The rights of persons with disability bill, 2014: Implications for neurological disability

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Abstract

India ratified the United Nations Convention on the Rights of Persons with Disabilities (UNCRPD) in 2007. This is a welcome step toward realizing the rights of the persons with disability. The UNCRPD proclaims that disability results from interaction of impairments with attitudinal and environmental barriers, which hinders full and active participation in society on an equal basis with others. Further, the convention also mandates the signatory governments to make suitable changes in the existing laws of the country, to identify and eliminate obstacles and barriers, and to comply with the terms of the UNCRPD in order to protect the rights of the person with disabilities, hence the amendments of the national laws. Hence, the Government of India drafted the Right of Persons with Disabilities Bill (RPWD Bill), 2014. It is evident that neurological disorders are emerging as priority health problems worldwide. They not only contribute to mortality but also contribute to huge morbidity. Further, shortage of neurologists, huge treatment gap, and stigma add to the burden. The situation becomes worse with regard to providing quality care, comprehensive rehabilitation, and social welfare measures to persons with neurological disability. There is no doubt that persons with neurological disability do not get adequate representation, stigmatized and discriminated across the civil societies, which hinders full and active participation in society. Hence, this article is a critique of the RPWD Bill, 2014 from the perspective of persons with neurological and neurosurgical disability. Further, this article also discusses challenges in quantifying and certifying disability in neurological disability.

Key Words

Disability, neurological disability, persons with neurological disability

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Introduction

The first ever world report on disability, produced jointly by the World Health Organization and the World Bank, suggests that more than a billion people in the world today experience disability. This report highlights the very fact that people with impairment face disability largely because of lack of services available to them in the society and also the attitudinal and environmental barrier they face in their everyday lives. [1,2]

The United Nations General Assembly adopted a landmark treaty on the Rights of Persons with Disabilities in December 2006, which is titled as the "United Nations Convention on

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the Rights of Persons with Disabilities (UNCRPD)."[2] The convention acknowledges that "disability" is an evolving, dynamic, and complex phenomenon. This convention also makes a paradigm shift from "charity"-based approach to "rights"-based approach for persons with disability, thus the dawn of new era. [3] The scope and coverage of the convention are very vast and it recognizes unequivocally the right of people with disabilities to dignity, to live in the community, to exercise their legal capacity, and to ensure their full and

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equal enjoyment of the rights recognized in the convention. The UNCRPD mandates to change the existing laws to bring them in conformity with the principles of the convention.^[2] In October 2007, India ratified the UNCRPD, [4] which has placed an international obligation to amend the existing law, Persons with Disability Act, 1995 to bring them in conformity with the principles of the convention. Hence, the process of drafting the new law started over a few years back in 2009 when a committee was set up by the Union Ministry of Social Justice and Empowerment. Now, the draft bill titled, "The Right of Persons with Disabilities Bill, 2014" (RPWD Bill, 2014) is placed before the parliament. [5] This article critically reviews the RPWD Bill, 2014 from the perspective of neurological disabilities to provide justice for persons with neurological disabilities. The article also discusses various challenges in quantifying and certifying disability in neurological disability.

Neurological Disorders and Disability

The World Health Organization in its landmark report on neurological disability titled, "Neurological disorders: Public health challenges" states that about one billion people worldwide suffer from neurological disorders and that 6.8 million people die annually from these disorders. [6] This report also highlights the change in trends over the next two decades. As per the estimates, the disability-adjusted life years (DALY's) was highest in stroke, Alzheimer's, and other dementias, epilepsy, migraine, and neuroinfections in that order. Multiple sclerosis and Parkinson's disease also had almost similar DALY's. The projections for 2030 are increased in global burden of stroke, Alzheimer's disease, and other dementias, and Parkinson's disease while reduction in neuroinfections is expected. Thus, there will be rise in the disability associated with these disorders. Neurological illnesses not only contribute to mortality but also contribute to huge morbidity because of their unique characteristics such as chronicity, progressive degeneration, limited therapeutic options, and lack of specific treatment for many diseases.[7] Further, shortage of neurologists, huge treatment gap, and stigma add to the burden. The epidemiological transition from communicable to noncommunicable diseases has caused paradigm shift in the global burden of illness. It is now evident that neurological disorders are emerging as priority health problems worldwide.[8-10]

In India, with more than 1.2 billion population, changing pattern of illness to more prevalent noncommunicable disorders has raised alarm. [9,11] Among the noncommunicable disorders, neurological disorders have been recognized to lead to significant mortality, morbidity, disability, and socioeconomic loss.[7] The neurological disabilities are unique and affect multiple domains of day-to-day functioning such as mobility, disturbance of cognition and behavior, causing pain, altered consciousness, bladder and bowel dysfunction, and inability to perform activities of daily living. [6,12] Neurological disability occurring in epilepsy, [13] neuroinfection, [14] cerebrovascular disorders,[15] migraine,[16] dementia,[17] Parkinson's disease,[18] motor neuron disorder,[19] traumatic brain injuries,[20] neuromuscular disorders,[21] demyelinating disorders,[22] and neurological disorders consequent to nutritional deficiency and exposure to neurotoxic substances contribute to significant burden.^[7] The prevalence rate of neurological disorders varies from 967 to 4070 per 100,000 population. However, most of these surveys have not included prevalence of infections and traumatic injuries of the brain. [7] In a landmark population-based neuroepidemiological survey, a total of 102,557 individuals in urban and rural Bengaluru in Southern India were included to determine the prevalence and pattern of neurological disorders. The prevalence rates per 100,000 population of the most frequent disorders in the descending order of frequency were headache, epilepsy, febrile convulsions, cerebrovascular disorder, and mental retardation.[23] There are only a few published reports on the magnitude and severity of disability consequent to neurological disorders. One hospital-based, 6-month follow-up study reported that the disability persisted in 79%^[24] and after 12 months the disability persisted in 60% of the patients treated with neurological/neurosurgical disorders. [25] The economic aspect of the burden of neurological disorders is huge. The annual cost of treatment of epilepsy per patient was found to INR 13755/- in one systematic study. [26]

The Rights of Persons with Disability Bill, 2014 and Neurological Disorders

Neurological disability was not taken as a separate entity under the Persons with Disability Act, 1995, but it is grouped under locomotor/orthopedic disability defined as "Persons inability to execute distinctive activities associated with moving both himself and the objects, from place to place, and such inability resulting from affliction of musculoskeletal and/or nervous system." However, the RPWD Bill, 2014 recognizes the lacuna in earlier bill and listed neurological and related disorders such as cerebral palsy, chronic neurological conditions, intellectual disability, locomotor disability, muscular dystrophy, multiple sclerosis, and speech and language disability in the bill. [27] Although the UNCRPD inspires to adopt social model for disability, RPWD Bill, 2014 adopts both medical (by including neurological illness) and social model for disability conceptualization.

Ambiguous Definition on Chronicity and Recurrence

The bill defines "chronic neurological conditions" as a condition that has its origin in some part of person's nervous system lasting for a long period or marked by frequent recurrence.[27] Although the RPWD Bill, 2014 recognizes above "chronic neurological conditions," it fails to specify the duration of illness or defining the frequency of recurrence. This ambiguity may hinder the certification process or may be misused for the purpose of welfare benefits. There is an urgent need to clarify this issue in the Bill because, in the era of consumerism, any time the certificate issued can become a part of legal proceedings. Multiple sclerosis has been included separately in the 2014 bill indicating special attention being paid to the illness, due to reasons best known to the persons involved in formulating the bill. In continuation with the principle of the UNCRPD about the "social model" of disability, the emphasis should have been on disabilities occurring as a result of multiple sclerosis and not the illness per se. More appropriately, all neurological illnesses such as multiple sclerosis and muscular dystrophy should be included in under the umbrella term: Chronic neurological illness/progressive neurological illness/remitting-relapsing neurological illness. The neurological illness can be described as any illness occurring as a result of involvement of the central nervous system (brain and spinal cord) and peripheral nervous system (which would include all motor neuron diseases [postpolio residual paralysis, amyotrophic lateral sclerosis being the most common] and neuromuscular disorders including muscular dystrophies).

Traumatic Brain and/or Spinal Injury

The Individuals with Disabilities Education Act, 2004 (IDE Act, 2004) of the United States of American ensures students with disability are provided with free and appropriate public education that is tailored to their individual needs.[28] This IDE Act recognizes "traumatic brain injury (TBI)" and defines it as "an acquired injury to the brain caused by an external physical force, resulting in total or partial functional disability or psychosocial impairment, or both, that adversely affects a child's educational performance. The term applies to open or closed head injuries resulting in impairments in one or more areas, such as cognition, speech and language, motor abilities, psychosocial behavior, physical functioning, and information processing. The term does not apply to brain injuries that are congenital or degenerative or to brain injuries induced by birth trauma."[29] Unfortunately, RPWD Bill, 2014 has not enlisted TBI in neurological disorders in spite of neurological disability occurring as sequelae are high, multiple, and grave. TBI is considered as one of the three epidemics because of the emerging health trends. The other two being an increase in age-related dementia and an increase in the stroke incidence.^[30] As compared to other two, TBI occurs more often in young adults leading them disabled for several years. However, the treating neurophysicians/neurosurgeons are forced to take refuge under "chronic neurological conditions" to issue disability certificate.

Legal Capacity and Neurological Disability

Article 12 of the UNCRPD enumerates equal recognition before the law, which is an important article for persons with disability. The same issue is reduced to "legal capacity" in Clause 12 of the RPWD Bill, 2014, which articulates that the persons with disabilities have right, equally with others, to own or inherit property, movable or immovable, control their financial affairs and have access to bank loans, mortgages, and other forms of financial credit. This contentious clause of the bill is reduced to "all or none" phenomenon, which is detrimental to persons with neurological disability affecting his/her decision-making capacity. Every person requires assistance or help in making decision (for example, any person planning to a buy a laptop requires assistance in the form of information, operating system, RAM capacity, hard disk capacity, processor, graphic capacity, review from various sources and so forth). As per the Clause 13 of the RPWD Bill, 2014, one has to approach the court for appointing a guardianship for getting assistance; however, this provision is enabled only for persons with mental illness. Under this clause, the District Court records a finding that a mentally ill person is incapable of taking care of himself/herself and of taking any legally binding decision on his/her own; it shall make an order

for appointment of "plenary" or "limited" (depending on the severity) guardianship to take care of such person and take all legal binding decisions on his/her behalf in consultation with such person. The Clause 13 of the RPWD Bill, 2014 is applicable only for people with mental illness. There are large numbers of neurological patients with poor decision-making capacity such as severe TBI, postencephalitic sequelae, stroke with aphasia, and dementia, who will not be able to get the benefit of this Clause 13. Unfortunately, this provision of appointing guardianship to persons with neurological disability affecting his/her decision-making capacity is not made available.

There are laws in various developed countries to provide assistance for neurological disabilities such as the Mental Capacity Act, 2005 of the United Kingdom, which is designed to protect and empower individuals who may lack the mental capacity to make their own decisions about their care and treatment. This Act also makes provisions for supported decision-making keeping the "best interest principle" of the client. Hence, there is an urgent need to include persons with neurological disability in Clause 13 of the RPWD Bill, 2014 to provide justice.

Further, the RPWD Bill, 2014 discusses appointing of "plenary" and "limited" guardianship in Clause 13. The bill should have discussed about the assisted/supported decision-making keeping the "best interest principle" of the client rather than just legalizing the process of "plenary" and "limited" guardianship through the District Court. This "plenary" and "limited" guardianship is not in the spirit of UNCRPD in protecting the rights of the persons with neurological disability.

Challenges in Assessment and Certification of Neurological Disability

Characteristics of the neurological illness pose a great challenge in assessment and certification of illness [Table 1].

Temporary versus permanent disability certificate

The very nature of fluctuating, episodic, waxing, and waning course of neurological illness can pose a great challenge for consistent assessment of disability. Hence, in accordance with the recommendations of the expert committees and according to the Persons with Disabilities Act rules, the Ministry of Social Justice and Empowerment issued a gazette notification in 2001 and notified that neurological assessment should be done minimum 6 months after the onset of the disease for the sake of disability certification and benefits. However, the exact period is to be decided by the physician evaluating the case and has to recommend the review of certificate as required depending upon nature of neurological illness and whether the patient is like to deteriorate/improve over a period. [32] This gazette notification allowed flexibility for issuing temporary disability certificate, which is a welcome sign for persons with neurological disability. In case of ambiguous presentation or not on regular optimal treatment or the diseases in the process of evolution, it is always advisable to certify temporary disability only and ask for recertification after 6–12 months period. [33] Owing to the above challenges, various countries have adopted certain mechanisms such as need for minimum duration of documentation of illness, optimal and adequate duration of

Table 1: Challenges in assessment and certification of neurological disability

Characteristics	Challenges
Dynamic nature of the illness	Course of neurological illness could be nonprogressive, progressive, episodic, remitting, and relapsing. Hence, it becomes difficult to quantify the disability percentage cross-sectionally. Usually, in a particular illness, symptoms vary across population and also within same population across time
Multi-dimension/ system involvement	Neurological illness affects multidimension/system such as consciousness, motor, sensory, cognitive, affect, language, behavior, gait, and balance. Hence, assessing all the above impairment and quantifying them into a percentage are very difficult task. There is no single instrument to assess disability
Invisible impairment	Pain (neuralgia, migraine), aphasia, memory loss, loss of sensation, cognitive impairment, bladder/bowel incontinence, sexual dysfunction, and so forth cannot be seen. Certain signs and symptoms of neurological illness are often difficult to quantify
Dominant versus nondominant	Depending on the involvement of dominant versus nondominant lobe, manifestation of the illness, and disability varies
Treatment/ intervention	Availability of timely treatment (continuity of treatment) and rehabilitation can limit the disability. Nonavailability of treatment, lack of insight, or refusing to take treatment for certification can pose a great challenge
Improvement/ recovery	There is illness in which spontaneous remission or recovery can occur
Nonavailability of investigation	There is certain neurological illness are diagnosed by ruling out other causes
Stigma	Illness such as epilepsy continues to have stigma

treatment, and not been able to earn at least "X" number of dollars per month in the past 6 months. These safeguards are essential so that the disability welfare measures are not miss-utilized.

Severity of illness versus severity of disability

It is important to differentiate between the severity of neurological illness and severity of disability. Severity of illness can broadly be defined as the degree of organ system derangement in any given patient and is generally assessed using a variety of demographic, clinical, physiological, and laboratory variables.[34] However, severity of disability is not interpretation of the diagnosis/disease per se but the measurement of the clinical manifestations and the interaction between persons with impairments and attitudinal and environmental barriers that hinder their full and effective participation in society on an equal basis with others. [2] Severity of illness on a particular/specific scale may be 100%, but the person may not be severely disabled. For example, patient may have complete loss of sensation in one or more limbs and he/she may score 100% severity on a particular scale, but his/her disability score may not coincide with his severity of illness. Hence, one should understand that the assessment of neurological disability is not the assessment of disease (clinical) severity but the evaluation of its impairments and ensuing disability. Thus, severity of illness is a "clinical" construct whereas severity of disability is a "legal" construct. "Clinical" construct is used for management/treatment of patient, whereas

"legal" construct is used for compensation or welfare measures. According to the guidelines of the Persons with Disability Act, 1995, a person with more than 40% disability score is entitled to avail State-sponsored welfare benefits/measures.^[32]

Current Status and Suggestions for Disability Certification for Persons with Neurological Disability

Stroke is the major cause of disability among adult population across the country and the world, with almost equal number of patients suffering from right or left hemiplegia. It is baffling to note that currently there are no guidelines to assess speech and language dysfunction (aphasia) in stroke survivors. This anomaly needs immediate attention and correction. The number of the stroke survivors with disability will increase substantially in future; hence, there is urgent need to include stroke in the core of the definite illnesses in this bill. Similarly, epilepsy, probably the most commonly seen illness in neurology clinic, has not been included for disability assessment and certification (posthead injury epilepsy has been included in the existing guidelines for disability assessment and certification though). Due to coexisting psychosocial issues and stigma in epilepsy, they have problems in getting jobs and leading a normal life in the society. Thus, clear guidelines regarding the certification are urgently needed in epilepsy. Due to epidemics of meningoencephalitis in certain parts of the country (Japanese encephalitis in Eastern Uttar Pradesh and Assam, other bacterial and arboviruses), there is an increase in people who have neurological sequelae and would need certification and benefits.

Parkinson/Parkinsonian disorders (extrapyramidal disorders), which are progressive degenerative disorders commonly seen in neurological clinics, have not been included in the disability assessment and quantification. Some of them may have severe postural instability, ataxia, and recurrent falls, thus making them incapacitated and dependent (progressive supranuclear palsy, multiple system atrophy, and hereditary spinocerebellar ataxias). Patients suffering from these ailments have been denied disability benefits as currently no criteria exist for quantification of disability for the sake of benefits. There is also a significant number of people suffering from migraine and other primary headache syndrome such as intractable migraine, trigeminal neuralgias, cluster headaches, and other neuralgias who are incapacitated due too severe pain; however, due to lack of any clear physical finding, they are not given any benefit because there is a great deal of variability in symptoms. There is need to touch upon this in the current bill too so that at least short-term benefits can be provided. Developmental/ metabolic disorders/multiaxial neurological illnesses similarly meeting the same fate with no criteria to quantify disability provide benefits to patients depriving them of their rights.

TBI requires special attention because of the wide prevalence. Nearly 100% of those with severe, 50% with moderate, and 10%–20% of those with mild brain injuries need long-term rehabilitation services covering physical, psychosocial, vocational, and economic rehabilitation for their survival. [35] The outcome assessment of patients with TBI is often restricted to quantification of physical impairment. Survivors of TBI have

mixture of cognitive and physical impairment. [36] An outcome assessment tool across all the three International Classification of Functioning domains along with neuropsychological assessment should be done to quantify disability due to TBI. The examples of these assessment tools include Disability Rating Scale and Glasgow Outcome Scale Extended.[37] Although the incidence of spinal cord injury (SCI) is less than that of TBI, the neurological deficits due to SCI are more severe and disabling. The current guidelines for assessment of neurological disability do not include terms such as paraplegia and quadriplegia; however, the disability assessment is done on the same grounds as orthopedic and locomotor disability, which is not appropriate. The disability is not only due to lack of mobility but also due to other factors such as spasticity, pressure sores, deep venous thrombosis, urinary tract infection, and pneumonia, which needs to be accounted.

There is an urgent need to form a committee comprising all the stakeholders such as neurosurgeons, neurologists, physiatrist, survivors, and legal expert to form consensus guidelines on the assessments and certification. The RPWD Bill, 2014 also needs to take inputs from the professional medical bodies (especially from neurology, neurosurgery, and physiatrist) before it becomes the law of the land. Professional bodies also need to work toward formulating a simple but comprehensive assessment tool for assessing neurological disability.

Conclusions

The UNCRPD is a welcoming step toward realizing the rights of the persons with disability. The drafted RPWD bill, 2014 is in the spirit of UNCRPD. However, there are several shortcomings in the RPWD Bill, 2014 from the persons with neurological disability. It needs major overhaul to confirm the spirit of UNCRPD. There is an urgent need to amend the Clause 13 of the RPWD Bill, 2014 so that the persons with neurological disability also do get the benefit. There is also need to bring paradigm shift from "plenary/limited guardianship" to "supported decision-making," keeping the "best interest principle" of the client. There are several shortcomings in the assessment and certification of the neurological disability, which should be dealt with collaborative discussion with neurological and legal professional bodies.

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