



Parents and Their needs having children with intellectual and developmental disabilities (IDD): An assessment through NIMH- Family Needs Schedule

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Abstract

Parenting a child with disability, whether a child has a physical disability, a learning disability, an emotional difficulty, or a developmental disorder, can require the development of particular skills, such as caregiving or advocacy, as well as a time and energy commitment that may put careers, marriages, and relationships with other children in danger. Researchers have extensively researched parenting over the years. But, in recent years, it has been noticed that this parenting study has placed a greater emphasis on constructive methods. The present study aimed to understand and assess the needs of parents who have children with Intellectual and Developmental Disability. The main objective of the study is to assess the needs of parents having children with Intellectual and Developmental Disability. Twenty parents (both mother and father) were included in the study as sample from Shishumangal child development centre in Raiganj, Uttar Dinajpur district. The assessment was done by using NIMH-Family Needs Schedule (Parents) to measure needs of the parents. In the present study data were collected by Descriptive Survey method. The collected data were analysed by descriptive statistics and percentage count. The result of the study indicated that the majority of parents showed strong needs in the domain of information condition, child management, services available for their child, Govt benefits and legislation, financial needs, vocational planning, personal-emotional and personal-social relationships. Parents showed less expected needs towards the sexuality, marriage and hostel related information. Mothers showed more needs in the domain of child management and information condition; while fathers expressed needs in the domain of financial help, vocational planning and Govt benefits. This study contributes to a better understanding of parents' needs from their perspectives, as well as their descriptions of the strengths and gaps of the present system. A deeper comprehension of parents' demands could help communities execute government policies and service models more effectively and provide financial assistance to families with poor socioeconomic status.

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Introduction

Disability in children causes a variety of needs in parents, which might differ based on the nature of the condition and parental attributes. Parenting a child with disability, whether a child has a physical disability, a learning disability, an emotional difficulty, or a developmental disorder, can require the development of particular skills, such as caregiving or advocacy, as well as a time and energy commitment that may put careers, marriages, and relationships with other children in danger. The term Intellectual and Developmental Disability (IDD), formerly known Mental Retardation, refers to conditions that typically manifest at birth and have an adverse impact on a person's trajectory of physical, intellectual, and/or emotional development.

Mishra (2005) argued that the degree of motivation among owners varies according to the owners' perceptions of challenges and opportunities. Financing is one issue that might have a big impact on the owners' growth motivation. While previous research indicates that small businesses may have access to financing, there appears to be a reluctance among owners to employ external financing (Claessens 2006). As a result of advances in unravelling the development and functionality of the brain and identifying the etiologic basis of Intellectual and Developmental Disability, there has been a significant change in the terminology, placement of the condition, classification, and defining features (Girimaji, 2018). Current approaches view IDD from a developmental perspective and rely on both intellectual abilities and adaptive functioning. According to American Association on Intellectual and Developmental Disabilities (AAIDD, 2010), Intellectual and Developmental Disability (IDD) is a disability characterized by significant limitations in both intellectual functioning and in adaptive behaviour, which covers many everyday social and practical skills. This disability condition originates before the age of 18.

The presence of a child with Intellectual and Developmental Disability in the family calls for a lot of adjustment on the part of the parents and the family members (Peshawaria & Menon, 1991)^[6]. Some families cope better with the situation than others (Peshawaria, 1995)^[8]. Researchers have extensively researched parenting over the years. But, in recent years, it has been noticed that this parenting study has placed a greater emphasis on constructive methods. Research has indicated that approaches that focus on meeting needs of all members of the family are more effective in helping the family to cope with the situation than approaches that focus only on the child with Intellectual Disability. Identifying and supporting the parents in their efforts to meet the needs of all the family members (including themselves) is one of the most efficient ways of developing parental skills which can enhance the development of all family members. Research has also indicated that greater the number of unmet needs, greater is the number of emotional and physical problems reported by the parents (Dunst & Leet, 1987)^[4].

For parents, the birth of a child with Intellectual and Developmental Disabilities is a shock, and they go through antagonistic stages like shock, denial and anger before accepting the child. As a result, they demand specific needs and extra requirements for the child and family for the child's complete growth. The needs of families with children who have intellectual and developmental disabilities are extremely complicated, necessitating the implementation of support programmes specifically for these families. In their study, Bailey et al. (1992)^[2] found that the factor structure for fathers was noticeably different from that discovered for mothers. Women stated much greater needs than fathers, primarily in terms of family and social support, explaining to others, and childcare. They generally mentioned having financial needs. For programme planning in early intervention, Bailey and Simeonsson (1988)^[3] suggested a collection of needs articulated by families.

In this study, the term "needs of parents" corresponds to needs related to the child's condition, needs related to child management, needs related to the facilitation of interaction, services, emotional and social needs, physical support, financial support, family relationships, future planning, and needs related to government benefits and legislation for parents with children with Intellectual and Developmental

disabilities.

With the widespread adoption of the international classification of functioning and disability and health (WHO 2001), which considers a person's functioning and disability as a dynamic interplay between health condition and contextual circumstances, assessment of family needs has become essential. Contextual variables encompass both individual and societal elements, such as sex, age, health issues, upbringing, coping mechanisms, social background, and formal and informal social institutions. Understanding how the nature of needs of parents having children with Intellectual Disability changes over time would enable service providers to design appropriate support services.

2. Objective

The main objective of the study is to assess the needs of parents having children with Intellectual and Developmental Disability (IDD).

3. Methodology

3.1. Research Design

A non experimental descriptive research design was undertaken to conduct the study.

3.2. Sample

The study was conducted on purposive sampling of twenty (20) parents (both mothers and fathers having children with Intellectual and Developmental Disabilities) taken from Shishumangal child development centre in Raiganj, Uttar Dinajpur district. The study included only parents of IDD children belong to the age group of 1-5 years.

3.3. Tool Used

NIMH Family Needs Schedule (NIMH – FAMNS) for parents was used to assess the needs of the parents who have children with Intellectual and Developmental Disabilities. The tool was developed by Peshawaria, Menon, Ganguly, Roy, Pillay and Gupta in 1995. NIMH- FAMNS is a semi structured interview schedule and it is used for the following purposes:

1. To identify needs of the Indian families having individuals with Intellectual Disability.
2. To priorities the needs for family intervention.
3. To objectively evaluate family intervention programme.

The schedule contains 45 items organised into 15 categories, including information-condition, child management, facilitating interaction, services, vocational planning, sexuality, marriage, hostel, personal-emotional support, personal-social support, physical support, financial security, family relationships, future planning and Govt benefits.

The area "information condition" consists of 6 items, "child management" area consists of 8 items, "facilitating interaction" consists of 2 items, "services" consists of 5 items, "vocational planning" consists of 1 item, "sexuality" consists 1 item, "marriage" consists of 1 item, "hostel" consists of 2 items, "personal-emotional" consists of 4 items, "personal-social" consists of 2 items, "support-physical" consists of 3 items, "financial support" consists of 3 items, "family relationship" area consists of 2 items, "future planning" area includes 2 items and last "Government benefits and legislation" domain consists of 2 items.

3.4. Procedure for Data Collection

Written consent was taken from the Director of Sishumangal to proceed for data collection. Consent was also taken to interview each of the respondents (parents) separately. They were briefed about the nature of the study. Adequate rapport with the parents of IDD children was made initially. The questions included in the schedule were asked in the same sequential manner. Each question was asked in a way that did not influence the responses of parents.

4. Data Analysis

The collected data were analysed by Descriptive Statistics (Frequency Distribution and Percentage Count). Frequency Distribution of respondents on the basis of gender and age are presented in Table 1 and Table 2. Data analysis of parents' needs based on parent variable are presented in Fig. 1.

5. Results and Discussion

Table 1: Distribution of Respondents (Parents) based on Gender (N=20)

Parents	Frequency	Percentage (%)
Mothers	14	70
Fathers	6	30

Table 2: Distribution of Respondents (Parents) based on Age

Age	Frequency	Percentage (%)
20-30	5	25
31-40	13	65
41-50	2	10

Table 1 and Table 2 show the distribution of parents based on their gender and age. The above tables indicate that majority of parents were mothers (70%) and most of the parents belonged to the age group of 31-40 (65%).

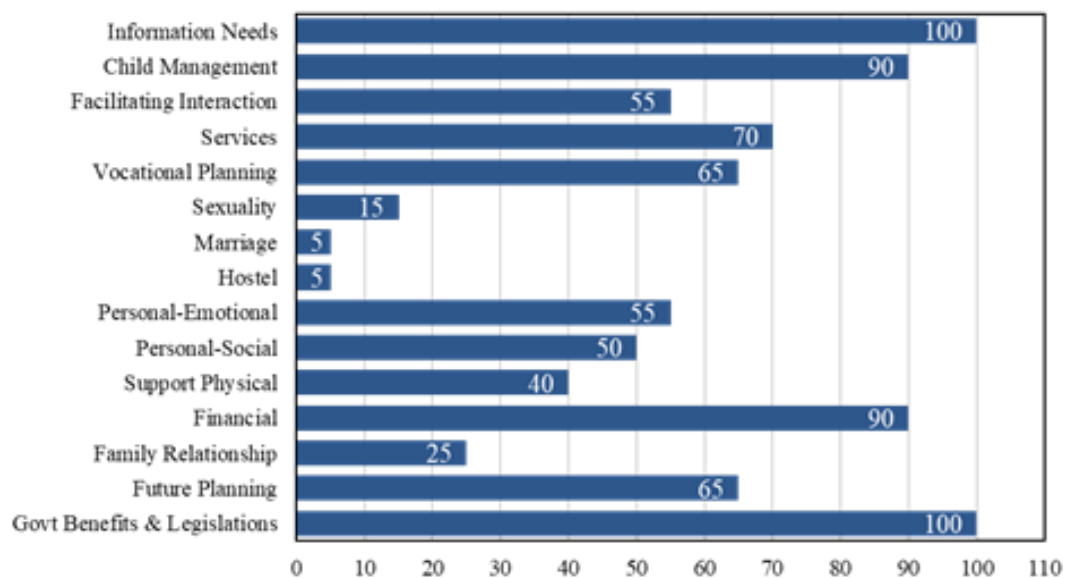


Fig 1: Percentage Endorsement of Needs of Parents

The study was designed to assess the needs of parents having IDD children under 15 domains.

Figure 1 shows percentage of responses of parents relating to each of the domains and needs identified in the NIMH-FAMNS (Parents) Schedule. The top percentage level was observed in the domain of "information-condition" of their child and Govt benefits and legislation (100%). All the parents of Intellectually and Developmentally Disabled Child showed a strong need in the domain of "information condition" and "Govt benefits and legislation". Regarding "information" area parents wanted to know more about the disability condition of their child, assessment report, expected achievement, adverse sequelae, reading material and nutrition of their child. They wanted to know what the Government is doing for the children with IDD and their families which was expressed in the last domain of NIMH-FAMNS Schedule "Govt Benefits and Legislation. 90% parents expressed their strong needs in the domain of "child management" and "financial help". The needs related to "services" (70%), "vocational planning" (65%) and "future planning" (65%) do not however figure as front rank needs. Mostly parents show less concerns in the domain of "personal-social" (50%) and "personal-emotional" needs (55%). It is unquestionably the case for Indian parents that

their children come before their own needs, as was aptly demonstrated by the findings of the study. The needs for "support-physical" and "family relationships" were expressed by 40% and 25% parents respectively. The lowest endorsement of needs was expressed in the domain of "sexuality", "marriage" and "hostel" by 15%, 5% and 5% parents respectively. Therefore, by analysing parents' needs with the help of NIMH Family Needs Schedule, the findings of the study indicated that parents having IDD children reported significantly greater needs in the area of information-condition and Govt benefits followed by child management, financial help and services available for their child. The findings of the study also indicated that mothers of IDD children showed more needs in the domain of child management and information condition; while fathers expressed needs in the domain of financial help, vocational planning and Govt benefits.

6. Conclusion

The present study was undertaken with the objective to assess the needs of parents having children with Intellectual and Developmental Disability. Given that parents strongly expressed their needs in the current study, it is necessary to examine the current, primarily child-centred programmes and

realign them to address the needs of parents of children with Intellectual and Developmental Disabilities. This study contributes to a better understanding of parents' needs from their perspectives, as well as their descriptions of the strengths and gaps of the present system. A deeper comprehension of parents' demands could help communities execute government policies and service models more effectively and provide financial assistance to families with poor socioeconomic status.

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