View Point

Critical Appraisal of Guidelines for Evaluation and Certification of Specified Neurological Disabilities

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Abstract

New disability law called "Rights of Persons with Disabilities Act 2016" has been acted in 2016. The United Nations' Convention for Rights of Persons with Disabilities is the sole of this new act. Of the total 21 categories, three new neurological legal disability categories such as chronic neurological conditions, Parkinson disease (PD), and multiple sclerosis have been notified first time in the new act. The new guidelines have been notified in the year 2018 for evaluation and certification of specified disabilities. As a new addition in these guidelines, modified Rankin scale score has been added to measure locomotor disability of stroke. Certainly, newer guidelines have many lacunae also. There are no recommendations of any method of disability measurement associated with movement disorders such as PD, chronic neurological conditions such as migraine, epilepsy, and ataxia. The tables of older guidelines for disability calculation in conditions such as unconsciousness and epileptic fits have been removed in newer guidelines. Professional bodies should come into action immediately and do effort for rectifying these shortcomings and/or fallacies in new guidelines.

Keywords: Disability, disability law, guidelines

Introduction

In the year 2006, the United Nations General Assembly had adopted the Convention on the Rights of Persons with Disabilities (CRPDs). The aim of convention was empowerment of persons with disabilities (PWDs).[1] The CRPD proclaims that disability results from an interaction of impairments with attitudinal and environmental barriers which hinders full and active participation in society on an equal basis. India was a signatory to the said convention. For implementation of CRPD, our country passed a new law in December 2016. It was named rights of PWD (RPWD) Act 2016 (49 of 2016).[2] This new law replaced the older PWD Act of 1995.[3] The Central Government of India has issued the *Gazette* notification of new rules in relation with this law, in the year 2017.

In 2018, the Department of Empowerment of PWD (Divyangjan), under the Ministry of Social Justice and Empowerment has notified new guidelines for evaluation and procedure for certification of various specified disabilities.[4] The new guidelines have superseded the earlier guidelines of the year 2001.

In this article, we will critically appraise the newer guidelines and highlights the new addition and deletions in comparison with the older guidelines. We will also express our views about strengths and limitations of newer guidelines for the assessment and certification of various specified disabilities. First, we will discuss briefly about the new act and then thoroughly about new guidelines.

Rights of Persons with Disability Act 2016 and Neurological Disabilities

In RPWD Act 2016,[2] the total disability categories have been increased from 7 to 21. Of all newly added categories, three neurological disability categories are added first time. These are chronic neurological conditions, Parkinson disease (PD), and multiple sclerosis (MS). Two other neurological categories including muscular dystrophy and cerebral palsy get recognition as separate-specified disability categories in the new act, which are previously notified under locomotor disability category. Speech and language disability category has also been added as a new specified disability category which may be related to neurological diseases. Pure dementia-like illnesses can be certified in chronic neurological conditions or mental illness disability category according to new guidelines.

A review article by Math *et al*.[5] was published in 2016. That article had discussed thoroughly about RPWD bill 2014 and its implications for neurological disability. Authors also highlighted challenges in disability assessment and gave practical suggestions to deal with these challenges.

Addition of chronic neurological conditions as a separate-specified disability category is a very novel addition. However, in the act as well as in the new guidelines, it is not clearly mentioned that which all diseases/disorders are included

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in this broad category. Everywhere in the law and guidelines, chronic neurological conditions category was exemplified by PD and MS, although both of these are notified as separate disability categories also. Here, as its name suggests, we are assuming that any chronic neurological disabling condition irrespective of diagnosis can be certified under this category.

In a previous review article,[5] authors thoroughly criticized the new act regarding ambiguity of definition of chronicity and issues of recurrence related with neurological conditions. They also highlighted the nonenlisting of traumatic brain injury/spinal cord injury in chronic neurological condition and issues of rules regarding legal capacity for neurological disability.

On the same note, we also want to highlight that in Section 34 of RPWD Act 2016 (49 of 2016), there is provision for 4% reservation in every government establishment for specified PWD. Although chronic neurological condition has been included as specified disability category in this new act, this category has not been included in categories which would be benefited by reservation. In our personal experience of certification, chronic neurological condition is not an uncommon category among all disability categories. This omission of chronic neurological condition category in Section 34 is against the principles of nondiscrimination and equality of opportunity of CRPD. This issue has medicolegal implications for certifying authority also. We want to emphasize here that all professional bodies related to neurological disability should give a strong recommendation to the central government for amendment of this section, so PWD due to chronic neurological conditions also get the benefit of reservation.

Guidelines for Evaluation and Certification of Neurological Disabilities

The new guidelines have been notified in 2018 by the Department of Empowerment of PWD (Divyangjan) in the *Gazette of India*.[3] These guidelines have been suggested after recommendations of eight subcommittees. These were constituted with three aims: (i) review the existing guidelines, (ii) formulate guidelines for 12 newly introduced disabilities in RPWD Act 2016 (49 of 2016), and (iii) look into the best practices of certification prevailing across the nations. In our personal views, guidelines should be easy to apply in the whole country. It should be clear and without an ambiguity in both Hindi and English language versions.

We have critically appraised the new guidelines and highlighted the changes in comparison to old guidelines in the form of eight issues. We restricted our discussion only to neurological legal disability and newer guidelines. These eight issues are as follows.

Issues related to chronicity, relapse, episodic nature, and fluctuation in neurological conditions

As previously highlighted that the definition of chronicity has not been given in guidelines, Few suggestions for decision regarding chronicity are available in guidelines such as (1) any neurological assessments for the purpose of certification have to be done 6 months after the onset of illness, (2) exact time period should be decided by the medical doctor who is evaluating the case, (3) neurological condition which is reversible and without sequel should not be certified, (4) only neurological conditions which are permanent should be certified, (5) permanent disability certificate can be issued in irreversible/progressive cases, and (6) in specified cases re-evaluation of disability can be done after a period of 1 year.

For few common chronic neurological conditions with disabilities such as (i) relapsing diseases such as MS and chronic inflammatory demyelinating polyrediculoneuropathy, (ii) episodic diseases such as migraine, ataxia, and epilepsy, and (iii) fluctuating diseases such as myasthenia gravis and PD with drugs, it is not clearly mentioned that when and how someone would certify these above conditions.

We suggest that fluctuating, relapsing, and episodic chronic diseases associated disability can be certified on the basis of quality of life (QOL) scale and functional scales instead of scales which measure permanent impairment only.

Addition of disability scale for stroke

As one of the terms of reference for the expert committee was review the older guidelines, so committee members have added the modified Rankin scale (mRS) score for calculation of locomotor disability [Table 1] among stroke victims. We think, this addition makes the life easy of certifying medical authority. As mRS score can be calculated by graduate medical doctor also, stroke patients can be certified at primary health center/community health center.

In 2006, Radhakrishna[6] expressed beautifully his views regarding neurological legal disability. He suggested the use of various disability scale score for calculation of disability percentage because of fallacies in older certification guidelines. He suggested the use of few scales for calculation of disability percentage, mRS was one out of all. We also think that more and more functional scales should be used to measure disability.

Ambiguity in assessment of movement disorders' disabilities

Various new disability categories have been notified in RPWD Act 2016 like chronic neurological conditions, PD. Hence,

Table 1: Modified Rankin scale score and corresponding disability percentage in respect to affected limbs

mRS score	Percentage of PPI
0	Nil
1	<40
2	40-50
3	51-60
4	61-80
5	>80

Adopted from the Gazette of India - Extraordinary, Part II-Section 3-subsection-ii. PPI=Permanent physical impairment, mRS=Modified Rankin scale

in the new law, there are provisions that under these new categories, most of disabilities associated with movement disorders can be certified. However, new guidelines for evaluation and certification are incomplete in respect of these new disability categories. For example, PD has been established as a separate neurological disability category as like chronic neurological conditions. The new guidelines do not suggest evaluation and quantification of motor disability associated with PD. It is not clear that disability measurement of Parkinson patients should be done during on period or off period, with drugs or without drugs. There is no provision for using either H and Y staging or Unified Parkinson Rating Scale Score for calculation of motor disability of Parkinson which is used in clinical trials. Similar to hypokinetic movement disorder like PD, there are no provisions for calculation of disability due to hyperkinetic movement disorders such as chorea and dystonia under the category of chronic neurological conditions.

We suggest that in existing literature, many scales and scores are available to measure disabilities associated with disorders such as PD, chorea, and dystonia. These scales should be recommended for disability calculation of movement disorders associated with disabilities. We accept that these scales are not easy to apply by nonneurologist, but solutions are available in the form of provision for telecommunication with the specialist.

Issues of psychosocial disability in chronic neurological conditions

The new guidelines suggested that chronic neurological conditions have multidimensional disabilities, including musculoskeletal (motor/movement) as well as psychosocial behavior (mental) components. It has been recommended that the Indian Disability Evaluation and Assessment Scale (IDEAS) should be used for the assessment of psychosocial disability. Now, this recommendation is problematic in real life because IDEAS scale is validated for mental disability in condition who has no associated physical disability, for example, psychosis and[7] dementia. It is very well known that chronic neurological conditions have both components of physical as well as mental disability. Psychiatrist/clinical psychologist has been notified as authority that would assess mental illness component due to chronic neurological conditions. Most of the psychiatrists are reluctant for using IDEAS in a patient of PD, MS, and other chronic neurological conditions. If someone is kind enough to use IDEAS for calculation of disability, he/she would not be able to differentiate between disability due to motor component and a mental component. There are chances that same disability will be counted twice, the first time as physical disability andthe second time as mental disability. It will overestimate the real disability if some use well-known formula of guidelines, a + b (90-a) divided by 90 where a is higher disability score.

This issue can be resolved with new validation studies of IDEAS scale in conditions which have physical disability as well as mental components. This can be resolved using different scales for chronic neurological condition like disease-specific disability scale or generic disability scale like WHO disability assessment schedule 2.0 (WHODAS 2.0)[8] which is already validated for these types of conditions.

Issues of disability calculation in epilepsy

Epilepsy is a chronic neurological condition, and it can be certified in this category. In older guidelines, there were suggestions available mainly for posttraumatic epilepsy associated with physical disability in the form of table [Table 2]. In newer guidelines, disability calculation in epileptic disorders has been removed [Table 2]. Hence, in older law, there was no provision for disability certification in nontraumatic epilepsy or posttraumatic epilepsy without physical disability. Now, in the new law, there is provision for certification of nontraumatic epilepsy with or without physical disability under chronic neurological conditions. Certainly, new guidelines are silent about disability calculation of these epilepsy patients.

We recommend that episodic conditions such as epilepsy and migraine where disability is not permanent, we can use QOL scales also for calculation of benchmark disability, because these QOL scales consider many aspects of episodic disorders and give more real picture of disabled life. Epilepsy societies and associations should give their representation to proper authority for inclusion of these scales in newer guidelines, so these real PWDs get their rights.

Removal of few tables from older guidelines

In newer guidelines, person with altered sensorium like patients with vegetative state cannot be certified. There is no suggestion for calculation of disability for person with altered sensorium in new guidelines. PWD with disability due to the involvement of cranial nerves was also excluded from new guidelines. There has been nothing described for calculation for facial weakness and/or numbness as well as weakness of chewing and swallowing muscles.

We suggest tables of older guidelines for altered sensorium and cranial nerves can be included again.

No correction of fallacies of older guidelines

In his letter to editor, Murali *et al*.[9] had expressed their views clearly regarding the fallacies of 2001 guidelines. In their opinion “Evaluation of the disability in lower motor neuron lesions is lengthy and takes a lot of time. Other important parameters in upper motor lesions such as cognitive deficits,

Table 2: Posthead injury fits and epileptic convulsions

Severity of disability	Numbers of convulsion	Disability percentage
Mild	One convulsion only	Nil
Moderate	1-5/months	25
Severe	6-10/months	50
Very severe	>10/months	75

Adopted from the Gazette of India, Extraordinary, Part I Section 3subsectionI

swallowing dysfunction, spasticity, dystonia, rigidity, tremors, and bowel incontinence and so on are not addressed." These fallacies have not been corrected in newer guidelines also.

We suggest that more and more function-based scales should be used which measure true disability instead of measuring impairment only.

Issues related to translated Hindi version of notification in English

Speech and language disability category has been added as a new category in RPWD Act 2016. In this category, conditions which affect speech components include dysarthria and apraxia of speech. Dysarthria of speech has been notified in Hindi version as stuttering (Haklahat) and apraxia of speech as stammering (Tutlahat). This improper translation of dysarthria and apraxia of speech has manifested as exponential increase in application for benchmark disability by persons who either have stuttering or stammering. These all lead to delay in assessment of genuine PWD and increase in the pendency of certification.

This issue can be rectified immediately with new notification to avoid unnecessary applications and delay in evaluation of genuine applicants of speech and language disability.

In our experience, with digitalization and simplification of the application process for disability and concurrent wide dissemination of knowledge of various newly added disability categories, applicants of probable PWD increased exponentially. But with incomplete and unclear guidelines, pendency of certification has also increased. It is very difficult for the medical authority to either issue certificate or rejects application with proper reason in writing within 1 month of date of application. Professional bodies related to neurological legal disabilities should come into action immediately and do effort for rectifying these shortcomings and/or fallacies in new guidelines.

Conclusion

Various new neurological disability categories have been notified in the RPDW 2016 law. New disability evaluation and certifications guidelines have many lacunae. Professional bodies should made effort for improvement in guidelines, so PWD gets their rights.

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Conflicts of interest

There are no conflicts of interest.

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