

Unseen Heroes: Parental Perceived Roles in Supporting Out of School Adolescents with Intellectual Disabilities in Zimbabwe

Ncube Mercy¹, Makaruke Kumbirai²

^{1,2}Zimbabwe Open University Department of Psychology

Abstract

The study explored parental perceived roles in supporting adolescent school leavers with intellectual disabilities. Parents play a crucial role in the lives of adolescents with and without disabilities. They contribute towards social inclusion and the overall well-being of adolescents with intellectual disabilities (IDs). The paper is premised on the ecological systems theory which assumes that human development and behaviour are a contextual specific phenomenon. The study employed the qualitative methodology within the phenomenological approach. Unstructured interviews were used to collect data from 6 purposively sampled parents of adolescents with IDs. From the findings, it emerged that parents' roles are influenced by family dynamics, community resources, societal structures, and available resources. The study revealed that parents lack the knowledge and skills and face financial constraints to support their adolescent children with IDs. The study suggests that professional support and informal training should be provided to parents and school leavers with IDs. As a recommendation, parents should be encouraged to join groups for parents of children with disabilities such as Zimbabwe Parents of Handicapped Children Association.

Keywords: Adolescents, asexual, counselling, intellectual disability, support,

Introduction and background

Adolescence is a critical stage in human development (Raza, 2023) characterized by physical, social, emotional, and cognitive changes, all contributing to mental health vulnerability (Scripps et al., 2025). This stage poses many challenges to all parents. Those with children with intellectual disabilities (IDs) are not spared the ordeal of dealing with adolescents. Adolescents with disabilities face many challenges common to their typically developing peers (Maxey and Berkert, 2017). Although not all young people go through these changes in the same way, young people with disabilities are disproportionately more prone to face difficulties than their typically developing peers (ibid). The situation is compounded by the presence of the disability which is characterized by challenges in intellectual functioning and a lack of adaptive skills. According to the American Association of Intellectual and Developmental Disabilities (AAIDD) (2025), intellectual disability is a condition characterized by significant limitations in both intellectual functioning and adaptive behaviour that originates before the age of 22. Adaptive behaviours encompass daily living skills such as eating, personal care, conceptual skills that include reading and writing, reasoning, and social skills, for example, communication and turn-taking. Due to the nature of their disability, these adolescents often do not proceed to secondary and tertiary education, their parents

shoulder the responsibility to ensure that they adjust to community life with minimum hassles. Regardless of that, with support, they are capable of learning essential life skills.

Globally, care for adults with IDs is provided by their families, particularly in low- to middle-income countries (McKenzie and McConkey, 2016). This role begins very early in life and may continue throughout life depending on the degree of IDs. Intellectual disability places extra demands on parents, and this is exacerbated in the adolescent developmental period (Ahamad, 2023). Parents of adolescents with intellectual disabilities have additional responsibilities and roles in caring for them (Chauke et al., 2021). Parents' role to adolescents with IDs cannot be emphasized because, according to McMahon et al. (2023), they are the primary caregivers of adolescents with complex needs.

Various studies have been conducted on parents' experiences in raising adolescents with IDs. In a study by White and Hastings (2004) on social and professional support for parents of adolescents with severe IDs involving thirty-three participants of adolescent children with moderate–profound IDs, it was found that complete measures of parental well-being include stress, anxiety and depression, and caregiving satisfaction, social support (informal and formal sources, and practical and emotional support), and child characteristics (adaptive and problem behaviours). Parental well-being was associated with the child's adaptive and problem behaviours and with the child's autism diagnosis. Parents' ratings of the helpfulness of informal sources of support such as spouses, extended family, and friends, were most reliably associated with parental well-being. Parents' access to service and professional support was not associated with parental well-being, but there was some evidence that it was related to their child's needs.

A study on caregivers carried out by McKenzie and McConkey (2016) in Cape Town using focus group discussions with 37 family caregivers found that family caregivers showed strong commitment to care despite the heavy responsibility and burden of care that women especially experience. They recognize the limited personal growth opportunities for people with IDs that increase the caregiving burden. They identified support and resources in the community that assisted them with their care responsibilities but were let down by services. They concluded that improved family support appropriate to the resources in LAMIC are needed especially when existing carers are no longer able to provide care.

Research by Leonard et al. (2016) on the transition to adulthood for young people with IDs focusing on the experiences of their families with down syndrome in Western Australia and Queensland including information on health, functioning, and service needs, and about specific transition-related issues; and Part 2 collected information about the health and well-being of their family. The study found that the majority (87 %) of parents were involved in decision-making about transition planning but less than two-thirds (59.5 %) of young people were involved in this process. The parents indicated that the provision of more information about financial assistance, the school transition program, and the building of informal community-based supports were helpful strategies.

Keer (2022) explored the experiences of parenting children during adolescence in line with disability services throughout the island of Ireland using focus groups with twenty-five parents of adolescents and young adults with intellectual or developmental disabilities. It was found that parents needed to manage several different stressors with and for their children on the journey from childhood to adolescence. These occur at societal, service provision, familial, and personal levels, with each stressor interacting with others to create vicious circles of struggle. He concluded that parents' struggles are multi-fold and are not discreet entities that can be separated. The struggle is dynamic and continuous.

A study by Chauke (2021) on the experiences of parents of an adolescent with intellectual disability in Giyani, South Africa, found that the parents experienced stress caused by challenges that come from

having such adolescents. The degree of the adolescent's intellectual disability determined how physically and emotionally such difficulties affected the parents. Having an adolescent with an intellectual disability turns into a burden if the challenges are not addressed.

The above studies have contributed to the literature on the role of parents during the adolescent stage of children with IDs. None of the studies focused specifically on the voices of parents concerning their roles at this critical stage of life. This study is unique in the sense that parents participating in this study have their unique experiences and contextual settings. Considering this, the study aims to provide parents with an opportunity to share their perceived roles in raising adolescents with IDs and suggest how challenges they encounter could be alleviated. Parents reported significantly higher levels of distress after their child transitioned out of school McKenzie et al. (2017). The paper is arranged as follows: theoretical framework, methodology, findings, discussion, and conclusion.

Statement of the problem

Parents shape the future of their adolescent children in various ways. Adolescents with IDs also face crises like some of their typically developing peers that may be challenging to navigate without support from parents. According to Big (2000) cited by Gwosami, (2018), parents of children with IDs provide care at home until their death or illness prevents them from offering support. Greater numbers of older parents provide care at home for their sons and daughters with IDs (Weeks et al., 2009). In low-income countries, adults with IDs continue to live with their families unlike in developed countries where they leave the family home to live in groups or on their own through government aid. Based on this, the study sought to explore the role of parents in supporting adolescents with IDs.

Research questions

The study sought to address the following questions:

1. How do parents support adolescents with IDs?
2. What are the challenges faced by parents with adolescents with IDs?
3. What support services are required by parents to support adolescents with IDs into adolescents?

Theoretical framework

The paper is premised on the ecological systems theory that was proposed by Bronfenbrenner, and Urie (1979) because it provides a comprehensive understanding of the complex factors influencing parental perceived roles in supporting adolescent school leavers with intellectual disabilities. Bronfenbrenner's ecological systems theory suggests that a person's growth is influenced by various interconnected environmental systems, including their family and larger social structures (Guy-Evans, 2024). The environment is divided into five systems: the microsystem, mesosystem, exosystem, macrosystem, and chronosystem, each representing different levels of environmental influences on an individual's growth and behaviour. This microsystem includes home and child-care (for example, parents, teachers, and peers), the mesosystem which is an interaction among two or more microsystems, a Customising instructional strategies to meet the diverse needs of students with IDs the exosystem does not directly influence children, but it can affect the microsystem. It still may positively or negatively affect children's development through the parent's workplace, the neighbourhood, and financial difficulties whilst the macro system does not influence children directly; it can impact all the systems such as economic, social, and political systems (Alam, n.d). The exosystem consists of the external environment, including social services, healthcare, and community resources, interaction between the family, parents, teachers,

community, and political system determines parents' roles and how they assist students' development outcomes. The macrosystem is composed of the broader cultural and societal context and lastly, the chronosystem which includes the temporal dimension, including changes over time. Cultural beliefs and social norms can greatly influence the perceived roles of adolescents with IDs. Interactions between various systems in society impact parents' roles, challenges, and availability of resources to support their adolescents with IDs. At the microsystem level, interactions at the family level focus on relationships between parents and adolescents, their needs and abilities, and parents' roles and responsibilities. In this study, the theory helps to understand the social context in which parents operate to live with their adolescents with IDs and the factors that influence their supportive roles.

Literature

Families play a pivotal role in promoting decision-making and self-determination and creating opportunities for adolescents with IDs to demonstrate self-determination at home (Taub and Werner, 2023). Parents act as fierce advocates and creative problem solvers of post-secondary adolescents with intellectual and developmental disabilities, their roles include attitudinal facilitators, advocacy efforts and perceptions, and strategic actions (Rossetti et al., 2016).

The journey through adolescence is fraught with varied experiences for different individuals that necessitate parental support. Despite notable progress in educational inclusion for students with intellectual and developmental disabilities, their access to sexual health education is limited (Roach and Stair, 2024). Individuals with IDs can face challenges, including the right to express their sexuality and access necessary education and support (Brown and Mccan, 2018). People with disabilities are presumed to be asexual (Ashyby, 2020). Hence, parents are essential in providing sex education to adolescents with intellectual disabilities. They also provide emotional support, which is crucial for the well-being and quality of life of adolescents with intellectual disabilities.

Young adults with IDs have poorer postsecondary outcomes in employment and living independently, which places additional stress on their families due to the young adults' dependency (Davies and Beamish, 2009). Young adults with profound intellectual disability face delayed transition to independent living causing families to experience higher burdens, psychological distress, and lower social support compared to families of typically developing children (Roos and Søndena, 2020). Families in wealthy countries have the option to choose living arrangements for their adolescents with IDs so that they can leave the family home because their governments can afford such provisions. Parents play a significant role in advocating for their children's rights and interests, to ensure that they receive the necessary support and accommodations (Advocacy for Children, 2024).

An individual with disabilities transitioning from childhood to adolescence poses new challenges for parents, particularly mothers (Maxey and Bercket, 2017). Whilst the transition from school to adult roles can be challenging for any adolescent, Leonard et al. (2016) note that this period is difficult for those with an intellectual disability and their families. When children are out of school, according to McKenzie et al. (2017), families lose the support and respite offered by schools. Parents of adolescents with intellectual disabilities face increased mental health issues and reduced well-being compared to parents of typically developing adolescents (Scripps et al., 2025). Parents of adolescents with mild to borderline IDs more often perceive their parenting behaviour as flawed, suggesting that a sense of competence, among these parents, may be lower than for other parents (Maxey and Bercket, 2017). Most parents of adolescents with IDs have various support needs that are frequently unmet, service providers should provide information, activities, child mental health care, and parental counselling and where they can access support (Douma

et al., 2006). Adolescent children with intellectual disabilities often experience distress and require significant parental attention, assistance, and support (Chauke et al., 2021). The next section discussed the methodology that was employed to conduct the study.

Methodology

The study is grounded in the interpretivist paradigm which focuses on comprehending social phenomena through the experiences and perspectives of individuals (Bryman, 2016). Qualitative research design was employed to explore parental experiences, challenges, and strategies in supporting out-of-school adolescents with IDs. A phenomenological approach was used to gain deep insights into the lived experiences of parents supporting their adolescents with IDs. Phenomenological enabled exploration of lived experiences of parents of adolescents with IDs, and provided an in-depth understanding and awareness of the meaning they attribute to those experiences (Creswell, 2014). Six parents of adolescents with intellectual disabilities in the 16-20 years age range were purposively sampled. They were recruited through assistance from disability organizations. Data was collected using semi-structured interviews over a period of six months to enable scheduling interviews with parents who were residing in three different urban areas. Informed consent was obtained from the participants before data collection and confidentiality was maintained by using codes to identify the participants throughout the study. Data was presented using thematic analysis.

Findings and Discussion

Demographic data of the participants

Six parents of adolescents with IDs participated in the study. They were assigned the following codes: P1, P2, P3, P4, P5 and P6. All the parents were females and were not formally employed. P5 worked as a teacher. Two parents, P4 and P6, had male adolescents the remaining 4 had females. P5's daughter had attended school up to Form 2 level and the rest had attained primary school education with some failing to complete the course as they dropped school at the grade 5 level. The adolescents had moderate to mild IDs.

Supporting adolescents with IDs

Parents of adolescents with IDs have many responsibilities which are compounded by the presence of a disability. According to Jacinto et al. (2021) being a parent of a child with special needs is more than what meets the eye. They have a responsibility to teach them even those simple skills which their typically developing peers can master at once. Adolescents with IDs are very disturbing and require appropriate attention, assistance, and support from parents (Chauke et al., 2021). Parents provide all round support to adolescents with IDs. They learn skills and concepts slowly and forget easily. Positive interactions in the microsystem show that there are good parent-child relationships that facilitate socialization. The study revealed that parents provide support to adolescents with IDs to enable them to acquire home management and personal care. Because of that support, the parents have high expectations of their children. This could also be attributed to the level of IDs of these adolescents which is within the moderate range. P1 proudly said: I helped her to learn to take care of herself, but it was not an easy task, she is very smart, she does her laundry. She also assists with cooking family meals and cleaning dishes. None in the family could do it because they lack the patience needed with these children. P5 said, 'She assists with cooking but at times if I do not monitor and provide guidance the meals are not properly done because she does not focus on her work. I have taught her self-care, and she does not have challenges with menstrual cycles. P3 complained saying: She needs someone to assist her with cooking and cleaning the house if I am busy at

the market, but she can do her own laundry. Cooking meals for the family is difficult because she cannot use her right hand properly.

Most participants indicated that their children did not attend secondary school education but dropped school at primary school level. Despite the implementation of inclusive education in schools, adolescents with IDs do not complete primary school education, yet education affords them the opportunity to develop social skills. Mapuranga et al (2015) found that parents complained that IE does not provide suitable learning environments for children with IDs because the infrastructure in the schools does not cater for the children with IDs. Peers looked down upon children with IDs and called them ZIMCARES, imbeciles or morons (ibid). In Rwanda Mutezigaju et al (2018) found that the enrolment rate of children with mild which had increased in primary schools dropped due to lack of expertise by teachers, lack of material and financial resources to support these children. Society views people with IDs as incompetent and unable to learn. The parents sponsor the education of children without disabilities but failure to encourage their children to complete even the primary school course shows that they have low expectations of their children with IDs. This could be attributed to lack of knowledge about IDs by parents. P3 said: She just started by returning home early from school at times she would attend school for three days until we came to a point when she refused to go to school at all. There was nothing we could do, that is why she is alone at home during the day when her siblings are at school. P6 indicated that: The boy cannot continue with primary school at 18 years of age. Bhargava and Umrigar, (2017) state that individuals with (IDs) face numerous challenges in their academic performance and daily life.

Community participation enhances the inclusion of people with IDs. Parents expressed mixed feelings about community participation by their children. Some of the parents have low expectations of their adolescents with IDs. Support provided by parents enables the child to connect with others in the neighbourhood at the mesosystem level. Interactions at this level either positively or negatively affect community participation by adolescents with IDs. The study revealed that while some parents encourage their adolescents to engage in religious activities and socialize with peers, others are overprotective. Maxey and Beckert (2016) observe that most adolescents with disabilities desire to have developmental experiences and social opportunities like their typically developing peers. Parents who attend church services as families expect their children with IDs to do so even in their absence. P3 had this to say: She can prepare to attend church and leave me behind because she can go and come back home on her own since the church is not far away from our residence.' P4 revealed that I taught him how to behave in church. My son attends church services with his grandmother, and he seems to get on well with others. On the contrary, P1 indicated that Jane (not their real name) spends most of her time at home and has no friends. Lack of friendship could be due to stigma and discrimination against people with disabilities. Malapela and Thupayagale-Tsweagae (2019) observe that labelling of individuals with ID lead to isolation, loneliness, limited friendships and peers interactions.

Decision-making is an essential skill during adolescence. Parents play a crucial role in fostering autonomous decision-making among adolescents with disabilities by providing them with personal life choices, thereby promoting self-determination (Taub and Werner 2023). Adolescents with IDs face challenges in making life decisions due to their disability, but parents should support and guide them as needed. Self-determination is important at this stage where adolescents want to take control of their lives and plan about their future. The study found that some adolescents with IDs can visit their relatives in nearby locations easily. Community participation is enhanced through such visits. P3 reported that I usually take my daughter to my sister in –law and at times she requests permission to visit by herself. She

gets there easily, and she can phone. Other parents do not allow their children to travel alone. P1 said that: My daughter is always at home and does not associate with anyone except family members. She can use her phone but mostly she calls me and her sister. She also manages her monthly periods very well. P6 indicated that: The boy is now old enough to leave the place and visit his friends, he gets on well with his peers and they even visit him to play soccer within the yard.

Parents are the source of emotional support for their adolescents with IDs. It is the role of the parent to engage with the child in open communication so that they understand their needs and interests. They encourage children with IDs to partake in activities with peers. P1 revealed that: My daughter often cries and reports her disagreements with her siblings to me after work, requiring me to console her and discuss the matter with them. P5 also reported that: There are always some misunderstandings between Irene and her brother and I must intervene to avoid fights between the two.

Challenges faced by parents

Sexuality education is important at the adolescence stage because it helps boys and girls at this stage to understand physical and emotional changes that take place so that they behave properly. However, youth with intellectual disabilities face barriers to receiving sex education including a dearth of educational tools accessible for multiple cognitive and emotional learning styles (Colarossi et al., 2023). The macrosystem layer is comprised of cultural values, customs, and laws (Berk, 2000) that may influence the role of parents to impart sexuality education. African societies often view individuals with disabilities as asexual, leading parents to overlook the interests of adolescents with IDs. Parents indicated that they face challenges in discussing sexuality with their children. This is not acceptable in their culture, and they were not comfortable fearing that they would say too much leading their children to engage in sex activities. P3 revealed that: I am worried that my daughter is dating an elderly man and I am afraid she might impregnated and it seems this man lures her when she is alone at home. I spent most of my time at the market. I wish I could find something for her to do. P5 indicated that: My daughter expresses interest in her classmates' love affairs, but I discourage her from interacting with these old boys, fearing the outcome. She cannot get married.

It is common for all parents to worry about the future of their children but those of parents of adolescents with IDs are compounded by the fact that their children depend on them greatly. The chronosystem relates to changes due to time, such timing of a parent's death, and physiological changes that take place as the child ages. These changes influence the parents' role and psychological state as opined by Chauke et al. (2021) who found that parents of adolescents with intellectual disability experienced negative emotional responses. Similarly, Gwosami (2018) found that parents expressed that their adult children with IDs were not entirely independent of activities in daily living, very slow in daily work, presented problem behaviour, lack of proper socialization & sexual behaviour. P3 indicated that: My son wants to get married and wed a certain girl from his last class. He keeps on saying her name and even says that they want to have two children. I am worried because he will not be able to fend for his family since he is not employed. He is my only child, what if they give birth to children with the same problem, I may not be able to handle it. The findings align with those of Kruithof et al. (2021) who reported that most parents were despaired by their concerns regarding an anticipated decline in their child's quality of life and who will fulfil their roles in the future if they die and outlived their children with profound intellectual and multiple disabilities.

Worrying about the future of adolescent children is a concern for all parents, especially when they have not been able to achieve independence to manage their own lives or are self-sufficient. The case is worsened by the presence of IDs. Weeks et al. (2009) found that older parents were worried about the

following issues: future care of their son or daughter; services funding; having housing and care options; lack of provider understanding of carer's needs; and helping son or daughter become a productive and active member of society. P4 was most worried about her son having physical difficulty which made it difficult for him to help with gardening at home as well as to do his laundry. The condition could have been worsened by a lack of access to physiotherapy services. According to Diyvapath (2024), physiotherapy enhances the lives of individuals with IDs because the condition at times affects physical capabilities and coordination, which can lead to limitations in mobility, strength, and daily functioning. Physiotherapy enables individuals to attain greater independence, enhance their motor skills, and improve their overall quality of life. However, access to such services may be limited due to financial constraints.

Support services required by parents

Though participants showed that they are doing their best to support their adolescents with IDs, they indicated that they needed some professional help to address some challenges they encountered. The exosystem level depicts the resources that are available in the environment that affect the parent's role in supporting their adult children with ID. They needed information about how to impart sex education and vocational skills so that they could get some employment and develop self-help skills. P4 said the following: I think I need some knowledge on how I can best teach my daughter about sex and marriage. She seems to show interest in the opposite sex, and I am afraid that she might be abused by these boys. P5 said: I do not feel comfortable discussing marriage issues with my daughter, she may not be able to manage the family because she still needs my support and guidance all the time. Sex education strategies equip parents and families to manage and safely mentor children and adolescents with intellectual disabilities (Andre et al, 2023). Similarly, Bhargava and Umrigar (2017) state that literature on parents with intellectual disability is scant but they engage in the valued social role of raising children, but their parenting attracts negative attention based on an expectation of their limited capacities to parent their own children.

Adolescents with IDs benefit from comprehensive life skills training that encompass daily living, vocational and social skills development. Vocational training programmes could help them to acquire skills to earn a living and contribute to family upkeep. In Zimbabwe vocational training centres are scattered and there are some specifically meant for people with IDs such as Homefield in Harare. Special schools also provide sheltered workshops for students with IDs but these may not be accessible to students in inclusive settings. P6 said that: My son is not working but assists with gardening and if we visit our rural home, he likes herding cattle, but he cannot do anything meaningful to earn a living. He did not proceed with secondary education; in town, he spends most of his time at home doing nothing productive. Whilst P1 said that: There is nothing profitable my daughter is doing now except assisting with household chores. If there was a training centre in the community, I could encourage her to get some training even in baking. These sentiments signify the importance of vocational skills to adolescents with IDs.

Counselling is another critical service that was identified by the parents. Counselling services are offered for free and by professionals who require payment. Some counsellors may lack the skills to counsel parents of children with disabilities and lack knowledge about IDs. This makes it difficult for parents to access counselling services for themselves and their children. They also required support from local support groups so that they could always share information and learn from others in similar situations. Mkabile et al. (2021) observe that in Africa specialised services for people with IDs and their families are limited or non-existent. P2 expressed the following views: I try to counsel my daughter whenever there are some disagreements with her siblings, but they continue to fight over petty issues, requiring a neutral ally to

address their concerns and help them understand her limitations. The siblings complain that I am in favour of her.

Conclusions

The findings of the study revealed that parents emotionally, physically and socially supported their adolescent children with IDs. They cultivated positive relationships with their children and ensured that they acquired some relevant skills to participate in household chores and self-care. Whilst some parents encouraged community participation among adolescents with IDs, others did not afford that opportunity. The study found that mothers are the primary supporters of adolescents with IDs and that they are very worried about the future of these children in their absence. Adolescents with IDs have similar desires for friendship, intimate relationships and marriage as some of their peers without disabilities. Adolescents cannot fend for themselves and cannot sustain their own families. Parents require support to effectively play their role of supporting adolescents with IDs to develop life skills for a brighter future without their parents. The study recommends the following:

1. Schools should provide community service by continuing to offer support to the parents of school leavers with IDs and help them to identify services in their communities for vocational training and guidance and counselling services.
2. Different government ministries should collaborate to ensure that parents of adolescents with IDs get help to support their adolescent children.
3. Organisations for people with disabilities should follow up on parents and adolescents with disabilities and help them join support groups so that they can learn from other parents in similar situations. Parents can enhance skills and knowledge to support adolescents with IDs.

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