

**PARENTAL AWARENESS AND INTERVENTION PREFERENCES FOR
CHILDREN WITH INTELLECTUAL DISABILITIES:
IDENTIFYING GAPS AND SUPPORT NEEDS**

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Abstract

This study examines parental awareness and intervention preferences for children with intellectual disabilities, identifying knowledge gaps and support needs. A survey of 40 parents, primarily mothers (60%), revealed that while most prefer educational and behavioural interventions, awareness of medical treatments remains limited. The findings indicate a strong reliance on special education and behavioural strategies, yet formal training on behaviour management is lacking. Additionally, lack of information (65%) and limited access to professionals (35%) were identified as key challenges. These results highlight the need for targeted parental education programs, increased access to professional guidance, and community-based interventions. Enhancing these support systems will empower parents to make informed decisions and improve outcomes for children with intellectual disabilities.

Keywords: Parental awareness, intervention preferences, intellectual disabilities, special education, behaviour management, parental training, support systems.

1. Introduction

Intellectual disability (ID) is a neurodevelopmental condition characterized by significant limitations in intellectual functioning and adaptive behavior, which affect a person's ability to learn, reason, and function independently in daily life (American Psychiatric Association [APA], 2013). Children with ID often experience delays in cognitive, social, and practical skills, making it challenging for them to perform age-appropriate tasks such as communication, self-care, and academic learning (Schalock et al., 2021). The impact of ID extends beyond the individual, influencing family dynamics, parental roles, and societal perceptions. Given these challenges, early identification and appropriate interventions play a crucial role in enhancing the quality of life for children with ID and their families (Guralnick, 2017).

Parental awareness of intellectual disabilities is essential in managing the condition effectively. Parents serve as the primary caregivers and decision-makers in their child's development, and their understanding of ID can influence the timely adoption of appropriate interventions (Pelchat et al., 2020). A well-informed parent is more likely to seek early diagnosis, engage with specialized educational services, and adopt evidence-based strategies to support their child's learning and social development. However, many parents, particularly in low-resource settings, may have limited knowledge of ID, leading to delayed interventions and increased stress within the family (Kyzar et al., 2021). Enhancing parental awareness

through education and training can bridge this gap, ensuring that children with ID receive the necessary support at an early stage (Bailey et al., 2019).

This study aims to explore three key objectives: (1) to assess parental knowledge about intellectual disabilities, including their understanding of symptoms, causes, and prognosis; (2) to examine the intervention preferences of parents, such as medical, educational, and behavioral approaches; and (3) to identify gaps in awareness and support systems that hinder effective intervention. Understanding these aspects is crucial for designing policies and programs that cater to the needs of families with children who have ID.

The significance of this research extends to multiple stakeholders, including parents, educators, and policymakers. For parents, the study provides insights into effective intervention strategies and the importance of early recognition of ID. For educators, it highlights the role of parental engagement in special education programs, emphasizing collaborative approaches to enhance learning outcomes for children with ID. For policymakers, the findings offer valuable information on the need for accessible resources, parent training programs, and inclusive education policies. By addressing these aspects, the study contributes to a more supportive and informed society, ultimately improving the well-being of children with intellectual disabilities (Turnbull et al., 2020).

2. Literature Review

Parental awareness and intervention preferences significantly influence developmental outcomes in children with intellectual disabilities (ID). Well-informed parents are more likely to seek early interventions, improving cognitive, social, and adaptive functioning (Guralnick, 2017). However, factors such as socioeconomic status, cultural beliefs, and service accessibility shape parental decision-making. This section reviews literature on parental awareness, intervention strategies, and influencing factors while identifying research gaps.

Parents play a key role in identifying developmental delays and seeking timely interventions. Awareness of developmental milestones increases the likelihood of early diagnosis and support (Guralnick, 2017; Zuckerman et al., 2018). However, barriers such as low socioeconomic status, cultural stigma, and limited healthcare access contribute to delayed recognition and intervention (Emerson & Hatton, 2014; McKenzie & McConkey, 2016; Durkin et al., 2015).

Intervention strategies for children with ID include medical, educational, behavioural, and social approaches. Medical interventions manage co-occurring conditions like ADHD and epilepsy (Matson & Neal, 2009). Educational strategies, including individualized education plans (IEPs) and inclusive learning, enhance academic and social development (Smith, 2020). Behavioural interventions, such as Applied Behaviour Analysis (ABA) and Parent Management Training (PMT), improve communication and behaviour when parents receive proper training (Kazdin, 2017). Social interventions, like peer-mediated learning, foster interpersonal skills (Carter et al., 2015).

Interventions are either parent-led or professional-led. Parent-led approaches, supported by training programs, reinforce behavioural consistency at home, particularly in

low-resource settings (Kaminski et al., 2008; Guralnick, 2017). Professional-led interventions, involving therapists and educators, provide structured strategies but require parental follow-through (Matson & Neal, 2009). A combination of both yields the best outcomes (Totsika et al., 2011).

Parental intervention choices are influenced by socioeconomic status, education, cultural beliefs, and service accessibility. Higher-income families access specialized care, while lower-income families rely on government support (Emerson & Hatton, 2014). Educated parents are more proactive in seeking evidence-based interventions (Zuckerman et al., 2018). Cultural stigma may discourage formal diagnosis and treatment (McKenzie & McConkey, 2016). Geographic disparities in healthcare further limit access to early intervention (Durkin et al., 2015).

Despite extensive research, gaps remain in understanding how parental awareness shapes intervention choices and the barriers to accessing support. Most studies focus on intervention effectiveness rather than decision-making processes (Kazdin, 2017). Socio-cultural influences on parental preferences, particularly in low-resource settings, remain underexplored (Guralnick, 2017). This study aims to address these gaps by examining parental knowledge, intervention preferences, and access barriers, informing policies and support programs.

3. Method:

3.1. Research Design:

This study follows a descriptive survey design to explore parental awareness and intervention preferences for children with intellectual disabilities. The design enables the collection of quantitative data, providing insights into parental knowledge, treatment choices, and the challenges they face in managing their child's condition. This approach allows for the identification of patterns and the development of targeted support strategies for families.

3.2. Participants:

The study involves 40 parents or guardians of children with intellectual disabilities, selected using convenience sampling. Among the participants, 60% are mothers, 32.5% are fathers, and 7.5% are guardians. The children's ages range from 6 to 34 years, with the largest age group being 19 years (20%). The gender distribution of children shows 57.5% male and 42.5% female, consistent with existing research on the higher prevalence of intellectual disabilities in males. The sample is diverse in terms of parental roles, providing a broad perspective on the issue.

3.3. Data Collection:

Data was collected through a structured questionnaire developed to assess various aspects of parental awareness and intervention preferences. The questionnaire consists of closed-ended questions and covers the following key areas:

- a. **Demographic Information:** Includes parental details such as age, gender, and educational background.
- b. **Parental Awareness:** Assesses parents' understanding of the causes, symptoms, and available treatment options for intellectual disabilities.

- c. **Intervention Preferences:** Evaluates the types of interventions parents prefer, including medical treatments, educational strategies, and behavioural therapies.
- d. **Challenges and Barriers:** Identifies the main obstacles faced by parents, such as access to resources, financial constraints, and lack of awareness.

The questionnaire was administered in person or via an online survey, ensuring broad accessibility and response rate.

3.4. Data Analysis:

The data collected from the questionnaire responses were analysed using descriptive statistics. Frequencies and percentages were calculated to summarize the responses and identify trends and patterns in parental knowledge and preferences. Key themes, including medical treatment preferences, educational interventions, behavioural strategies, and the need for training, were identified through thematic analysis of the responses.

4. Result and Discussion:

The survey reveals that mothers (60%) are the primary caregivers and decision-makers in managing their child's intellectual disability, with fathers (32.5%) and guardians (7.5%) also involved. Additionally, 65% of respondents are female, highlighting their active role in seeking interventions. Educational backgrounds vary significantly, with 42.5% completing secondary education and 27.5% having no formal education, indicating a gap in specialized knowledge that may influence parental awareness and decision-making.

Children in the study range from 6 to 34 years, with the highest representation at 19 years (20%). The gender distribution shows 57.5% are male and 42.5% are female, consistent with research suggesting a higher prevalence of intellectual disabilities among males. Regarding diagnosis, 49.5% of children have moderate intellectual disabilities, 42.5% have mild intellectual disabilities, and a smaller percentage have severe (5%) or profound (2.5%) disabilities. This suggests that while most children have some level of functional independence, they still require structured support.

The findings highlight significant gaps in parental awareness, with 70% of parents requiring more guidance and 20% lacking understanding of intellectual disabilities. While 77.5% have received training, 22.5% remain unsupported, underscoring the need for broader outreach and accessible education programs. Parents primarily rely on doctors (58.1%) and special education teachers (35.5%) for guidance, while peer support groups and online resources remain underutilized. Additionally, the lack of information (65%) is identified as the most significant challenge, followed by limited access to professionals (35%), emphasizing the need for better awareness initiatives and enhanced professional support services.

A majority (65%) of parents prefer educational and behavioural strategies over medical treatment, yet 100% of respondents have never attended training on managing problem behaviors, highlighting a critical gap in parental education. Among those who sought medical

intervention (35%), 71.4% opted for neurological treatments, while 28.6% used medication for attention and hyperactivity, with no reports of nutritional or genetic interventions.

Regarding education, 82.5% of children attend special education programs, though accessibility remains a concern. Among them, 72.5% are enrolled in special schools, 22.5% follow home-based learning, and only 5% receive support in mainstream schools, with no reported use of Individualized Education Plans (IEPs). These statistics emphasize the need for inclusive educational policies and enhanced learning support.

When asked about the support they require, parents prioritized behaviour management training (45%), followed by school-based interventions (22.5%), therapy (17.5%), and support groups (15%). Encouragingly, 85% of parents recognize the benefits of early intervention, with 42.5% reporting significant improvements in their child's development. These findings highlight the urgent need for practical training programs, structured interventions, and comprehensive parental support systems.

Overall, the survey results emphasize key factors influencing parental awareness and intervention choices. While mothers take the primary caregiving role, many parents lack the necessary education and support to make informed decisions. Addressing these gaps through targeted awareness campaigns, improved access to professional guidance, and community-based interventions can strengthen parental capacity to support their children's development effectively.

5. Conclusion:

In conclusion, the findings of this study emphasize the critical need for enhanced parental education and support systems to improve the management of children with intellectual disabilities. The significant gaps in parental awareness and the barriers to accessing appropriate interventions underscore the importance of targeted awareness programs and structured training for parents. By focusing on increasing access to specialized knowledge, support services, and community-based resources, policymakers and practitioners can empower parents to make more informed decisions and provide better care for their children. Ultimately, these efforts will lead to improved outcomes for children with intellectual disabilities and foster a more inclusive and supportive environment for their development.

References

- American Psychiatric Association. (2013). Diagnostic and statistical manual of mental disorders (5th ed.). American Psychiatric Publishing.
- Bailey, D. B., Raspa, M., & Fox, L. C. (2019). What is the future of family outcomes and family-centered services? *Topics in Early Childhood Special Education*, 39(1), 6–20.
- Guralnick, M. J. (2017). Early intervention for children with intellectual disabilities: Current knowledge and future prospects. *Journal of Applied Research in Intellectual Disabilities*, 30(2), 211–229.

- Kyzar, K. B., Turnbull, A. P., Summers, J. A., & Gómez, V. A. (2021). The relationship of family support to family outcomes: A synthesis of the literature. *Journal of Early Intervention*, 43(3), 246–264.
- Pelchat, D., Lefebvre, H., & Perreault, M. (2020). Differences and similarities in mothers' and fathers' experiences of parenting a child with a disability. *Journal of Child and Family Studies*, 29(5), 1324–1338.
- Schalock, R. L., Luckasson, R., & Tassé, M. J. (2021). *Intellectual disability: Definition, classification, and systems of supports* (12th ed.). American Association on Intellectual and Developmental Disabilities.
- Turnbull, A. P., Turnbull, H. R., Wehmeyer, M. L., & Shogren, K. A. (2020). *Exceptional lives: Special education in today's schools* (9th ed.). Pearson.
- Carter, E. W., Asmus, J. M., Moss, C. K., Biggs, E. E., Bolt, D. M., Born, T. L., & Wier, K. (2015). Randomized evaluation of peer support arrangements to support the inclusion of high school students with severe disabilities. *Exceptional Children*, 82(2), 209–233.
- Durkin, M. S., Maenner, M. J., Newschaffer, C. J., Lee, L. C., Cunniff, C. M., Daniels, J. L., & Schieve, L. A. (2015). Advanced parental age and the risk of autism spectrum disorder. *American Journal of Epidemiology*, 182(2), 102–111.
- Emerson, E., & Hatton, C. (2014). *Health inequalities and people with intellectual disabilities*. Cambridge University Press.
- Guralnick, M. J. (2017). Early intervention for children with intellectual disabilities: An update. *Journal of Applied Research in Intellectual Disabilities*, 30(2), 211–229.
- Kaminski, J. W., Valle, L. A., Filene, J. H., & Boyle, C. L. (2008). A meta-analytic review of components associated with parent training program effectiveness. *Journal of Abnormal Child Psychology*, 36(4), 567–589.
- Kazdin, A. E. (2017). Evidence-based psychosocial treatments for conduct problems in children and adolescents. *Journal of Clinical Child & Adolescent Psychology*, 46(4), 477–499.
- Matson, J. L., & Neal, D. (2009). Psychotropic medication use for challenging behaviors in persons with intellectual disabilities: An overview. *Research in Developmental Disabilities*, 30(3), 572–586.
- McKenzie, K., & McConkey, R. (2016). Caring for adults with intellectual disabilities: The perspectives of family carers. *Journal of Applied Research in Intellectual Disabilities*, 29(4), 356–365.
- Smith, T. (2020). Inclusive education for students with intellectual disabilities: Perspectives, practices, and progress. *Educational Review*, 72(4), 423–439.
- Totsika, V., Hastings, R. P., Emerson, E., Berridge, D. M., & Lancaster, G. A. (2011). Behavior problems at 5 years of age and maternal mental health in autism spectrum disorders and intellectual disabilities. *Journal of Abnormal Child Psychology*, 39(8), 1137–1147.

- Zuckerman, K. E., Lindly, O. J., Reyes, N. M., Chavez, A. E., Macias, K., & Smith, K. N. (2018). Disparities in diagnosis and treatment of autism in Latino and non-Latino white families. *Pediatrics*, 142(5), e20180131.