

Original Article

FAMILY AWARENESS OF LEGISLATIVE ISSUES ON CHILD WITH CEREBRAL PALSY: CROSS SECTIONAL SURVEY

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ABSTRACT

A disability is restriction or lack of ability to perform an activity in a manner or within the range considered normal for a human being. The prevalence of disability is 7 per 1000 live births in India. 20% are not aware about the legal issues for person with disability in developing countries. It has never received adequate attention from society. Ignorance, lack of awareness and lack of knowledge make the disability invisible. Most of the authorities appointed the legislation are not fully functional. This study was to find out family awareness of legal rights of person with disability to ensure dignity and legal rights.

224 legal adult family members were surveyed through schedule method with a questionnaire about disability and acts (Person with disability act, mental health act, united nation convention of person with disability and national trust act) of Indian constitution including awareness. The questionnaire consisting of 20 questions about these acts were content validated for these purpose. The data were analyzed by using percentage values to make interpretation.

Out of 224 surveyed 72.32% (162) did not know about the Indian constitution for disabled people. Remaining 27.67% (62) knew about the acts and only 11.60% were getting benefitted from such acts. Family awareness about legislation in child with disability is less and needs immediate attention to improve quality of life and rehabilitation of persons with disabilities.

KEYWORDS: Person with disability, Legal rights.

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INTRODUCTION

A disability is restriction or lack of ability to perform an activity in a manner or within the range considered normal for a human being.¹ According to the Census 2001, there are 2.19 thousand people with disabilities in India who constitute 2.13 % of the total population. 1.8% (49-90 million) of the Indian population- National Sample Survey Organization (NSSO).²

Disability occurs in every society throughout the world and has done so down through the centuries. Common responses have been shame, prejudice and exclusion from community life. As we have discovered in industrialized countries, the millions of pounds which have

been spent on services and the veritable army of professionals that have been recruited, have not resulted in fulfilling those rights. Our institutions, our special schools, our sheltered workshops have not created a full and decent life for people with disabilities. And so we look to the bold new approach of community care to fulfill that aspiration. Likewise in developing countries, 90% of the world's citizens with disabilities live.³

In 1993, 3D Projects carried out a study of knowledge, attitudes and practice in three areas in Jamaica (Thorburn, 1993).⁴ The findings are of interest, especially in relation to two previous qualitative studies carried out in 1987 and 1992.

These had indicated that some of the main parental experiences which militated against parent involvement included lack of a supportive family, poor experiences with services at the time of discovery of their child's disability, misunderstanding of the nature of disability and the scope and possibilities of rehabilitation (Terwindt, 1992). In conclusion, the main barriers to community integration were seen to be:

- some persistent supernatural beliefs;
- the lack of awareness of the possibility that community and home based services can be effective;
- the persistent belief that special institutions are best;
- the lack of recognition of some human rights, particularly to full participation, integration and equality of opportunity.^{5,6,7}

India, often described as an emerging superpower, has a population of one billion, out of which approximately seventy million are characterized as disabled. Public consciousness of the issues and concerns that affect the lives of those with disabilities is a fairly recent phenomenon. It was only in the forty-ninth year of India's independence that the first legislation advocating equal rights for disabled people came into effect. Though notified five years ago, the act still awaits proper implementation. Notwithstanding the legislation, the State continues to be largely apathetic.⁸ Owing to a complete lack of public planning, responsiveness to any special condition such as disability is missing. Consequently, the physical environment is largely inaccessible and inconvenient.

Dissemination of information in formats accessible to people with sensory impairments is very restricted. For instance, there is a single televised sign-language news bulletin per week for people with hearing impairments. The range of accessible reading materials for people with vision impairments also is extremely limited. The non availability of other assistive technology devices such as electrically powered wheelchairs at an affordable price adds to the miseries experienced by disabled people.⁹ An example of indifference is the nationwide protests that people with disabilities had to engage in order to be counted in the forthcoming census.

Notwithstanding some small steps toward inclusion, the lives of disabled people remain mired in humane patterns of helpless cynicism, political inertia, and resistance to social innovation. In this climate, long-term solutions are neither sought nor found. The State continues to rely on the voluntary sector for the provision of basic services for disabled people, although this sector, stretched beyond its resources, is unable to serve even a miniscule proportion of those in need. Needless to say, the disabled are relegated to the margins in every avenue of opportunity, be it education, employment, transportation, or any other significant life area. While disability advocates in the developed world have progressed from issues of service delivery and rehabilitation to an engagement with the multiple nuances/ meanings of disabled existence, the developing world continues to agonize over securing the very basic elements that disabled people need to survive. Thus, the meaning of disability in India is embedded in this basic struggle for survival.^{7,10}

For poor families with a hand-to-mouth existence the birth of a disabled child or the onset of a significant impairment in childhood is a fate worse than death. The situation worsens because in addition to hopeless life conditions, disabled people often have to contend with cultural constructions marked by negativity and stigmatization.¹¹ Within the Indian cultural context, disability implies a "lack" or "flaw" leading to a significantly diminished capability; images of the disabled also are associated with deceit, mischief, and devilry.¹² Even today, many institutions regularly receive food, old clothes, and money from society at large, which makes these charitable gestures not out of a sense of commitment to the issue of disability but as a response to a cultural expectation to do one's *dharmic* (religious) duty toward the needy, in the same spirit as one would give alms to beggars.

Even now, most government efforts are targeted at strengthening nongovernmental organizations without making any direct interventions. Western disability studies often fail to comprehend the reality of disability in India, which is marked by a complex amalgam of class, gender, and caste issues. 40% of the parents are not aware about the legal issues for person with

disability in developing countries. It has never received adequate attention from parents, relatives and people living in surroundings. Ignorance, lack of awareness and lack of knowledge make the disability invisible. Most of the authorities appointed the legislation are not fully functional.

MATERIALS AND METHODS

Study design: Cross sectional survey

Study setting: Department of Pediatric physical therapy, Dhiraj general hospital, Sumandeep vidhyapeeth, Vadodara.

Selection criteria: Legal adult family members of children diagnosed with cerebral palsy, volunteering to participate in survey after signing informed consent form.

Sample size: 112 legal adult family members of cerebral palsy subject between May 2011 and October 2011.

Method of data collection: Personal interview with questionnaire made for this purpose.

PROCEDURE: The study was approved by institutional ethical committee of Sumandeep vidhyapeeth, Vadodara. Legal adult family members of various CP children visiting the department were asked to participate voluntarily. Cerebral palsy, defined in person with disability acts subjects was included for this survey. The family members of CP subjects were included in survey after signing the informed consent form. The questionnaire was prepared for this study and was content validated for these purpose. The questions were asked by the principal investigator.

Following introductory questions were asked,

1. Age Group

18 – 27/ 28 – 37/ 38 – 47/ 48 – 57/ 58 – 67

2. Sex

Male & Female

3. Literacy Level

Illiterate, School, Graduate & Post Graduate

4. Are You Aware About These Acts?

Yes / No

They were surveyed through schedule method with a questionnaire about four acts:

1. Person with disability act,

2. Mental health act,

3. United nation convention of person with disability and

4. National trust act of Indian constitution.

Following questions were asked for the acts:

1. How do you know about this act?

By NGO/school/media

2. What you have done to reach the benefit of this act?

Help of NGO/ Negotiation with government/ Fighting with the government

3. Are you getting benefit of this act?

Yes/no

4. Are you satisfied with the benefits of act?

Strongly Agree/ Agree/ Neutral/ Disagree/ Strongly Disagree

The answers of the client were noted in questionnaire form and were analyzed.

FINDINGS : The data analysis was done by using Microsoft office excel 2007. They were analyzed by using percentage values to make interpretation. All introductory questions were interpreted in pie charts. Graphical presentation was made for acts' questions. Moreover, various disabilities were presented in graphs.

Fig. 1: Distribution of age.

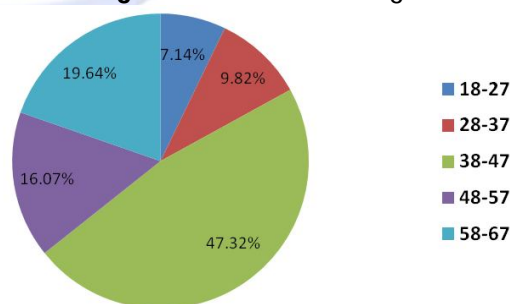


Figure shows distribution of age out of 112 legal adult family members of CP.

Fig. 2: Sex distribution.

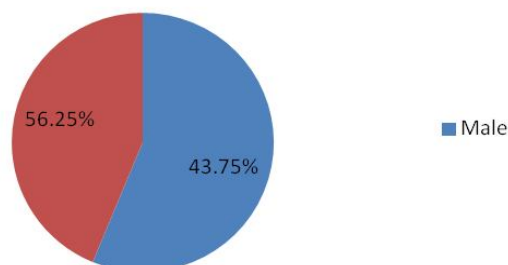


Figure shows distribution of sex out of 112 legal adult family members of CP.

Fig. 3: Distribution of literacy level.

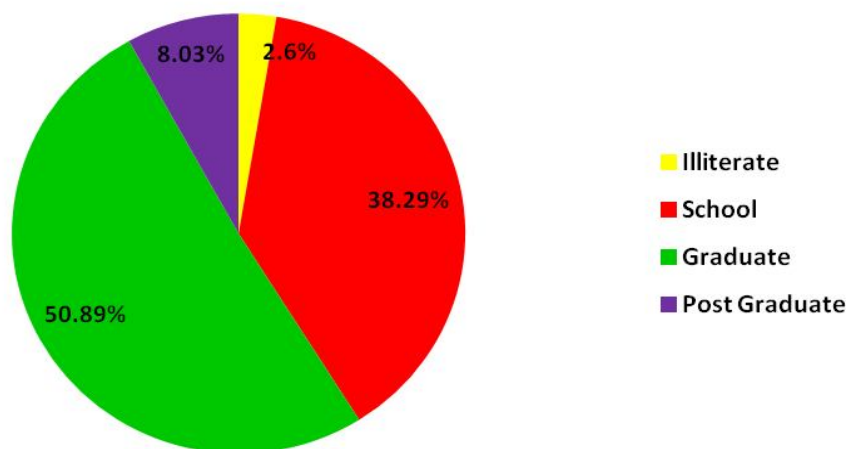


Figure shows distribution of literacy level out of 224 legal adult family members of CP.

Fig. 4: Distribution of awareness about acts.

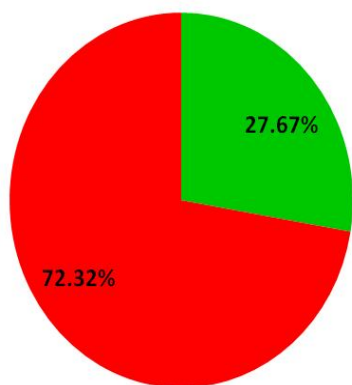


Figure shows percentage value of people who know about acts (27.67%) and who do not know about acts (72.32%).

Fig. 5: Distribution of question 1.

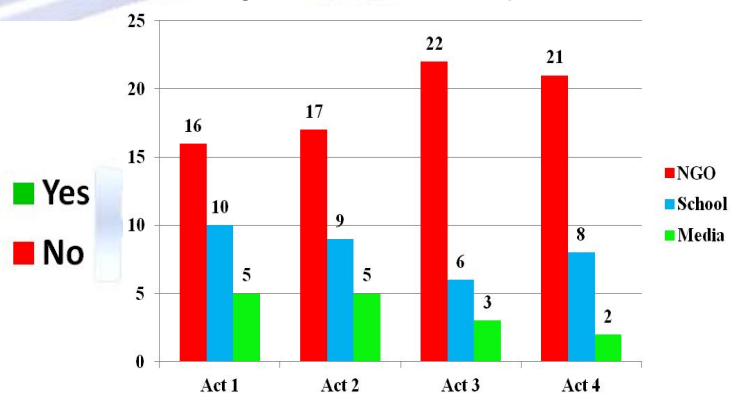


Figure shows distribution of question 1, says how do you know about this act? It shows that more people came to know through NGO about these acts, 15-20% came to know from schools and very least people through media.

Fig. 6: Distribution of question 2:

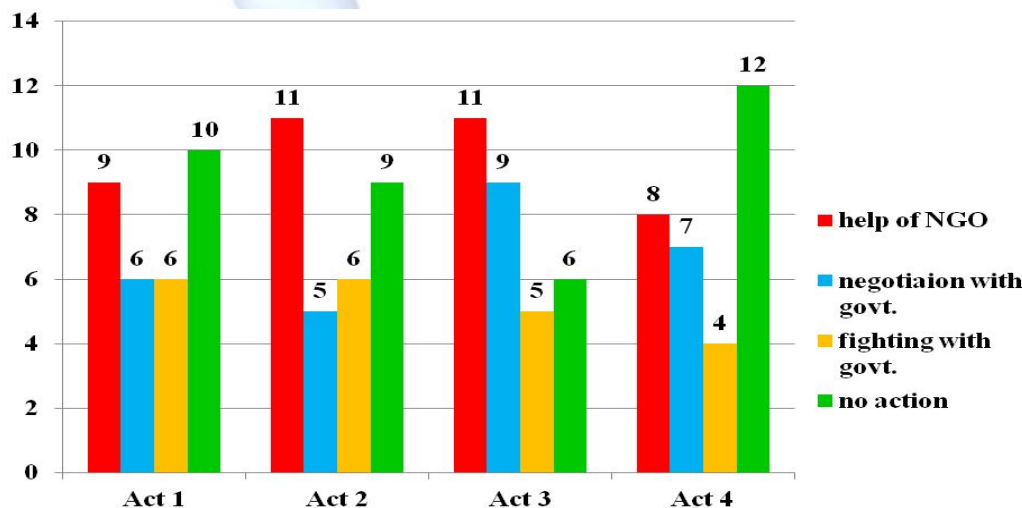


Figure shows distribution of question 2, what you have done to reach the benefit of this act? It shows different peaks of columns. Out of that highest peak suggests people took help from the NGOs more to reach the benefits of acts except for national trust act of Indian constitution. For this act people didn't take any action.

Fig. 7: Distribution of question 3:

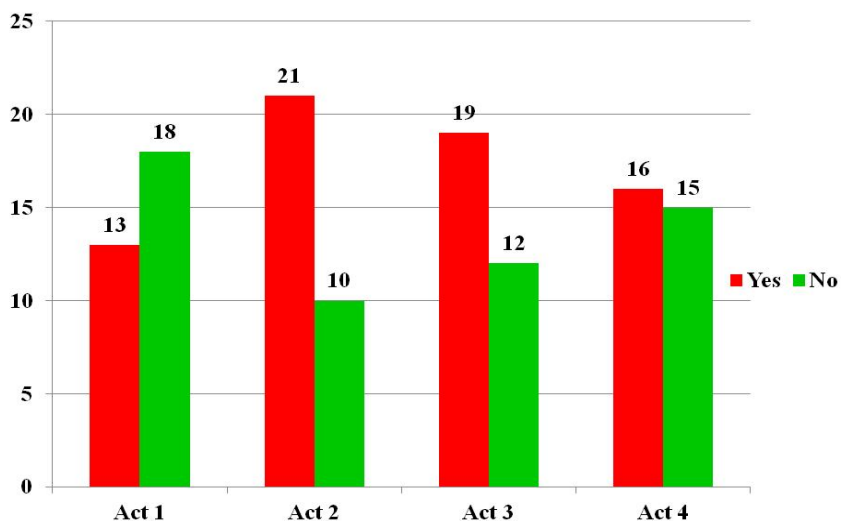


Figure shows distribution of question 3, are you getting benefit of this act? In this for act 1 less of the people got benefits. For act 2 more people got benefits. For act 3 and 4 more people got benefits.

Fig. 8: Distribution of question 4:

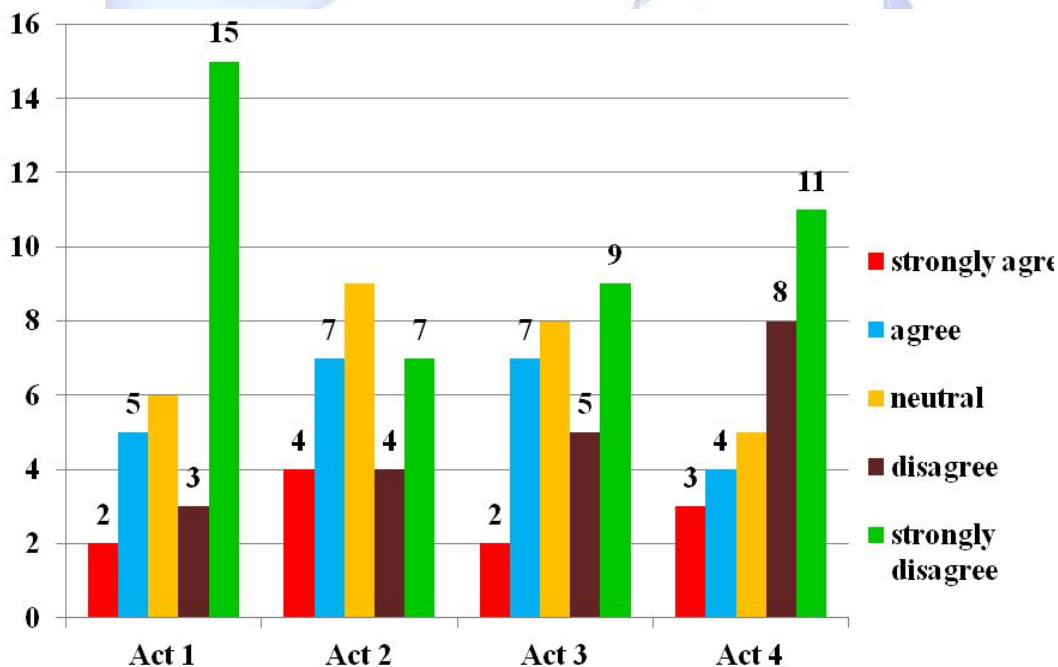


Figure shows distribution of question 4, are you satisfied with the benefits of act? For this maximum people didn't satisfy with the acts for all acts.

DISCUSSION

The purpose of this study was to find out family awareness on legal rights of child with disability. The implication of this study may ensure the dignity and legal rights of disabled people. The cross sectional survey was done to find out the awareness among the family members of disabled people. Content validated questionnaire was made to carry out the study. Four laws of

disability were included for the study which involves United nation convention of person with disability, Person with disability act, Mental health act and National trust act. All participants (N=224) were surveyed through personal interview. Result of the survey found that most of family members of disabled people do not know about the acts made for person with disability.

Although many people knew about the legislation of disabled, they were unable to reach the benefits of different laws of disability.

Disability occurs in every society throughout the world and has done through the century. Approximately 10% of world's population is person with disability. India has a population of billions, out of which approximately 70 million characterized as disabled. Disabled people are facing problems of social inclusion throughout the nation. That may due to lack of awareness of family members and / or community. Study shows that to be the lack of recognition of some human rights particularly to full participation, integration and equality of opportunity.¹⁴

Disability is an evolving concept, and that disability results from the interaction between persons with impairments and attitudinal and environmental barriers that hinders full and effective participation in society on an equal basis with others'. Public consciousness of issues may affect the lives of those with disabilities. Indian government has been provided opportunities for disabled but the physical environment is largely inaccessible and inconvenience. In spite of that images of the disabled in India are associated with diminished capability of disabled.

Survey includes personal interview with the questions of four different laws along with demographic data and literacy level. Result led to interface that out of 224 people, 162 people (72.32%) did not know about the acts. Remaining 62 people (27.67%) only knew about the acts. Among them nongovernmental organizations was the commonest way to communicate with the people. Most of the people came to know about the acts through the nongovernmental organizations and least from the media. So it has been suggested that media was very less effective communicating bridge in India.

Persons with disabilities are not viewed as "objects" of charity, medical treatment and social protection; rather as "subjects" with rights, who are capable of claiming those rights and making decisions for their lives based on their free and informed consent as well as being active members of society. Participation is important to correctly identify specific needs,

and to empower the individual. However, as shown in result, though people were getting benefits from the laws of constitutions, they were not satisfied with the benefits of acts. Many people did efforts to reach the benefits of these acts, but they left their efforts in midway due to lack of not taking any action.

There is need for implementation of Convention principles in the internal operations of organization and also there is great need to include persons with disabilities in all stages of implementation, and build capacity of organizations of persons with disabilities to do so. In conclusion, this study provided data that family awareness is still lacking among disabled people. Efforts made for creating awareness from government and / or nongovernmental organizations are still need to be more efficacious.

Suggestions for future study:

- Parents counseling can be useful at the time of birth / (before birth along with PPTCT) for all high risk babies.
- Counseling of different laws of Indian constitution for disability can be given to the family members of CP children.
- Health care professionals can be educated about legislative issues of disability.
- Awareness of different laws of disability can be created in future to fight for rights of disability.

CONCLUSION

Out of 112 surveyed 72.32% (81) did not know about the Indian constitution for disabled people. Remaining 27.67% (31) knew about the acts and only 11.60% were getting benefitted from such acts.

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Through this thesis, I acknowledge my strengths and weaknesses as this task has been fulfilled only by the grace of The Almighty and I praise Him for leading me through.

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Conflicts of interest: None

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