

Full Length Research Paper

Awareness among family members having children with mental retardation on relevant legislations in India

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In India, Acts and legislations are in place for persons with mental retardation. Three major Acts namely Rehabilitation Council of India Act (1992), Persons with Disabilities (Equal opportunities, protection of rights and full participation) Act (1995) and National Trust for welfare of persons with Autism, Cerebral Palsy, Mental retardation and Multiples disabilities Act (1999). Many families having persons with mental retardation are not aware of such Acts. This present study was undertaken to find out the level of awareness on legislations relating to mental retardation among family members having children with mental retardation. A sample of 103 respondents, attending home based training services for their wards at National Institute for the Mentally Handicapped (NIMH) were administered a thirty item questionnaire, classified into four groups namely, awareness of legislations, awareness of rights, concessions and benefits and life cycle needs. The result of the study showed that there is an overall moderate level of awareness on legislative aspects. Educated respondents showed better awareness of Acts and legislations than less educated persons. Among the various aspects of legislations, the respondents were better aware of the benefits and concessions because of the direct utility in their day-to-day activities. There is a need for creation of awareness and sensitization programme among parents and caregivers having persons with mental retardation to enable them to receive optimum benefits. To reach the uneducated population, the materials must also be made available in nonprint media including television, posters and illustrated pamphlets.

Key words: Legislations, acts and rights for persons with mental retardation, concession and benefits for persons with mental retardation, guardianship for persons with mental retardation, families of persons with mental retardation / intellectual disabilities.

INTRODUCTION

Acts and policies in the area of disability is a recent development in India. In the constitution of India, there is a guarantee for equality and non-discrimination among its citizens (Article 14, 15 and 16). In addition, Article 45 refers to "Education for All" while Article 41 refers to "Rights to education and work" for persons including those with disabilities. However, exclusive legislations to ensure the rights of persons with disabilities were enacted in the 1990s. As noted by Mohit (2004) with the increased awareness regarding disability-based discrimination, extra legal safeguards have now been

provided in several jurisdictions.

The major Acts relating to disabilities in India include, Rehabilitation Council of India Act (1992) (RCI Act), Persons with disabilities (Equal opportunities, Protection of rights and full participation) Act (1995) (PWD Act) and 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 mental retardation also. PWD Act ensures the rights of persons with disabilities, particularly, the seven covered by the Act namely those with blindness, low vision, hearing impairment, locomotor disabilities, leprosy cured, mental retardation and mental illness. NT Act focuses on providing guardianship to

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persons with disabilities covered by the Act. This is essential because, India is a country where persons with disabilities naturally form part of the family. The parents and family members of such children look after them all through their life, if the children are dependents. NT Act aims to meet the demand of families who seek suitable arrangements for their children when there is no one to look after such children.

Though these Acts are in place, awareness about these Acts and the rights of persons with disabilities, especially in the area of mental retardation (also known as intellectual disabilities) is limited among parents and families (Venkatesan, 2004). Persons with mental retardation have difficulty in comprehending the rights and benefits due to their limited intellectual ability. Therefore, the family members are to be sensitized regarding the rights of their wards with mental retardation. For the legislations to be of optimum benefit to individuals with mental retardation and their families, it is necessary that they are aware of the Acts.

The current study was undertaken to find out the awareness on legislations relating to mental retardation among family members having children with mental retardation.

Specific objectives

1. To compile information regarding awareness about legislations for persons with mental retardation among their family members,
2. To analyze the compiled information in terms of
 - a. Legislations and Acts,
 - b. Rights,
 - c. Concessions and benefits and
 - d. Life cycle needs covered by the Acts.

METHODS

The method involved a survey to find the level of awareness on legislations among family members of persons with mental retardation.

Tool

The 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 retardation of their ward, locality of living, religion and literacy level of the respondents. Face validity was established before using the tool on the target group.

Sample

The sample of the study consisted of families whose wards were registered with National Institute for the Mentally Handicapped (NIMH) for services. One of the modes of service delivery at NIMH

is home-based services for persons with mental retardation of all ages and levels of retardation. The parents are provided with information on their child's diagnosis and management plan for equipping their child with required skills for independent living. The professionals consisting of medical, psychological, educational and therapeutic specialties provide the required intervention for the client. The sample for the study was chosen from such clients who were receiving services at NIMH. The family members were informed about the purpose of the study and those who consented to participate were included in the sample. The data was collected over a period of six months and a total of 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 (1) of the client.

Procedure

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 do not know English and their responses were recorded. The data these collected is compiled and analyzed.

RESULTS AND DISCUSSION

For analysis of the 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 (Appendix 1). As can be seen from the appendix, 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.

Table 1 reveals that majority of the children of the subjects were male (69.9%). Almost one third of the total children belong to the age group of 6 to 10 years (32%). About half (48.5%) of the clients were having mild mental retardation. Among additional disabilities, those having locomotor disability/cerebral palsy were the highest (11.7%) followed by those with epilepsy (8.7%) and those with autism (7.8%), respectively. As the data was collected from the parents of clients who visited NIMH for services on given days and those who were willing to participate in the study, the reason for the aforementioned representations cannot be generalized for prevalence. However, it is seen that the number in terms of degree of mental retardation is proportionate when compared to the general trend in registration at NIMH in a year, - Mild MR :(31.2%), moderate MR:(19.1%), severe MR:(11%), profound MR: (2%), additional disabilities:(38.3%) (2005)]. It can be assumed that those with profound mental retardation may be less in number due to functional difficulty in reaching the service center.

Religion of the participants and awareness level

The participants belonged to various religion including

Table 1. Profile of clients with mental retardation N=103.

S/N	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 (0.9)
Additional disabilities																
5	Hearing	-	-	-	-	-	1	-	-	-	-	-	-	-	1	1 (0.9)
6	Visual	1	-	-	-	-	-	1	-	1	-	-	-	1	2	3 (2.9)
7	Locomotor and 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%)		

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 subjects belonging to various religions are not of uniform distribution, a generalization cannot be drawn.

Educational status of the 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 educated persons.

Place of living and level of awareness

When considering the place of living of the subjects, it was noted that 73 (71%) lived in urban area, 17 in rural areas (17%) and 13 (13%) in semi urban areas. Among those who lived in urban areas, 52% gave correct responses, among those who lived in rural areas, 47% gave correct

responses and among those who lived in semi-urban areas, 38% gave correct responses. It was also evident that 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 the access to media. Majority of the semi urban population who participated in the study were from urban slums 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 level of retardation of their wards. Irrespective of the level of retardation of the child, the respondents seem to be having relatively better awareness of

Table 2. Level of mental retardation of clients versus correct responses of awareness among respondent, N=103.

S/N	Responses	Clients level of retardation			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 and 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)

Table 3. Awareness among respondents with reference to specific provision of various legislations, N=103.

S/N	Specific provision of various legislations	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 and 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)

concessions and benefits (59 to 62%). This may be because; the benefits are directly useful in their day-to-day activities such as travel concession, tax benefits, pension and educational allowances provided by central government and respective state governments. There is need for creating awareness about rights among the respondents.

As seen in Table 3, all respondents were more or less having equal level of awareness about legislations irrespective of the relationship to 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 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. As noted by UN, persons with disabilities are entitled to exercise their civil, political, social, economic and cultural rights on an equal basis with others under all the international treaties (UN Enable, 2002). This reflects an urgent need for creating awareness about the rights of persons with 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. This may be because most of the times, 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 rather than their male counterparts.

Awareness levels on various aspects of legislations were almost the same among the parents irrespective of the age of their child (Table 5). It is interesting to note that though the number of parents of children in the age range of 6 to 10 years is the highest (33), their awareness level is found to be relatively the least in all the areas of

Table 4. Gender of the clients versus correct response of awareness among respondents, N=103.

S/N	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 and 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 and female out of 31 in parenthesis].

Table 5. Age of clients versus correct responses of awareness among respondents, N=103.

S/N	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 and Benefits (6)	7 (63.6)	18 (54.5)	13 (61.9)	16 (64)	3 (75)	7 (77.7)	63 (61.5)
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)

legislations except on awareness of rights. It is also to be noted that the higher the age of the children the better the parents are informed about concessions and benefits except for the parents of children in the age range of 0 to 6 years. This can be attributed to perhaps the parents' motivation to know more about the chances of receiving help 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 clients having awareness of legislation could be because of one of the Acts (NT Act) covering guardianship related information. This Act is focused on answering the question of the parents, "Who will take care of our child after us?"

It can also be because the benefits and concessions cover areas related to pension,

income tax relief, transfers on job to parents of such children at their choice to places where services are available for their child and such other privileges which they might be utilizing as and when they have/had a need.

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Conclusions

The study reveals that there is an overall moderate awareness of legislative aspects among

parents and caregivers of persons with mental retardation. Age of the child, place of living, level of retardation of the child and religion of the family did not seem to influence the level of awareness. However, educational status of the respondents showed better awareness among the educated persons though not a vast difference in the level of awareness.

Among the various aspects of legislations, the respondents were better aware of the benefits and concessions, probably because of the direct and instant access to it and utility of it. It was also noted that the male respondent were better aware of aspects related to acts and legislations when compared to female counterparts There is a need for intense focus and drive towards creating awareness of legislation among the families.

Various print and nonprint modes are to be used

for this purpose so that even the illiterate persons will benefit from the information provided. Similar studies are to be constantly conducted to analyze the changing trends in the awareness levels.

REFERENCES

- Government of India, Ministry of Social Justice and Empowerment (1992). Rehabilitation Council of India Act, New Delhi, Government of India, Ministry of Social Justice and Empowerment (1995). Persons with disabilities (Equal opportunities, protection of rights and full participation) Act, New Delhi.
- Government of India, Ministry of Social Justice and Empowerment (1999). National Trust for welfare of persons with Autism, Cerebral Palsy, Mental retardation and Multiples disabilities Act, New Delhi.
- Mohit A (2004). Human Rights for persons with Disabilities in C.S.Mohapatra (Ed) Disability Management in India, Secunderabad: NIMH.
- UN Enable (2002). Informal consultative meetings on International Norms and standards for persons with disabilities, Human Rights and Persons with Disabilities, Department of Economic and Social Affairs, Division for Social Policy and development. <http://www.un.org/esa/socdev/disber10.htm> accessed on 25/06/2005.
- Venkatesan S (2004). A Survey of knowledge and opinion on rights immunities and privileges for persons with mental retardation, Asia Pac. Disabil. Rehabil. J., 15(1): 59.

Appendix 1.

Q. No	Specific provision of various legislations
I	Awareness of legislations of Acts (9)
1	There are Acts for persons with disabilities in India
3	Each state has special office to carry out activities related to Act for persons with disabilities
6	There is no provision to regulate the implementation of Acts
7	There are two Acts directly involving persons with mental retardation
9	Any professional can certify a person as having mental retardation
19	There is an Act to regulate qualification of those professionals working with persons with mental retardation
20	There is a certification procedure for persons with disabilities in the country
22	There is an exclusive Act to ensure equal opportunities, Protection of Rights and Full Participation
23	There is an Act to deal with problems of those person with mental retardation who do not have family support
II	Awareness of Rights (7)
2	Persons with mental retardation have similar rights as others in India
5	There is a provision to protect persons with mental retardation from discrimination
8	There is no provision for grievance redressed in the Acts
13	There is no law to ensure user friendly barrier free environment
27	There is a procedure for appointment of guardians and trustees for persons with mental retardation without approaching the courts
28	There is no concessional provisions for persons with mental retardation in the legal system
29	There is no provision to particularly address sexual abuse of persons with mental retardation
III	Concessions and Benefits (6)
10	There are no concessions provided to persons with mental retardation in terms of travel
11	Government employees having children with mental retardation have certain privileges in the interest of the child with mental retardation
12	There is no relaxation in tax to parents of children with mental retardation
16	There is a scheme of grant-in-aid by Government of India to voluntary agencies to set up facilities for persons with mental retardation
25	There is provision for allotment of land at concessional rates for persons with mental retardation for housing and rehabilitation purposes
30	Certification ensures eligibility for certain benefits and concessions
IV	Life cycle needs covered in Acts (8)
4	There is no right to education for persons with mental retardation
14	Scheme of integrated education/inclusive education does not include children with mental retardation
15	There is no job reservation for persons with mental retardation
17	There are provisions in the Act towards prevention and early detection of mental retardation
18	There is job reservation for persons with mental retardation in Central Government jobs
21	There is provision in the Act to provide long term/short term care for persons with mental retardation
24	There is provision for free education for children with mental retardation up to the age of 18 yrs
26	There is a special employment exchange for persons with mental retardation to seek employment in Government organizations/public sector undertakings