



Needs Assessment of Families with a Person with Intellectual Disability

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ABSTRACT

Background: Intellectual disability is a condition characterized by arrested or incomplete development of the mind. Individuals with intellectual disability (PWID) are often highly dependent on their families or caregivers, particularly their parents. To improve mental health services and overall quality of life, assessing the needs of families caring for PWID is a crucial step. It is also important to explore related variables such as family efficacy, family resilience, pathways to care, the stigma experienced by caregivers, and their help-seeking behaviour, especially in the context of a tertiary care setting in this region. **Objectives:** The study aimed to assess the needs of families of persons with intellectual disability, evaluate family efficacy and resilience, examine pathways to care and caregiver-experienced stigma, and explore associations among these variables. **Method:** This was a cross-sectional, institution-based descriptive study. Using criteria-based sampling, 37 parents of PWID who attended the outpatient department (OPD) of a tertiary care hospital were recruited. All participants lived with the PWID, met the inclusion and exclusion criteria, and provided written informed consent. The diagnosis of mental retardation was confirmed according to ICD-10 criteria. Data collection tools included the Socio-demographic and Clinical Data Sheet, NIMH Family Needs Schedule, NIMH Family Efficacy Scale, Family Interview Schedule (FIS), Resilience Scale for Adults (RSA), and Goldberg's Pathways to Care Instrument. **Results:** The study found that parents of PWID expressed high levels of needs and family efficacy. Families with higher resilience reported greater needs, indicating that resilience may increase awareness or articulation of needs. A negative association was found between caregiver stigma and family efficacy, with higher stigma linked to lower efficacy. Overall, families showed above-average resilience but experienced a high degree of stigma.

Keywords: Intellectual disability, mental retardation, family needs, family efficacy, family resilience, caregiver stigma

INTRODUCTION

Intellectual disability (ID), formerly known as mental retardation (MR), is increasingly recognized under more respectful and accurate terminology, although both terms are still used interchangeably in scientific literature (Salvador-Carulla & Saxena, 2009). ID is defined as a condition of arrested or incomplete

development of the mind, particularly evident during the developmental period, and is characterized by impairments in cognitive, language, motor, and social functioning (WHO, 1992). Diagnostic criteria include significantly sub-average intellectual functioning ($IQ \leq 70$) along with limitations in adaptive behavior across various domains such as communication, self-care, and social skills (Census of India, 2011). Historically, terminology has evolved from terms like "idiocy" and "feeble-mindedness" to "mental deficiency" and finally to "intellectual disability" (Goodey, 2005; Mercer, 1992). The classification of ID is commonly done using psychological (IQ-based), educational (functional), and medical (etiological) criteria, with levels ranging from mild to profound (Agarwal & Sharma, 2002). The prevalence of ID varies by region and methodology,

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with global rates in children ranging from 3–14 per 1,000 and Indian estimates around 20 per 1,000 in the general population (King et al., 2009; Jayachandran, Gadkari, & Mishra; Panda, 1999). Ongoing debates remain regarding its classification in international systems, with the World Psychiatric Association viewing it as a meta-syndrome and the AAIDD framing it as a disability to be included in the International Classification of Functioning (Salvador-Carulla & Bertelli, 2007; AAIDD, 2010).

Countries like India parents and family members largely have been involved in the basic care of their mentally retarded child or member. Care giving to a person or child with intellectual disability is not an easy task it's challenging and needs a specific skills and persistent efforts. Understanding the unique needs of Indian families having a mentally retarded person is required to work with this population.

Needs of Families: The needs expressed by families of children with intellectual disabilities are diverse and vary significantly across individuals and households. Some families primarily require emotional and informational support, while others face pressing needs related to financial assistance, access to services, or behavioral management strategies. The presence of a mentally challenged child often has both positive and negative impacts on the family, but many parents report experiencing initial emotional distress—including shock, denial, and anger—before reaching acceptance (Rao, 2008). Consequently, these families require tailored support to help them navigate the unique challenges they face. Key areas of need include alleviating parental stress, maintaining family stability, managing maladaptive behaviors in children, identifying appropriate placement and intervention options, and planning for the child's long-term future. Singh et al. (2008) reported that approximately 25% of families experienced negative impacts, particularly related to the physical care of the child and financial strain. Many parents struggle to allocate adequate resources for their child's care, training, and other household needs. Additional commonly expressed needs include better understanding of the child's condition, guidance on management, access to current and future services, educational and vocational planning, societal inclusion, legal rights, government support, and relief from caregiving burdens. These complex and multifaceted needs highlight the urgent requirement for comprehensive support programs designed to empower and assist families of children with intellectual disabilities.

Family Efficacy: Self-efficacy, or the belief in one's competence within a specific domain, has emerged as a crucial variable influencing parental outcomes, particularly in the context of raising children with

intellectual or developmental disabilities (Bandura, 1989). Parenting self-efficacy has been linked to lower psychological distress and better adaptation, especially when facing stressors such as child behavior problems (Coleman & Karraker, 1998; Taylor, 1983). Research indicates that child-related variables like behavior challenges and caregiving demands can impact parental self-efficacy, which in turn influences stress levels and perceptions of parenting competence (Frey et al., 1989; Heller, 1993). Systems theory suggests that caregiver responses to challenging behaviors may inadvertently sustain those behaviors, highlighting the importance of self-efficacy in mediating outcomes for both parent and child (Hastings & Brown, 2000). *Family Resilience:* Resilience refers to a family's or individual's ability to recover and adapt positively despite adversity. It is not merely about resistance but about growth, adaptability, and the capacity to regain mental well-being after significant stress (Garmezy et al., 1984; Masten, 1994; Rutter, 1985). Resilience is fostered in structured, caring family environments with high expectations and social support systems, enabling individuals to thrive despite biological, psychological, or environmental challenges (Gordon, 1995; Benard, 1991). For families raising children with intellectual disabilities, resilience serves as a critical buffer, promoting emotional stamina, collaborative coping strategies, and psychological well-being. Studying resilience among these families is essential for developing effective interventions and enhancing long-term outcomes.

Experience of Stigma by the Families: Stigma refers to society's negative perceptions and evaluations of certain conditions, often resulting in socially constructed identities that are tainted or devalued (Ablon, 2002). Intellectual disability is among several conditions, including leprosy, cancer, and mental illness, that are subject to societal stigma, which manifests in various forms such as shame, secrecy, blame, isolation, and discrimination (Byrne, 2000; Mak & Cheung, 2008). Importantly, this stigmatization extends beyond the individual with the condition to include family members and caregivers, who often experience what is termed “courtesy stigma” or associative stigma (Hebl & Mannix, 2003; Schulze, 2000). Such stigma can lead to social exclusion, limited access to housing and employment, and delayed help-seeking behavior due to fear of labelling and marginalization (Link et al., 1997; Sartorius, 1999). Families may internalize negative societal perceptions, contributing to emotional burden, secrecy, and withdrawal from social engagement, all of which hinder effective caregiving and support for individuals with intellectual disability.

Need for the Study: In India, an estimated 2% of the population is affected by intellectual disability (Shalini, 1982), with prevalence rates ranging widely across

different regions. Individuals with intellectual disability are heavily reliant on familial care, particularly from parents, making families a central focus in both support and intervention frameworks. Despite this, there is a paucity of research on the comprehensive needs of these families, especially regarding variables such as family efficacy, resilience, and perceived stigma. Unmet family needs can adversely affect treatment outcomes and the overall quality of life for both the individual with disability and their caregivers. Moreover, the stigma associated with intellectual disability is comparable to that of severe mental illnesses, which significantly delays help-seeking and appropriate intervention (Link et al., 1989; Crisp et al., 2000). Therefore, assessing the perceived stigma, coping strategies, and psychosocial dynamics within families is essential for designing effective, family-centered care models. This study aims to fill this research gap by examining these variables within a tertiary care setting in the regional context.

OBJECTIVES

The objectives of the present study are to assess the needs of families who have a person with intellectual disability (PWID), evaluate the level of family efficacy within these families, examine the degree of family resilience, measure the extent and nature of stigma experienced by these families, and explore the associations among these key variables.

METHODS AND MATERIALS

The present study is a cross-sectional, institution-based descriptive research conducted at the Department of Psychiatric Social Work, Institute of Psychiatry, Kolkata. The study on the individuals diagnosed with mental retardation according to ICD-10 criteria for mental retardation (WHO, 1992) by a consultant psychiatrist and attending the outpatient department (OPD) at the Institute of Psychiatry, along with their family members. A criteria-based sampling method was employed, and a total of 37 participants were included in the study. Parents (either mother or father) of persons with intellectual disability who were living with them, and who consented to participate, were recruited, subject to inclusion and exclusion criteria.

The inclusion criteria for persons with intellectual disability required that, be between 5 to 60 years of age, of either sex, able to comprehend and speak fluently in Bengali, Hindi, or English, and provide written consent to participate. Family members were eligible if they were between 18 to 65 years of age, of either sex, able to comprehend and speak fluently in Bengali, Hindi, or English, resided in the same household as the person with intellectual disability, and provided written consent. Exclusion criteria for persons with intellectual disability included the presence of any comorbid major mental illness, major physical disability, or substance

dependence (except nicotine). Family members were excluded if they had any psychiatric disorder, major medical illness, physical disability, substance dependence (except nicotine), or had not given consent to participate in the study.

The study employed five tools for data collection:

A Socio-demographic Data Sheet, developed by the researcher, gathered information about both the person with intellectual disability (PWID) and their caregivers, including age, sex, education, occupation, income, illness duration, and family structure.

The NIMH Family Needs Schedule (NIMH-FAMNS), adapted from Peshawaria et al. (1995), was used to assess parental needs across 15 domains using a 3-point scale, with higher scores indicating greater need; it demonstrated a test-retest reliability of 0.75.

The NIMH Family Efficacy Scale (NIMH-FES), developed by Peshawaria et al. (2000), measured family strengths and coping across 15 themes, scored on a 3-point scale, where higher scores reflected better efficacy.

The Resilience Scale for Adults (RSA), developed by Friborg et al. (2003), consisted of 33 items assessing five dimensions—personal competence, social competence, family cohesion, social resources, and structured style—using both positively and negatively phrased items, with several requiring reverse scoring; the scale showed good reliability with Cronbach's alphas ranging from 0.67 to 0.90.

Lastly, the Stigma Section of the Family Interview Schedule (FIS), used in WHO's ISOS study and later adapted by Thara and Srinivasan (2000), assessed caregiver experiences of stigma through 14 items rated on a 4-point scale, addressing areas such as social embarrassment, fear of disclosure, and challenges with community acceptance.

RESULTS

Socio-demographic Background

In the present study, the mean age of PWID was 13.70 $\pm$ 6.07 years, with 89% under 18, reflecting the developmental onset of intellectual disability. Males slightly outnumbered females (51.35%), indicating near-equal gender distribution. Most PWIDs (89.19%) were unmarried, aligning with their age and condition. Educationally, 62.16% had primary education, and most attended formal integrated schools—an unusual finding compared to national trends, where children with disabilities are largely excluded from regular education. Additionally, 75.68% were students, 18.92% unemployed, and none reported income, consistent with their young age and dependency.

Table 1 Socio-demographic Profile of Persons with Intellectual Disability (N = 37)

Variables	Variables Category	Mean $\pm$ SD / N (%)
Age in Years (Range 6 - 33)		13.70 $\pm$ 6.07
Sex	Male	19 (51.35)
	Female	18 (48.65)
Marital Status	Married	4 (10.81)
	Unmarried	33 (89.19)
Education	No formal education	7 (18.92)
	Primary	23 (62.16)
	Secondary	7 (18.92)
Type of education	Integrated Education	23 (62.16)
	Special Education	7 (18.92)
	Home based	7 (18.92)
Employment status	Self-employed	0
	Full time employed	0
	Part time employed	0
	Unemployed	7 (18.92)
	Student	28 (75.68)
	House wife	2 (5.41)
Monthly Income in Rs.		00.00

Clinical Profile

In the present study, a majority (64.86%) of PWIDs had mild intellectual disability, followed by moderate (24.32%) and severe (10.81%), which contrasts with findings from Wagh & Ganaie and Singh, where moderate and severe levels were more prevalent. The mean age of diagnosis was 4.61 years, with about 78% diagnosed by age six, possibly due to improved awareness and early identification efforts in recent years. The average treatment duration was 5.63 years, with 1.35 years at the current institution. Most PWIDs (59.46%) were on medications, with only 16.22% reporting side effects, likely due to co-morbid conditions. Epilepsy (35.14%) was the most common co-morbidity, followed by psychiatric disorders (16.22%), physical disability (5.41%), and hearing impairment (2.70%), differing from Singh's study where 91% had co-morbidities. A majority (62.16%) had no family history of intellectual disability, aligning somewhat with Singh's findings. The average number of hospitalizations was low (0.43), and nearly half (51.35%) were not receiving psychosocial interventions, potentially due to limited service availability or lack of awareness.

Table 2 Clinical Profile of Persons with Intellectual Disability (N = 37)

Variables	Variables Category	Mean $\pm$ SD / N (%)
Level of disability	Mild	24 (64.86)
	Moderate	9 (24.32)
	Sever	4 (10.81)
	Profound	0
Age of diagnosis in years		4.61 $\pm$ 5.57
Duration of treatment in years		5.63 $\pm$ 5.39
Treatment duration in IOP in years		1.35 $\pm$ 1.79
On medication	Yes	22 (59.46)
	No	15 (40.54)
Side effects of medicines	Yes	6 (16.22)
	No	31 (83.78)
Associate condition (Co-morbidity)	No	15 (40.54)
	Epilepsy	13 (35.14)
	Physical handicap	2 (5.41)
	Hearing handicap	1 (2.70)
	Psychiatric feature	6 (16.22)
Family history of MR	Yes	14 (37.84)
	No	23 (62.16)
Number of hospitalization (Range 0 – 3)		.43 $\pm$.65
Psychosocial intervention	Yes	18 (48.65)
	No	19 (51.35)

Family Background

In the present study, either parent of the PWID was interviewed, though information for both was collected where available. The mean age of fathers was 44.67 $\pm$ 9.75 years, and for mothers, it was 39.54 $\pm$ 10.49 years. Over one-third (35.14%) of both parents had education up to the primary level; 32.43% of mothers and 24.32% of fathers completed secondary education; 18.92% of mothers and 16.22% of fathers studied up to higher secondary; 13.51% of fathers and 8.11% of mothers were graduates; and 10.81% of fathers and 5.41% of mothers had no formal education. Most fathers (83.78%) were employed, including self-employed (35.14%), full-time (32.43%), and part-time (16.22%) workers, while 10.81% were retired and 5.41% unemployed. In contrast, the majority of mothers (75.68%) were housewives, with 18.92% self-employed and 5.41% full-time employed. Religiously, 78.38% were Hindu and 21.62% Muslim. Most families (70.27%) were urban dwellers, and 62.16% belonged to nuclear families. The mean monthly family income was Rs.7135 $\pm$ 6080, and the average family size was 5.05 $\pm$ 3.18, ranging from 2 to 20 members.

Need of the Families

Table 4 Needs of the Family Members

Need Area	Obtained Score	Max Score
Information condition	7.16 ± 4.10	12
Child management	7.86 ± 4.61	16
Facilitating Interaction	3.65 ± 2.77	10
Services	6.81 ± 3.30	10
Vocational Planning	1.32 ± 0.82	2
Sexuality	1.57 ± 1.50	9
Marriage	1.00 ± 0.91	2
Hostel	1.84 ± 2.08	8
Personal-Emotional	4.70 ± 2.35	8
Personal-Social	1.73 ± 1.52	4
Physical-Support	4.08 ± 2.36	6
Financial	5.62 ± 2.77	10
Family relationship	1.57 ± 1.14	4
Future planning	2.54 ± 1.59	4
Government benefits	2.73 ± 1.28	4
Grand Total Score	63.62 ± 26.73	116

Table 4 presents the mean NIMH-FAMNS scores reported by parents of persons with intellectual disability (PWID) across 15 domains. The overall score (63.62 ± 26.773) indicates a high level of expressed needs. Specifically, high needs were reported in areas such as information about the condition, child management, services, vocational planning, marriage, emotional and physical support, finances, future planning, and government benefits/legislation. Lower needs were noted in facilitating interaction, sexuality, hostel, personal-social, and family relationships.

Family Efficacy

Table 5 Family Efficacy

Area	Mean Score
Sacrifice	2.00 ± .82
Faith in God	2.14 ± .86
Financial	1.95 ± .88
Values	2.24 ± .93
Health	1.86 ± .88
Trust	2.08 ± .89
Acceptance	2.08 ± .76
Crisis	2.08 ± .86
Social Support	2.00 ± .85
Communication	2.08 ± .86
Role & Responsibilities	2.00 ± .81
Optimism	2.00 ± .88
Decisions	1.59 ± .83
Time	2.03 ± .60
Independence	1.84 ± .80
Total Score (Range 1-45)	38.89 ± 15.27

Table 5 presents the mean scores on the NIMH Family Efficacy Scale (NIMH-FES) reported by parents of persons with intellectual disabilities (PWID) across 15 domains. The overall mean score of 38.89 ± 15.27 indicates an above-average level of family efficacy. Domain-wise analysis showed higher efficacy in areas such as sacrifice, faith in God, values, health, acceptance, crisis management, social support, communication, roles and responsibilities, optimism, and time. In contrast, lower efficacy was observed in the domains of finances, trust, decision-making, and independence.

Family Resilience

Table 6 Family Resilience

Area	Obtained Score	Score Range
Social Competency	9.73 ± 1.73	6 - 12
Social Resource	11.11 ± 2.16	7 - 14
Family Cohesion	8.84 ± 1.95	6 - 12
Personal Competence	15.03 ± 2.97	10 - 20
Structure Style	6.24 ± 1.59	4 - 8
Over all	59.32 ± 20.20	33 - 66

Table 6 presents the mean RAS scores reported by parents of persons with intellectual disability (PWID) across five domains. The overall score (69.32 ± 20.20) indicates above-average family resilience. Domain-wise, resilience levels were average in all areas: social competence, social resources, family cohesion, personal competence, and structured style.

Experience of Stigma

Table 7 summarizes the stigma experienced by parents of persons with intellectual disability (PWID) using the Family Interview Schedule – Stigma Items. With a mean score of 19.76 ± 10.17 out of a maximum of 42, the results indicate a high level of perceived stigma. Most items scored high, except for "Effort to keep as secret." Notably, 100% of families reported feelings of grief or depression, 96% felt the need to hide the facts, and 92% sought support from other families with PWID. Many parents felt blamed (78%), ashamed or embarrassed (70%), feared social exclusion (65%), and were concerned about public perception (62%). Additionally, 54% made efforts to keep the disability a secret, and 51% were worried about their child's marriage prospects.

Table 7 Stigma Experienced by the Family

Cortex: 0 = Not at all, 1 = Sometime, 2 = Often, 3 = A lot

Stigma Items	0	1	2	3	1+2+3	%
Felt grief or depression	0	6	11	20	37	100.0
Sought out families with a person with ID	3	14	12	8	34	91.89
Felt it might be your fault	8	10	8	11	29	78.38
Helped other people to understand	8	14	10	5	29	78.38
Spend time worrying	11	5	11	10	26	70.27
Ashamed / Embarrassed about it	11	4	10	12	26	70.27
Neighbours would treat differently	11	4	11	11	26	70.27
Worry that you would be blamed	12	7	11	7	25	67.57
Worry that neighbours would avoid	13	7	11	6	24	64.86
Worried about taking him/her out	14	3	9	11	23	62.16
Explaining to others that he/she is not crazy	14	12	5	6	23	62.16
Marriage	17	5	8	7	20	54.05
Need to hide fact	18	7	7	5	19	51.35
Total Mean Score $\pm$ SD (Range 2 – 42) 19.76 $\pm$ 10.17						

Association between Variables**Table 8 Correlations of Variables**

Variables	Family Needs	Family Efficacy	Resilience	Stigma
Family Needs	1	.021	.779**	.061
Family Efficacy	.021	1	.261	-.434**
Resilience	.779**	.261	1	-.137
Stigma	.061	-.434**	-.137	1

Table 8 summarizes the Pearson correlation among family efficacy, family needs, resilience, and stigma in parents of persons with intellectual disability (PWID). A strong positive correlation was found between family needs and resilience ($r = .779$, $p < .01$), indicating that as family needs increase, resilience also tends to increase.

Family efficacy showed a significant negative correlation with stigma ($r = -.434$, $p < .01$), suggesting that higher efficacy is associated with lower perceived stigma. Other correlations among the variables were not statistically significant.

DISCUSSION**Need of the Families**

Result shows overall needs expressed by the parents of a person with intellectual disability (PWID) were high (very much) which is not very unexpected finding.

Needs expressed by the parents of a person with intellectual disability (PWID) were high (very much) in the various areas - information-condition, child management, services, vocational planning, marriage, personal-emotional, physical support, financial, future planning, government benefit and legislation. This finding is somewhat consistent with the findings of a study by Wagh & Ganaie (2014) where parental needs were knowing about the child, getting information on dealing with the emotions of the child, training for the discipline which is acceptable by the society, training for activities of daily living, services, education, planning their child's future and understanding their child's legal rights and government benefits. There are similarities in findings of other studies (Sahay et al., 2013; Bailey et al., 1992; Bailey and Simeonsson, 1998; Barnhart et al., 1994; Cooper and Allred, 1992; Garshelis and McConnell, 1993; Sexton et al., 1992; Rao, 2008) as well. Upadhyay & Singh (2009) in a study research reported that the needs expressed by the parents of mildly retarded children were more of preventive and adjustment nature whereas parents of moderately retarded children were more concerned with lifelong adjustment and financial security, including government help, of their child.

All persons with intellectual disabilities were living with parents in their family but needs expressed by the parents of a person with intellectual disability (PWID) were low (little) in the areas facilitating interaction, hostel, personal-social and family relationship. This could be because the characteristics of Indian family where members are ready to sacrifice their personal and social comfort of life for other members of the family. Indian family is known for their unique structure and interaction pattern which is non individualistic so it can accommodate a person with disability though some time they are shunted aside. There are very few adequate affordable hostel for this kind of person and also might be with the same reason family has low need for this.

Sexuality for a person with disability is not taken seriously in Indian community. A study by Sahu et al. (2010) reveals that key support providers (professional staff) were not aware about the sexual needs (expression/problem) of 63.3% of residents in a

Halfway Home. It could be because the residents do not disclose it. However the socio-cultural background from where they come from might be one of the important factors which made them unable to express about sexual needs. The age range of the study population could be another reason for not considering sexual needs.

Family Efficacy

Overall the parents of a person with intellectual disability (PWID) were having above average level of family efficacy, higher in the following areas: sacrifice, faith in god, values, health, acceptance, crisis, social support, communication, role & responsibilities, optimism and time. This is an interesting finding generally disability had negative impact on family efficacy. The present study finding is contradictory to a study by Kumar & Mohanty (2011) which reveals that the family efficiency of both fathers and mothers is affected equally due to the presence of a child with mental retardation. Both the parents are adversely affected by the disability of their children.

Parental self-efficacy mediates relations between maternal competence and other psychosocial variables and may play a crucial role in determining parenting behaviour and infant psychosocial risk (Teti & Gelfand, 1991).

Financial, trust, decisions and independence were lower in family efficacy of the parents of a person with intellectual disability (PWID) which is obvious finding.

Family Resilience

Overall the parents of a person with intellectual disability (PWID) were having above average resilience in the all areas of family resilience: social competency, social resource, family cohesion, personal competence, structure style. Parents also affect each others' more resilient adaptations in ways that have not been previously considered (Gerstein, Crnic & Blacher 2009).

Experience of Stigma

In the present study population, overall family members of a person with ID had to experience a high degree of stigma. All family members of study population had the feeling of grief or depression (because of one person was having ID in the family). Various dimension of stigma experienced by the family members of a person with ID. 92% family members sought out families with a person with ID. 78% felt it might be construed as their fault that a person was suffering from ID in the family. 70% family members spent time worrying about their PWID, they felt ashamed/ embarrassed about their PWID and feared that 'neighbours would treat them differently. 68% family members worried that they would be blamed' for a person was having ID in the family. 65% family members worried that neighbour's would avoid them. 62% family members worried about taking him/her

(PWS) outside the home and helped other people to understand that his/her relative (with ID) was not crazy. 54% family members made effort to keep (ID) a secret and 51% were concerned about the marriage of their PWID wards. 96% family members needed to hide the facts. Other studies also reported various aspect of stigma experienced by the family members of a person with ID (Xue Yang, 2015; Mak & Cheung, 2008; Edwardraj et, al. 2010; Ali et, al. 2012).

Association between Variables

Correlation of various studied variables e.g. family efficacy, family needs, resilience and stigma suggests:

Family needs has strong positive correlation ($r = .779$, $p < .01$) with resilience. Means when family is having good resilience they expressed more needs.

Family efficacy has negative correlation ($r = -.434$, $p < .01$) with stigma. Means when family members (parents) were more stigmatized family efficacy decrease.

Rest of the variables have not statistically significant correlation. That means family needs have not influenced by family efficacy and stigma. Family efficacy has not influenced by resilience and resilience has not influence by stigma experienced by the family members of a person with intellectual disability.

Various studies findings suggested that there is a significant relationship between parental attitude and needs of the parents, those who have high positive attitude then their needs will be more (Wagh & Ganaie, 2014).

CONCLUSION

Overall family members of a person with ID had to experience a high degree of stigma.

Most preferred first place to seek help was general physicians in private practice followed by primary health centre and traditional healer/sub-division hospital each and tertiary care hospital. Second most preferred place to seek help was also general physicians in private practice followed by psychiatrist in private practice, sub-division hospital, tertiary care hospital, traditional healer and rest others. Third most preferred place to seek help was tertiary care hospital which was the least preferred as first point followed by traditional healer, others and rest others.

Treatment or care heavily relies on faith healer which is somewhat consistent with the other studies finding.

This study can be taken further with large sample size and random sampling technique for better generalizability

ETHICS APPROVAL AND CONSENT TO PARTICIPATE

Taken

COMPETING INTERESTS

The authors declare that no competing interests.

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