

Issues and Concerns related to Psychological Assessment Intervention and Rehabilitation of Disability in India-Current Status

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ABSTRACT

People with disabilities are subject to multiple deprivations with limited access to basic services, including health, education, vocation, rehabilitation, recreation facilities etc. Despite various legal safeguards and existing policies in India, at the ground level, persons with disabilities are often reported to face multiple challenges and disadvantages. At the same time even after the revised guidelines under the RPwD Act (2016), Clinical Psychologists involved in the Assessment and Quantification of various disabilities have many issues and concerns, due to which they are facing many problems and challenges in their day-to-day work. The present review article is based on the findings from various online published Indian studies on disability assessment, intervention and policies which have been analyzed and summarized. The findings are presented under predefined categories as outlined at the outset of stating the analysis as per the categories framed. These five major categories identified for this article are- Prevalence of Disability in India; Current Indian laws and policies for PwDs; Current challenges in disability assessment and certification; Psychological Intervention & Rehabilitation Approaches for PwDs; and Welfare Schemes for PwDs. The current challenges, issues and concerns related to these categories have been presented here to think upon and make possible changes in the current clinical practice of assessment and intervention of some of the disabilities.

Keywords: *Psychological assessment of disabilities; Issues and concerns related to disability assessment and intervention; Current Indian Laws and Policies; Disability Certification; Welfare Schemes*

INTRODUCTION

The World Health Organization (WHO) has defined 'Disability' as "an umbrella term, covering impairments, activity limitations, and participation restrictions. According to the WHO, impairment is a problem in body function or structure; an activity limitation is considered as a difficulty encountered by a person in executing a task, action or activity. When a person experiences a problem in getting involved and participating in day to day life situations, it is termed as participation restriction. Thus, as per WHO, "disability is a complex phenomenon, which reflects an interaction between aspects of a person's body and aspects of the society in which he or she lives." The WHO has estimated that more than one billion people, that is approximately 15 percent of the world's population lives with some form of disability (WHO, 2011) arising due to varied causes like congenital defects, chronic diseases, injuries, violence, infectious diseases, malnutrition, and other causes related to poverty.

People with disabilities are subject to multiple deprivations with limited access to basic services, including health, education, vocation, rehabilitation, recreation facilities etc. Despite the world today talking so much about inclusion, widespread social stigma still prevails and plays a major role in hindering the normal social, occupational and economic life of persons with disabilities (PwDs). Despite various legal safeguards

and existing policies, at the ground level, persons with disabilities, not only in India but worldwide are often reported to face multiple disadvantages. Multiple social policy processes and other institutional arrangements have been responsible for keeping disability issues out of the purview of social recognition for long. Society at large, has till date not been able to create a suitable environment for the inclusion of persons with disabilities mainly due to the 'conspicuous invisibility' in the realms of health care, education, laws, development policy, social and institutional practices, political advocacy, academic engagements, intervention services, community-based rehabilitation, and public support systems.

In the past few years, there have been attempts towards major global shift in the understanding of disability with an emphasis on recognizing rights of persons with disabilities while acknowledging human diversity. Although, disability is an important public health concern, however, systematic research into prevalence, analysis of assessment techniques, intervention methodologies and determinants of disability has been scanty in India.

METHODOLOGY

The present article is based on various online published studies collected for the purpose of review. Findings from Indian studies on disability assessment, intervention and policies have been analyzed and

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summarized. Literature review articles in Google Scholar and PubMed electronic database, and website of various departments of Government of India was done, using search questions decided and framed by the authors. The search terms used were disability status in India, disability assessment, disability policies, intervention for disabled, and social welfare schemes for PwDs. The articles were reviewed for ideas and concepts, which were then categorized under broader themes, and these broad categories are being discussed here based on the relevance to clinical and practical issues and concerns related to the field of disability in present time. Information gathered from these studies/articles is presented under findings here. These categories have been framed as per the questions and challenges based on the difficulties faced by Clinical Psychologists in the assessment and interventions of different disabilities.

The five major categories identified for this article are-

1. Prevalence of Disability in India
2. Current Indian laws and policies for PwDs
3. Current challenges in disability assessment and certification
4. Psychological Intervention & Rehabilitation Approaches for PwDs
5. Welfare Schemes for PwDs

Findings:

Based on research questions, the following concepts which are important from the point of views of clinicians, PwD and caregiver perspective are discussed.

1) Disability Prevalence in India

According to the Census 2011, the differently abled population in India was reported to be 26.8 million. In terms of percentage, the population stands at 2.21 %. Compared to the census of 2001, there has been a marginal increase in the PwD population in India, with the reported PwD population rising from 21.9 million in 2001 to 26.8 million in 2011. In a recent study by Pattnaik et al (2023), the overall prevalence of disability in India has been reported to be 4.5%. The study reports locomotor disability (44.7% of all disabilities) as the most common type of disability among Indian population. As per the reported findings of this study, mental disabilities account for 20.28% of all the disability in Indian population (Pattnaik et al.2023).

2) Current Indian laws and policies for PwDs

India signed the United Nations Convention on the Rights of Person with Disabilities (UNCRPD) and subsequently ratified the same on October 1, 2007. According to the UNCRPD, disability is a result of an

interaction of bodily impairments with attitudinal and environmental barriers which hinders full and active participation in society on an equal basis. Further, because the UNCRPD convention mandated the signatories to change their national laws, to identify and eliminate obstacles and barriers on disability rehabilitation, the Government of India introduced the amendment of the existing Persons with Disability Act, 1995 (PWD Act 1995). The Rights of PWD Act, 2016 (RPWD Act 2016) replaced the PWD Act 1995 and was introduced to secure the rights of PwD.s in accordance with UNCRPD convention and it has been fine-tuned considering the socio-cultural needs of Indian society, while considering the available resources.

Subsequent to the RPWD Act 2016, on January 4, 2018, the Department of Empowerment of Persons with Disabilities, Ministry of Social Justice and Empowerment notified the specific guidelines for the purpose of assessing and certifying the extent of specified disability (GOI, 2018). The Government of India has launched “Unique ID for Persons with Disabilities”(2018) project which is being implemented with a view of creating a National Database for PwDs, and to issue a Unique Disability Identity Card to each person with disabilities. The project would not only encourage transparency, efficiency and ease of delivering the government benefits to the person with disabilities, but also ensure uniformity. The project would also help in stream-lining the tracking of physical and financial progress of beneficiary at all levels of hierarchy of implementation – from Village level, Block level, District level , State level and National level. Even after more than five years of its launch, the project is facing several challenges like non availability of specialists in many hospitals that are notified for disability assessment and certification, limited infrastructure, lack of awareness among people about the process and procedure of applying and issuance of UDID. Even after the successful launch and prevalent use of Digital India program, still there are people, like illiterates, extremely poor, elderly or rural people who lack Smart phones or access to Internet facilities, making difficult for them in getting registered for UDID, and to track the process.

3) Current Challenges in Psychological Assessment and Certification of Disabilities

With the introduction of Gazette notification, 4th January 2018, Government of India has laid down specific guidelines for assessment and quantification of disability for certification. However, clinical experience and expert opinions suggest that there is a need to have updated tests. For example, for the assessment of Intellectual Disabilities (Mental Retardation) Para 21.3 of the Gazette has recommended only two tests for IQ

assessment (BKT/MISIC), and the percentage of Disability has to be decided by SQ, as assessed by Vinland Social Maturity Scale (VSMS). Many a times a discrepancy is found between the IQ score and SQ score, and it becomes a problem for the clinician to decide about the category and percentage of Intellectual Disability. Also, all the three tests prescribed have very old norms, and items also appear obsolete seeing the changes in the pattern of education and wide exposure of children to various sources at present in comparison to 20-30 years back, when those tests were developed.

For some other categories of disabilities, there needs to be more specified and notified tests for Psychological assessments. For instance, as per para 25.5, of Gazette notification dated 4th January 2018, for chronic neurological conditions, the medical authority should comprise of a trained psychologist to administer IQ test. This needs to be reconsidered as a person with chronic neurological condition, most of the times, would also require detailed Neuropsychological assessment (NPA) in addition to/ instead of IQ assessment. Since, no Neuropsychological assessment tools have been notified in the gazette, most notified centers for assessment of chronic neurological conditions, having qualified clinical psychologists are using the Neuropsychological assessments as per their own expertise. Also, the currently available and used NPAs do not provide any clear cut guidelines regarding identification and quantification of disability; and also deriving at the percentage of disability.

In respect to assessment of Specific learning disability, the Gazette (Para22.4) has notified NIMHANS battery for Specific Learning Disability assessment. However, as already pointed out by Math et al. (2019), the battery is not comprehensive for all ages and is standardized only till Grade 7 (approximately till age 14 years) and also does not give specific percentage of disability. Therefore, there is a pressing need to develop psychological assessment tools which give specific disability scores and disability percentage. Standardized SLD assessment tools are also required for PwDs who are above the age of 14 years as currently there is no standardized tool for SLD assessment of this age group. Another problem regarding SLD certification is related to repeated assessments, which is required theoretically to assess the changes which might have occurred due to age and / or remediation techniques. The initial assessment and certification has to be done for children aged eight years and above only, and the child will have to undergo repeat assessment and certification at the age of 14 years and at the age of 18 years. The referral for repeat certification is required from school, as per gazette notification, which is not being followed by most of the schools leaving persons with SLD in a

difficult situation and adding to their distress, therefore there is a dire need to sensitize schools on this aspect.

4) Psychological Intervention & Rehabilitation Approaches for PwDs

Rehabilitation interventions at early stages of disability are highly recommended as early intervention can minimize progression to severe disability. It has been reported that very few persons with disability gets benefit from rehabilitation services in India. (NSSO,2003; Kumar et al. 2008). In general, data reports that of all PwD.s in India, 1/3 need no rehabilitation, 1/3 can be helped through CBR alone and 1/3 needs specialized referral services (Sharma and Praveen,2002).

The interventions for disabled in India largely focus on catering to six main categories namely health, education, livelihood, social, empowerment, advocacy and governance. According to the, National Policy for the Persons with Disabilities, Government of India (2006), rehabilitation measures can be classified into three distinct groups:

- i. Pphysical rehabilitation, includes early detection of problem and intervention including medical interventions, counseling provision of aids, if need be. It will also include the development of manpower in terms of training of rehabilitation professionals.
- ii. Educational rehabilitation including vocational education and
- iii. Economic/financial rehabilitation including job placements for a dignified life in society.

In a review by Saran et al.2023, it has been summarized that all these various types of interventions play a vital positive role towards improvement of social inclusion of PwDs. These authors have further reported that interventions at the individual level which include social and communication training lead to significant improvement in the social adaptive behaviour and social skills of people with disabilities. The review has concluded that the studies targeting broad-based social inclusion have shown a large and significant positive effect, while only moderate effect was reported from interventions designed to improve interpersonal relationships between people with disabilities and their families and communities.

According to the Alma Ata declaration (1978), comprehensive primary health care should include preventive, promotive, curative, and rehabilitative care. Further, it states that there are three approaches to rehabilitation, namely institution based, outreach based, and community based. In India, in the recent years, focus has been on Community based rehabilitation (CBR), which is a comprehensive approach at primary

health care level used for situations where resources for rehabilitation are available in the community. The major objective of Community Based Rehabilitation (CBR) is to ensure that PwDs are able to maximize their physical and mental abilities, have access to regular services and opportunities, and achieve full integration within their communities (Sharma and Praveen, 2008). In CBR model, in addition to transfer of knowledge related to skill development in various rehabilitation methods, community is also involved in planning, decision making, and evaluation of the rehabilitation program/s with multi-sectoral inputs. It also includes a referral system for those PwDs who cannot be managed at community level and require individual or institutional rehabilitation services.

The service delivery system for CBR requires coordinated efforts by ministries, local, district and provincial authorities, and nongovernmental organizations in the different sectors involved in rehabilitation. It has been reported that for most PwD.s (70%), interventions can be done effectively at the community level by local rehab professionals and school teachers. A study by Ganesh et al. (2011) concluded that psychosocial intervention increases the quality of life and reduces the disability severity among mentally disabled adolescents. Additional services need to be set up in response to the needs of the community. At district or provincial level there is a need to sensitize general physicians, intermediate level supervisors, orthopedic technicians, resource teachers and vocational trainers. National level professionals need to be involved in delivery of complex rehabilitation services as well as training and supervision of rehabilitation professionals for district, provincial, and national levels.

Basic principles of a CBR program for the disabled include inclusion, participation, sustainability, empowerment, and advocacy. These principles are overlapping, complementary, and interdependent and they cannot be addressed in isolation. Hospital based interventions are often considered to lead to social isolation and have limited accessibility when it comes to rural and semi urban population. While selecting the mode of intervention- hospital based versus community based, it is important to prioritize in terms of resources like finance, manpower and aids/equipments that may be required. Currently, there is limited evidence towards efficacy of various approaches of rehabilitation. Another major challenge in Indian scenario is professionals not maintaining professional boundaries as per their professional training and licensing and many untrained professionals claiming to be trained expert professionals which rather than alleviating the problems, can become hindrance in adequate intervention and rehabilitation of the PwD.

There needs to be adequate coordination between different sectors, departments and all stakeholders for optimum outcome of intervention services. For example, the primary health care system must play a key role in early identification, and providing initial support and guidance to PwD.s and their caregivers with initiatives such as early identification of symptoms/ impairments, initiating basic intervention, referrals to appropriate specialized services such as Clinical Psychologists, Occupational therapist, speech therapist and other medical and para medical specialities. The educational sector needs to be more inclusive not just in reserving the number and percentage of seats for PwD.s but in real terms by adapting newer educational techniques with respect to content of the curriculum, teaching methodologies and teaching aids and adaptations being used. Many rehabilitation centres are working in vocational training of PwD.s but this rarely leads to any real life occupational placement.

There is no dearth of Indian studies on Parenting stress, caregiver burden, WQol of PwD and their caregivers(Malhotra et al. 2012; Malhotra et al.2019); . However, the question arises that despite so much research into these aspects how much we have been able to utilize these findings in laying down policies for identification, assessment and intervention. Periodic monitoring and evaluation of intervention and rehabilitation programmes in critical component. There need to be a system for periodic monitoring and evaluation of intervention programmes.

2) Welfare Schemes for PwDs

In order to give focused attention to Policy issues and meaningful thrust to the activities aimed at welfare and empowerment of the Persons with Disabilities, a separate Department of Empowerment of Persons with Disabilities (Divyangjan) (DEPwD) under Ministry of Social Justice & Empowerment was set up in May 2012. The DEPwD is the nodal department for implementing various Programmes, Schemes and other initiatives for the welfare of persons with disabilities. Empowerment of persons with disabilities is an inter-disciplinary process, covering various aspects namely, prevention, early detection, intervention, education, health, vocational training, rehabilitation and social integration. Some of the schemes of Government of India to empower PwD are presented in the table below.

SchemeName	Aims of the Scheme
Deendayal Disabled Rehabilitation Scheme (DDRS)	to provide grant-in-aid to non-governmental organizations (NGOs) for projects relating to rehabilitation of persons with disabilities aimed
Assistance to Disabled Persons for Purchase / Fitting of Aids / Appliances (ADIP)	Assist the needy PwDs to procure durable, sophisticated, certified aids/ any parts of aids to promote their independent functioning

SchemeName	Aims of the Scheme
Scheme for Implementation of Rights of Persons with Disabilities Act, 2016 (SIPDA)	providing financial assistance for undertaking various activities like skill development, educational training, vocational training, providing accessible infrastructure
National Trust	To- to enable and empower persons with disability to live as I ndindependently and as fully as possible within and as close to their community as possible; to facilitate the realisation of equal opportunities, protection of rights and full participation of persons with disability; to extend support to its registered organisations to provide need based services; and to evolve procedures for appointments of guardians and trustees for persons with disabilities
National Handicapped Finance and Development Corporation (NHFDC),	works for Socio-economic empowerment of PwDs. Provides concessional loan through its partner agencies to PwDs and to self help groups
GHARAUNDA	Life long shelter and care of Persons with Disability (PwD), under National Trust
Nirmaya	Scheme of National Trust- Health insurance upto 10 lakhs to PwD
Badhte Kadam	Raise awareness in the public, regarding Person with Disability (PwD) covered under the NationalTrust Act and encourage their inclusion in the society, social integration and participation of persons with disabilities in all aspects of life.

SUMMARY

Despite being a widely discussed issue, there are many lacunae and challenges in the assessment, intervention and rehabilitation of PwD.s. There is a need to update notified assessment tools for certification of disability. Further, attempts should now be focused more on developing evidence based multidisciplinary interventions which are in sync with the ground realities and enable further research. It is of utmost importance to involve PwDs in development of policies, support services and training. Capacity building is another major area that requires focus. Thus, although we have many policies and guidelines in place, the pace of work happening at ground is very slow due to the lacunae discussed above indicating the scope of further evidence based efforts to fill the gap in knowledge and practice.

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