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# A Study of How Families of Children with Learning Disabilities Perceive Their Children and the Disorder

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#### **Abstract**

Parents impact academic and social success. Most parents lack reliable ideas for helping their children, affecting both. Few studies on learning disabled parents (LD). Current study examines how LD families saw their children. A family LD interview-based study was conducted. 100 LD parents participated. Everyone has LD. After permission, an open-ended 45-60minutes interview was conducted. Parents lacked LD symptomatology and treatment guidelines. After their child's LD diagnosis, they rejected, denied, overprotected, and despaired. Child care strained most parents physically, personally, socially, economically, and emotionally. The research shows the hardships and ignorance of LD parents.

Keywords: Family, Burden, Learning disorder, Perception

## INTRODUCTION

Primary caregivers may help children prosper. Stress-free, loving households aid learning-challenged kids (LD). Family-focused LD educational treatment is recommended [1,2]. Many parents miss LD because to lack of knowledge and awareness. Slow action is criticised. Parents dispute instructors' claims that their children have learning challenges. After a child's diagnosis, parents may deny, reject, and self-blame [3–6]. Unhappy, resentful, or overprotective parents don't make reasonable demands. Failure or poor performance despite effort and expertise can upset parents. Financial problems and decreased living quality may occur [7–9].

## Study design

To learn about the family's perspectives and experiences with LD, we conducted interviews. There were 100 LD parents in this research. All of the children of the parents were found to have LD. The interview started with open-ended questions after receiving consent and lasted 45-60 minutes.

## **Participants**

100 parents with LD were examined. All of the kids have LD. Parents living with a child with a learning disability and seeking therapy for them (ages 5-7) were eligible for the research if they were between the ages of 27 and 45 and provided written consent.

## **Procedure**

The objective and confidentiality of the study were explained to all screened parents. After receiving consent, the interview lasted between 45 and 60 minutes and started with open-ended questions.

1 https://jrtdd.com

eISSN: 2589-7799 2022June; 5 (1s): 01-05

## **Analysis**

Interview-derived qualitative data were submitted to content analysis.

## Results

When questioned about their child's learning issue, the majority of parents said they lacked understanding because of a lack of awareness, a delay in diagnosis, and a lack of advice on the matter.

## MAJOR FACTS IDENTIFIED

## Lack of knowledge

60% didn't understand LD. They wouldn't see LD in a newborn or diagnosed youngster. Most had just heard "LD" a few months before. Before their child was diagnosed with LD, mom and dad felt their child's low academic accomplishment was related to poor behaviour and attitudes and would improve with maturity. [26]

## **Delayed Identification**

Almost 90% of parents noticed their child's learning problems in nursery school but only understood it was linked to sickness afterwards. LD was identified in 3rd or 4th grade, after two and a half to three years of symptoms, or when the child was 10 years old, depending on the circumstances. 18 parents approved postponing LD diagnosis.

## Lack of Guidance

Participants didn't obtain adequate support to understand or manage LD. The child's learning difficulties were explored in the Bollywood film "Taare Zameen Pe- Stars on Earth." Parents or relatives told some parents about LD. Parents reported instructors and counsellors did not assist them manage their child's learning difficulties, instead reporting activities and bad academic achievement. Parents' unfavourable views regarding reading and arithmetic were also noted. Rejection, perhaps, parents and family members required more time to adjust.

## ATTITUDE TOWARDS DIAGNOSIS

## Denial

Most parents (n = 60) denied LD diagnosis. Failure wasn't a learning issue. They opposed the diagnosis, blaming the school system, instructors, curriculum, and children's conduct. Some parents refused a psychoeducational examination.

## Rejection

At first, a significant portion of parents (n = 50) were unaware of their child's illness. Parents and other family members took a while to adapt since they found it difficult to accept the problem.

## Overcommitment and Despair

Some (20) parents provided assistance to their LD-affected children. Parents give up their jobs to support their kids' education. They worked with the youngster for a long period, but they weren't thrilled with the outcomes. Some parents have concerns about their child's growth and future plans.

## Burden perceived by the parents.

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## **DISCUSSION**

According to the findings of the study, parents' awareness of the condition was poor, and many reported feeling overwhelmed by the responsibility of caring for their children.

## Lack of information

Parental ignorance regarding LD was the major problem. Parents have little knowledge of LD [10] and other developmental problems despite being well educated and from affluent homes. [11] Parents were ignorant of their child's learning and behaviour problems at home and school because they had a poor knowledge of LD. They misdiagnosed LD as a child's focus, attitude, and behaviour problems that didn't need immediate attention. In the past, the majority of parents were unable to define "LD" exactly or identify its cause. [12] "Difficulties or troublesome behaviours in learning and self-care in daily activities," according to parent accounts of LD. Neither LD nor its causes were known to any of the parents. [13] Parents therefore believed the child's learning challenges were normal and would get better with age [2].

The child's learning difficulties were apparently noticed by the daycare. But because of their terrible ignorance, they misunderstood it. They made the diagnosis that it was a disease after 23 years or ten years. Parental inaction delayed child interventions by preventing early mental health assessment. [14,15] When LD was first identified in 2007, it took 5.8 years [16]; in 2014, it took 3.4. [17] Schools and others failed to effectively address a child's learning handicap. Alone or in collaboration with other parents or relatives, they looked into the child's learning difficulty. According to a study, 3 out of 25 parents were informed about the disease by psychoanalysts and mental health nurses.

## AttitudesToward the Diagnosis

The mild signs of learning problems delay identification and therapy. [18] It could also lead to family intolerance. Themes of denial, rejection, pessimism, and over participation were prevalent. Most relatives found it difficult to accept the child's circumstances. Similar to how grieving parents negotiate for acceptance, the majority of parents were unaware of their child's learning disability [19, 20, and 21]. [22] After receiving the diagnosis, parents' over-involvement in their child's schoolwork and homework aggravated the situation. Additional research revealed that some parentages lost trust in their children's academic and professional futures [2].

## **Burden Perceived by Parents.**

Parentages of children with LD were burdened in this study. Early studies also emphasised the difficulties these parents face. [13] Parents were worn out from assisting with their child's academics. They prohibited social and family activities, as well as typical family pursuits and hobbies [13]. [13,24] Teachers gave up when parents complained about their children's poor behaviour and unmanaged schoolwork. [15] Parents' worries and fears are related to their child's poor school performance, life projections, and therapy visits. [13] Child care is made simpler and less stressful when parents are aware of LD and have access to resources and support. [7,13,14] Psychological, emotional, and practical support decreases caregiver stress and anxiety, says a research. Mental health doctors should teach families about LD, remedial programmes, and behavioural parenting strategies. [7,13] Better sickness knowledge, caring skills, and family, friend, and community support may assist. [13].

## **CONCLUSION**

Parents with children with disabilities are more likely than other parents to experience long-term stress. Like any other kid, a child with disabilities is impacted by family and environment. The stress on a family is increased when relatives, friends, and/or members of society have negative opinions regarding a child's handicap. Disabled people's participation and acceptance may be hampered by the general public's ignorance of their skills. Self-advocacy group formation, which is only getting started, has to be accelerated. People with

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disabilities can improve their skills and independence with the aid of education, counselling, and vocational training. Participation and social support are also necessary.

## References

- 1. Smythe I, Everatt J, Salter R. *The international book of dyslexia: A guide to practice and resources.* Edinburgh, UK: John Wiley & Sons; 2005.
- 2. Pattanayak RD, Sagar R, Choudhary V. Caregiver perspectives based of focus group discussion: Parental burden, experiences and unmet needs. In: Sagar R, Pattanayak RD, editors. *Specific Learning Disorder: Indian Scenario*. New Delhi, India: Department of Science and Technology (DST), AIIMS; 2014. pp. 265–77.
- 3. Kearney PM, Griffin T. Between joy and sorrow: Being a parent of a child with a developmental disability. *J adv nurs*. 2001;34:582–92.
- 4. Maxwell V, Barr O. With the benefit of hindsight: A mother's reflections on raising a child with Down Syndrome. *J Learn Disabil*. 2003;7:51–64.
- 5. Chandramuki D, Venkatakrishnashastry I, Vranda MN. Attitudes of parents towards children with specific learning disabilities. *Disabil CBR Inclusive Dev.* 2012;23:63–9.
- 6. Heiman T. Parents of children with disabilities: Resilience, coping, and future expectations. *J DevPhysDisabil.* 2002;14:159–71.
- 7. Karande S, Mehta V, Kulkarni M. Impact of an education program on parental knowledge of specific learning disability. *Indian J Med Sci.* 2007;61:398–406.
- 8. Karande S, Kulkarni S. Quality of life of parents of children with a newly diagnosed specific learning disability. *J Postgrad Med.* 2009;55:97–103.
- 9. Simon A, Easvaradoss V. Caregiver Burden in Learning Disability. Int J Indian Psychol. 2015:86–90.
- 10. Mehta M, Sagar R. Specific learning disability comprehensive diagnostic battery (SLD: CDB) New Delhi, India: Psycho Matrix Pub; 2013.
- 11. Sheehan DV, Sheehan KH, Shytle RD, Janavs J, Bannon Y, Rogers JE, et al. Reliability and validity of the mini international neuropsychiatric interview for children and adolescents (MINI-KID) *J Clin Psychiatry*. 2010;71:313–26.
- 12. Chang MY, Hsu LL. The perceptions of Taiwanese families who have children with a learning disability. *J ClinNurs*. 2007;16:2349–56.
- 13. Chien WT, Lee IY. An exploratory study of parents' perceived educational needs for parenting a child with learning disabilities. *Asian Nurs Res.* 2013;7:16–25.
- 14. Buschgens CJ, Van Aken MA, Swinkels SH, Altink ME, Fliers EA, Rommelse NN, et al. Differential family and peer environmental factors are related to severity and comorbidity in children with ADHD. *J Neural Transm.* 2008;115:177–86.
- 15. Hill C, Rose J. Parenting stress in mothers of adults with an intellectual disability: Parental cognitions in relation to child characteristics and family support. *J Intellect Disabil Res.* 2009;53:969–80.
- 16. Karande S, Satam N, Kulkarni M, Sholapurwala R, Chitre A, Shah N. Clinical and psychoeducational profile of children with a specific learning disability and co-occurring attention-deficit hyperactivity disorder. *Indian J Med Sci.* 2007;61:639–47.
- 17. Chakraborty S, Kommu JV, Srinath S, Seshadri SP, Girimaji SC. A comparative study of pathways to care for children with a specific learning disability and mental retardation. *Indian J Psychol Med.* 2014;36:27–32.
- 18. O'Hara DM, Levy JM. Family Adaptation to Learning Disability: A Framework for Understanding and Treatment. *Learn DisabilInterdiscip J.* 1984;3:63–77.
- 19. Blacher J. Sequential stages of parental adjustment to the birth of a child with handicaps: Fact or artifact? *Ment Retard.* 1984;22:55–68.
- 20. Marvin RS, Pianta RC. Mothers' reactions to their child's diagnosis: Relations with the security of attachment. *J Clin Child Psychol*. 1996;25:436–45.
- 21. Keller D, Honig AS. Maternal and paternal stress in families with school-aged children with disabilities. *Am J Orthopsychiatry*. 2004;74:337–48.

eISSN: 2589-7799 2022June; 5 (1s): 01-05

22. Kenny K, McGilloway S. Caring for children with learning disabilities: An exploratory study of parental strain and coping. *Br J Learn Disabil*. 2007;35:221–8.

- 23. Gannon S, McGilloway S. Children's attitudes toward their peers with Down Syndrome in schools in rural Ireland: An exploratory study. *Eur J Spec Needs Educ*. 2009;24:455–63.
- 24. Karande S, Kumbhare N, Kulkarni M, Shah N. Anxiety levels in mothers of children with a specific learning disability. *J Postgrad Med.* 2009;55:165–70.
- 25. Sahu A, Bhargava R, Sagar R, Mehta M. Need to develop a home-based intervention for specific learning disorder in the Indian setting. *Indian J Psychol Med.* 2017;39:548–9.
- 26. Sahu, Anamika et al. "Perception of Families of Children with Specific Learning Disorder: An Exploratory Study." *Indian journal of psychological medicine* vol. 40,5 (2018): 406-413. doi:10.4103/JJPSYM\_JPSYM\_148\_18

5 https://jrtdd.com