

Building Legal Capacity and social networks among caregivers of Persons with Intellectual or Development Disabilities (PwIDDs) for Social Transformation

Dr. S. Joyce Jeyarani,

Assistant Professor, Madurai Institute of Social Sciences, Madurai

Abstract

We are living in a period of transformation, with new paradigms arising in the area of human rights, knowledge, and networking. The Persons with Intellectual or Development Disabilities (PwIDDs) face discrimination, denial, stigmatization and they remain as the most marginalized in the society. To change this scenario, co-building is needed for Social Workers to work with caregivers of PwIDDs to bring transformation, by enabling them to recognize the legal capacity to attain social, educational and economic inclusion through social networks. To bring social transformation, the researcher did a study 60 caregivers of PwIDDs at Madurai to initially know the level of awareness on legislative provisions and social networks among caregivers by adopting simple random sampling technique. Quasi Experimental Research design was used. It was found that majority of the caregivers were unaware of legislative provisions and social networks for them. So, an awareness session was conducted for caregivers of PwIDDs, on legal capacity building and they were linked with social networks to benefit each other. The post evaluation results showed that the level of awareness on legal capacity for PwIDDs and social networking was improved among caregivers. The research study suggests that social transformation could be achieved by co-building with caregivers of PwIDDs, for transformation of the marginalized in the society, to have inclusiveness of PwIDDs by building legal capacity and social networks.

Keywords: Legal Capacity, Awareness, Social Networks, caregivers, Persons with Intellectual or Development Disabilities.

1. Introduction

Disability, according to the World Health Organization (WHO), is a broad word that encompasses impairments, activity limitations, and participation restrictions. Intellectual impairment is a condition in which both intellectual performance and adaptive behaviour are severely limited. Reasoning, learning, and problem solving are examples of intellectual functioning. Adaptive behaviour encompasses a wide range of daily, social, and practical abilities. This covers Specific Learning Disabilities (SLD) and Autism Spectrum Disorder (ASD). Development Disability is the one that occurs during childhood. A mental or physical handicap, such as Cerebral Palsy or Mental Retardation, that interferes with normal physical, intellectual, or emotional development usually lasts the rest of one's life.

The majority of people with other problems, such as vision, hearing, or locomotion, do not have comprehension issues, but those with Intellectual and Developmental Disabilities do, in varied degrees, in mild, moderate, and severe categories. As the world becomes increasingly digital, PwIDDs face a common problem: Digital Inclusion.

Special legislative provisions for persons with Disabilities can be found in many laws, such as Civil, Criminal, and Contract law. The United Nations Convention on Rights of Persons with Disabilities (UNCRPD) in 'Article 12 states Equal recognition before the law'. "Legal capacity" is the legal word for the ability to make decisions. Self-determination and full citizenship are important elements that underpin the potential enjoyment of human rights for

people with intellectual and developmental disabilities.

Individuals with Intellectual Disabilities (ID) continue to be the most marginalised members of society. Mental retardation/ ID, Autism/ ASD, and Multiple Disorders with ID as one of the disabilities are examples of intellectual disabilities. These people have one or more disabilities, such as poor cognitive

ability, sensory integration issues, and poor communication skills. As a result of all of this, they are unable to communicate themselves and comprehend the ways of the world. The social stigma associated with intellectual disability makes it much more difficult for people with intellectual disabilities to achieve educational, social, and economic inclusion.

Population of persons with disabilities in India as per census 2011:

In Seeing	5032463
In Hearing	5071007
In Speech	1998535
In Movement	5436604
Mental Retardation	1505624
Mental Illness	722826
Any Other	4927011
Multiple Disability	2116487
TOTAL	26810557

2. Review of Literature

Angothu H, Chaturvedi SK (2016) states that Regardless of the cause of disability, caregivers for people with disabilities are critical in the healing and rehabilitation process. Their services are equally crucial as of the health experts. Caregivers often bear the brunt of the burden, assisting with daily needs of persons with disabilities in addition to providing financial and social support to their disabled dependents. They may have to renounce their opportunity to attend employment of their choosing, earn money, advance in their careers, have a satisfying social life, and even spend time leisurely while caring for others. However, civic societies and governmental systems have paid less attention to the informal caregiving process and caregivers as service providers for people with disabilities. However, recent changes in this field have been brought about by a shift in the paradigm of caregiving from family responsibility to society's collective responsibility, as well as a stronger voice of caregiver associations.

Kuppusamy B,B. et. al (2012) found that in India, There is a fair amount of knowledge on legal issues. Respondents with a higher level of education were more aware of laws than those with a lower level of education.

Because of their direct utility in their day-to-day operations, respondents were more aware of their direct utility in their day-to-day activities

T. Lippold and J. Burns (2009) found that the Adults with Intellectual disability had more restricted social network than adults with physical disability. Social Support for the persons with Intellectual Disability was given only by the family members.

3. Research Methodology

3.1 Objectives

1. To understand the socio demographic characteristics of the caregivers of the PwIDDs.
2. To find out the level of awareness on various legislative provisions and social networks among the respondents
3. To give awareness to the caregivers of PwIDDs on legal capacity and social networks.
4. To find the level of awareness on various legislative provisions and social networks among the caregivers of PwIDDs after the awareness program and networking.
5. To suggest suitable measures for building legal capacity of caregivers of

PwIDDs and social networking for social transformation in the society.

3.2 Research Design

Quasi Experimental Research Design was adopted for the study. The level of awareness about the legal capacity and social network was studied among the caregivers of PwIDDs. Later, an awareness program was arranged online, aiming at building the legal capacity of the caregivers as well as the social networks. After the awareness program, the level of awareness on Legal capacity and social networks was found to be high among the caregivers of PwIDDs.

3.3 Universe and Sampling

All the caregivers coming to a particular psychiatric nursing home and to a particular Counseling centre in Madurai constitute the universe. There were around 70 caregivers who had persons with Intellectual or Developmental Disabilities (PwIDDs).

Simple random sampling technique was used to do the study among 60 caregivers of PwIDDs.

3.4 Tools for Data collection

A self developed questionnaire was prepared by the researcher to know the level of awareness about the Mental Health Legislative provisions among the caregivers and the social networks. It had socio demographic characteristics as well as questions related to awareness level on legal capacity and social networks.

4. Findings

4.1 Findings related to Socio Demographic variables:

- More than half of the PwIDDs (58%) were females
- Majority (61%) of the caregivers were males
- 42% of the caregivers were belonging to 36 to 45 years of age, 33% of the respondents were belonging to 56 to 65 years of age and the remaining 25% of the caregivers were belonging to 46 to 55 years
- 42% of the respondents had children with Mental Retardation, 33% of them had children with cerebral palsy and 25% of them had children with Autism

spectrum disorder, Attention Deficit Hyperactive Disorder (ADHD).

- Majority (75%) of the respondents were from urban area, 17% of them were from rural area and only 8% of them were from Semi urban area
- 42% of the respondents were earning upto Rs. 30000/- per month, 25% of them had their monthly income between Rs. 30001 and Rs. 60000, 15% of the respondents had their monthly income between Rs. 60001 and Rs. 90000 and another 15% of the respondents had their monthly income above Rs.90000
- 42% of the PwIDDs had no siblings, another 42% of the PwIDDs had only one sibling, 8% of the PwIDDs had two siblings and another 8% of the PwIDDs had more than two siblings
- 34% of the respondents had education upto secondary level. 25% of the respondents were graduates, 17% of the respondents were post graduates, 8% of the respondents had education upto Primary level, another 8% of the respondents had education upto Higher secondary level, another 8% of the respondents had their education upto doctorate level.
- Half of the respondents (50%) were government employees, 42% of them were working in private concerns and the remaining 8% were homemakers.
- Majority (75%) of the respondents were living in a nuclear family set up
- Half of the PwIDDs (50%) were put in regular schools, 25% of the PwIDDs were kept at home, 17% of the PwIDDs were in Special school and only 8% of the PwIDDs were in colleges.

4.2 Findings related to Willingness to attend an Awareness program

- Majority (83%) of the respondents showed their willingness to attend a session on Legislative provisions for the PwIDDs
- Majority (83%) of the respondents showed their willingness to attend the

awareness session through online mode only.

4.3 Findings related to Legal Capacity: (n=60)

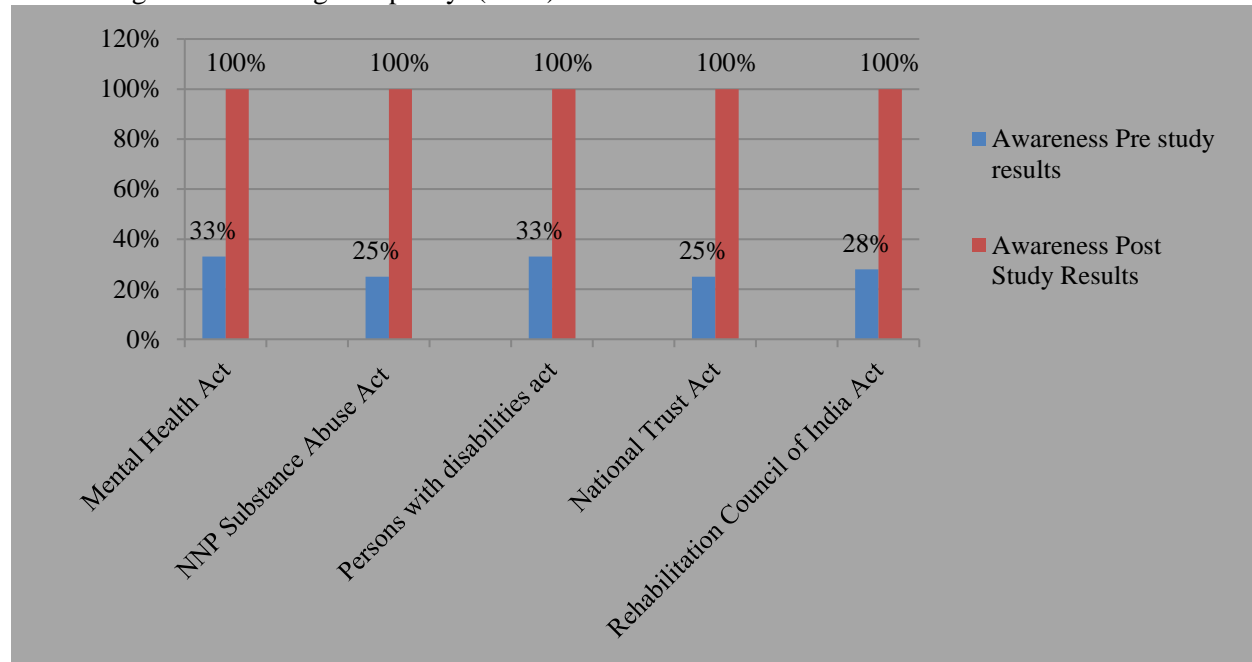


Figure 1: Findings related to level of awareness among care givers on Legal Capacity before and after the awareness program

Figure 1 depicts the level of Awareness among care givers on Legal Capacity of PwIDDs before the awareness program and after the awareness program. It was found before the Awareness program that only 33% were aware of Mental Health Act, only 25% of caregivers were aware of National Narcotic and Psychotropic Substance Abuse Act, 33% of caregivers were found to be aware of persons with Disabilities act, 25% of caregivers were aware of National Trust Act for persons with Autism, Cerebral Palsy, Mental Retardation and Multiple disabilities act and 28% of caregivers were aware of Rehabilitation Council of India Act.

But after the Awareness program done online among the caregivers, they (100%) became fully aware of Mental Health Act, National Narcotic and Psychotropic Substance Abuse Act, Persons with Disabilities Act, National Trust Act for persons with Autism, Cerebral Palsy, Mental Retardation and Multiple Disabilities Act and Rehabilitation Council of India Act.

4.4 Findings related to Social Networks before Awareness Program (Pre- Study):

- Majority (75%) of the respondents were not in any social networks, where only 25% of the respondents were associated with Social Networks
- Majority (75%) of the respondents were liked to be part of any social networks

4.5 Findings related to Social Network after awareness program: (Post Study)

- All the respondents (75%) who were willing to be part of Social network were linked with social networks of their choice.

5. Salient Findings

- The overall level of awareness about legislative provisions was found to be 28.8% before the awareness program. The legal capacity was improved among the caregivers through an awareness program. After the awareness program, the legal capacity was found to be 100% among the caregivers.
- Majority of the caregivers (75%) were not part of any social network but after the awareness program, majority of

them (75%) were linked to social network of their choice.

6. Suggestion

Free counseling centers for parents or caregivers and people with intellectual and developmental disabilities are needed, as well as services delivered to their homes to help them build their legal capacity and assure full involvement in all parts of their lives.

Rehabilitation specialists, teachers, lawyers, and other concerned government and non-government officials should be well-versed on the legal provisions for people with disabilities, particularly people with intellectual and developmental disabilities. By doing so, individuals will improve their legal ability by engaging in significant social and political activities on an equal and complete basis.

7. Conclusion

The most crucial connection in bridging the gap between human rights and the legal guardianship framework is parents or caregivers. If parents or caregivers are made aware of the functionalities involved in the decision-making process, they can teach their son or daughter with ID to make simple routine decisions at the very least. The responsibility of the government is to empower the caregivers with legal capacity.

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