

BRIEF REPORTS

Awareness among Family Members of Children with Intellectual Disability on Relevant Legislations in India

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ABSTRACT

Purpose: *The present study was undertaken to assess the level of awareness on legislations relating to intellectual disability among family members in India.*

Method: *A sample of 103 respondents attending home based training services for their wards at National Institute for the Mentally Handicapped (NIMH), India, were administered a thirty item questionnaire, classified into awareness of legislations, awareness of rights, concessions and benefits and life cycle needs.*

Results: *There is a moderate level of awareness on legislative aspects. Educated respondents showed better awareness about legislations than less educated persons. Respondents were better aware of benefits and concessions because of their direct utility in their day-to-day activities.*

Conclusion: *There is a need for creation of awareness and sensitization among parents and caregivers having persons with intellectual disability to enable them to receive optimum benefits. To reach the uneducated population the materials must also be made available in non-print media such as television, posters and illustrated pamphlets.*

Key words: *Legislation, Rights, Intellectual disability, Guardianship*

INTRODUCTION

In the constitution of India, there is a guarantee for equality and non-discrimination for its citizens. However, exclusive legislations to ensure the rights of persons with disabilities came about in the 1990s. As noted by Mohit (2004) with the increased awareness regarding disability-based discrimination, extra legal safeguards are now being provided in several jurisdictions.

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The major Acts relating to disabilities in India include, Rehabilitation Council of India Act (1992) (RCI Act), The Persons with Disabilities (Equal opportunities, Protection of Rights and full participation) Act (1995) (PWD Act) and The National Trust for Welfare of Persons with Autism, Cerebral Palsy, Mental retardation and Multiples disabilities Act (1999) (NT Act). RCI Act regulates human resource development in the area of disability rehabilitation, which includes intellectual disability. The PWD Act ensures the rights of persons with disabilities, while the NT Act focuses on providing guardianship to persons with disabilities. Though these Acts are in place, awareness about these Acts and the rights of persons with disabilities, especially in the area of intellectual disability, is limited among parents and families (Venkatesan, 2004).

The present study was undertaken to assess the awareness on legislations relating to intellectual disability among family members, in terms of legislation, rights, concessions and benefits, and life cycle needs covered by the Acts.

METHOD

A survey was carried out to assess the level of awareness on legislations among family members of persons with intellectual disability.

The survey tool was a closed-ended questionnaire with 30 statements covering various aspects of the Acts with options of 'correct', 'false' and 'not aware' responses. The tool also included provision for collection of demographic data of the respondents including age, gender, level of disability, locality of living, religion and literacy level of the respondents. Face validity was established before using the tool on the target group.

The sample of the study consisted of families whose children were registered with National Institute for the Mentally Handicapped (NIMH), Secunderabad, India for home-based services for persons with intellectual disability of all ages and levels of retardation. In this service, parents are provided with information on their child's diagnosis and management plan for equipping their child with required skills for independent living. Professionals from medical, psychological, special education and therapeutic specialties provide the required intervention for the clients. The chosen family members were informed about the purpose of the study and those who consented to participate were included in the sample. The data were collected over a period of six months and a total 103 subjects including 48 fathers (47%), 35 mothers (34%) and 20 significant others (19%) participated

in the study. The significant others included siblings (5), grandparents (4) and uncles (11) of the clients.

The clients who attend the services are from various part of India speaking varied languages. As the questionnaire was in English, the questions were translated verbatim in their mother tongue to those who did not know English.

For analysis of data, the statements in the questionnaire were classified into four groups namely, awareness of legislations, awareness of rights, concessions and benefits and life cycle needs. The number of items in each category varied based on its classification. Awareness of legislation had 9 items, awareness of rights had 7 items, concessions and benefits had 6 items and life cycle needs had 8 items.

RESULTS AND DISCUSSION

Table 1 reveals that majority of the children with intellectual disability were males (69.9%). Almost one third of the sample belonged to the age group of 6 to 10 years (32%). About half (48.5%) of the clients had a mild degree of retardation. Regarding additional disabilities, those with mobility disability/cerebral palsy were the highest number (11.7%) followed by those with epilepsy (8.7%) and those with Autism (7.8%). As the data were collected from the parents of clients who visited NIMH for services on given days and from those who were willing to participate in the study, these figures cannot be generalized for prevalence. However, the numbers in the study in terms of degree of disability is comparable to the general trend in annual client registration at NIMH in 2005: mild (31.2%), moderate (19.1%), severe (11%), profound (0.2%), additional disabilities (38.3 %). It can be assumed that those with profound intellectual disability may be less in number due to difficulties in reaching the service center.

Religion of Participants and Awareness Level

The participants belonged to different religions including Hinduism (84%), Islam (9%) and Christianity (7%). Religion did not have an influence on awareness levels, as the correct responses from the subjects ranged between 44% and 57 % [Hindus (49.9%), Muslim (44.4%) and Christians (57%)]. However as the persons belonging to various religions are not of uniform distribution a generalization cannot be drawn.

Table 1: Profile of Clients with Intellectual Disability

N=103

Sl. No	Category	0-5 years		6-10 Years		11-15 Years		16-20 Years		21-25 Years		25 Above		Total		Grand Total
		M	F	M	F	M	F	M	F	M	F	M	F	M	F	
1	Mild	3	2	10	6	11	3	8	2	2	-	1	2	35	15	50 (48.5%)
2	Moderate	2	-	-	-	1	1	7	-	1	-	1	3	12	4	16 (15.5%)
3	Severe	-	-	-	-	-	-	2	-	-	-	1	-	3	-	3 (2.9%)
4	Profound	-	-	-	1	-	-	-	-	-	-	-	-	-	1	1 (.9%)
<i>Additional Disabilities</i>																
5	Hearing	-	-	-	-	-	1	-	-	-	-	-	-	-	1	1 (.9%)
6	Visual	1	-	-	-	-	-	1	-	1	-	-	-	1	2	3 (2.9%)
7	Locomotor & Cerebral Palsy	-	-	5	1	1	1	2	2	-	-	-	-	8	4	12 (11.6%)
8	Autism	2	1	4	1	-	-	-	-	-	-	-	-	6	2	8 (7.7%)
9	Epilepsy	-	-	4	1	1	1	1	-	-	-	1	-	7	2	9 (8.7%)
	Total	8	3	23	10	14	7	20	5	3	1	4	5	72 (69.9%)	31 (30%)	103 (100%)
	Total	11 (11%)		33 (32%)		21 (20%)		25 (24%)		4 (4%)		9 (9%)		103 (100%)		

Educational Status of Participants and Awareness Level

Educational levels of the participants varied from illiteracy to post graduation: illiterates (9.7%), secondary school education (28.2%), intermediate education (8.7%), graduation (30.1%) and post-graduation (23.3%). Educational level of the respondents did have an influence on awareness levels, as the correct responses of the subjects ranged between 37% to 60% within the group: [illiterates (37%), secondary school educated (49.3%), intermediate educated (47.7%), graduates (45.8%), postgraduates (60%)], revealing that there is better awareness among more educated persons.

Place of Living and Level of Awareness

It was noted that 73 (71%) lived in urban areas, 17 in rural areas (17%) and 13 (13%) in semi urban areas. Those who gave correct responses comprised 52% of persons from urban areas, 47% from rural areas 38% from semi-urban areas. 38% from urban areas, 41% from rural areas and 69% from semi urban areas were not aware of specific information on legislations. It is understandable that urban population is relatively better informed than rural population because of their exposure to media. A majority of the semi urban population who participated in the study were from urban poor communities with low socio economic and literacy levels and therefore they were poorly informed about the various aspects of legislations.

Table 2 shows the level of awareness among the respondents when compared to the degree of disability of their wards. Irrespective of the degree of disability of the child, the respondents seem to be have relatively better awareness about concessions and benefits (59% to 62%). This may be because the benefits are directly useful in their day-to-day activities, for example, travel concession, tax benefits, pension, maintenance and educational allowances provided by central government and respective state governments.

Table 2: Level of Intellectual Disability of Clients vs. Correct Responses on Awareness received from Respondents

N=103

S. No	Responses	Clients level of disability			Total
		Mild (75)	Moderate (21)	Severe (7)	
1	Awareness of legislations of acts (9)	36 (48%)	12 (57%)	4 (58.7%)	52 (50%)
2	Awareness of rights (7)	30 (40%)	10 (48%)	3.1 (44.8%)	43 (42%)
3	Concessions & Benefits (6)	45 (60%)	13 (62%)	4.2 (59.2%)	62.2 (60.4%)
4	Life cycle needs covered in acts (8)	35 (47%)	10 (48%)	4.2 (59.2%)	49.2 (47.8%)

As seen in **Table 3**, all respondents had more or less equal level of awareness about legislations irrespective of their relationship with the child. The number of correct responses on an average was 50%, 'not aware' responses were about 44% and false responses were about 8%. It is also seen that

Table 3: Awareness among Respondents with Reference to Specific Provisions of Various Legislations

N=103

S. No.	Specific Provisions	Father (48)			Mother (35)			Others (20)			Total		
		Correct	False	Not aware	Correct	False	Not aware	Correct	False	Not aware	Correct	False	Not aware
1	Awareness of legislations of acts (9)	25 (52%)	2 (4.1%)	21 (43.7%)	17 (48.5%)	2 (5.7%)	16 (45.7%)	10 (50%)	3 (15%)	7 (35%)	52 (50%)	7 (7%)	44 (43%)
2	Awareness of rights (7)	21 (43.7%)	4 (8.3%)	23 (47.9%)	14 (40%)	3 (8.5%)	18 (51.4%)	8 (40%)	2 (10%)	10 (50%)	43 (42%)	9 (9%)	51 (49%)
3	Concessions & Benefits (6)	29 (60.4%)	3 (6.2%)	17 (35.4%)	20 (57.1%)	1 (2.8%)	13 (37.1%)	14 (70%)	1 (5%)	5 (25%)	63 (61%)	5 (5%)	35 (34%)
4	Life cycle needs covered in acts (8)	24 (50%)	4 (8.3%)	20 (41.6%)	15 (42.8%)	4 (11.4%)	16 (45.7%)	9 (45%)	2 (10%)	9 (45%)	48 (47%)	10 (10%)	45 (43%)
	AVERAGE	25 (52%)	3 (6.2%)	20 (41.6%)	16 (45.7%)	3 (8.5%)	16 (45.7%)	10 (50%)	2 (10%)	8 (40%)	51 (50%)	8 (8%)	44 (42%)

correct responses were maximum (63%) and false responses (5%) as well as ‘not aware’ responses (34%) were minimum in the area of concessions and benefits. The other three areas did not show any major difference in the extent of awareness among the respondents. This reflects an urgent need for creating awareness about the rights of persons with intellectual disabilities among their family members.

As seen in **Table 4**, the general awareness among the male respondents was more than that of the female respondents except in the area of concessions and benefits.

Table 4: Clients’ Gender Vs. Awareness of Specific Provisions in Various Legislations

N=103

S. No.	Specific Provision Of Various Legislations	Gender of Clients		Total
		Male (72)	Female (31)	
1	Awareness of legislations of acts (9)	37 (51%)	15 (48%)	52 (50%)
2	Awareness of rights (7)	31 (43.1%)	12 (38.7%)	43 (42%)
3	Concessions & Benefits (6)	43 (59.7%)	20 (64.5%)	63 (61%)
4	Life cycle needs covered in acts (8)	34 (47.2%)	14 (45.1%)	48 (47%)

[% of male out of 72 & female out of 31 in parenthesis]

This may be because it is usually the mothers or the female family members who bring the children for services and therefore they use the benefits such as travel concession, more than their male counterparts.

Awareness levels on various aspects of legislations were almost the same among parents irrespective of the age of their child (**Table 5**). Though the number of parents of children in the age range of 6-10 years is the highest (33), their awareness level is relatively the least in all the areas of legislations except on awareness of rights. It was also noted that higher the age of the children, the better informed were the parents about concessions and benefits. This can be attributed to parents' motivation to know more about the chances of receiving support for improving their child in early years and therefore they tend to seek information regarding every aspect related to their child and his/her future. Parents of older children possibly had more awareness of legislation because one of the Acts (NT Act) covers guardianship-related information, focusing on answering the question "Who will take care of our child after us?".

Table 5: Clients Age Vs. Correct Responses on Awareness among Respondents

N=103

S. No.	Specific provision of various legislations	Clients Age						Total
		0-5 Years (11)	6-10 Years (33)	11-15 Years (21)	16-20 Years (25)	21-25 Years (4)	Above 25 Years (9)	
1	Awareness of legislations of acts (9)	6 (54.5)	14 (42.4%)	11 (52.3%)	14 (56%)	2 (50%)	5 (55.5%)	52 (50%)
2	Awareness of rights (7)	4 (36.3%)	13 (39.4%)	9 (42.8%)	11 (44%)	2 (50%)	4 (44.4%)	43 (42%)
3	Concessions & Benefits (6)	7 (63.6%)	18 (54.5%)	13 (61.9%)	16 (64%)	3 (75%)	7 (77.7%)	63 (615)
4	Life cycle needs covered in acts (8)	5 (45.4%)	13 (39.4%)	11 (52.3%)	12 (48%)	3 (75%)	5 (55.5%)	48 (47%)

CONCLUSIONS

The study reveals that there is moderate awareness of legislative aspects among parents and caregivers of children with intellectual disability. Age of the child, place of living, degree of disability and religion of the family did not seem to influence the level of awareness. However, more educated persons showed better awareness.

Among the various aspects of legislation, the respondents were better aware of benefits and concessions, probably because of the direct and instant access to it and its utility. It was also noted that the male respondents were better aware of aspects related to legislation when compared to their female counterparts.

There is a need for intense focus and drive towards creating awareness of legislation among families of persons with intellectual disability. Various print and non-print modes are to be used for this purpose so that even illiterate persons will benefit from the information provided.

Similar studies need to be conducted over time to analyze the changing trends in the awareness levels.

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