transition to adulthood. *Journal of Marriage and Family, 83*(4), 1176–1193. https://doi.org/10.1111/jomf.12760

Gadisi, M., Owusu-Sekyere, E., & Ogundeji, A. A. (2020). Impact of government support programmes on household welfare in the Limpopo Province of South Africa. *Development Southern Africa, 37*(6), 937–952. https://doi.org/10.1080/0376835x.2020.1757414

Gameren-Oosterom, H. B. M. van, Fekkes, M., Buitendijk, S. E., Mohangoo, A. D., Bruil, J., & Van Wouwe, J. P. (2011). Development, problem behaviour, and quality of life in a population-based sample of eight-year-old children with Down syndrome. *PLOS ONE, 6*(7), e21879. https://doi.org/10.1371/journal.pone.0021879

Glasson, E. J., Jacques, A., Wong, K., Bourke, J., & Leonard, H. (2016). Improved survival in Down syndrome over the last 60 years and the impact of perinatal factors in recent decades. *The Journal of Paediatrics, 169,* 214–220.e1. https://doi.org/10.1016/j.jpeds.2015.09.073

Hetherington, S. A., Durant-Jones, L., Johnson, K., Nolan, K., Smith, E., T., S., & Tuttle, J. (2010). The lived experiences of adolescents with disabilities and their parents in transition planning. *Focus on Autism and Other Developmental Disabilities*, *25*(3), 163–172. https://doi.org/10.1177/1088357610373760

Kamat, A. (2024). *Down syndrome screening: A practical guide.* Springer Nature. https://books.google.com/books?id=rJHvEAAAQBAJ

Karaca, A., & Şener, D. K. (2021). Spirituality as a coping method for mothers of children with developmental disabilities. *International Journal of Developmental Disabilities, 67*(2), 112–120. https://doi.org/10.1080/20473869.2019.1603730

Karkera, S. (2021). A current knowledge of Down syndrome: A review. *International Journal of Dental and Medical Sciences Research, 3*(1), 805–810. https://doi.org/10.33552/IJDMSR.2021.03.000562

Kotzé, L. J. (2010). Phiri, the plight of people experiencing poverty and the perils of climate change: Time to rethink environmental and socio-economic rights in South Africa? *Journal of Human Rights and the Environment, 1,* 135–160. https://doi.org/10.4337/jhre.2010.01.08

Long, K. L., Karimi, A., Mini, A., Stephens, D. P., & Nelson, E. L. (2024). The meaning of adulthood for emerging adults with Down syndrome: Parent perspectives on relevant skills. *Journal of Applied Research in Intellectual Disabilities, 37*(5). https://doi.org/10.1111/jar.13286

Loveall, S. J., Channell, M. M., Burke, M. M., & Rodgers, D. B. (2022). Post-high school transition outcomes for young adults with Down syndrome. *American Journal on Intellectual and Developmental Disabilities, 127*(2), 135–148. https://doi.org/10.1352/1944-7558-127.2.135

McConkey, R., Allen, S., Mlambo, C., Kambarami, P., & Martin, K. (2024). Creating family-centred support for children with developmental disabilities in Africa: Examples of local community interventions. *International Journal of Environmental Research and Public Health, 21*(7), 925. https://doi.org/10.3390/ijerph21070925

McGlinchey, E., Fortea, J., Vava, B., Andrews, Y., Ranchod, K., & Kleinhans, A. (2025). Raising awareness and addressing inequities for people with Down syndrome in South Africa. *International Journal for Equity in Health, 24*(1), 7. https://doi.org/10.1186/s12939-024-02349-3

McKeever, M. (2024). Social stratification and inequality in South Africa. *Sociology Compass, 18*(2), e13173. https://doi.org/10.1111/soc4.13173

Moons, P., Bratt, E.-L., De Backer, J., Goossens, E., Hornung, T., Tutarel, O., Zühlke, L., Araujo, J. J., Callus, E., & Gabriel, H. (2021). Transition to adulthood and transfer to adult care of adolescents with congenital heart disease. *European Heart Journal, 42*(34), 3251–3260. https://doi.org/10.1093/eurheartj/ehab388

Motegi, N., Morisaki, N., Suto, M., Tamai, H., Mori, R., & Nakayama, T. (2021). Secular trends in longevity among people with Down syndrome in Japan, 1995–2016. *Pediatrics International*, *63*(1), 94–101. https://doi.org/10.1111/ped.14354

Musa, S. M., Haruna, U. A., Manirambona, E., Eshun, G., Ahmad, D. M., Dada, D. A., Gololo, A. A., Musa, S. S., Abdulkadir, A. K., & Lucero-Prisno, D. E., III. (2023). The scarcity of health data in Africa is an obstacle to digital health implementation and evidence-based practice. *Public Health Reviews, 44,* 1605821. https://doi.org/10.3389/phrs.2023.1605821

Muvua, A. M., Van Hove, G., & Struthers, P. (2008). Preparation of adolescent learners with Down syndrome in Western Cape schools for transition to work. In *IASSID World Conference Proceedings* (pp. 688–688). https://biblio.ugent.be/publication/684749

Parveen, S., Ahmad, A., & Reshi, A. A. (2024). Empowering lives: Navigating the landscape of Down syndrome support in Saudi Arabia. *Journal of Disability Research, 3*(3), 20240044. https://doi.org/10.3390/jdr3030044

Reyneke, L. K., & Hoosain, M. (2020). Dynamic seating in learners with Down syndrome in South Africa. *South African Journal of Occupational Therapy, 50*(1), 20–27. https://doi.org/10.17159/2310-3833/2020/vol50no1a4

Schutz, M. A., Awsumb, J. M., Carter, E. W., & McMillan, E. D. (2022). Parent perspectives on pre-employment transition services for youth with disabilities. *Rehabilitation Counseling Bulletin, 65*(4), 266–278. https://doi.org/10.1177/00343552211993542

Sium, A. F., Shimels, T., Abdosh, A. A., Diress, T., Tsegaye, T., Yifrashewa, T., Terefework, Z., & Gudu, W. (2023). Indications, types, and diagnostic implications of prenatal genetic testing in Sub-Saharan Africa: A descriptive study. *PLOS ONE, 18*(11), e0294409. https://doi.org/10.1371/journal.pone.0294409

Snyder, H. M., Bain, L. J., Brickman, A. M., Carrillo, M. C., Esbensen, A. J., Espinosa, J. M., Fernandez, F., Fortea, J., Hartley, S. L., & Head, E. (2020). Further understanding the connection between Alzheimer's disease and Down syndrome. *Alzheimer's & Dementia, 16*(7), 1065–1077. https://doi.org/10.1002/alz.12112

Squires, A. (2009). Methodological challenges in cross-language qualitative research: A research review. *International Journal of Nursing Studies, 46*(2), 277–287. https://doi.org/10.1016/j.ijnurstu.2008.08.006

Sujarwo, S., Kusumawardani, E., Prasetyo, I., & Herwin, H. (2021). Parent involvement in adolescents' education: A case study of partnership models. *Cypriot Journal of Educational Sciences, 16*(4), 1563–1581. https://doi.org/10.18844/cjes.v16i4.6030

Taylor, J. P., Whittenburg, H. N., Rooney-Kron, M., Gokita, T., Lau, S. J., Thoma, C. A., & Scott, L. A. (2022). Implementation of pre-employment transition services: A content analysis of Workforce Innovation and Opportunity Act state plans. *Career Development and Transition for Exceptional Individuals, 45*(2), 60–70. https://doi.org/10.1177/2165143421993027

Tekola, B., Kinfe, M., Girma, F., Hanlon, C., & Hoekstra, R. A. (2020). Perceptions and experiences of stigma among parents of children with developmental disorders in Ethiopia: A qualitative study. *Social Science & Medicine, 256*, 113034. https://doi.org/10.1016/j.socscimed.2020.113034

Test, D. W., Fowler, C. H., White, J., Richter, S., & Walker, A. (2009). Evidence-based secondary transition practices for enhancing school completion. *Exceptionality, 17*(1), 16–29. https://doi.org/10.1080/09362830802590144

Tod, C. J. (2013). *Employment in Down syndrome: The experiences of individuals with Down syndrome, their employers and families in KwaZulu-Natal* (Doctoral dissertation). https://citeseerx.ist.psu.edu/document?repid=rep1&type=pdf&doi=704bb34c7fbfd1ebe9574fecdfd2fd98c25e75cd

Turchi, R. M., Kuo, D. Z., Rusher, J. W., Seltzer, R. R., Lehmann, C. U., & Grout, R. W. (2024). Considerations for alternative decision-making when transitioning to adulthood for youth with intellectual and developmental disabilities: Policy statement. *Pediatrics, 153*(6), e2024066841. https://doi.org/10.1542/peds.2024-066841

Van Biljon, H. M., Salie, B., Van Wyk, J. C., Daniel, J., Kersop, L.-M., Naidoo, M., & Van Niekerk, L. (2022). Access to public healthcare rehabilitation services by persons with disabilities in South Africa: A scoping review. *Disability, CBR & Inclusive Development*, *33*(3), 41–67. https://doi.org/10.47985/dcidj.475

Washington-Nortey, M., Ohayagha, C., & Serpell, Z. (2025). Parental expectations for their children with developmental disabilities: A systematic scoping review. *Journal of Child and Family Studies*, *34*(4), 1114–1134. https://doi.org/10.1007/s10826-025-03043-w

Wehman, P. (2013). Transition from school to work: Where are we and where do we need to go? *Career Development and Transition for Exceptional Individuals*, *36*(1), 58–66. https://doi.org/10.1177/2165143413482137

Zhang, X. N., Zhang, S., Liu, C. Y., Ni, Z. H., & Lv, H. T. (2025). Caregivers’ experience of having a child with Down syndrome: A meta-synthesis. *BMC Nursing, 24*(1), 66. https://doi.org/10.1186/s12912-025-01866-5