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Research Articles...

ASSESSMENT OF DISABILITY IN PERSONS SUFFERING FROM MENTAL RETARDATION – PART I: THE ADPMR SCALE

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ABSTRACT

Background: Disability certification in mental retardation often relies on Intelligence Quotient (IQ) score but Disability as a concept is different from Intelligence or even Social Adaptation. Disability is defined as the restriction or lack of ability to perform an activity in the manner or within the range considered normal. Disability assessment is essential not only to ensure better management of the person as a whole, but also for accurately deciding the quantum of social support required for the individual for better integration in the society. However, there is paucity of studies exploring disability in mental retardation, primarily due to lack of availability of simple, validated and reliable tools to assess the same. **Method:** A five item semi-structured, fully anchored, trained observer rated scale (Assessment of Disability in Persons suffering from Mental Retardation, ADPMR) was developed in consultation with an experienced team of clinical psychologists, psychiatrists, special educators, social workers and parents of children suffering from mental retardation. After pilot and field testing, ambiguous terms were rephrased with consensus of the team. The final scale was used for training students of Diploma in Mental Retardation, who then applied the same on target population and reported their feedback regarding its usage. Intelligence Quotient (IQ) and Social Quotient (SQ) were also determined for each child. **Results:** It was possible to develop a new instrument to try to assess disability in persons suffering from mental retardation. The scale could be successfully applied on target population after three hour training to personnel working in the field of mental retardation. Their mean (± SD) age was 14.02 (± 5.03) years. The mean (± SD) IQ was 33.59 (± 11.67); their mean (± SD) SQ was 45.31 (± 15.69). 60.8 % children were suffering from multiple disabilities. Feedback on its usage was uniformly satisfactory with no major problems reported which could preclude the use of the instrument in the sample studied. **Conclusions:** The ADPMR scale can be applied to assess disability in mental retardation. The scale can be used by persons working in the field after a small training.

Key words: disability, assessment, mental retardation, scale.

Declaration of interest: none.

Introduction

Disability is defined as a restriction or lack of ability to perform an activity in the manner or within the range considered normal for a human being (WHO, 1993). Disability level is used for determining the quantum of social support for a person. It has been observed that worldwide, the concept of objective quantification of disability is gaining momentum (Trivedi, 1999). Quantification of disability in most of the conditions takes into account the degree of support required by the person to attain social competence. While quantification of physical disabilities (like visual, as

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corrected eyesight poorer than 6/60) is relatively well established, the scenario is different for conditions like mental retardation and mental illnesses.

There have been attempts to quantify disability in the long-term course of various mental illnesses (Sharma & Tripathy, 1986). However, efforts are conspicuous by their absence in the field of quantification of disability in mental retardation.

Accurate guidelines for assessment of quantum of disability in mental retardation are important because the degree of disability can justify the amount of social help required by the person. This help is often at a considerable cost to the society. In the United States, $ 25.8 billion is reportedly spent on the long term care of the persons suffering from Mental Retardation/ developmental disorders (Braddock, 2002).

Such enormous effort by the society towards disability benefits necessitates accurate quantification of disability in mental retardation. However, while there are specific criteria for assessment of the level of disability for most conditions (like visual and hearing disability, etc), for assessing the same in mental retardation, no specific tool has been developed. Often the Intelligence Quotient (IQ) scores are used as a measure of disability. Intelligence refers to a general mental capability. It involves the ability to reason, plan, solve problems, think abstractly, comprehend complex ideas, learn quickly and learn from experience. It is represented by IQ scores, which are obtained from standardized tests given by trained professionals. IQ is more a measure of cognitive ability than of disability per se. Disability refers to personal limitations that represent a substantial disadvantage when attempting to function in the society. A disability should be considered within the context of the environment, personal factors and the need for individualized supports (American Association on Mental Retardation, 2002; International Classification of Functioning, Disability and Health, 2001).

It appears that IQ score is not the ideal index to assess disability. Herrnstein & Murray (1994) have shown that a correlation between IQ and measures of job performance is not robust (only around 0.4). Flynn (1991) has also reported that persons with lower recorded IQ scores were more successful in gaining professional occupational status as compared with those having higher IQ scores. Howe (1997) has also noted that there is little evidence to show that firm statements about a person's actual achievement capabilities can be deduced from his/her IQ level.

Thus, disability as a construct in the context of mental retardation should be measured more in terms of adaptive functioning level rather than only cognitive functioning (as reflected by I.Q. score). Even the very diagnosis of Mental Retardation has to take into account the level of adaptive functioning, as per the latest definition statement from the American Association on Mental Retardation (American Association on Mental Retardation, 2002).

Disability is conceptualized as being different from both cognitive ability and social development level, in the sense that it is a measure of restriction in ability to perform activities otherwise considered normal, thereby reflecting the combined effect of mental retardation as well as other associated conditions (multiple disabilities) in a person.

Following the observation that the lack of a validated instrument was proving to be an impediment in the award of social benefits to the disabled (Trivedi, 1999), the Indian Psychiatric Society has come out with a scale named as "Indian Disability Evaluation and Assessment Scale (IDEAS)" (IDEAS, 2002) for measuring and quantifying disability in specified conditions, which however, does not include mental retardation. The Government of India has officially included IDEAS as the tool for assessment of disability in persons suffering from certain specified mental illnesses (Government of India, Ministry of Social Justice and Empowerment, 2002; 1999), but for assessing the disability in mental retardation, no such tool has yet been recommended, apart from the IQ score.

The lack of a standardized tool appears to be one of the main reasons for use of a theoretically unsound construct of IQ to be used for disability measurement in Mental Retardation.

Moreover, there is uncertainty over the guidelines for assessment of persons suffering from multiple disabilities, where the disabilities due to various associated conditions may not be significant individually when seen in isolation from each other, but together they can be quite disabling for the child. As for example, one may find an autistic child who may be having IQ slightly below the normal, yet remains severely disabled as far as normal activities are concerned. Such children may not receive their due share of social support if only IQ is used for quantification of disability.

In light of these issues, an attempt was made to develop a scale for measuring disability in persons suffering from mental retardation.

Materials and Methods

Following a discussion among a team of personnel experienced in the field of mental retardation, including psychiatrists, clinical psychologists, social workers, special educators and parents of children suffering from mental retardation, five major domains were chosen as conforming to areas reflecting disability in mental retardation. These included (I) Perceptual Motor, (II) Self-care, (III) Communication and Socialization, (IV) Academic and (V) Occupational.

A detailed 5 point anchored (0 – 4) rating system was described for each item. The ratings moved from "no disability" (score of 0) to profound disability (score of 4) for individual items. With the total score ranging from 0 – 20, disability percentages could be calculated from the total scores (40 % or more disability = score of 8 or more).

The first draft of the Assessment of Disability in Persons suffering from Mental Retardation (ADPMR) scale was applied on 5 children and the findings were discussed among the panel of experts. Based on the initial effort, several changes were proposed. An effort was made to keep the usage of scientific terms to a minimum to facilitate the use of ADPMR even by non-professionals, with minimal training. The new draft was again field-tested on 10 children. Criteria that were considered ambiguous or difficult to apply were rephrased by consensus. The final version of ADPMR (Appendix I) was then used to train counselors and special educators working in the special school "Deepshikha Institute of Child Development & Mental Health" in a single three hour session. ADPMR was applied on all children coming to "Deepshikha" during a two-month period who were diagnosed as having mental retardation as per ICD-10, DCR (WHO, 1993), after taking informed consent from their key relatives. Each rater was asked to provide feedback regarding difficulties in its usage which precluded its use in such population.

IQ scores were obtained using Binet-Kulshreshtha Test (standardized for Indian population; Kulshreshtha, 1971) and Social Quotient (SQ) scores were determined using Vineland Social Maturity Scale (VSMS, Malin, 1992). Each instrument was applied by different, suitably trained persons, who were blind to each other and to other details of the subjects. All ratings of a particular tool were done by a single rater. SPSS version 11.0 for Windows was used for data analyses.

Results

The total sample size was 51. The socio-demographic characteristics are summarized in Table 1. Majority of the children (60.8 %) were suffering from multiple disabilities (presence of more than one disability, i.e., mental retardation with any other disability) (Table 2). However, the scale could be successfully applied on each subject. None of the raters reported any instance where the instrument could not be applied due to any reason, even though the children had heterogeneous problems with multiple disabilities being the norm.

Table 1: Sociodemographic variables

Variable		Number (%) / Mean (± S.D.)
Sex	Male	36 (70.6 %)
	Female	15 (29.4 %)
Socio-Economic Status	High	09 (17.6 %)
	Upper middle	10 (19.6 %)
	Lower middle	26 (51.0 %)
	Low	06 (11.8 %)
Age (in years)		14.02 (5.03)
IQ		33.59 (11.67)
SQ		45.31 (15.69)
Mean Disability score		11.49 (2.67)
Mean Disability percentage		57.45 (13.36)

Table 2: Other Disabilities associated with Mental Retardation

Associated Conditions with MR	Frequency	Percentages
None	20	39.2 %
Multiple disability (overall)	31	60.8 %
Cerebral Palsy	6	11.8%
Autism	6	11.8%
Visual problem	2	3.9%
ADHD	4	7.8%
Speech problems	1	2.0%
Others (2 or more)	12	23.5%
Total	51	100.0%

Discussion

Majority of the children (60.8 %) were suffering from multiple disabilities, as evidenced by the presence of at least one associated condition along with mental retardation. Overall, 23.5% had a total of three or more disabilities (mental retardation with two or more associated conditions, Table 2). This is a reflection of the real life picture, where multiple disabilities in children suffering from mental retardation is the norm, and attempts to quantify disability need to address this fact in order to have a holistic view of the problem in a given child. This also highlights that taking into consideration a single factor (e.g. Intelligence Quotient or a measure of physical disability taken in isolation) may not reveal the overall picture in a child having several co-morbid conditions.

Nevertheless, ADPMR could be successfully applied on each subject without fail. This shows that the tool has sufficient flexibility to accommodate children with diverse disabilities presenting with mental retardation.

A single training session of three hour duration was sufficient to familiarize the raters with the instrument so that they could apply the same independently.

Conclusion

The ADPMR scale can be used to assess disability in persons suffering from mental retardation. It may be well suited to quantify the overall percentage of disability in persons previously diagnosed as suffering from mental retardation, who may also have additional associated conditions (as multiple disabilities). A small number of items and use of minimal jargon appear to be helpful for easy administration.

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ADPMR scale

ASSESSMENT OF DISABILITY IN PERSONS WITH MENTAL RETARDATION (ADPMR)

[A Scale for measuring and quantifying Disability
in persons with Mental Retardation]

Developed by: Alka Nizamie, Baxi Neeraj Prasad Sinha, Vinay Kumar Singh, Sumita Sinha, Masroor Jahan, S. Haque Nizamie

Main features of ADPMR

1. ADPMR is best suited for the purpose of measuring and certifying the level of disability in persons with mental retardation.
2. It is brief, quick and simple instrument, which can be used, even in busy clinical settings.
3. It comprises of five areas namely Perceptual-motor, Self care, Communication and Socialization, Academic and Occupational.
4. Basic training is required to use/ administer ADPMR
5. This can be applied either in clinical set-up or even in community based programme.
6. Rating/scoring is very simple and is based on direct observation of persons with mental retardation and interview of primary care giver. Case records can be used as supplementary information. For brevity, "he" represents either "he" or "she".
7. Rating can also be done on the basis of information from teachers / guardians of persons with mental retardation
8. Rating is done on the basis of discrepancies in age appropriate performance.
9. No standardized kit is required for assessment.

Who does the assessment?

Proper diagnosis and certification can be done jointly by the Psychiatrist, Clinical psychologist and special educator. However administration of ADPMR can be done by social worker, rehabilitation personnel, schoolteachers,nurses and grass root level workers after basic training in administration and scoring.

Items :

I. **Perceptual-Motor:** Describes and measures performance in cross motor and fine motor areas in which movement, coordination, balances and postures of the body and its part can be assessed.

II. **Self-care:** Describes and measures performance in eating, toileting, brushing, bathing, dressing, grooming maintaining healthy body hygiene and safety.

III. **Communication and Social:** Describes and measures performance in receptive and expressive verbal or non-verbal communication .Maintaining relationships within immediate community in socially accepted manner.

IV. **Academic:** Describes and measures performance in formal and non-formal educational activities. Concepts like body, its parts, colour, shape, size, sex, number, time, money, reading, writing, arithmetic, reasoning and problem solving ability.

V. **Occupational:** Describes and measures performances in domestic, pre-vocational and vocational activities.

   a. **Domestic:** Competencies like cooking, stitching maintaining cleanliness in house, small repair and maintenance work, taking care of younger siblings and belongings etc.

   b. **Prevocational:** Visits for vocational placements such as work habits, work related behaviors, unskilled and semi unskilled etc. Competency in using simple tools like scissor, hammer, screwdriver, stapler etc. Has a work habit, able to work under supervision, aware of works hazards.

   c. **Vocational:** Includes performances in work settings, quality and quantity of work, job related behaviors and skills.

Scores for each item:

0- NO disability (none, absent, negligible)
1- MILD disability (slight, low)
2- MODERATE disability (medium, fair)
3- SEVERE disability (high, extreme)
4- PROFOUND disability (total, cannot do)

Percentages:

Score of 0 : No Disability = 0%
1 – 7 : Mild Disability = < 40 %
8 and above : => 40 %
(8 – 13 Moderate Disability; 14 – 19 = Severe Disability; 20 = Profound Disability)

MANUAL FOR ADPMR

General Instructions: All ratings should be done considering deviation from age appropriate criteria. Information in the 5 areas is to be obtained by direct observation of the persons with mental retardation, interview of the parents or primary caregiver with case reports as supplementary service. In case of doubts in severity rating, the criterion which is fulfilled more frequently should be

coded. In selected conditions, intermediate scores like 1.5, 2.5, 3.5 can be used.

I. Perceptual-Motor: describes and measures the physical developmental patterns with regard to body balance, coordination of muscles, postures, movement of joints etc as per the person's chronological age.

Broadly classified into two areas :

a. *Gross motor:* Neck holding, rolling over, sitting, squatting, kneeling, standing, walking , running, climbing up and down the stairs etc.

b. *Fine motor:* holding, screwing/ unscrewing, locking / unlocking, cutting with scissors, threading beads / needles etc.

Guiding observations / questions:

a. Does he sit, walk, run well?
b. Does he climb up and down the stairs?
c. Does he hold objects (rattle, milk bottle, glass using both hands)?
d. Does he screw / unscrew jar / bottle lid and take out small objects?
e. Does he hold pencil using his three fingers and scribble?

SCORING DISABILITY:

0-No disability: **Age appropriate performance** is observed. Problem in coordination, balance, movement are not present or reported.
1-Mild: **Mild impairment in coordination, balance or movement** is observed. Performances in activities in Gross motor and Fine motor areas are mildly delayed. One side of the body may have impaired functioning, but not or little effect on the total movement.
2-Moderate: Functionally independent performance in gross-motor and fine-motor areas. **Clumsiness** in walking pattern, moderately in-coordinated movement and balance may be observed.
3- Severe: Marked impairment in coordination, poor balance and restricted movement. Markedly delayed gross motor and fine motor areas. **Needs assistance for mobility.**
4- Profound: Immobile, **very restricted movement** of joint or little mobility requires **physical assistance for mobility even in familiar settings**; hand functions are severely impaired; no or little balance, uncoordinated movement or little coordination may be present.

II. Self Care: describes and measures the adaptability in the area of personal care as per the age and social norms.

Broadly classified into two areas:

a) *Self Help Activities:* such as eating, drinking, toileting, brushing, bathing, dressing and grooming skills etc.
b) *Personal Hygiene, Physical Health and Safety.*

Guiding observations / questions:

a. Does he indicate for toilet needs / independent in toileting?
b. Does he eat independently using hands or spoon?
c. Does he brush self, bath, wear shirts/ frock, unbutton / button?
d. Does he wear shoes / slippers correctly and tie laces of shoes?
e. Does he/she apply oil, powder, comb hair, shave, or keep cleanliness during menstrual period?
f. Does he maintain cleanliness and orderliness?
g. Does he take note of danger and hazards like broken glass, fire?
h. Does he cross roads independently?

Scoring Disability:

0-No disability: Age appropriate independent performances are observed as per the social norms of his immediate environment.
1-Mild: Mild impairment in age appropriate self-care. At times needs **intermittent assistance** (Cluing / Gestural/ Verbal prompts). The person does most of the self-help skills, personal care of health; maintain hygiene and cleanliness matching near to the age level (if not exactly). Generally aware of danger and hazards.
2-Moderate: Functionally independent performance in Self-care areas. May needs **regular and consistent** verbal prompting. Fairly aware of danger and hazards. Maintain cleanliness and orderliness with reminder.
3- Severe: Marked impairment in self help skills areas. Needs assistance (physical prompt) for most of the daily living activities.
4- Profound: Totally dependent on others for Self care, maintenance of hygiene and cleanliness. Requires continuous custodial care for self-help activities. Inconsistent / absence of bowel or bladder control.

III. Communication and Socialization: describes and measures the ability to follow the commands and instructions and receive the messages whether those are verbal gestures or any other indications. Ability to express their needs at one word level / two word level using phrases or sentences or by nonverbal mode such as pointing, using signs gestures etc.

Ability to interact with others in this immediate environment; developing and maintaining relationship with familiar persons and strangers in socially accepted manners.

Broadly classified into three areas:

a. *Receptive Communication*

coded. In selected conditions, intermediate scores like 1.5, 2.5, 3.5 can be used.

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2-Moderate: Functionally independent performance in Self-care areas. May needs **regular and consistent** verbal prompting. Fairly aware of danger and hazards. Maintain cleanliness and orderliness with reminder.
3- Severe: Marked impairment in self help skills areas. Needs assistance (physical prompt) for most of the daily living activities.
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III. Communication and Socialization: describes and measures the ability to follow the commands and instructions and receive the messages whether those are verbal gestures or any other indications. Ability to express their needs at one word level / two word level using phrases or sentences or by nonverbal mode such as pointing, using signs gestures etc.

Ability to interact with others in this immediate environment; developing and maintaining relationship with familiar persons and strangers in socially accepted manners.

Broadly classified into three areas:

a. *Receptive Communication*

b. Expressive Communication
c. Interpersonal relationships

Guiding observations / questions:

a. Does he respond to his name?
b. Does he say papa, baba, mama etc.?
c. Does he follow one-step simple instructions like "Give me the ball"?
d. Does he express his needs using two words phrases / gestures like "Give Ball", "Come Mama" etc.?
e. Does he greet others or waves hands to say "bye-bye"?
f. Does he use sentences or communicates through multiple gestures/signs?
g. Does he share possessions with others or play with others?
h. Does he express distress or defends self when teased / bullied / exploited by others?
i. Does he go about in nearby areas, places / town and come back safely?

Scoring Disability:

0-No disability: Communication meets expectation as per his age and socio cultural context. No difficulty in comprehension and expression. Interactions with others are well maintained. No Problem behaviors observed or reported.

1-Mild: Mild impairment in age appropriate comprehension and expressive verbal or non-verbal language. Social behaviors are generally accepted by others. However, occasionally problem behaviors may be reported in maintaining social interaction.

2-Moderate: A narrow range of verbal and non-verbal expressions. Follows very simple commands. Has inappropriate social interaction, has frequently reported problem behaviors, quarrelsome, shy or may have isolation tendency.

3- Severe: Marked impairment in verbal and non-verbal expressions or limited expressions. Marked difficulty in following simple commands. May have serious difficulty in interacting with others or maintaining relationships. Problem behavior may be commonly reported.

4- Profound: Almost nil verbal and non-verbal expressions. Inability to follow even very simple instructions. Total absence of reciprocal social interactions.

IV. Academic: describes and measures the level of cognitive functioning, concept formation (colors, shapes, sizes, familiar / unfamiliar objects, numbers etc.) pre-academic and academic performances in the areas of Reading, Writing and Arithmetic. Scholastic performances (if attended/attending school) are assessed, recorded and scored accordingly.

Guiding observations / questions:

a. Does he point/name body parts?
b. Does he point /name common objects?
c. Does he differentiate colors, sizes (big/small), shapes, etc.?
d. Does he write 3-letters words, name and address?
e. Does he know addition, subtraction?
f. Does he do minor purchasing?
g. Does he read/write sentences or paragraphs?

Scoring Disability:

0-No disability: Average or above average scholastic performances as per his age. If the person is from rural background, he has the concept of reasoning and calculating as per his age.

1-Mild: Mild discrepancies in academic achievements (formal / non-formal). Has basic number concepts. Has basic problem solving ability. Can do simple additions and subtractions. Can read and write small paragraphs. Money Exchange Present.

2-Moderate: Marked discrepancies in academic achievements (formal / non-formal). Has limited number concepts. Needs help in doing simple addition and subtractions. Functional reading and writing present like read and write name, address, telephone number. Minimal money exchange present.

3- Severe: Very poor academic performances, appears to be uneducable. May have pre-academic (shape, size, color, etc.) concepts.

4- Profound: Nil or negligible or minimal academic performances, even absence of pre-academic (shape, size, color, etc.) concepts.

V. Occupational: describes and measures the performances in occupational activities including house-hold work, prevocational activities, and competencies in work at job site.

Guiding observations / questions:

a. Does he help mothers/family members/teachers in routine household/classroom activities?
b. Does he perform simple household activities like dusting, cleaning, sweeping etc.?
c. Does he cook, operate mixer/stone grinder, operate kerosene stove, etc.?
d. Does he fetch milk/water, participates in gardening?
e. Does he do household repair and maintenance work?
f. Does he work in-group without disturbing others, follow group norms?
g. Does he maintain standard of work and increase production of items as per demand?

Scoring Disability:

0-No disability: Attends regular work at home and at work place as any other persons of his age.

1-Mild: In general the person is able to do the required work appropriate to his age, sometimes needs supervision or prompting. In general, maintains quality of work. At times quality may not be up-to the mark.

2-Moderate: Needs regular and continuous prompting in household or job site activities. Unable to maintain regular work behaviors. Quality of the work is poor.

3-Severe: Requires physical assistance to perform the task. Makes mistakes in simple activities. Cannot be left alone to perform simple tasks. May disrupt others at home or at work place.

4-Profound: Nil or negligible work performances.

ASSESSMENT OF DISABILITY IN PERSONS WITH MENTAL RETARDATION (ADPMR)

A Scale for measuring and quantifying Disability
in persons with Mental Retardation

Information Checklist and Scoring Sheet

Name	:	Date	:
Date of Birth	:	Regn. No.	:
Age	:	Sex	:
Date of Admn.	:	Education/Class	:
SES	:	Informant's Name	:
Education	:	Income per month	:
Address	:		

Level of Retardation [IQ] (Tools used) :
Social Maturity [SQ] :
Associated Conditions :
a) *Disability (Specify)* :
b) *Behavioral Problem (Specify)* :

DISABILITY SCORES

ITEMS	0	1	2	3	4
I.Perceptual-Motor					
II. Self-Care					
III. Communication and Socialization					
IV. Academics					
V. Occupational					
Total Score :					

PERCENTAGE OF DISABILITY: