



Understanding the Needs of Parents of Children with Intellectual Disability: A Study

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Abstract

The present research work, entitled “Understanding the Needs of Parents of Children with Intellectual Disability: A Study,” was undertaken to explore the multifaceted needs-emotional, informational, social, and practical-of parents raising children with intellectual disabilities. Parents of such children often face unique challenges that can significantly impact their well-being, family dynamics, and ability to access services and resources. The study seeks to identify these needs systematically and suggest avenues for support and intervention. Provides an introduction to intellectual disabilities. It also elaborates on the concept of parental needs and institutional resources presents a comprehensive review of related literature, highlighting national and international studies on the challenges, coping mechanisms, and support systems relevant to parents of children with intellectual disabilities. Outlines the research methodology, including the research design, sampling procedures, selection of population, and use of standardized tools. The methodology is carefully chosen to ensure the reliability and validity of the data collected. Presents the results and analysis of data gathered from students and parents associated with the Special Education and Rehabilitation Lab. It includes statistical interpretation, graphical representation, and in-depth discussion on emerging patterns and themes. provides a summary of the key findings, draws conclusions, and offers practical recommendations for stakeholders including educators, policymakers, and service providers. The chapter emphasizes the urgent need for family-centered support services, policy implementation, and parent empowerment programs. This research report is based on both primary data collected through interviews and checklists and secondary data from existing literature and official sources. It aims to contribute to the growing body of knowledge focused on strengthening support systems for families of children with intellectual disabilities.

Keywords: Intellectual Disabilities (ID), Parental Support Needs, vocational planning, personal-social, support physical, family relationship, Family Needs Schedule (NIMH-FAMNS)

Introduction

Parenting a child with intellectual disability (ID) involves unique responsibilities. Intellectual disability affects a child's learning, behavior, and daily functioning. Parents become full time caregivers, educators and advocates for their children. Parents often face difficulty understanding their child's condition and accessing help. They often experience emotional stress, anxiety, and burnout. Understanding these needs is essential for effective support systems. Parents require emotional, social, and practical support to ensure the well-being of the entire family. Lack of awareness, social stigma and Parents of children with intellectual disabilities often struggle to balance family life, work, and care giving roles. They need information for proper guidance, counseling, and community support. Thus,

understanding their needs is the key to supporting both the parent and the child. As Parents are the most important parts in child's life and play a vital role in supporting their children's in needs, proving emotional support, creating a supportive home environment, and their needs.

Literature Review

Introduction: Without the review of the related literature no research activity can be start. The review of related literature can be start only with the research work or scientific investigation. The important steps in the planning of any research study is a careful review of the related sources of literature on the problem to be investigated.

1. Aqeel Abdul Amir Noman and Amean A. Yasir (2022)^[9] was of the view that the most urgent needs of parents

of children with intellectual disabilities, it can be noted that the material most urgent needs, followed by the cognitive needs, then the social needs and the emotional needs.

2. Karina Huusa, Lena M. Olssona, Elisabeth Elgmark Anderssona, Mats Granlunda, and Lilly Augustine (2017) ^[7], was reported that on the research, the result show in finding the perceived needs among parents referred a strong needs of information in future support and Most parents reported informational needs, both concerning currently available support.
3. Amrita Sahay, Jai Prakash, Abdul Khaiku, Priti Kumar (July. 2013) was of the view that to find out the needs of the parents of intellectual disabilities. Finding suggested that parents referred to strong needs about information of current and future service available in society and the community.
4. Kholoud A. Al-Dababneh Merfat Fayeze Osama Bataineh (2012) ^[3] reported that a survey of Needs of Caring Parents was developed to achieve the purposes of this study. Parents most important needs belong to the information dimension, in the caring process and the least important in family needs is counseling support and family support areas of identify needs.
5. Atilla Cavkaytar, Oktay Cem Adigüze, Esra Ceyhan, Hakan Uysal (October 2012) ^[2] was of the view that the highest family needs is information about child's diagnosis, its properties, progress and education and support from consultants and social surroundings.

Materials and Methods

Objectives of the present study

The major objectives of the study were:

- To identify the needs of the parents of children with Intellectual disabilities.
- To compare the Pre intervention and Post intervention of the needs of Parents.
- To examine the parent's needs in respect of gender of children with the ID, education, age, area of residence.
- To compare the parents needs of the vocational planning in the pre and post intervention.
- To compare the parents needs of Personal-Social in the pre and post intervention.
- To compare the parents needs of support physical in the pre and post intervention.
- To compare the parents needs of the family relationship in the pre and post intervention.

Hypothesis

- **H₁:** There will be a significant difference in the needs of the parents of Intellectual Disabled children.
- **H₂:** There will be a significant difference in the needs of the parents in the Pre-intervention and Post-intervention phases.
- **H₃:** There will be a significant difference in respect of gender of children with the ID, education, age, area of residence.
- **H₄:** There will be a significant difference in the parents needs of the vocational planning during the pre and

post-intervention.

- **H₅:** There will be a significance difference in the parents needs of personal - social in the pre and post intervention.
- **H₆:** There will be a significance difference in the parents needs of the support physical in the pre and post intervention.
- **H₇:** There will be a significance difference in the parents needs of family relationship in the pre and post intervention.

Inclusion Criteria

1. Parents who are willing to participate and provide informed consent.
2. Parents of children diagnosed with intellectual disabilities.
3. Parents of children who are having the disability certificate.

Exclusion Criteria

1. Parents who do not give consent or withdraw during the study.
2. Parents of children other than intellectual disability.
3. Parents of children who do not have the disability certificate are excluded.

Sample & Tools Used: The Institute of the Department of Special Education & Rehabilitation lab, ICFAI University Tripura is selected for these research work. From the total beneficiary list of 120 parents of the special needs children from the special Education Lab, ICFAI University, Tripura out of which 63 parents of only the intellectually disabled children who are having the disability certificate are selected for the research study using stratified random sampling method.

Tool

NIMH Family Needs Schedule (Parent) - Developed by Reeta Peshwaria, D.K. Menon, Rahul Ganguly, Sumit Roy, and Rajam. P.R.S Pillay, Asha Gupta, (1995) and designed to identify the family needs of mentally disabled individuals for program planning in family intervention. It is a rating scale and consists of 44 items, and these items are divided into 15 Domains. Out of these 15 domains, we have chosen four parameters to determine the needs of parents of children with intellectual disabilities. The selected parameters are: (a) Vocational Planning (b) Personal-Social (c) Support Physical (d) Family Relationships.

Significance of the study

The present study tries to bring the needs of the parents of the intellectual disabled children with respect to the availability of the information and facilities they face while utilizing this information. The needs expressed by families of children with Intellectual Disability are different from person to person and family to family. The needs arise to study how the vocational planning, personal-social, physical support, family relationship, so that they can adjust and management themselves with the environment and society.

Results

Background details

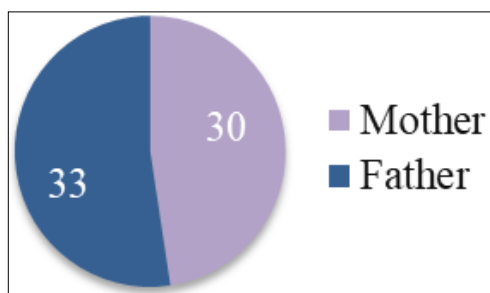


Fig 1: The study collected information from the parents of both the fathers and mothers of Intellectual disabled children

Parents: The study collected information from the parents of both the fathers and mothers of Intellectual disabled children those who were enrolled in the Special Education Lab in the Department of Special Education & Rehabilitation ICFAI University, Tripura. Among them 33 were Fathers and 30 were Mothers. The information gathered from them was useful to understand thoroughly the needs of the parents, the means of needing information, about the problems they faced and their opinion and suggestions they could make out for further improvement from the needs of the parents of intellectual disabled children. Background information of the parents and the students including sex, age, Education, residence is well studied.

Area I: Vocational Planning

The needs help in finding vocational Rehabilitation for the child in Information on responses of parents regarding the needs on Vocational planning.

The majority of the parents i.e. 31.34% of the parents need helps in finding vocational Rehabilitation for the child. As in comparison based on the collection of the needs of information the majority of parents needs in Services in Pre-Intervention is lower than the needs of the parents in Post – Intervention.

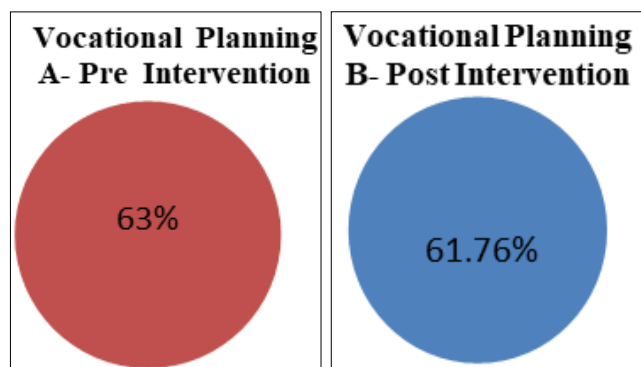


Fig 2: Graphical Representation on percentage on Vocational Planning

Area II: Personal – Social

The area II shows detail about the needs of discussion with friends share joys and sorrow, discuss with other parents having children with similar condition. Information on responses of parents regarding the needs on Personal -

Social. The needs of the parents on Personal - Social i.e. 48.67% of the parents reported that they need more friends to discuss or share their joys and sorrow with friends. While 52.11% of the parents need to meet and discuss with parents having children with similar conditions. While comparing the pre intervention and post intervention on the parents, about the Personal-Social, the pre intervention is higher than the post intervention.

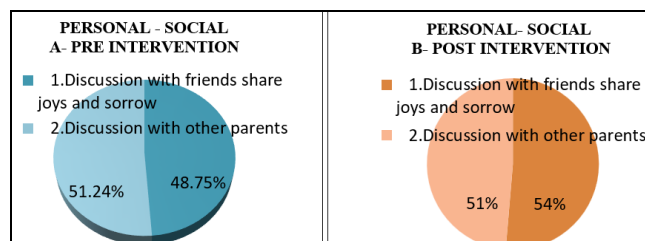


Fig 3: Graphical Representation of percentage on Personal-Social

Area III: Support – Physical

The needs of transportation for child's training, manual support for transportation, domestic support for children, information on responses of parents regarding the needs on Support- Physical. It shows that the needs on support-physical of the parents i.e. 38.77% of the parents reported that they need transportation for the child's training, while 33.58% of the parents need on manual support for transportation and need somebody to drop and bring back their child from school/service center. 27.64% parents need domestic support for children that someone or worker to look after the child at home in daily/ occasionally/ part time/ full time. While comparing the pre intervention and post intervention of the parents needs on support- physical, the pre intervention is higher than the post intervention.

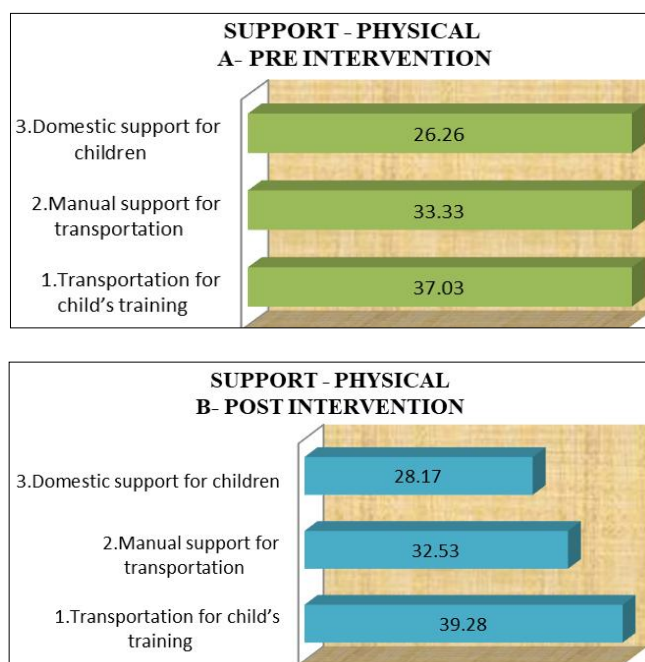


Fig 4: Graphical Representation of percentage on Support-Physical

Area IV: Family Relationship

It is about the needs of Family problems and finding solutions with Spouse, parent child, between siblings and

with other significant other family members.

Information on responses of the parents regarding the needs Family Relationship of the majority of the parents i.e. 22.41% needs help in discussing family problems and finding solutions in spouse and also 22.41% needs help in finding solutions with the parent child. 16.68% needs help in finding solutions with between siblings and 16.81% needs help with other significant family members. The parents

were also asked if they had ever faced any type of problems and disturbances in relation to imparting to the education to the students and solving their problems. They had to solve it according to the problem. As in comparison of both the Pre intervention and Post intervention based on the collection of the needs on regarding Family relationships, the majority of parents needs in Pre-Intervention were 438 and is more than in Post-Intervention.

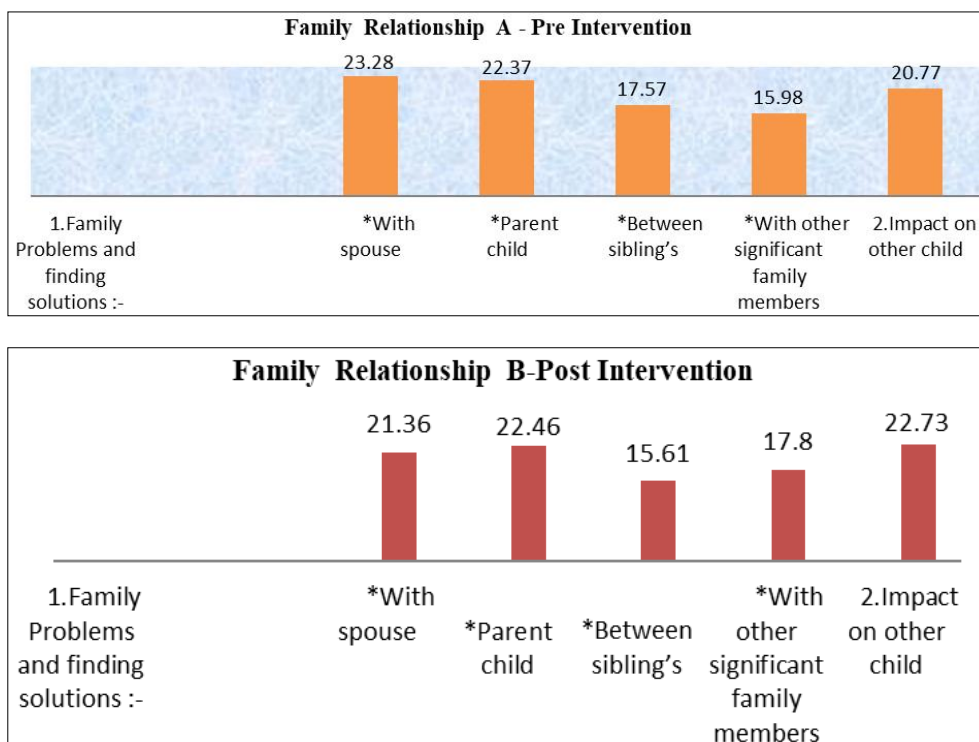


Fig 5: Graphical Representation of percentage on Family Relationship

Parents needs profile in Pre-Intervention and Post-Intervention

Table 1: Distribution of the total Parents needs profile of the parents

AREAS	Total possible Scores	Obtained Score	
		A*	B*
1. Vocational Training	201	99	102
2. Personal Social	378	201	177
3. Support Physical	539	297	252
4. Family relationship	803	438	365
NIMH-FAMNS (Parents)			
Grand Total Scores	1,921	1,035	896

A* Pre-Intervention Scores: 1035

B* Post-Intervention Scores: 896

The above table shows in detail that the total scores in the NIMH –FAMNS (parents) in the needs of the parents, i.e., 1,035 scores in the Pre-intervention, were higher than the needs of parents in Post Intervention, i.e., 896.

Main Finding of the Present study

Special Needs Children

The findings of the special needs children help in understanding fully the prevalence of Intellectual disabled children.

1. The number of male intellectual disabled students in the

Special Education Lab, ICFAI University Tripura is higher (62%) than the female i.e. 26%.

- 19.04% of the students are under the age of 5-10. 39.68% are under the age group of 11-15. 28.57% are under the age group of 16-20. 9.52% are under the age group of 21-25. 3.17% are under the age group of 25-30.
- The students of Intellectual Disabled children have to pass the examination of different classes to reach to the Vocational classes 4.54% of the students are in Pre-primary, 28.40% are in Primary I and 10.22% are in Primary II, 20.45% are in secondary class, 27.27% are in Pre-Vocational and 9.09% are in vocational class.
- The Intellectual disabled children in Tripura are available mostly in the West Tripura as majority of the students are from West Tripura.

Parents

The main findings of the parents on the basis of the present study help in the effective functioning and proper development of the institute. The findings consisted of:

- The number of the fathers of the intellectual disabled children is higher 52.38% than the mothers i.e. 47.62%.
- The present study also confirmed that in the vocational planning the need of parents in finding the most appropriate vocational rehabilitation for the child were the highest needs 31.34%. The needs of the parents in vocational planning in pre intervention is lower than in

post intervention.

3. The personal-social needs of the parents the highest needs are discuss with parents having children with similar condition were 52.11%.
4. About the needs of parents in support-physical the highest needs are the transportation for child training were 38.77%. The needs in pre- Intervention is higher than in post intervention.
5. It is found that the parents need in regarding family relationships the needs with both the siblings and spouse were 22.41%. It is seen that the needs of information in pre- Intervention is higher than in post intervention.

Discussion

The study was sought to find out the needs of the parents of intellectual disabled children. The study revealed that parents expressed a strong need for the information about the family relationship in their family for the children with intellectual disability. The needs of the family are all different.

On the basis of the collected responses from the parents on the Pre-Intervention and Post-Intervention, the needs expressed by parents in the pre- intervention is higher than that of the post intervention. After communicating and collecting data to the parents of intellectual disabled children for the pre- intervention in the month of March 2025 and the post intervention in the month of June 2025 there are a lots of things which the parents are needed for the information can be seen.

The Pre Intervention rate was higher than that of Post Intervention needs in the parents. Therefore, the hypothesis 'there is a significant difference in the needs of the parents of Intellectual Disabled children in the Pre-Intervention and Post-Intervention phases' is accepted.

The Area of Vocational Planning in the Pre intervention is 99 and is lower than the Post Intervention i.e.102. The finding suggests that there is a significant difference between the pre- intervention and post- intervention. Hence, the hypothesis is accepted.

The Area of Personal-Social in Pre-Intervention is 201 and higher than in Post-Intervention i.e.177. The findings showed that in the majority, the parent's needs were less than the previous months. Hence, the hypothesis 'there is a significant difference in the needs of the personal – social of parents during the pre-and post-intervention' is accepted.

The Area of Support- Physical in Pre-Intervention is 297 and is higher than in Post-Intervention i.e.252. Thus, it can be said that the needs of parents for the intellectual disabled children about the support physical in the pre-intervention is higher than that of the post- intervention. Hence, the hypothesis 'There is a significant difference in the support physical needs of information of Parents' is accepted.

The Family Relationships in Pre-Intervention is 438 and is higher than in Post-Intervention i.e.365. There was a significant difference found between the responses collected from parents. Therefore, it is essential to provide proper information of the family relationship. Hence, the hypothesis 'there is a significant difference in the need for information on family relation on the needs of the parents' is accepted.

Limitations

In the areas of the information needs of the parents of the intellectual disabled children there are certain limitations:

1. Language barriers
2. Negative barriers
3. Lots of questions
4. Asking for help
5. Lack of support from the Government.
6. Not getting the adequate fund.

Conclusion

On the basis of the study it may be concluded that as parents are the most important parts in child's life and play a vital role in supporting their children's in needs, proving emotional support, creating a supportive home environment, and their needs. This study was aim to examine the needs of parents under 4 domains such as vocational planning, personal social, support physical, family relationships. Understanding of parent's needs may help them to improve the appropriate implementation of personal- social model in community. So based on the present study it helps us to find out the needs of parents of intellectual disabled children in Tripura and also find out the support need for information about the child condition or disabilities, building a good relationship in the family. The present study aimed to help the parents of children with intellectual disabilities to be informed about four essential domains, viz., a) vocational planning, b) Personal- social, c) support physical d) family relationship. This study contributes to the growing evidence base to know the parent's awareness level about needs of parents in specific areas. So, based on this present study helps us to find out the parents needs of intellectual disabled children in Tripura and also find out the support needed for information about the child's condition or disabilities and family relationship.

Future Studies

1. The future could explore cultural difference in parent's needs.
2. The impact of intellectual disability on siblings and how families can be supported.
3. Understudied needs of fathers in care giving roles differently from mothers.
4. Compare needs across health care, education. So, the present study can be supplemented for further research work. It would be very helpful in the future.

References

1. Peshawaria R, Menon DK, Ganguly R, Roy S, Pillay RPRS, Gupta A. NIMH Family Needs Schedule (NIMH-FAMNS). Secunderabad (India): National Institute for the Mentally Handicapped; c1995. ISBN: 81-86594-00-1.
2. Cavkaytar A, Ceyhan E, Adiguzel OC, Uysal H, Garan O. Investigating education and support needs of families who have children with intellectual disabilities. International Journal of Humanities and Social Science. 2012;3(4):79–99.
3. Al-Dababneh KA, Fayez M, Bataineh O. Needs of parents caring for children with physical disabilities: a case study in Jordan. International Journal of Special Education. 2012;27(3):120–133.
4. Siebes R, Ketelaar M, Gorter JW, Alsem M, Jongmans

- MJ. Needs of families with children who have a physical disability: a literature review. *Critical Reviews in Physical and Rehabilitation Medicine*. 2012;24(1–2):1–16. Available from: <https://www.dl.begellhouse.com/journals/757fcb0219d89390,373c5a543c29d4b5,02abea9148f31d02.html>
5. Sahay A, Prakash J, Khaique A, Kumar P, Meenakshi SP, Ravichandran K, *et al.* Parents of intellectually disabled children: a study of their needs and expectations. *International Journal of Humanities and Social Science Invention*. 2013;2(7):1–8.
 6. Banerjee S. Impact of play on socialization of mentally retarded children (differently abled). Kolkata (India): Special Education & HEPSN Cell, Jadavpur University; 2013. ISBN: 978-81927525. Available from: https://drive.google.com/file/d/1RDhSE9_Yjo2mTgeC97hoEtrx4Oe_yn_a/view
 7. Huus K, Olsson LM, Elgmark Andersson E, Granlund M, Augustine L. Perceived needs among parents of children with a mild intellectual disability in Sweden. *Scandinavian Journal of Disability Research*. 2017;19(4):307–317. doi:10.1080/15017419.2016.1167773
 8. Banerjee S. Skills for counselling parents of students with special needs: factors of unwanted behavior and remedies. Kolkata (India): [Publisher unknown]; c2020 Mar. ISBN: 978-93-87879-73-7.
 9. Noman AAA, Yasir AA. Parents' needs of children with intellectual disability. *International Journal of Health Sciences*. 2022;6(Suppl 3):8385–8399. Available from: https://sustainability.uobabylon.edu.iq/uploaded/Sustain_2022_10442295.pdf

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