

## **A study of available family support for persons with intellectual disability in the community**

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### **Abstract**

**Background:** In India, informal support services are backbone of entire rehabilitation process of children with intellectual disability. Caregiving for persons with intellectual disability is predominantly family based, with parents, siblings, grand-parents and extended relatives forming the core support group. Despite policy advances and disability legislation, formal support services remain limited, unevenly distributed, and often inaccessible, especially in rural and semi-urban areas. It is important to understand that families having children with intellectual disability are often isolated, stigmatized and marginalized in community (Murthy, 2025).

Consequently, informal support services play a critical role in caregiving and promoting wellbeing of persons with intellectual disability.

**Aim & objective:** The main objective of the study was to assess available support; quantum of support being utilized and their satisfaction level with support being received by the families having children with intellectual disability in chosen community.

**Method:** The methodology used in the present study was field survey to identify various sources and quantum of support available in the family having children with intellectual disability in the selected community.

**Results:** All families in the study were utilizing support of mother (100%), followed by fathers (40%), paternal grand-mother (30%), paternal grand- father (20%), siblings (20%), paternal aunt/uncle (20%) and maternal grand-mother (10). Six families having children with intellectual disability were satisfied with support and four families were not satisfied with support available in the family.

**Key Words:** Family support, Intellectual disability, informal support.

### **Introduction:**

Caring of intellectual disability considered more disadvantaged than those presenting

with other disabilities. This is because of long term physical, neurological, cognitive, sensory psychological challenges affecting their interactions and functioning in the society (United Nations 2006). As the primary caregiver in the life of child with intellectual disability, family faces variety of stressors and stress reactions (Orr et al., 1993). In India, while formal support systems such as government schemes, institutional services play an important role, informal support services form the backbone of entire rehabilitation process. Informal supports are assistance provided by parents, relatives, neighbors, friends, peer and community. Parents play a central and lifelong role in the care, rehabilitation and advocacy of persons with intellectual disability. Studies have shown that family supports were most effective when caregivers received informal supports in addition to formal supports (Bronheim et al., 2006).

According to Dunst et al (1986) family support is broad concept that encompasses formal support (Respite services, healthcare services, rehabilitation and special educational services) and informal supports (e.g., family, friends, neighbors. Support from spouses, grand-parents, siblings, and extended family members helps parents share caregiving responsibilities, manage stress, and ensure continuity of care (Kalyanpur, 2008).

### **Types of family support**

Recognizing special needs of family with intellectual disability, various types of support are available in the community such as parental support, sibling support, support extended by grandparents and support provided by relatives.

**Parental support:** Mothers typically assume direct caregiving tasks including feeding, personal care, therapy and educational support (Kumar 2006) Father and mother helps each other in caregiving responsibilities. While fewer studies focus exclusively on father's support in caregiving. Fathers contribute by seeking medical and educational resources and by facilitating therapy access.

**Sibling support:** Research has identified multiple caregiving role pattern among sibling with intellectual disability such as primary caregivers (assuming principal caregivers' role), joint caregiver (sharing caregiving duties with parents), anticipating caregivers (expected to take up future caregiving responsibilities). Closer sibling bonds correlate with higher caregiving support (Levante et al 2024). Chung Eun Lee et al 2019 found in their study that sibling's step in more often when parents are less able to maintain caregiving tasks.

**Grandparents support:** Studies shows that grandparents provide affection, encouragement and stability for the family amidst caregiving challenges (Baena et al 2024) they frequently contribute to practical caregiving tasks. They help with daily routine, childcare task, and supervision, thereby enabling parents to engage in therapy, or educational intervention. (Teresa Dionisio Mestre et al 2025).

**Extended family members:** Extended family includes uncles, aunts, cousins. They help distribute caregiving demands across multiple members, reducing the burden on a single individual. Hamdani et al (2014) found that where no formal respite care existed, extended family members such as cousins, aunts, uncles provided short term caregiving relief to the primary caregivers. They also contribute to emotional caregiving by offering empathy, reassurance, and encouragement to parents and other caregivers.

**Friend's support:** Support provided by friends are very important in rehabilitation process of family as well as to individual concerned with disability. In study conducted by Chakarborty et al 2021 found that peer support helps strengthen family caregivers by fostering shared experiences, emotional support and practical information exchange. Satore et al 2021 found that peer mentoring and support groups help reduce isolation and stress by connecting caregivers with others who understand their experiences and can share coping strategies.

In India, caregiving for persons with intellectual disability is predominantly family based, with parents, siblings, grand-parents and extended relatives forming the core support group.

Despite policy advances and disability legislation, formal support services remain limited, unevenly distributed, and often inaccessible, especially in rural and semi-urban areas. It is important to understand that families having children with intellectual disability are often isolated, stigmatized and marginalized in community (Murthy, 2025). Consequently, informal support services play a critical role in caregiving and promoting wellbeing of persons with intellectual disability. Most disability research in India focuses on children with disabilities, parental stress, or educational interventions, while informal support mechanisms remain under-explored, particularly for children with intellectual disability in semi-urban settings

**Objectives:**

- To assess various sources of support in personal domain which are used by the parents having children with intellectual

disability in the community.

- To assess quantum of support utilized by the parents having children with intellectual disability in the community.
- To assess level of satisfaction of utilized support by parents having children with disability in the community.

## **Method**

The methodology used in the present study was field survey to identify various sources and quantum of support available in the family having children with intellectual disability in the selected community.

### **Sample:**

The study used purposive sampling of mothers having member with intellectual disability.

In the selected community, total of ten children with intellectual disability were identified. The age range of children with intellectual disability were 6 years to 12 years and mean age of the children with intellectual disability was 8 years. Majority of 6 (60%) of children with intellectual disability were in mild category and 3 (30%) in moderate level and remaining one child was in severe level of intellectual disability.

Total 10 parents were taken as sample. The respondents belonged to the age group of 20 to 45 years. With regard to structure of family, majority (70%) belonged to joint family and remaining 30% were of nuclear family. All the families had intact status. Details of subject demographics and children's demographics are displayed in Table 1 & 2.

## **Table 1 Subject demographics**

S.No.	Selected family	Characteristics	n	%
1	Mother education	<12	1	10
		12	2	20
		Graduation	6	60
		PG	1	10
2	Mother employment	Not working	3	30
		Working (a) part time	5	50
		(b) Full time	1	10
3	Status of family	Intact	10	100
		broken	0	
4	Religion	Hindu	9	90
		Muslim	1	10
		Christian	0	
5	Type of family	Nuclear	3	30
		Joint	7	70
		extended	0	0

Children records indicated the following diagnosed disabilities. Nine out of ten were intellectually disabled and one was multiple disabled having intellectual disability with

cerebral palsy. Out of ten, two children were attending special school and remaining 8 were attending near by general school in locality.

**Table-2 Children’s Demographic**

S.no	Case no.		Characteristics		Age	Type of school
		Sex	Severity	Diagnosed disability		
1	1	Male	Mild	Intellectual disability	12	Gen
2	2	Male	Mild	Intellectual disability	10	Gen
3	3	female	Mild	Intellectual disability	6	Spl
4	4	female	Moderate	Intellectual disability	10	Spl
5	5	male	Moderate	Intellectual disability	8	Gen
6	6	male	Mild	Intellectual disability	9	Gen
7	7	female	Mild	Intellectual disability	10	Gen
8	8	male	Mild	Intellectual disability	11	Gen
9	9	male	Moderate	Intellectual disability	12	Gen
10	10	female	Severe	Intellectual disability with CP	12	Gen

**Tools Used:**

NIMH Family Support Scale was used to assess family support in physical domain.

This scale was developed by Dr Reeta Peshawaria, Dr D.K Menon, Don Bailey and Debra Skinner in year 2000 at NIEPID, Secunderabad.

**Setting:** The survey was conducted at every door step of family having children with intellectual disability in the selected community.

### Results

Objective 1 To assess various sources of support in personal domain which are used by the parents having children with intellectual disability in the community.

Results shows that all families are utilizing support of mother (100%), followed by fathers (40%), paternal grand-mother (30%), paternal grand- father (20%), siblings (20%) , paternal aunt/uncle (20%) and maternal grand-mother (10). The result of the study is in line with study undertaken by Cithambaram, et al (2024). Similarly, support provided by fathers is consistent with findings of Kumar, (2006) Coverman & Sheler 1986 where they concluded that father participation was occasional in nature but much close to mother’s participation. The results of the study were analyzed and presented below in the table 3

Table: 3 Various sources of support available to participating family in research

S.No.	Sources of Support	Physical area
1.	Mother	10 (100%)
2.	Father	4(40%)
3.	Siblings	2(20%)
4.	Paternal Grandfather	2(20%)
5.	Paternal Grandmother	3(30%)
6.	Maternal Grandfather	—
7.	Maternal Grand mother	1(10%)
8.	Paternal Aunt/Uncle	2(20%)
9.	Maternal aunt/uncle	—
10.	Friends	—

Objective 2 To assess quantum of support utilized by the parents having children with intellectual disability in the community.

Results shows that two families of case no, 6 & 8 are utilizing maximum informal support of 70%, followed by three families of case no.1,5, and 7 having utilizing 60% of

informal support. Families of case number 2,4, and 10 are utilizing support of 50%, family of case number 8 (40%) and case number 10 of 30%. Thus, two families are fully using available support and eight families are not fully using support service. The results of the study were analyzed and presented below in the table 4 &5

Table:4 Utilization of support

Areas	CASE 1	CASE 2	CASE 3	CASE 4	CASE 5	CASE 6	CASE 7	CASE 8	CASE 9	CASE 10
Persona 1	12 (60%)	10 (50%)	8 (40%)	10 (50%)	12 (60%)	14 (70%)	12 (60%)	14 (70%)	10 (50%)	6 (30%)

Objective 3 To assess level of satisfaction of utilized support by parents having children with disability in the community

Table:5 Level of satisfaction

Areas	CASE 1	CASE 2	CASE 3	CASE 4	CASE 5	CASE 6	CASE 7	CASE 8	CASE 9	CASE 10
Persona 1	10 (50%)	8 (40%)	6 (30%)	8 (40%)	10 (50%)	14 (70%)	10 (50%)	12 (60%)	10 (50%)	6 (30%)

Result shows that family of case number 6 was at highest level of satisfaction (60%), followed by families of case number 1, 5, 7 and 10 with level of satisfaction at 50%. Minimum level of family satisfaction is with families of case number 3&6 of 30%.

Overall, case number 6 was placed in very satisfied category, while majority of six families had performed under satisfied level and two families of case number 3 & 6 were not satisfied with family support.

Major findings of the study

1. Results shows that all families were utilizing support of mother (100%), followed by fathers (40%), paternal grand-mother (30%), paternal grand- father (20%), siblings (20%), paternal aunt/uncle (20%) and maternal grand-mother (10).
2. Results shows that two families are fully utilizing available support services in

personal area, and remaining eight are not using available support in the family.

3. Six families having children with intellectual disability were satisfied with support and four families were not satisfied with support available in the family

#### Implications

The results of the present study will help professionals, teachers in understanding parental support available in the family in rehabilitation of children with intellectual disability, and exploring for its maximum utilization and thereby improving quality of life and satisfaction level of family functioning.

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