

## Disability certification and utilization pattern in persons with mental illness

Subhash Das<sup>1</sup>, Rosy Arora<sup>2</sup>, Kamlesh Kumar Sahu<sup>3\*</sup>

<sup>1</sup>Professor, <sup>2</sup>Counsellor, <sup>3</sup>Associate Professor (PSW),  
Department of Psychiatry, Government Medical College and Hospital, Chandigarh, India

### ABSTRACT

**Background:** Disability certification is an essential requirement to avail of the various disability benefits including disability pension, family pension, insurance, income tax rebate, travel concession etc. The lack of awareness among persons with mental illness and their caregivers is a major barrier in availing such benefits. **Aim of the study:** To assess the socio-demographic and clinical variables along with the pattern of utilization of disability certificates for disability benefits by the persons with disability (PwD) having a mental illness. **Materials and Methods:** Consecutive patients who obtained disability certificates due to mental illness in the last 5.5 years were contacted and their responses were recorded on a semi-structured questionnaire telephonically. **Result:** Over a period of 5.5 years 123 certificates were issued to individuals of which 100 were contacted. Out of the 123 cases, 11 could not be contacted, one patient didn't collect the certificate to date, 6 patients expired after obtaining the certificate and 5 didn't come for reassessment. Out of the 100 cases who participated in the study, 91 persons (91%) mentioned that these certificates were useful for them. Regarding the disability-related benefits, 51% had received a disability pension, 43% used it for travel concession and the rest (1% to 9%) used it for getting income tax rebates, insurance and family pension. While exploring and interviewing for additional benefits other than those available currently by the Government of India, 13% wanted to get free medicines, 17% wanted increased job opportunities and 2% wanted to have a smooth procedure for availing benefits. Of those contacted, 19% also disseminated the information about the disability certification and the related benefits to other needy persons. **Conclusion:** The utilization of disability certificates by those with mental illness is largely limited mostly to availing pension or travel concession.


**Keywords:** Disability, certification, utilization, mental illness

### INTRODUCTION

Disability is a complex phenomenon and it has been defined in “Merriam- Webster” online dictionary as “a physical, mental, cognitive, or developmental condition that impairs, interferes with, or limits a person's ability to engage in certain tasks or actions or participate in typical daily activities and interactions”. Nearly 31% of the world’s disability is accounted for by mental disorders and five of the top ten causes of disability are due to mental illness.<sup>[1,2]</sup> Disability associated with mental illness is a major contributor to the

global burden of disease. According to the Global Burden of Disease study, 2010, mental and substance use disorders were the fifth leading disorder category of global disability-adjusted life years (DALYs).<sup>[3]</sup> The study of disability associated with mental disorders, therefore, becomes a matter of prime importance.<sup>[4]</sup>

The Census 2011 of India revealed 20% disability in movement, 19% in vision, another 19% in hearing, 18% any other disability, 8% multiple disabilities, 7% disability in speech, 6% disability with Mental Retardation and

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#### Address for Correspondence:

Ms. Rosy Arora  
Counsellor, Department of Psychiatry,  
Government Medical College and Hospital,  
Chandigarh - 150030, India  
Email: rosy.arora28@gmail.com

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only 3% disability was due to Mental Illness. However, a community-based study in India found mental disability to be the most common type of disability accounting for 36.7% of total disability.<sup>[5]</sup> National Mental Health Survey of India, 2015-16 reports that three out of four persons with a severe mental disorder experience self-perceived disability affecting multiple domains like work, social and family life.<sup>[6]</sup> The proportion of disability experienced was relatively higher among individuals with the bipolar affective disorder (59-63%), major depressive disorder (67-70%) and psychotic disorders (53-59%). Similarly, a significantly large proportion of people with common mental disorders also reported a high level of disability. Nearly 50% of persons with major depressive disorders reported difficulties in carrying out their daily activities.

Thus, needless to say, the assessment of disability due to mental illness is of paramount importance as it can predict the factors like service needs, level of care (primary, speciality care etc.), outcome (prognosis), length of treatment or hospitalization and disability benefit and so on, which in turn would help in planning out rehabilitation so as to reduce disability. In India, any person who suffers from more than 40% disability is entitled to disability benefits like maintenance allowance/disability pension, subsidy on purchase of petrol/ diesel, travel concession, income tax deduction, unemployment allowance etc.<sup>[7]</sup>

To certify disability due to mental illness, the 'Indian Disability Evaluation and Assessment Scale (IDEAS)' has been notified in the Gazette of India and recommended by the Ministry of Social Justice and Empowerment in February 2002.<sup>[8]</sup> However often it has been seen that many are not aware of the process of certification. Many find it difficult to obtain such certificates and they may not be aware of the various disability benefit. Thus, it would be very helpful if we can have an idea regarding: the utilization of disability certificates, how much difficulty the persons with mental illness had in obtaining such certificates and whether they were also able to share their experiences with other similar people. As the Department of Psychiatry, Government Medical College and Hospital is also the State Resource Centre for Disability

and has been issuing disability certificates for mental illness since August 2002, it was an excellent opportunity to look into these issues and this study was thus its logical outcome.

*Setting:* The Department of Psychiatry, Government Medical College and Hospital, Chandigarh has been providing tertiary mental health care services since February 1994 to the residents of the Union Territory of Chandigarh. However, its catchment area also includes the neighbouring states of Punjab, Haryana, and Himachal Pradesh, extending up to New Delhi and parts of Rajasthan, Uttar Pradesh and Uttarakhand.

*Referral and Process for Disability Assessment:* Patients undergoing treatment in the psychiatry OPD/IPD can be referred to the Disability Clinic (held every Wednesday; from 9:00 am to 13:00 hours) by a treating psychiatrist. Then such a patient is given an appointment by the Medical Social Worker (MSW) and the patient is counselled briefly about the required documents at the time of assessment. In the Clinic, the patient is again reassessed by a team of three members comprising the Head of the Department of Psychiatry, a Consultant Psychiatrist and a Clinical Psychologist. Indian Disability Evaluation and Assessment Scale (IDEAS) is used to assess the level of disability and if the disability is more than 40% then the patient is recommended for issuance of a disability certificate (permanent or temporary) and sent to Director Health Service, Chandigarh for his signature. At the time of collection of the disability certificate in the Disability Clinic, the patient and the caregivers are counselled regarding the disability benefits by a Clinical Psychologist or Psychiatric Social Worker.

## MATERIALS AND METHODS

*Research Design:* This was a retrospective chart review of patients certified for disability due to mental illness from October 2010 to April 2016, 123 certificates were issued by the Disability Board. Out of these 123 individuals, information from 100 cases could be obtained. Of the remaining 23 cases, 11 could not be followed up (phone number does not exist), 1 never collected the certificate despite repeated reminders, 6 patients had expired and 5 who received temporary certificates didn't come for reassessment.

After explaining the study in detail to all those who attended the Disability Clinic, verbal consent was taken over the phone from the patient and family members; those who were willing to participate and provide information were called telephonically. Strict confidentiality of the participants was ensured. Then using the tools mentioned below, information was gathered and recorded. Standard descriptive statistics and percentage (%) were used to analyse the characteristics of participants.

*Tools Used:* Semi-structured socio-demographic proforma (already being routinely used in the department) to document the details like patient's name, age, gender, socio-economic status etc.

A semi-structured questionnaire seeking information on the difficulty in getting a disability certificate, nature of benefits availed after receiving the disability certificate etc. This was designed for the study with the help of senior and experienced Faculty of the Department of Psychiatry working in the field of disability for several years.

**RESULTS**

The socio-demographic and clinical profile (Table 1) revealed that the majority of the patients who were given disability certificates in the last 5.5 years were less than 40 years of age (57%), males (75%), unemployed (74%) and were from urban area (55%). Most of the individuals were Hindu (77%) by religion and only a few (9%) were illiterate. The majority of the patients had schizophrenia (74%) and most of the individuals (70%) had a moderate level of disability as assessed on IDEAS.

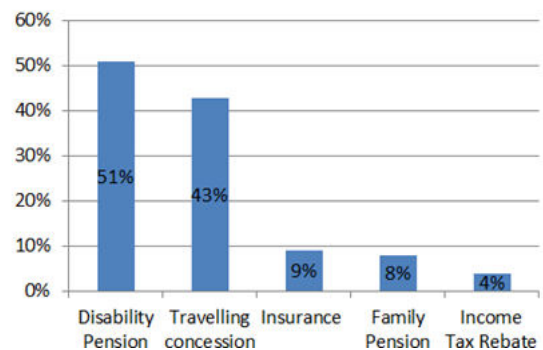
A permanent disability certificate was issued to 78% of the individuals while 22% received temporary disability certificates. Regarding time taken to receive disability certificates, 76% of patients had received their certificates in about 1-2 months, 13% received them after 2 months and 11% received them within a month.

Figure 1 it shows that 51% of the individuals had received a disability pension, 43% used the disability certificate for travel concession and the rest for insurance (9%), family pension (8%) and income tax rebate (4%).

Table 1: Sociodemographic and clinical profile of the patients (n = 100)

Socio-demographic Variables	Variable Category	%
Age in years	20-30	26
	31-40	31
	41-50	24
	Above 50	19
Area of Residences	Urban	55
	Semi-urban	21
	Rural	24
Place	Chandigarh	52
	Panjab	23
	Haryana	25
Education	Illiterate	9
	Primary	13
	High School	35
	Intermediate & Graduates	37
	Post-Graduation	6
Religion	Hindu	77
	Sikh	21
	Muslim	2
Employment	Unemployed	74
	Employed	18
	Retired	2
	Others	6
Degree of Disability	Moderate	70
	Severe	28
	Profound	2
Types of Illness (some patients have more than one diagnosis)	Schizophrenia	74
	Bipolar Affective Disorder	13
	Dementia	10
	Other organic disorders	3

Figure 1: Benefits availed by the individuals getting a disability certificate



On enquiring about additional benefits that the individuals would like to have (other than those available currently) it was seen that 13% of patients wanted to get free medicines, 17%

wanted increased job opportunity for those with disability and 2% wanted to have an easy and smooth procedure for availing the disability benefits; 68% did not give any response. 19% of people also disseminated the information about the disability certification and the related benefits to others in their vicinity.

## DISCUSSION

There are few studies pertaining to mental illness and disability certificates. In fact, in the last few years, hardly much work has been done in this area. A not so recent study explored the various issues related to mental illness and disability certification (severity of disability, utilization of disability certificates etc.) over a period of 3 years.<sup>[9]</sup> Another study looked at the profiles of patients with schizophrenia only and having disabilities over five years.<sup>[10]</sup> This study explored various disability-related issues over a period of five and half years. However, it may be mentioned here that, unlike the other studies, our study comprised of fewer cases. This could be due to multiple reasons like lack of awareness by the people, Chandigarh being a UT and thus having a smaller population group feeling the need for disability benefits and so on. This is one area which can be explored later on.

Males had higher disability compared to females as reported by some of the studies,<sup>[9,11]</sup> in one study on disability in individuals with schizophrenia who sought certificates, males outnumbered females, the majority were unemployed, and few were illiterate.<sup>[10]</sup> In our study too it was found that males availed more disability certificates than females, most were unemployed and few were illiterate. Most of the people getting disability certificates had a diagnosis of Schizophrenia in our study and it is similar to some other studies as well.<sup>[9,10]</sup> Schizophrenia is a very disabling condition and as per the estimates for the global burden of a disease study, schizophrenia is the sixth leading cause of years lived with disability.<sup>[12]</sup> Another study in an outpatient setting also mentioned that schizophrenia was mostly responsible for causing disability.<sup>[13]</sup>

In a community-based study, mild disability was mostly present in those with mental illness followed by severe disability, moderate disability and profound disability.<sup>[14]</sup> In the present study, most of the individuals with

mental illness had a moderate level of disability followed by severe disability and profound disability; there were none with mild disability. This is understandable as the current study was carried out in a hospital setting and comprised of individuals who had received disability certificates and as such excluded those with mild disabilities.

The current study aims to assess the utilization of disability certificates for disability benefits by patients with mental illness. Patients who are issued disability certificates are granted various benefits from the Ministry of Social Welfare, Government of India like pension, free education up to the age of 18 years, free legal aid, railway concessions etc.<sup>[9]</sup> However, people were not much aware of the various disability benefits<sup>[2,15]</sup> and disability certificates were often underutilised;<sup>[4]</sup> a study mentioned that, 47.6 % of persons with a disability of more than 70% were not availing of any benefits other than the disability pension and a staggering 99.4% of the persons with disabilities from rural areas had availed only disability pension benefit.<sup>[9]</sup> Likewise, another study pointed out such underutilization of the disability benefits mostly in rural areas with disability pension being the most utilized benefit.<sup>[10]</sup> In our study too, those with disability certificates mostly used it to avail disability pension (51%), followed by travel concession (43%); the patients/caregivers appear to have only partial information and awareness about the remaining schemes. When we asked those who availed of disability certificates, that whether they disseminated the information related to the procedure of certification as its benefit to others in their vicinity, only 19% replied in affirmative. Thus, increasing awareness regarding the various disability benefits among those with mental illness is the need of the hour.

Our study also attempted to see the difficulty in obtaining a disability certificate. Though the patients did mention facing difficulty, it is worth mentioning here that the majority of them could get a disability certificate in less than two months. We couldn't find other studies which had looked into this aspect. Prompt disability assessment and availability of disability certificate would certainly help in building confidence and hope in those with disability and will thus encourage others to seek this useful certificate.

Another aspect highlighted by our study is that many with a disability would like the benefits to be increased, like getting more jobs reserved for them, free medicines and ease of access to get the disability benefits.

## CONCLUSION

This study does throw some light on the utilization of disability certificates by those with mental illness which unfortunately is limited mostly to availing pension or travel concession

People are still not aware of other benefits that can be availed through these certificates or it could also be possible that the people may find the process of getting the benefits to be too challenging,<sup>[15]</sup> Thus restricting their utility. Apart from creating awareness, a quick and easy process with the availability of a "single window" facility to avail the disability benefits will go a long way in rehabilitating those with mental illness.

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