# Parental Involvement and Learners with Intellectual Disability

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Intellectual disability is a lifelong condition with an estimated prevalence rate of 1–3% of the global population. Intellectual disability has a prehistorical origin that can be traced back to the Greek and Roman eras. Historic intellectual disability definitions were based solely on intelligence, with an emphasis on routine care and maintenance rather than treatment and care. Considering that learners with intellectual disabilities require more support in adaptive behavior and reasoning than their peers without intellectual disabilities, meeting these needs can be challenging for parents shortly after learning of the intellectual disability diagnosis; thus, parenting a child with intellectual disabilities is likely to result in some stress for parents. Therefore, parents require information, knowledge, and additional support in raising a learner with intellectual disabilities to enhance their support for these learners and increase their level of independence and development.

intellectual disability    parental involvement    learners    mainstream school    special school

# 1. Introduction

Parents who have disabled children are frequently despised and rejected by their families and communities [1]. For these parents, the sudden realization of their children's intellectual disability and the transition from mainstream to special schools are often coupled with emotional and psychological trauma when parents begin to comprehend the long-term implications of their child's diagnosis [2][3][4][5]. Parents of children with intellectual disabilities frequently feel awkward discussing it and are hesitant to admit that their children have an intellectual disability because of the continued patriarchy and discrimination in South African society [6].

Intellectual disability is a lifelong condition with an estimated prevalence rate of 1–3% of the global population [7]. However, Chaturvedi [8] discovered that data on the global intellectual disability population is limited and at times unreliable, which is complicated and influenced by a variety of factors, such as poor recognition of individuals with intellectual disabilities, educational levels, cultural aspects, and socio-environmental factors, which may affect intellectual disability recognition and identification. Despite a severe lack of reliable information on the nature and prevalence of intellectual disability globally, McKenzie et al. [9] and Chauke et al. [10] suggest that the overall prevalence rate of intellectual disability in South Africa could be 3.6%, implying that South Africa has a higher prevalence of intellectual disabilities than developed countries. The Gauteng Education Department statistical report highlighted that in 2021, there were 2,671,184 learners enrolled in public ordinary schools, with 63,985 of those learners attending special schools, reflecting an increase in learner numbers from 47,769 learners over the previous five years [11]. Meanwhile, 5831 learners were presently enrolled in Soweto's 13 public special schools for

learners with disabilities [11]. Despite the increasing number of learners with intellectual disabilities in mainstream schools, culture and the effects of apartheid continue to have an impact on how parents perceive their role and interact with learners with intellectual disabilities [6]. Therefore, it is worth noting that the prevalence of intellectual disabilities is often overlooked, and diagnosis is usually made at a later age; subsequently, parents hardly receive timely information about their children's conditions [8]. Parents demonstrate limited understanding, information, and knowledge about the nature and implications of intellectual disability [3].

Intellectual disability has a prehistorical origin that can be traced back to the Greek and Roman eras [12][13]. Historic intellectual disability definitions were based solely on intelligence, with an emphasis on routine care and maintenance rather than treatment and care [12]. Subsequently, individuals who were slow to learn and immature were therefore referred to as idiots or morons [12]. Similarly, McKenzie et al. [9] argued in their study that South Africa's colonial period appeared consistent with other countries in terms of classifying people with intellectual disabilities as mentally deficient, with three categories to describe their reduced intellectual and functional abilities: "idiot", "imbecile", and "feeble-minded." Throughout history, there have been changes in diagnostic criteria and variations in the occurrence of intellectual disabilities [7]. It was in 2005 that the term "intellectual disability" was formalized to identify individuals who meet the standards of mental deficiency and demonstrate evidence of reduced development and functioning in the community [14][15].

Learners with intellectual disabilities can learn and are unique in terms of their needs; however, these learners progress slowly when compared to peers and struggle with abstract thought, making them less capable of learning on the spur of the moment and unable to apply what they learn in new situations and cope independently, which subsequently play a far more minor role in their development than learners with average intelligence [8][16][17]. Hence, their learning differences necessitate appropriate parental attention and support to encourage learning progress [12][16]. Considering that learners with intellectual disabilities require more support in adaptive behavior and reasoning than their peers without intellectual disabilities [1][18][19], meeting these needs can be challenging for parents shortly after learning of the intellectual disability diagnosis; thus, parenting a child with intellectual disabilities is likely to result in some stress for parents [3][4]. Therefore, parents require information, knowledge, and additional support in raising a learner with intellectual disabilities to enhance their support for these learners and increase their level of independence and development [3].

Parents and their disabled children have always been ignored and isolated from the rest of society and the educational system [17]. As a result, studies on disabilities have been concentrated in cities, with little documentation in rural and suburban areas, and the majority of the few studies conducted in South Africa have only focused on people with disabilities rather than those who live with and care for them [4][5]. According to the findings of the limited studies, many parents in rural and suburban areas have little or no knowledge or understanding of intellectual disabilities and how to support learners with intellectual disabilities [19][20][21]. Similarly, according to a study conducted by Lushozi [3], parents at four Soweto special schools appeared to have limited understanding, knowledge, and information about the implications of intellectual disabilities and the challenges their children face. These parents face difficulties in supporting their children with intellectual disabilities as they transition from mainstream to special schools [18].

## 2. Parents' Perceptions of Intellectual Disabilities

Determining the cause of intellectual disabilities can be challenging; a learner may be intellectually disabled for various reasons that are unknown [13]. According to Patel et al. [22], over 75% of individuals with intellectual disabilities have mild intellectual disabilities. The underlying specific causes are likely to be identified. In contrast, an underlying biological cause is highly probable within a small percentage of individuals with severe intellectual disabilities. For those with severe to profound intellectual disabilities, genetic abnormalities, inborn errors of metabolism, and brain malformations are considered significant causes. Subsequently, parents of learners with intellectual disabilities are often unfamiliar with the disability, lack accurate information, and lack access to effective guidance [22]. However, because of high illiteracy levels among parents, including various speculations and beliefs about the causes of intellectual disability, it seems like parents are not well-informed about intellectual disability and its causes [4]. This contributes to the negative traditional perception and the classification of people in wheelchairs as a single group that represents people with disabilities, simply because disability is often associated with physical defects [6].

Furthermore, Adesina et al. [12] established in their study that biblical perspectives have played a significant role in beliefs and decision making during the Ancient Greek eras. Consequently, the birth of a child with congenital anomalies was considered a sign that their parents had angered the gods or that anomalies were caused by demonic affliction [12]. Similarly, according to traditional beliefs in African countries, such as Ghana, Nigeria, and Côte d'Ivoire, it was also believed that children born with disabilities were a result of evil spirit possession, witchcraft, and parents' punishment for sinful adultery [5][23]. It also appears that South African parents of learners with intellectual disabilities in Khayelitsha, Cape Town, believe the cause to be evil spirits from jealous neighbors, witchcraft, and fear of ancestors; thus, they resort to traditional healers for a cure or perform rituals for ancestors [24]. According to Xaba [17], parents in KwaZulu Natal believed that intellectual disabilities were caused by cultural norms that were not respected and that the only solution to the child's problem was ritual performance. Similarly, parents in Free State also believed that witchcraft, incorrect adherence to customs, and the father's refusal to perform rituals caused intellectual disability [4]. In Sekhukhune and Giyani, Limpopo parents and communities considered having a child with intellectual disabilities a punishment for the parents or because of witchcraft [5][10]. As a result, parents have always been hesitant to come forward out of shame and fear of discrimination, and their children with disabilities have been hidden from the community and have remained at home with no access to school or have been forced to leave home and move to private facilities, while those who have attended school have frequently faced embarrassment, discrimination, and misunderstanding [25]. Subsequently, because of a lack of knowledge, having a disabled child is regarded as a source of shame for parents, and many children grow up with their parents and siblings due to lack of education, social support, and social services [14].

## 3. Understanding the Concept of Parental Involvement

Parental involvement and its positive impact on academic achievement and the development of learners with intellectual disabilities have long piqued the interest of educational researchers [26][27]. However, parental involvement has been challenging to define because it has been assigned and operationalized in so many contexts

that the concept's exact meaning has become speculative. As a result, the concept appears vague, with many definitions, and not everyone has the same understanding of the concept [28][29][30]. Parental involvement as a research concept should consider parental differences. Parents and parent groups differ in many ways, including behaviors, beliefs, convictions, and situational characteristics, such as socioeconomic and ethnocultural background, language skills, level of education, and home situation [31]. According to research, teachers and school communities define parental involvement as being involved in educational processes, such as helping with school activities, homework, and attending parent meetings to promote academic achievement. In contrast, many parents perceive parental involvement as being more involved in their children's everyday life, such as providing proper care in the home and involving their children in the community or in church-based educational activities; subsequently, parents seem to act in ways that reflect lessons learned from their own experiences, culture, education level, and economic status [32][33][34][35][36]. Despite the prevalent belief that parental involvement plays a critical role in children's academic success and development, there seem to be limited data applying this to learners with intellectual disabilities [28][37]. Parents who have never been exposed to or cared for individuals with disabilities might not know how to raise a learner with intellectual disabilities; furthermore, how they treat learners with intellectual disabilities is influenced by what they have learned about disability from their surroundings [5]. This simply means that individual experiences, cultural values, and religious worldviews influence how parents perceive and interpret disabilities, which influences parental stress [38]. Women are frequently abandoned by their partners, leaving them to raise these learners independently due to the superstition that evil spirits, witchcraft, or a mother's improper relationships cause intellectual disabilities [21]. As a result, parents spend a lot of money on African medicine with the hopes of curing the learner's disabilities [5]. On the other hand, parents with religious beliefs regard their children with intellectual disabilities as God's gifts because they seek comfort in their religions, which assists them in dealing with their circumstances as well as accepting their children's disabilities [5]. According to Bergeson [39], emotional readiness to parent includes being ready to prioritize the learner's needs, being ready to accept changes in social life, and being ready to accept the changes that parenting brings to marital/partner relationships.

# References

1. Aldersey, H.; Kavira, S.; Kiasimbua, J.; Lokako, W.; Miaka, P.; Monte, L. Stigma experienced by families with members with intellectual disabilities in Kinshasa, Democratic Republic of the Congo. Intervention 2018, 16, 119–128.

2. Dibakoane, K.A. Primary Care Givers Experience of Taking Care of Children with Intellectual Disability in Mpumalanga Province, Bushbuckridge Region. Master's Thesis, University of the Witwatersrand, Johannesburg, South Africa, 2016.

3. Lushozi, B.B. Parents' Experiences of Support in the Process of Understanding Learners with Intellectual Challenges. Ph.D. Thesis, University of Pretoria, Pretoria, South Africa, 2015.

4. Nhlabathi, M.G. The Experiences of Parents with Children with Severe Intellectual Disability in a South African Township. Master's Thesis, North-West University, Potchefstroom, South Africa, 2016.

5. Tigere, B. The Experiences of Parents of Children Living with Disabilities at Lehlaba Protective Workshop in Sekhukhune District of Limpopo Province. Master's Thesis, University of Limpopo, Mankweng, South Africa, 2017.

6. Office of the Deputy President; Mbeki, T. Integrated National Disability Strategy: White Paper. 1997. Available online: https://www.gov.za/documents/integrated-national-disability-strategy-white-paper (accessed on 25 June 2022).

7. Oti-Boadi, M. Exploring the Lived Experiences of Mothers of Children With Intellectual Disability in Ghana. SAGE Open 2017, 7, 1–12.

8. Chaturvedi, S.K. Intellectual Disability in Rural Backgrounds: Challenges and Solutions. In Mental Health and Illness in the Rural World; Springer: Singapore, 2020; pp. 97–117.

9. McKenzie, J.A.; Abrahams, T.; Adnams, C.; Kleintjes, S. Intellectual disability in South Africa: The possibilities and limits of democratic rights. Tizard Learn. Disabil. Rev. 2019, 24, 204–212.

10. Chauke, T.; Poggenpoel, M.; Myburgh, C.P.H.; Ntshingila, N. Experiences of Parents of an Adolescent with Intellectual Disability in Giyani, Limpopo Province, South Africa. Health SA Gesondheid 2021, 26, 1–9.

11. Department of Education. Statistical Overview of Ordinary and Special Education in Gauteng. Prov. Data Wareh. 2021, 1–48.

12. Adesina, M.; Oladele, R.; Oduguwa, I.; Olufadewa, I.I. Historical Perspective and Classification of Disability. Yenagoa Med. J. 2021, 3, 17–24.

13. Shree, A.; Shukla, P.C. Intellectual Disability: Definition, classification, causes and characteristics. Learn. Community Int. J. Educ. Soc. Dev. 2016, 7, 9.

14. Ilyes, E. Psychology's eugenic history and the invention of intellectual disability. Soc. Personal. Psychol. Compass 2020, 14, e12537.

15. Platt, J.M.; Keyes, K.M.; McLaughlin, K.A.; Kaufman, A.S. Intellectual disability and mental disorders in a US population representative sample of adolescents. Psychol. Med. 2019, 49, 952–961.

16. Nene, S.S. The Role of Teachers and Parents in Empowering Special Needs Learners with Psychosocial Skills in Nkandla Circuit. Ph.D. Thesis, University of Zululand, Richards Bay, South Africa, 2016.

17. Xaba, T.E. Parental Involvement at Mainstream Schools Admitting Learners with Mild Intellectual Impairment: A Case of Sisonke District. Master's Thesis, University of South Africa, Pretoria,

South Africa, 2015.

18. Waters, C.L.; Friesen, A. Parent Experiences of Raising a Young Child with Multiple Disabilities: The Transition to Preschool. Res. Pract. Pers. Sev. Disabil. 2016, 44, 20–36.

19. Kadungure, T.P. Experiences of Caregivers Caring for Children with Different Special Needs in a Cluster Foster Care Village in Kzn. Master's Thesis, University of Kwa Zulu Natal, Pietermaritzburg, South Africa, 2017.

20. Mngadi, L.C. Experiences of Parents of Children with Autistic Spectrum Disorder Attending Special Schools at uMgungundlovu District. Master's Thesis, University of Zululand, Richards Bay, South Africa, 2018.

21. Taderera, C.; Hall, H. Challenges faced by parents of children with learning disabilities in Opuwo, Namibia. Afr. J. Disabil. 2017, 6, 1–10.

22. Patel, D.R.; Cabral, M.D.; Ho, A.; Merrick, J. A clinical primer on intellectual disability. Transl. Pediatr. 2020, 9, S23.

23. Arimoro, A.E. Persons with Intellectual Disability and Access to Justice in Nigeria: Challenges and the Way Forward. Hasanuddin Law Rev. 2019, 5, 180.

24. Mkabile, S.; Swartz, L. 'I Waited for It until Forever': Community Barriers to Accessing Intellectual Disability Services for Children and Their Families in Cape Town, South Africa. Int. J. Environ. Res. Public Health 2020, 17, 8504.

25. Jonasson, D.G. The Historical Development of Inclusive Education in a Large Urban Manitoba Division (2002–2015). Master's Thesis, University of Manitoba, Winnipeg, MB, Canada, 2017.

26. Jacobs, C.; Daniels, D. Their capital has value, too: Exploring parental educational support in low-socioeconomic single-mother families. J. Educ. 2019, 80, 160–175.

27. Ruholt, R.; Gore, J.S.; Dukes, K. Is Parental Support or Parental Involvement More Important for Adolescents? Undergrad. J. Psychol. 2015, 28, 1–8.

28. Boonk, L.; Gijselaers, H.J.M.; Ritzen, H.; Brand-Gruwel, S. A review of the relationship between parental involvement indicators and academic achievement. Educ. Res. Rev. 2018, 24, 10–30.

29. Dirks, E.; Szarkowski, A. Family-Centered Early Intervention (FCEI) Involving Fathers and Mothers of Children Who Are Deaf or Hard of Hearing: Parental Involvement and Self-Efficacy. J. Clin. Med. 2022, 11, 492.

30. Fisher, Y. Multi-dimensional Perception of Parental Involvement. Univers. J. Educ. Res. 2016, 4, 457–463.

31. Sibanda, R. "I'm not a teacher": A case of (dys)functional parent-teacher partnerships in a South African township. S. Afr. J. Educ. 2021, 41, 1–13.

32. Allen, Q.; White-Smith, K. "That's Why I Say Stay in School": Black Mothers' Parental Involvement, Cultural Wealth, and Exclusion in Their Son's Schooling. Urban Educ. 2018, 53, 409–435.

33. Myers-Young, S. Understanding Parental Involvement. Bachelor's Thesis, Murray State University, Murray, KY, USA, 2018.

34. Penn, W. Parental Involvement Matters: The Teachers' Perspective. Ph.D. Thesis, Concordia University St. Paul, St Paul, MN, USA, 2019.

35. Pope, M.B. An Exploratory Study of Parent Involvement in Church Schools in Tonga. Ph.D. Thesis, Bringham Young University, Provo, UT, USA, 2020.

36. Singh, R. Parental Attitudes Towards, and Their Understanding of, Barriers to Learning and Development. Master's Thesis, University of the Witwatersrand, Johannesburg, South Africa, 2019.

37. Young, T. Parental Characteristics and Parent-Child Relationship Quality in Families with Disabled Children. Ph.D. Thesis, Walden University, Minneapolis, MN, USA, 2018.

38. Zechella, A.N.; Raval, V.V. Parenting Children with Intellectual and Developmental Disabilities in Asian Indian Families in the United States. J. Child Fam. Stud. 2016, 25, 1295–1309.

39. Bergeson, C. Preparation for Parenting: Developing a Conceptual Framework and Strategies. Ph.D. Thesis, University of Manitoba, Winnipeg, MB, Canada, 2018.