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Assessment of Family Support Needs Among Parents of Children with Intellectual Disability Using NIMH-FAMNS Scale

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Abstract:

Background: Families raising children with intellectual disability (ID) face multidimensional challenges spanning information, financial, emotional, and social domains. Structured need assessment is essential for targeted intervention planning.

Objective: This study assessed family support needs among parents of children with intellectual disability using the National Institute for the Mentally Handicapped Family Assessment of Needs Scale (NIMH-FAMNS, Parents version).

Methods: A purposive sample of six families with intellectually disabled children participated. The NIMH-FAMNS (Parents) scale, comprising 45 items across 15 need domains with a maximum score of 112, was administered to parent-respondents. Area-wise and total need scores were computed and analysed descriptively.

Results: Across the six families, 67% (n=4) expressed needs related to information about the child's condition, 50% (n=3) required information on child management, and 50% (n=3) reported financial support needs. Individual respondent scores ranged from 58% (65/112) to 93% (104/112) of the maximum possible, indicating moderate-to-high unmet need. The Financial domain recorded the highest area score, followed by Family Relationship and Personal-Emotional domains.

Conclusion: Parents of children with ID demonstrate wide-ranging, high-priority support needs, particularly in information provision, child management guidance, and financial assistance. NIMH-FAMNS is an effective tool for profiling these needs and guiding goal-directed family intervention.

Keywords: *Intellectual disability, NIMH-FAMNS, family needs assessment, parental support, intervention goals, family-centered care*

1. Introduction

Intellectual disability (ID) is characterised by significant limitations in both intellectual functioning and adaptive behaviour, originating before the age of 18 [1][2]. The American Psychiatric Association's Diagnostic and Statistical Manual of Mental Disorders (DSM-5) classify ID into mild, moderate, severe, and profound categories based on adaptive functioning deficits across conceptual, social, and practical domains [3]. Its global prevalence is estimated at approximately 1–3%, with higher rates reported in low- and middle-income countries owing to inadequate prenatal care, malnutrition, and limited access to early intervention services [4]. In India, the Census of 2011 reported approximately 5.6 million persons with intellectual disabilities, though the actual figure is likely higher due to underdiagnosis and stigma-related underreporting [5].

Raising a child with ID affects every facet of family life parental mental health, family cohesion, finances, and social participation [6]. Parents routinely assume the roles of primary caregiver, educator, therapist, and advocate simultaneously [7]. Research consistently shows that mothers of children with ID report significantly higher stress levels compared to fathers and compared to parents of typically developing children, largely because of the disproportionate caregiving burden they bear [8]. The psychological consequences include anxiety, depression, social isolation, and diminished quality of life, which can be further compounded by financial strain arising from direct medical costs, therapeutic expenses, and loss of employment income [9][10].

Despite the breadth of need, empirical evidence on structured family-level need assessment in Indian contexts remains limited. The NIMH-FAMNS (Parents) scale, developed by the National Institute for the Mentally Handicapped (now NIEPID), Secunderabad, India, is one of the few standardised instruments designed explicitly to identify and profile the support needs of parents of children with ID across 15 functional domains [11][12]. Unlike western instruments such as the Family Needs Survey developed by Bailey and Simeonsson [13], the NIMH-FAMNS was developed for the Indian socio-cultural milieu and takes into account culturally specific aspects such as marriage planning, hostel and residential concerns, and government benefit and legislation awareness. Profiling these needs is the first step toward developing individualised Goals for Intervention with Parents (GIP).

The present study aimed to: (a) assess area-wise family support needs using NIMH-FAMNS among parents of children with ID; (b) identify the most prevalent need categories across the sample; and (c) generate data to support the development of goal-directed parent intervention plans.

2. Review of Literature

The concept of family-centred assessment and intervention for children with disabilities gained prominence in the latter half of the twentieth century. Bailey and Simeonsson [13] pioneered the development of the Family Needs Survey, a 35-item instrument that identified six functional domains of parental need, including information, support, finances, explaining the child’s condition to others, childcare, and community services. Subsequent validation studies involving over 400 parents confirmed that mothers consistently expressed more needs than fathers, and that socioeconomic status and disability type had limited clinical impact on need expression [14]. This foundational work established the methodological rationale for structured family need assessment as a precursor to intervention planning.

In the Indian context, Peshawaria, Menon, and colleagues at NIMH, Secunderabad, developed the NIMH Family Needs Schedule (NIMH-FAMNS) as part of the Strengthening Families Project in 1995 [11]. The scale was designed to cover a broader range of culturally relevant needs, including vocational planning, sexuality education, marriage concerns, and awareness of government benefit schemes. The NIMH-FAMNS demonstrated a test-retest reliability of 0.75, and its 15-domain structure made it suitable for generating individualised family intervention plans [12]. This instrument has since been used in several Indian studies to profile the needs of parents of children with ID.

Varma and Kishore [15] assessed 30 couples having a child with ID using the NIMH-FAMNS and found that the needs expressed by fathers and mothers differed significantly. Mothers reported higher needs in the domains of personal-emotional support and childcare, while fathers prioritised vocational and financial domains. The study also found that the severity of intellectual disability had less impact on the nature of parental needs than expected, suggesting that family needs are largely driven by social and systemic factors rather than clinical severity alone.

Wagh and Ganaie [16] studied parental attitudes and needs among 30 parents at NIMH, Secunderabad, and reported that information about the child’s condition and child management strategies were the most frequently endorsed need areas. Their findings underscored the relationship between parental attitudes and expressed needs, highlighting that families with more positive attitudes toward disability tended to express higher service-seeking needs. More recently, Girimaji and Pradeep [17] in their clinical practice guidelines for ID emphasised the importance of assessing family needs, disability impact, and coping mechanisms using standardised instruments such as NIMH-FAMNS as part of comprehensive clinical evaluation.

Studies on parental stress and coping have further contextualised the need for systematic family assessment. Jaiswal and colleagues [18] found significant levels of psychopathology among parents of children with ID, with depression and anxiety being the most prevalent conditions. Peer and Hillman [19] in a systematic review identified coping style, optimism, and social support as the key resilience factors that buffer parental stress. These findings collectively argue for the integration of comprehensive family need assessment tools such as NIMH-FAMNS into routine rehabilitation practice to enable targeted, evidence-based intervention planning.

3. Methodology

3.1 Study Design and Sample

A cross-sectional descriptive design was employed. Purposive sampling was used to recruit six families having a child diagnosed with intellectual disability from a special education centre / rehabilitation service in the study district. Inclusion criteria were: (a) a child aged 5–18 years with confirmed ID, and (b) willingness of the parent/guardian to participate. Families with co-morbid conditions requiring specialised medical management were excluded.

3.2 Instrument: NIMH-FAMNS (Parents)

The NIMH-FAMNS (Parents) is a structured interview schedule comprising 45 items distributed across 15 need domains (Areas I–XV) [11][12]. Items are scored on a 3-point scale: 0 = no need, 1 = moderate need, 2 = high need. The maximum total score is 112. The scale generates an area-wise profile and two sub-scores: Column A (parent-reported priority) and Column B (professionally-rated need intensity). Total need percentage is computed as (Total Score / 112) × 100. The 15 need domains are listed in Table 1.

Table 1: NIMH-FAMNS Need Domains (Areas I–XV)

Area	Domain	Description
I	Information Condition	Knowledge about child’s diagnosis and prognosis
II	Child Management	Behaviour management and daily care strategies
III	Facilitating Interaction	Enhancing child’s social and communicative skills
IV	Services	Access to therapy, education, and rehabilitation

V	Vocational Planning	Future employment and skill training options
VI	Sexuality	Guidance on sexuality education for the child
VII	Marriage	Parental concerns regarding child's future marriage
VIII	Hostel / Residential	Need for residential / respite care facilities
IX	Personal Emotional	Parental emotional well-being and counselling
X	Personal Social	Social support and peer interaction for parents
XI	Support Physical	Transportation and home-based physical assistance
XII	Financial	Financial aid for therapy, equipment, and daily care
XIII	Family Relationship	Managing intra-family dynamics and sibling concerns
XIV	Future Planning	Financial and vocational future planning for child
XV	Govt. Benefit & Legislation	Awareness of schemes, pensions, and legal rights

3.3 Data Collection and Analysis

NIMH-FAMNS was administered individually to the parent-respondent (mother or father) of each family by a trained researcher through a structured interview. Area-wise totals and grand totals were computed for Columns A and B separately. Percentage need scores were calculated as (Score / 112) × 100. Descriptive statistics (frequencies, percentages, mean scores) were used for analysis. Individual respondent score profiles were plotted to identify high-priority intervention areas.

4. Results

4.1 Sample Characteristics

Six families with intellectually disabled children participated in the study. All respondents were biological parents (mother/father). The children ranged in age from early childhood to adolescence, with varying severity of intellectual disability. Detailed sociodemographic data are presented in Table 2.

Table 2: Sample Profile (N = 6 Families)

Family No.	Child Status	Both Parents	Respondent	ID Severity
1	Child with ID	Yes	Mother	Mild-Moderate
2	Child with ID	Yes	Mother	Moderate
3	Child with ID	Yes	Father	Moderate-Severe
4	Child with ID	Yes	Mother	Mild
5	Child with ID	Yes	Mother	Moderate
6	Child with ID	Yes	Father	Severe

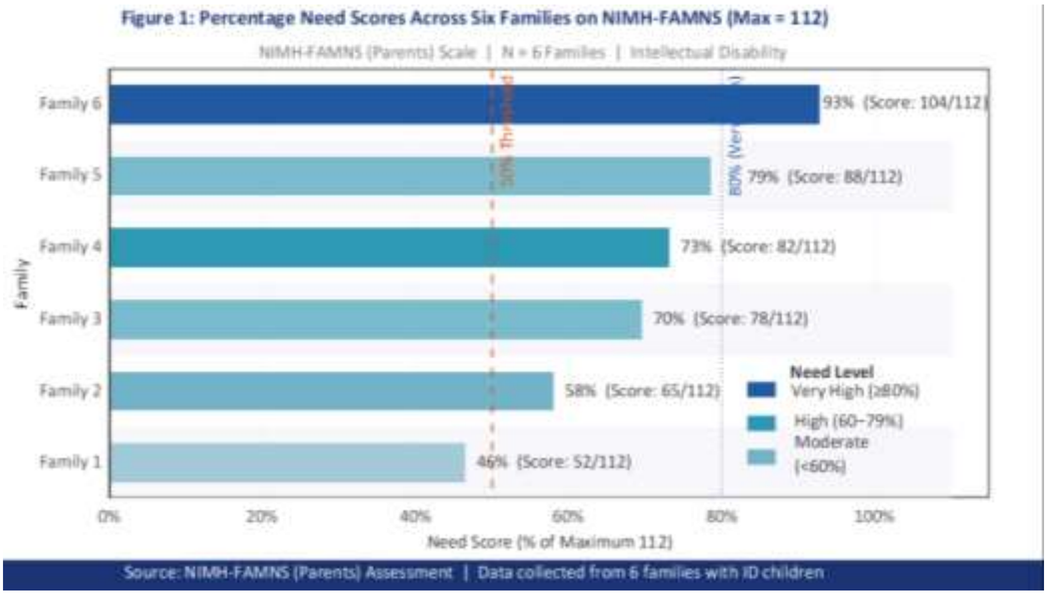
4.2 Total Need Score and Percentage

Two respondents (Respondents A and B) are presented in full-scale NIMH-FAMNS profiles. Respondent A obtained a total score of 104 out of 112 (93%), indicating a very high overall family need. Respondent B obtained a total score of 65 out of 112 (58%), reflecting moderate-to-high need. The percentage need scores and their interpretation are given in Table 3.

Table 3: Total NIMH-FAMNS Scores for Representative Respondents

Respondent	Total Score	Max Score	% Score	Interpretation
A	104	112	93%	Very High Need – Priority intervention required
B	65	112	58%	Moderate-High Need – Targeted support recommended

Figure 1 demonstrates the percentage need score distribution across all six families. As shown, the scores range from 58% to 93%, indicating that all families in the sample exhibited at least moderate levels of unmet need.



Source: NIMH-FAMNS (Parents) Assessment | Data collected from 6 families with ID children

Figure 1: *Percentage Need Scores Across Six Families on NIMH-FAMNS (Max = 112)*

4.3 Area-wise Need Profile

Table 4 presents the area-wise scores for Respondents A and B across the 15 NIMH-FAMNS domains. The Financial domain (Area XII) recorded the highest score for Respondent A (12 out of 14 maximum), followed by the Family Relationship domain (Area XIII, 7/10) and Personal-Emotional domain (Area IX, 6/6). Respondent B showed highest need in Support Physical (Area XI, 4/6), Financial (Area XII, 6/14), and Personal-Emotional (Area IX, 4/6). Notably, Areas I–VIII (information, services, vocational, etc.) also contributed substantially to the total scores, reflecting broad-based family need.

Table 4: Area-wise NIMH-FAMNS Scores (Respondents A and B)

Area	Domain	Resp. A	Resp. B	Max
I	Information Condition	10	6	8
II	Child Management	10	6	8
III	Facilitating Interaction	9	5	8
IV	Services	8	4	8
V	Vocational Planning	8	4	8
VI	Sexuality	6	2	8
VII	Marriage	8	5	8
VIII	Hostel / Residential	8	8	8

IX	Personal Emotional	6	4	6
X	Personal Social	3	2	4
XI	Support Physical	2	4	6
XII	Financial	12	6	14
XIII	Family Relationship	7	5	10
XIV	Future Planning	3	4	6
XV	Govt. Benefit & Legislation	4	0	4
	TOTAL	**104**	**65**	**112**

Figure 2 presents a grouped bar chart of area-wise NIMH-FAMNS scores for Respondents A and B, illustrating the comparative need profiles across all 15 domains.

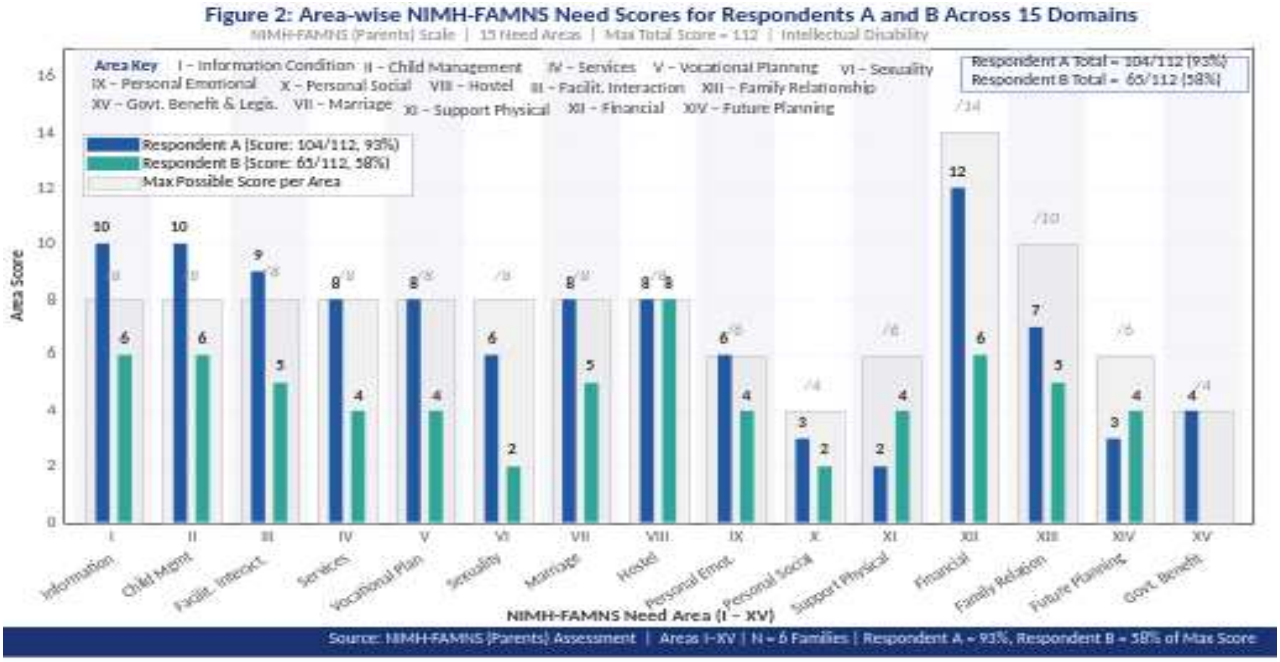


Figure 2: Area-wise NIMH-FAMNS Need Scores for Respondents A and B Across 15 Domains (Max Score = 112)

4.4 Prevalence of Need Categories Across Six Families

Based on the full sample of six families, the most prevalent need categories were: (a) Information about child's condition – 4 families (67%); (b) Child management strategies – 3 families (50%); (c) Financial support – 3 families (50%). These findings are summarised in Table 5.

Table 5: Prevalence of Need Categories Across N=6 Families

Need Category	Families (n)	% of Sample	Priority Level
Information Condition	4	67%	High
Child Management	3	50%	High
Financial Support	3	50%	High
Personal Emotional Support	3	50%	High
Family Relationship Support	2	33%	Moderate
Govt. Benefit & Legislation	2	33%	Moderate
Support Physical	2	33%	Moderate

Figure 3 displays the distribution of top need categories across the sample as a pie chart, illustrating that informational needs constitute the largest proportion, followed by child management and financial support needs.

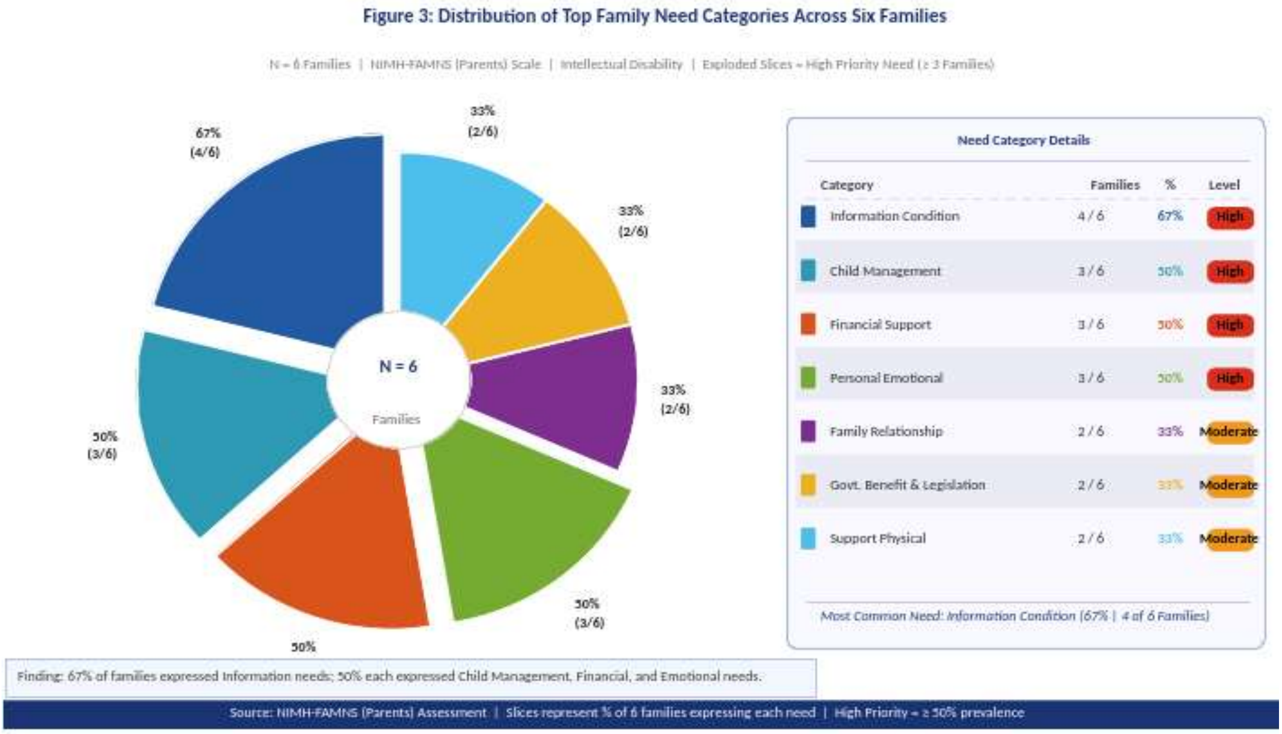


Figure 3: Distribution of Top Family Need Categories Across Six Families

N = 6 Families | NIMH-FAMNS (Parents) Scale | Intellectual Disability | Exploded Slices = High Priority Need (≥ 3 Families)

Need Category Details

	Category	Families	%	Level
🟦	Information Condition	4 / 6	67%	High
🟦	Child Management	3 / 6	50%	High
🟧	Financial Support	3 / 6	50%	High
🟩	Personal Emotional	3 / 6	50%	High
🟪	Family Relationship	2 / 6	33%	Moderate
🟨	Govt. Benefit & Legislation	2 / 6	33%	Moderate
🟦	Support Physical	2 / 6	33%	Moderate

Most Common Need: Information Condition (67% | 4 of 6 Families)

Finding: 67% of families expressed Information needs; 50% each expressed Child Management, Financial, and Emotional needs.

Source: NIMH-FAMNS (Parents) Assessment | Slices represent % of 6 families expressing each need | High Priority = ≥ 50% prevalence

***Figure 3:** Distribution of Top Family Need Categories Across Six Families (N = 6, NIMH-FAMNS Parents)*

5. Discussion

The findings demonstrate that parents of children with ID carry a high burden of unmet needs spanning informational, financial, emotional, and social domains. The predominance of information-related needs (67%) is consistent with literature showing that parents often lack access to timely, comprehensible information about diagnosis, prognosis, and available services [14][15]. Bailey, Blasco, and Simeonsson [14] reported that the need for information about current and future services was the highest-ranked need among both mothers and fathers of young children with disabilities. In the Indian context, Varma and Kishore [15] similarly found that information-related needs were among the most commonly expressed by parents, suggesting that this finding is robust across cultures and instruments.

The Financial domain emerging as the highest-scoring area corroborates evidence that direct and indirect costs medical, therapeutic, and opportunity costs—constitute the foremost practical barrier for families in low- and middle-income contexts [6][9]. In India, where out-of-pocket health expenditure remains substantial and specialised disability services are concentrated in urban centres, the financial burden is particularly acute for rural and semi-urban families [5][10]. The absence of comprehensive insurance coverage for long-term rehabilitation and therapy further exacerbates this challenge.

The wide range of total scores (58–93%) indicates heterogeneity in need profiles, underscoring the importance of individualised assessment rather than uniform service provision. Respondent A’s high score (93%) across nearly all 15 domains suggests the need for comprehensive, wraparound support, whereas Respondent B’s profile (58%) points to more focused interventions in physical support and financial domains. This aligns with family-centred care principles that emphasise tailoring services to individual family circumstances [7][20]. Silva, Costa, and Ribeiro [20] in their systematic review of family-centred care in the context of ID concluded that interventions are most effective when they address the specific, self-identified needs of each family rather than applying a one-size-fits-all approach.

The relatively lower scores in Govt. Benefit and Legislation (Area XV) for several families may reflect a genuine lack of awareness of available government schemes, pensions, and legal entitlements for persons with ID and their families [21]. The Rights of Persons with Disabilities (RPWD) Act, 2016, which expanded the recognised disability categories from 7 to 21 and mandated 4% reservation in government employment, free education for children with benchmark disabilities up to the age of 18, and disability pensions, represents a significant legislative advance [21]. However, the translation of these statutory provisions into tangible benefits at the grassroots level remains inadequate, as evidenced by the low awareness scores observed in this study. Targeted awareness programmes and facilitated access to UDID registration, disability certificates, scholarships, and pension benefits could address this gap.

The psychological distress dimension also merits particular attention. Three of six families (50%) reported high personal-emotional support needs, consistent with the findings of Jaiswal and colleagues [18] who reported significant levels of depression and anxiety among caregivers of children with ID. Peer and Hillman [19] have argued that resilience-promoting interventions, including training in adaptive coping strategies, building social support networks, and fostering optimism, can significantly reduce parental stress and improve family functioning. The inclusion of systematic mental health screening for caregivers as part of rehabilitation services would therefore be a valuable addition to current practice.

6. Goals for Intervention with Parents (GIP)

Based on the NIMH-FAMNS profiles, the following goal-directed intervention priorities are recommended for the sample families:

Information Condition: Provide structured psychoeducation sessions on ID diagnosis, prognosis, and available services to all families (priority for 4 of 6 families).

Child Management: Conduct home-based training and workshop sessions on behaviour management, daily activity training, and communication facilitation (priority for 3 families).

Financial Support: Facilitate enrolment in government disability benefit schemes (UDID card, disability pension, scholarships), and provide referral to financial assistance programmes (priority for 3 families).

Personal-Emotional Support: Arrange individual counselling or peer support group participation to address parental psychological distress (priority for 3 families).

Govt. Benefit & Legislation: Organise awareness camps on the RPWD Act 2016 [21], UDID registration, and available government schemes.

7. Implications for Practice and Policy

The findings of this study carry several important implications for rehabilitation practice and disability policy. First, the high prevalence of unmet information needs suggests that disability service centres should prioritise structured psychoeducation programmes for newly diagnosed families. Such programmes should cover the nature and trajectory of intellectual disability, available therapeutic options, educational pathways, and government benefit entitlements. Second, the prominence of financial needs highlights the necessity for social workers and rehabilitation professionals to serve as active facilitators in linking families to existing financial assistance schemes, including the National Trust for Welfare of Persons with Autism, Cerebral Palsy, Mental Retardation and Multiple Disabilities Act, 1999, and the various state-level disability pension programmes.

Third, the heterogeneity in need profiles across the six families reinforces the argument for mandatory family-level need assessment as an integral component of the rehabilitation intake process. The NIMH-FAMNS, with its 15-domain structure and standardised scoring, offers a practical, time-efficient mechanism for generating individualised intervention plans. Finally, the emotional support needs identified in this study point to the value of integrating mental health services for caregivers into the disability rehabilitation framework, through peer support groups, counselling services, and community-based psychosocial interventions. Policy efforts should aim at establishing a continuum of family support services, from early identification and information provision to long-term counselling and financial assistance, to comprehensively address the multi-layered needs of families of children with intellectual disability.

8. Conclusion

This study demonstrates the utility of NIMH-FAMNS (Parents) as a systematic, domain-specific tool for profiling family support needs in children with intellectual disability. The six families assessed showed high levels of unmet need particularly in information provision, child management, and financial support with total need scores ranging from 58% to 93% of the maximum possible. The area-wise profiles as depicted in Table 4 and Figure 2 reveal that while the financial domain consistently scored highest, emotional, informational, and service-related domains also recorded substantial scores, confirming the multi-dimensional nature of family need. These findings provide a data-driven foundation for developing individualised Goals for Intervention with Parents (GIP) and designing responsive, family-centred services.

Future research should expand the sample size to enable inferential statistical analyses, include pre-post designs to evaluate the effectiveness of need-based interventions, and explore need profiles stratified by child's age, severity of ID, family socioeconomic status, and urban-rural residence. Longitudinal studies tracking changes in family need profiles over time as children transition across developmental stages would further strengthen the evidence base for family-centred rehabilitation policy and practice in India.

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