

Parents of children with special needs and awareness of national trust Act 1999: In Varanasi District

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Abstract

The National Trust Act was established by the parliamentary act of 1999 to ensure the various rights of the four types of disabilities. There are many provisions and schemes run by the National Trust to provide safety and security to the person with disabilities and to protect their rights. So in the reference of such provisions and schemes of the National Trust Act 1999 the present study was conducted to find out awareness levels among the parents of children with Mental Retardation, Cerebral Palsy, Autism and Multiple Disabilities. The study is based on survey method and purposive sampling procedure was used. The sample includes total of 60 parents who are attending services at Sanjeevani Social Welfare Society and some special schools in Varanasi, Uttar Pradesh. The researcher developed a questionnaire which has 30 items to identify the levels of awareness among the parents of children with Mental Retardation, Cerebral Palsy, Autism and Multiple Disabilities on the provisions and schemes of The National Trust Act 1999. The t-test and simple percentage were used to analyze the data and result of the study indicated that there is lack of awareness among parents of children with special needs as well as highly significant difference with reference to gender, age, and socio economic status of the parents also noted on the provisions and scheme of The National Trust Act 1999 by means of questionnaire.

Keywords: national trust act 1999, provisions and schemes, awareness levels, parents of children with mental retardation, cerebral palsy, autism and multiple disabilities

Introduction

India, being a democratic country, the constitutional and legislation play an important role in the life of every citizen, irrespective of his being able or disabled. The preamble of the constitution of India states, "we the people of India having solemnly resolved to constitute India into a Sovereign, Democratic, Republic and to serve all its citizens".

Justice, social economic and political; Liberty of thought, expression, belief, faith and worth;

The preamble pledges "equality of status and opportunity to all the citizens of India".

By considering the basic feature and concept of our constitution, Indian Government has enacted several policies and acts time to time to fulfill the objective of preamble of our constitution. Such as The Mental Health Act 1987, Rehabilitation Council of India Act 1992, Person with Disabilities (equal opportunities, protection of rights and full participation) Act, 1995, National Trust Act 1999. The government of India had realized to pay more emphasis on the some other types of disabilities and their unavoidable requirement which were left by PWD Act 1995. Keeping these issues, on December 30, 1999, the National Trust Act for the welfare of person with autism, mental retardation, cerebral palsy and multiple disabilities Act was being passed. The act responds to the most felt need of parents and family members of persons with above disabilities in India. It addresses the frequently asked questions and concerns of parents and family members that who will look after their ward when they are no more? Further the act also takes care of the concern that who will care for the orphans with disabilities and how? Hence the primary focus of the act is to support the families of persons with disabilities to see that disabled persons live comfortably in the community even

after families are no longer in position to take care of their ward. The objectives of The National Trust Act are (a) to enable and empower persons with disability to live as independently and as fully as possible within and as close to the community to which they belong; (b) to strengthen facilities to provide support to persons with disability to live within their own families; (c) to extend support to registered organizations to provide need based services during period of crisis in the family of persons with disability; (d) to deal with problems of persons with disability who do not have family support; (e) to promote measures for the care and protection of persons with disability in the event of death of their parents or guardians; (f) to evolve procedure for the appointment of guardians and trustees for persons with disability requiring such protection; (g) to facilitate the realization of equal opportunities, protection of rights and full participation of persons with disability; and (h) to do any other act which is incidental to the aforesaid objects.

To accomplish such objectives of the trust, it has launched various schemes such as: Samartha is a Centre based which is introduced in July 2005 for residential services. Niramaya is a health insurance scheme for persons below the poverty line with the four disabilities covered under National Trust Act. Gyan Prabha is a scholarship scheme for children who are covered under National Trust Act. Uddyam Prabha is a subsidy scheme for self-employment for persons with disabilities who taken loan from any bank or NHFDC. Asitma is a group life insurance scheme for parents /guardians of persons with disabilities covered under National Trust Act. Gharunda scheme provides lifelong shelter and care for the persons with disabilities covered under National Trust Act.

There is something beyond thoughts, beyond feelings, beyond speech and beyond action. It is a place of awareness. Awareness is the ability of directly know and perceive or to be of events. It is the state or quality of being conscious of something. So the awareness is a purely depends on one's knowledge and observation.

From the above discussion, we can conclude that parenthood always brings responsibilities. The parents knowing and asserting their child's right can help guarantee that the child will receive the education and government benefits to which they are entitled. Therefore the present study tried to know the level of awareness among parents of children with autism, cerebral palsy, mental retardation and multiple disabilities about the provisions and schemes of the National Trust Act 1999.

Review of Literature

Bailey *et al* (1999) ^[1] interviewed 200 Latino parents of young children with disabilities to determine awareness, use, and satisfaction with services. They also examined use of alternative treatments and the relationship between child and family variables and awareness, use, and satisfaction. A high degree of awareness was noted, but only moderate degree of satisfaction was found. Mother were more aware of and perceived use of more services than fathers. With few exception, family and child variables bore little relationship to awareness, use or satisfaction. No families pursued alternative treatments as their primary source of help, although several used them in a minor way. Programme variable may be more likely determinants of service use and satisfaction than family factor alone.

Suha and Gardner (2002) ^[4] explained that bridging the gap between home and school is the responsibility of both educators and parents. Professionals should take the first step toward encouraging immigrant parents to become more actively involved in the educational process. Understanding the needs and the culture of immigrant parents helps in building a positive relationship between school and home. The outcomes include improved student achievement, increased teacher familiarity with other cultures, and a better understanding by parents of their rights and responsibilities. The future success of our society is just as closely tied to the education of today's immigrant children as our past success was to the education of the previous generations of immigrants.

A study conducted by Petra Engelbrecht *et al* (2005) ^[2] on South Africa parents to focus on the way in which equity, individual rights and freedom of choice manifest itself in the implementation of inclusive education with specific reference to the way in which parents experience it. Results of the study indicated that a child's inclusion into mainstream education is a challenge and dynamic process in that the parents' decision is essential to place their child in a mainstream setting. Despite having legislative provision and parent's yearnings, the development of practices of inclusive education in South Africa does not always reflect the values of equity and individual rights. As a result disappointment reflect into the establishment of collaborative and trusting relationships among teachers, parents and professionals which stances a major challenge and it can have a serious impact on the outcomes of inclusive education.

A study conducted by V. G. Kumar (2008) ^[6] which has indicated that families who are successful in coping with a disabled child are able to mobilize their internal and external means of support to deal effectively with the special needs of their child.

Kuppusamy *et al.* (2012) ^[5] conducted a study that undertaken to assess the level of awareness on legislations regarding to mental retardation among family members those 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 analysis of data showed an overall moderate level of awareness on legislative aspects among family members. The better awareness level of Acts was found among educated respondents whereas lower level awareness was assessed among less educated respondent regarding legislation. 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.

Kumar Sravan (2014) ^[8] studied as over the last few years, there have been many changes in the delivery of mental retardation services including the roles of special educator, therapist, parents and community. Mainstreaming of mentally retarded persons in society; integration and inclusion is turning point. There is an impending need to create a general awareness amongst the children of the regular schools about the special needs of the children with mental retardation. For inclusive atmosphere both in the families and in the society; the awareness will helpful. This study will be supportive to know the extent of awareness on mental retardation among regular school children with reference to gender and severity of education.

Husna (2015) ^[3] examined that Special Needs Education (SNE) highly plays a crucial for all those children and adults with disabilities. In this article, the aim is to research the awareness levels of SNE in various schools and communities in the city of Hyderabad, India. A qualitative approach was taken for this purpose. The research also includes a case study of a special needs child along with his family and academic background, in order to know the degree of awareness among parents. The case study has proved that the issue of special education and children with disability, the awareness is still not common among the general public, especially in lower class families and rural areas.

S. Prerna (2015) ^[7] focused on the study with the aims to find out the level of parents awareness with respect to human rights entitlements of their children. In the study a quantitative paradigm was used as the findings allow for generalization by using a large sample size and the work pre supposes that parents' awareness regarding rights of Children with Disabilities is affected by (i) personal factors of Parent (i.e. age, gender, educational accomplishment, religion, profession) (ii) socio-economic factors (no. of children,

family types, income of the family and per capita income) and (iii) concerning factors of the child with disability (i.e. age, gender, disability type, age at the inception of disability and birth sequence of child in the family). To establish the dominant factors from the personal and SES factors of respondent parents, which influence the awareness level of parents of child with disability; a decision tree method is used. It is also established that parents' educational accomplishment is the most dominant factor affecting their awareness levels. Birth order of the child in the family, disability type of child and number of children in the family are also dominant factors that affect the awareness regarding rights of child with disability among respondent parent.

Need and significance of the study

The change of approach from charity to right is to be reflected in the field of disability rehabilitation. In India right based approach is the outcome of the National Trust Act (1999). Most of the families of children with special needs are not aware about different legislations passed by Govt. of India. Among them National Trust Act is the one which is really helping and covering four types of disabilities., viz. Autism, Cerebral Palsy, Mental Retardation and Multiple Disabilities.

It is very essential to know the level of awareness among the families having the children with special needs about the provisions. Unless the parents are aware of the benefits of the National Trust Act; they would not be in a position to avail the benefits. Therefore; this study intended to know level of awareness on National Trust Act among parents of children with special needs by schedule on the provision and policies of National Trust Act 1999. So that further action could be taken regarding the outcome of the study.

Objectives of the study

- To know the Awareness Level about National Trust Act 1999 among the Parents of Children with Special Needs.
- To know the Awareness Level about National Trust Act 1999 among the Parents of Children with Special Needs with reference to age.
- To know the Awareness Level about National Trust Act 1999 among the Parents of Children with Special Needs with reference to gender.
- To know the Awareness Level about National Trust Act 1999 among the Parents of Children with Special Needs with reference to socio economic status.

Hypothesis

- There is no significant difference on level of awareness about National Trust Act 1999 among the Parents of Children with Special Needs.
- There is no significant difference of Awareness Level about National Trust Act 1999 among the Parents of Children with Special Needs with reference to age.
- There is no significant difference of Awareness Level about National Trust Act 1999 among the Parents of Children with Special Needs with reference to gender.
- There is no significant difference of Awareness Level about National Trust Act 1999 among the Parents of Children with Special Needs with reference to socio economic status.

Methodology

Research Design

The primary purpose of the research is to provide an accurate description or picture of the status or characteristics of a situation or phenomenon. In order to that descriptive research design and survey method was used for data collection.

Sampling Design

Non-Probability sampling design and purposive sampling technique has been used to select the 60 parents of children with special needs (mental retardation, autism, cerebral palsy and multiple disabilities) as sample from Varanasi District, Uttar Pradesh. Description of samples as follows:

Table 1: Sample Categorization based on these Sub-Variables

Sub-Variables	Group	N
Age	18-30	30
	30 & above	30
Education	Up to 10+2	30
	10+2 & above	30
Socio-Economic Status	Lower	19
	Middle	25
	Upper	16

Description of the tool

Demographic Record Sheet

The investigator prepared a Demographic Record sheet for collecting information regarding sub-variables of the study such as name, age, gender, socio-economic status and types of disabilities about parents of children with special needs.

Questionnaire on National Trust Act

A questionnaire was developed by the investigator after thorough studying about the provisions and schemes of National Trust Act 1999. The questionnaire has four domains such as items related with general information, objectives, guardianship and schemes of the Trust. The questionnaire consisted 30 items.

Pooling and selection of the items

Initially 45 items were listed from each domain such as general information, objectives, guardianship and schemes of the Trust. Then the listed items were circulated to twelve professionals working in the field of special education for validation. The total 28 items with 80% consensus were selected and 2 items were added with the suggestion of the experts whereas the rest of the 17 items were excluded on the ground of subjectivity. The revised version of the questionnaire with 30 items kept as the final questionnaire tool for collecting data regarding awareness about the NT Act 1999.

Scoring

Simple scoring pattern has been followed as the correct responses were given 'One' score and incorrect responses carrying 'Zero' score. So the maximum scores in the questionnaire having 30 scores.

Procedure for data collection

After describing relevance of the study to the parents of children with special needs, the investigator has collected the consent from the parents of children with mental retardation,

Autism, Cerebral Palsy and Multiple Disabilities by filling the consent form before administrating the questionnaire in order to collect the information regarding their willingness to

participate in the study. After that the researcher made questionnaires were distributed to the parents for data collection.

Result and Discussion

Table 2: Percentage of Awareness Level among Parents of Children with Special Needs

S.N.	Level of Awareness	No. of Parents	%age of Parents
1.	No awareness (o to 6)	16	26.67%
2.	Low Awareness (7 to 14)	22	36.67%
3.	Moderate Awareness (15 to 22)	12	20%
4.	High Awareness (23 to 30)	10	16.67%

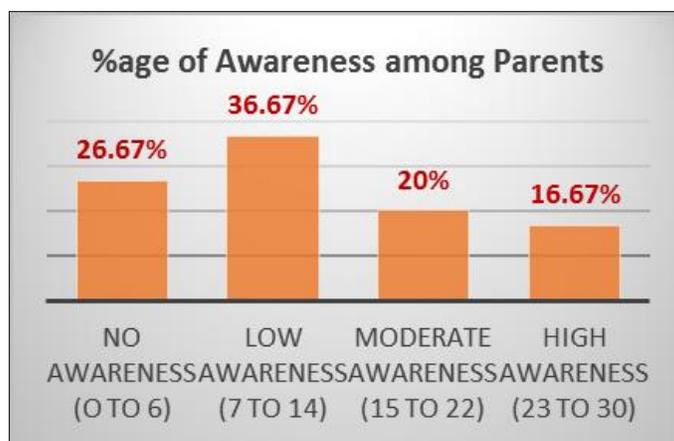


Fig 1

Table 2 shows the percentage of awareness level among parents of children with special needs. Such as out of 60 samples in 26.67% (16) parents awareness has assessed as No Awareness, 36.67% (22) as Low Awareness whereas in only 20% (12) parents comes under Moderate Awareness and 16.67% (10) belong to High Awareness level. The observation of data reveals that there is significant awareness difference exist among the parents of children with special needs and low awareness level rate is high as compare to other awareness level.

Table 3 shows Mean values, SDs and t' value based on age group of parents on awareness level. As the obtained t-value i.e. 2.51** is more than that of the table value, and its p-value is <0.015034, it can be inferred that, there is statistically significant difference at 0.05 level between the both age group as 18-30 and 30 & above. A close observation of the mean values reveals that parents belong to age group of 18-30 shows more awareness as compare to the parents belong to age group of 30 and above.

Table 3: Awareness Level based on the age of the Parents

Age Group	N	Mean	SD	t-value
18 – 30	30	15.10	6.74	2.51**
30 and above	30	10.33	7.71	

Table 4: Awareness Level of the Parents with reference to Gender

Gender	N	Mean	SD	t-value
Female	30	9.63	6.45	3.37**
Male	30	15.80	7.46	

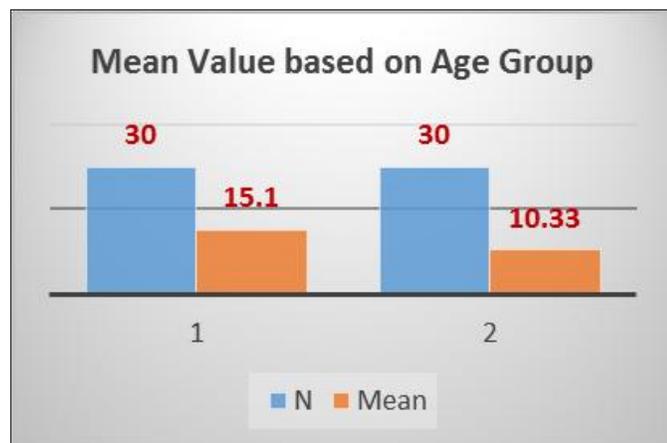


Fig 2

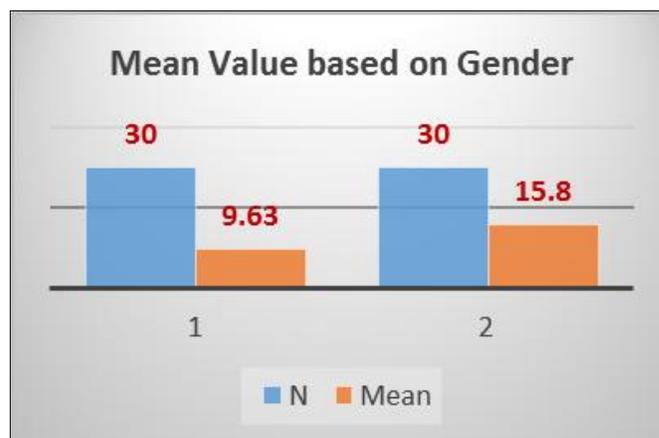


Fig 3

Table 4 shows Mean values, SDs and t' value of parents on awareness level with respect to gender. As the obtained t-value i.e. 3.37** is more than that of the table value, and its p-value is <0.001353, it can be inferred that, there is

statistically significant difference at 0.05 level between the male and female parents. A close observation of the mean values reveals that male parents shows more awareness as compare to the female parents.

Table 5: Awareness level based on the Socio-Economic status of the Parents

Awareness Level	Socio-Economic Group					
	Lower 19		Middle 25		Upper 16	
	N	%	N	%	N	%
No Awareness	8	42.11	6	24	2	12.5
Low Awareness	7	36.84	8	32	7	43.75
Moderate Awareness	3	15.79	5	20	4	25
High Awareness	1	5.26	6	24	3	18.75

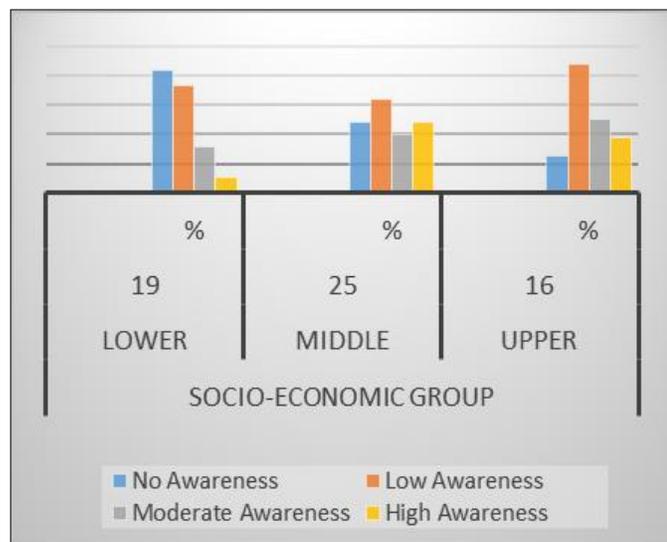


Fig 4

Table 5 shows the percentage of awareness level based on the Socio-Economic status of the Parents of children with special needs. The socio-economic status is divided into 3 groups such as Lower, Middle and Upper groups. 19 parents fall under Lower group, out of which 42.11% (8) showed No awareness, 36.84% (7) Low awareness, 15.79% (3) Moderate awareness and only 5.26% (1) showed high awareness. 25 parents come under Middle group, out of which 24% (6) showed No awareness, 32% (8) Low awareness, 20% (5) Moderate awareness and 24% (6) showed high awareness. In this group no difference has been found among parents between No awareness and high awareness level. 16 parents fall under Upper socio-economic group, out of which 12.5% (2) showed No awareness, 43.75% (7) Low awareness, 25% (4) Moderate awareness and only 18.75% (3) showed high awareness. In this group slight difference has been found among parents between No awareness and High awareness level.

Findings of the study

It has been found that there is a significant difference of awareness level among the parents. Only 16.67% parents having high awareness level whereas 26.67% parents belongs to No awareness group.

It is also found that there is a statistically significant difference between parents based on the age groups. Parents

belong to age group of 18-30 shows more awareness as compare to the parents belong to age group of 30 and above. The statistically significant difference was also found among parent's groups with reference to gender. Observation of the mean values reveals that male parents show more awareness as compare to the female parents. The difference in percentage of awareness level based on the Socio-Economic status of the Parents of children with special needs also found. Observation of percentage value showed the lower group have less high awareness as compare to middle and upper groups, whereas percentage of no awareness level found more. Difference is not found between no awareness and high awareness level in the middle group.

Conclusion

This study revealed that there is lack of awareness about the National Trust Act 1999 among the parents of children with special needs. By the data analysis, it is also found that there is significant difference of awareness level among the parents with respect to Age, Gender and the socio-economic status of the parents.

Suggestions

The result of the study indicates that the parents of children with special needs are lagging behind the awareness and knowledge about various scheme and provision of the National Trust Act 1999. As parents are closest of the close to their children, they must have knowledge and awareness regarding their children's rights. So there must be some awareness programme conducted on the schemes and provisions of the Trust, which provide various rights and safety measures for children with MR, Autism, CP and MD. So that the parents worries would be reduced to some extent. This study can also be conducted on large sample to generalize the finding of results.

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