

## Correspondence

### Stigma haunts persons with mental illness who seek relief as per Disability Act 1995

Sir,

Stigmatization of people with mental illness has persisted throughout history and it continues to prevail in the present civilized world. People with mental disorders are, or can be, particularly vulnerable to abuse and violation of their rights. Legislation is an important mechanism to ensure appropriate, adequate, timely and humane health care services<sup>1</sup>. It also helps in protection of human rights of the disadvantaged, marginalized and vulnerable citizens<sup>2</sup>.

In order to provide equal opportunities, protection of Rights and enable full participation, various schemes and assistance programmes, have been proposed for persons with disability through the Persons with Disability Act, (PWD 1995)<sup>3</sup>. However, reality is a far away from what this legislation had proposed to achieve. The three pillars of our democracy- legislature, executive and judiciary continue to discriminate and ignore the human rights of persons with mental illness.

In the international arena, The United Nations Convention on the Rights of Persons with Disabilities (CRPD)<sup>4</sup> marks a “paradigm shift” in attitudes and approaches to persons with disabilities by treating them as “subjects” with rights, who are capable of claiming those rights. Republic of India has signed the CRPD in March 2007 and ratified it in October 2007. India has international obligations towards the above principles of the Convention. Hence, there is an urgent need to amend the PWD Act of 1995 in accordance with CRPD. Though PWD (1995) has many positive aspects, focus is on the shortcomings and possible remedies from a mental health perspective.

#### **Mental illness: Challenging the public health system and social justice**

It is a well accepted fact that mental illnesses contribute to significant disability<sup>5</sup> and nearly 13-15

per cent of the India’s population suffer from various mental illnesses<sup>6</sup>. Five of the ten leading causes of disability are from the following mental disorders: major depression, alcohol dependence, schizophrenia, bipolar affective disorder and obsessive-compulsive disorder<sup>7</sup>. Mental illness can have a devastating impact on any family especially when the primary bread winner suffers from the same. Persons with mental illness drift to poverty adding to the suffering which is a double disadvantage. However, they have not been provided with the promised social assistance and mental health care.

In a country like India, mental health care is not perceived as an important aspect of public health care. Hence, disability legislation plays a very important role in upholding the rights of the mentally ill. The fundamental aim of this legislation is to protect, promote and fulfill the rights of the persons with disability. It also plays a vital role in dictating the terms and conditions of mental health care and protecting the human rights and fundamental rights of people with mental disorders<sup>8</sup>.

*Disabling ‘clause’ in the Disability Act:* The clause “the appropriate Governments and the local authorities shall, within the limits of their economic capacity and development will provide.....”<sup>3</sup> appears in many chapters of the PWD Act. Provision of this clause enables the benefit on papers and disables them completely in reality. Hence, this clause should be removed from the Act to uphold the rights of the disabled. It should be remembered that disability benefits offered are not “objects of charity”, but are, “the rights of the persons with disability”, who are capable of claiming those rights.

*Right to health:* Right to health for people with disability means, availability of reasonable health care services, accessibility to the services and quality of the

services with regard to both physical and mental health care<sup>8</sup>. However, there are no provisions in this Act that mandate the availability of such services especially with regard to mental health care. The emphasis thus needs to shift from 'respect', 'promote', and 'protect', to focus more on 'fulfill'. All persons with disability should be entitled to Right to health. In case of the services not being available in the locality, travel concession should be provided. This would help the people with disabilities reach their rehabilitation centre or hospital.

*Double discrimination:* Mentally ill patients continue to face discrimination at all levels compared to those with only physical disabilities. Many patients are deprived of disability benefits because of simple ignorance by the authorities. This issue requires comprehensive awareness-raising activities in the policy makers and legislation enforcing agencies. From day one till date there have been no representatives or representation of the mentally ill patient in the Central Coordination Committee. The absence of representatives of mentally ill patient raises a serious concern about the welfare of the persons with mental illness<sup>2</sup>.

The disability associated with chronic mental illness is invisible and the impact on family members and the community is enormous. The policy makers are playing the discriminative role even with regard to mental illness and employment. On one hand they acknowledge the disability due to mental illness, and on the other, they also hold the opinion that they will not be able to do anything if there is considerable amount of mental disability. Even the PWD Act does not have any reservations earmarked for mental disability. The PWD Act needs amendments to do justice to people with mental illness otherwise, the Act itself becomes a source of discrimination.

*Rehabilitation of mentally ill patients:* Community-based rehabilitation has been advocated by World Health Organization (WHO) and also by many international agencies for more than three decades<sup>9</sup>. Unfortunately, rehabilitation of mentally ill patients, which is highly essential, has been ignored.

All the mental health care centers such as, Mental hospitals, Psychiatric Nursing Homes, Private General Hospital Psychiatry centers and Convalescent homes (rehabilitation centers) are grouped together in the Mental Health Act (1987)<sup>10</sup>. The minimum standards applicable to psychiatric hospitals which deal with acutely disturbed patients with severe illness also

apply to convalescent homes, where the focus is on rehabilitation and reintegration into the community. These rehabilitation centers need to get registered for license under both the Disability Act of 1995<sup>3</sup> and the Mental Health Act 1987<sup>10</sup>. This dual registering requirement, is acting as a deterrent to establish any kind of mental health rehabilitation centers. Hence, there is an urgent need to define them separately under the Mental Health Act and minimum standards applicable also require to be stated separately according to the care they offer. Establishment of halfway homes, vocational training centers, social-skill training centers, cognitive re-training centers, day-care centers and long-stay centers for persons with mental illness need to be started at the district level.

*Measurement of disability:* The Rehabilitation Committee of the Indian Psychiatric Society evolved an assessment tool called Indian Disability Evaluation and Assessment Scale (IDEAS)<sup>10</sup>. The Ministry of Social Justice and Empowerment, Government of India gazetted it in 2002 after certain modifications in the scale<sup>11</sup>. However, duration of illness in the published version of the Gazette requires to be clarified because it is difficult to compute total duration of illness in episodic illnesses with inter-episode residual symptoms. However, the original version of the scale had a different method of assessment. The author of the scale had devised an excellent and simple method called Months of illness during the last two years (MY 2Y). This MY2Y version requires to be adapted with the earlier suggestion of mandatory rule that the total duration of illness should be at least two years for administering IDEAS and issuing the certificate.

The disability scores for mental illness are expressed in terms of range of percentages as follows: - Mild Disability (<40%), Moderate Disability (40 - 70%), Severe Disability (71-99%) and for Profound Disability (100%). Unfortunately, in many instances bureaucrats have refused to accept the ranges as declared in Gazette of India and have asked for a magical/specific number of percentage for providing benefits. This issue might be resolved by expressing the calculated score in percentages.

*Certification of the mental illnesses:* As per the gazette notification, disability certificate can be issued for any mental illness. However, there are many mental illnesses such as substance dependence syndromes, somatoform disorders, anxiety disorders, selective learning deficits, attention deficit hyperactive disorder, autism and so forth, where disability assessments are not carried out

and the certificate is not issued. Many mental health professionals argue and refuse to provide disability certificate for people with substance dependence syndrome. Mental health professionals need to know that disability certificate is not based on the diagnosis, but on the amount of disability experienced by the individual. Regarding this issue, policy makers have thought beyond the conventional way and included all mental illness for disability assessment and benefit.

In several States in India disability benefits are made contingent to the income of the persons with disability. This issue of income ceiling needs to be removed and should not be a criterion for upholding the rights of persons with disability. There should be a deadline earmarked both for the medical professionals in issuing the certificates and for bureaucrats in providing promised assistance in the Disability Act. Reasons for ineligibility for certificate need to be intimated.

In conclusion, the PWD Act (1995) is a landmark legislation by virtue of inclusion of the persons with mental illnesses under the purview of the Act. The above issues need to be addressed by appropriate amendments at the earliest, so that Rights of the persons with mental illness can be protected, promoted and fulfilled.

**Suresh Bada Math\* & Maria Christine Nirmala\*\***

Department of Psychiatry, National Institute of  
Mental Health & Neuro Sciences  
(Deemed University), Bangalore

\*\*Content Research, Strategic Human Resource  
Management India Pvt Ltd, Bangalore, India

\*For correspondence:

Dr Suresh Bada Math

Associate Professor of Psychiatry

Consultant, OCD Clinic

Department of Psychiatry

National Institute of Mental Health &  
Neuro Sciences (Deemed University)

Bangalore 560 029, India

nimhans@gmail.com, sbm@nimhans.kar.nic.in

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