

Preliminary Experiences with use of Disability Assessment Scales at Mental Disability Clinic, PGIMER, Chandigarh

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Abstract : Government of India has recently notified scales for ascertainment of disability in psychiatric disorders as well as in mental retardation. The present paper reports observations of initial 6 months of their use in Mental Disability Clinic in terms of [i] socio-demographic and clinical profile of patients referred for disability assessment, [ii] the various indices related to disability and [iii] certain qualitative observations regarding conceptual and operational difficulties existing in the present form of these scales.

Key words : Psychiatric disability, intellectual disability, disability assessment

INTRODUCTION

Defining disability is difficult, because there are dozens of definitions, each with a purpose to it. These range from the very narrow to the very broad, from the medical to the social, from the cultural to global, from the one intended to integrate them in society to the one intending exclusion and segregation. WHO¹ defined disability "as any restriction or lack of functioning resulting from an impairment of ability to perform an activity in the manner or within the range considered normal for a human being."

In India, in the year 1995, when Person with Disability Act (PDA)² was passed, and came into effect from 7th Feb. 1996, intended to integrate the people with disabilities to the main stream. The Act guarantees equality, participation, autonomy, protection and accessibility to all people with disabilities to the services and facilities needed in day to day living. According to the Act, a person is considered disabled if he is suffering from 40% or more of any disability as certified by a medical authority duly constituted under this Act. The diseases included are blindness, low vision, leprosy cured, hearing impairment, locomotor impairment, mental retardation and mental illness. The Act defines mental illness as any mental disorder other than

mental retardation. Mental retardation has been defined as a condition of arrested or incomplete development of mind of a person which is specially characterized by subnormality of intelligence. Later in 1999, National Trust Act (NTA) for the welfare of persons with autism, cerebral palsy, mental retardation and multiple disabilities was enacted and was targeted to enable and empower persons with these disabilities to live independently and as fully as possible within and as close to the community as possible and to strengthen the facilities for disabled persons.

Although, over these years, various laws have been enacted, but no specific instrument was available under this Act to assess and quantify disability. In the year 2001, rehabilitation committee of Indian Psychiatric Society submitted, to the Govt. of India [hereafter referred to as GOI], Indian Disability Evaluation & Assessment Scale [hereafter abbreviated as IDEAS] as an instrument for assessment of disability. IDEAS described four domains in the form of self care, interpersonal activities, communication and understanding, and work each rated from 0-4. It also included duration of illness as a separate domain rated from 1-4 to generate the total score. The instrument was

claimed to have good face and content validities as well as fair reliability. The psychiatric disorders included for disability assessment and benefits were Schizophrenia, Bipolar disorder, Obsessive compulsive disorder and Dementia. In 2002, GOI approved IDEAS with some modifications (described later) and issued a gazette notification.³ Guidelines for assessment of disability in Mental Retardation had been notified in 2001⁴. We present here our experience of the use of these instruments for calculating the disability during first 6 months.

MATERIAL AND METHODS

The Department of Psychiatry at PGIMER, Chandigarh has started a new specialty clinic named Mental Disability Clinic (MDC) with effect from 10.04.2003 with the objectives of assessment of disability for the purposes of facilitating disability certification, rehabilitation & research. It has been operationalized as having two limbs, one for children & adults with mental retardation [the group with intellectual disability] and the other for those with mental illnesses [the group with psychiatric disability]. This is a referral clinic, and receives cases referred by the other clinics of the department. The team includes a faculty member, a senior resident, junior residents, and a vocational guidance instructor. Patients are jointly evaluated by the team on tuesdays & saturdays on a specially designed intake proformas tapping sociodemographic & clinical variables in addition to factors related to disability & rehabilitation. Disability is assessed as per recent government of India guidelines as follows:

Psychiatric Disability

This is calculated using Modified IDEAS [hereafter abbreviated as M-IDEAS], the scale amended by Govt. of India and published as a gazette notification in February, 2002. Similar to the original IDEAS, it also has four domains in the form of self care, interpersonal activities, communication and understanding and work rated

from 0-4, to generate the total score. The instrument also suggests to rate duration of illness from 1-4, which is added to total score to generate global score. According to the global score scores the subject is ascribed to various disability groups ranging from no disability to profound disability (0 - no disability = 1-6; mild disability = 7-13; moderate disability = 14-19; severe disability = 20). However, it does not specify any lower limit of duration of illness and nor does it specify any particular disorders.

Intellectual Disability

There are no specific GOI guidelines for quantifying disability in mentally retarded persons. At our clinic, we used the table given for impairment versus IQ level given under neurological section of locomotor disability in the gazette notification of year 2001 to determine the disability.

RESULTS

Sociodemographic profile [Table-1]

Both the groups included 37 patients each. Patients with psychiatric illness were mostly male (86.5%), with mean age of 33 years (range 8-75), had received education upto class 10 (range 0-15), were predominantly married (62%), unemployed (62%), of middle socioeconomic status (62%), from nuclear families (75.6%) and came from in and around Chandigarh with a mean distance of 68.4 kilometers (range 2-500) from the hospital. The patients in the intellectually disabled group were also predominantly male (64.8 %), with mean age of 19 years (range 2.5-39), had received less education 2.65 years (range 0-18), were mostly unmarried (94.6 %), idle (75.6%), of middle socioeconomic status (78.4 %), from nuclear families (73%) and traveled a mean distance of 133.7 kilometers (range 5-2000) from the hospital.

Clinical Profile

In both the groups, patients were predominantly referred "for both certification and rehabilitation".

Table-1
Sociodemographic profile of persons with
Psychiatric disability (N=37) &
Intellectual disability (N=37)

VARIABLES	Psychiatrically ill patients (N=37)	Intellectually impaired (N=37)
Sex		
Male	32	24
Female	05	13
Age in years (range)	33(8-75)	19.01(2.5-39)
Number of years of education (range)	10.24(0-18)	2.65 (0-15)
Marital status		
Married	23	02
Unmarried	10	35
Divorcee	01	00
Occupation		
Employed	04	04
Unemployed/Idle	23	28
Student	08	03
Retired	01	00
Housewife	01	02
Economic status		
Low	10	07
Middle	23	29
High	04	01
Family type		
Nuclear	28	27
Joint	05	07
Extended	04	03
Distance from hospital in Kms (range)	68.4(2-500)	133.7(5-2000)

The most common diagnosis of psychiatric illness group was schizophrenia (59.6%), but the group also included patients with other illnesses also as shown in Table-2. Patients in intellectual impairment were subjects mainly with mild (32.43%) to moderate (29.72%) mental retardation.

Disability scores

The scores on M-IDEAS of subjects with psychiatric illness showed highest score in the

Table-2
Clinical Profile of persons with
Psychiatric disability (N=37) &
Intellectual disability (N=37)

VARIABLES	Person with Psychiatric illness	Person with Intellectually impaired
Reason for referral		
Certification only	07	06
Rehabilitation only	07	02
Both Certification & Rehabilitation	23	29
Diagnosis		
Schizophrenia	22	-
Dementia	03	-
Post head injury sequelae	03	-
Bipolar affective disorder	02	-
Agoraphobia with Panic	02	-
OCD	01	-
Dissociative	01	-
ADHD	02	-
Mild MR	-	12
Moderate MR	-	11
Severe MR	-	05
Profound MR	-	03
Borderline Intelligence	-	03
Borderline Intelligence + Mental Illness	-	01
Mental Retardation + Mental Illness	-	02

work domain (mean 2.8), but the score due to duration of illness (3.13) contributed the most to the total score (Table-3). Most of the subjects (67.5%) had moderate level of disability i.e. scores in the range of 7-13 and disability between 40-70%. Two patients did not have any disability, four had mild disability and 6 had severe disability (Table-4).

The percentage disability in intellectually impaired group was calculated by using the table under locomotor disability [Table-5], according to which patients with mild and moderate mental retardation had 50% and 75 % disability respectively. The adaptive functions of the group [based on items of DSM IV] were rated arbitrarily from 0-4. Most of the patients had limitations in

Table-3
Disability Scores as assessed on
M-IDEAS of persons with
Psychiatric disability (N=37)

Disability variables	Mean	Range
Self Care	0.97	0-4
Interpersonal activities	1.70	0-4
Communication & understanding	1.64	0-4
Work	2.80	0-4
Duration of Illness	3.13	0-4
Global Score	10.2	0-20

functional and academic skills, self direction skills, work skills, use of community resources and communication in descending order (Table-6).

DISCUSSION

Psychiatric Disability- The instrument states that definition of “mental illness” as conceived by PDA, 1995 is to be used to consider the eligibility of the subject for disability assessment. The instrument also does not specify any lower limit of duration of psychiatric disorder to be eligible for evaluation of disability. Further it doesn't specify any thing regarding the course of disorder, rather gives importance to the duration of illness, which also creates a difficulty while rating a patient with episodic illness, for example a patient of recurrent depressive disorder or bipolar affective disorder with 10 years of duration with 2 years spent in episodes is rated similarly like a schizophrenic of 10 years duration with

predominant negative symptoms. The qualifiers for different grades of severity of an item are also vague and lead to a lot of inter-rater variability. The instrument divides global disability scores into 5 groups ranging from no disability to profound disability (0=no disability, 1-6=mild disability, 7-13=moderate disability, 14-19= severe disability, 20=profound disability) and disability categories divided accordingly into 0%, <40%,40-70 %, 71-90% and 91-100 % respectively. These categories appear broad- ranged and vague, without giving exact values of percent disabilities that are actually required for administrative purposes. The total global score of 1-6, creates significant problem in specifying the disability in patients with multiple problems. For example, a patient with schizophrenia having global score of say 5 has comorbid hearing impairment with latter representing, say, 30% disability, can not be given a cumulative disability because for using the formula for multiple disabilities, one requires definite numbers of percent disability rather than a range.

Intellectual Disability- Some problems are obvious in the area of calculating disability for persons with mental retardation too. These include lack of any guidelines in the section on mental retardation regarding conversion of IQ scores to percent disability; how to reconcile when there is a discordance between IQ score and adaptive functioning of the subject; what assessment is to be done when a patient has both mental retardation as well as dementia [which is, by definition given in PDA, 1995, a psychiatric disorder other than mental retardation]resulting from the same etiology? Similar questions can

Table-4
Percentage disability as per M-IDEAS of persons with Psychiatric disability (N=37)

Severity of Disability	Scores of M-IDEAS	Percentage disability	Number of Patients
No disability	0	0	02
Mild disability	1-6	40	04
Moderate disability	7-13	40-70	25
Severe disability	14-19	71-99	06

Table-5

Percentage disability as per M-IDEAS of persons with Intellectual disability (N=37)

Diagnosis	% age disability	No. of cases
Mild MR	50	12
Moderate MR	75	11
Severe MR	90	5
Profound MR	100	3
Borderline intelligence	25	3
Borderline+ Mental ill.	25+?	1
Mod. MR+ Mental ill.	75 +?	1
Mild MR+ Mental ill.	50+?	1

Table-6

Adaptive functions as per DSM IV of persons with Intellectual disability (N=37)

Items	Mean	Range
Communication	2.12	0- 4
Self Care	1.62	0- 4
Home living	1.93	0- 4
Social /Interpersonal	2.28	0- 4
Use of community resources	2.31	0- 4
Self direction skills	2.65	0- 4
Functional Academic skills	2.93	0- 4
Work skills	2.59	0- 4
Leisure	1.90	0- 4
Health & Safety	1.93	0- 4

be raised about Autism, Specific Learning Disability, borderline Intelligence, etc.

It is gratifying to note that the Acts and the instruments are now available for persons with mental disability in India. However, there are certain problems that professionals are facing; these include: need for operational criteria for nature, severity and duration of mental illness; response to treatment; re-examination of qualifiers for different domains of disability; conversion of scores obtained on these instruments to exact percentages of disability; dealing with cases of psychiatric illness comorbid with mental retardation; and so on. Redressal of these issues may be viewed as a step in making barrier free environment for professionals so that

they can pass on the benefits of barrier free certification process to the persons with disability.

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