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# A Comprehensive Study of Community-Based Inclusion, Rehabilitation, and Multidisciplinary Approach toward Cross-Disabilities in Panchayats of North India

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## Abstract

**Background:** Demonstrated multidisciplinary, scalable, and replicable panchayat models for effective inclusion of persons with disabilities (PwDs) are much needed in a developing country like India, with its 70% of population being rural. Literature on disability suggests a shift in policy thinking from the charity-, medical-, and institutional-based models of disability to social, community-based rehabilitation (CBR), and rights-based models. This study explored in-depth the Community-Based Inclusion and Rehabilitation (CBIR) program model of the Chinmaya Organisation for Rural Development (CORD), a nongovernmental organization working with 1800 PwDs in 100 panchayats of Kangra district of Himachal Pradesh. **Objectives:** The objectives were to identify PwDs with all types of disabilities in ten selected panchayats associated under the CORD's CBIR program as per the definitions of disabilities under the PWD Act, 1995, and the National Trust Act, 1999, and to explore multidisciplinary, scalable, and replicable aspects and interventions under the CBIR as a model for inclusion of all types of PwDs in rural India with reference to the World Health Organization's (WHO's) CBR matrix. **Study Design:** This is a descriptive, qualitative, and quantitative study conducted on the CORD's CBIR model with reference to the WHO's CBR matrix. **Methods:** A convenient sample of ten panchayats out of 100 panchayats under the CORD's CBIR interventions was studied. The principal investigator with a team of two co-researchers and five field facilitators worked as a team to conduct this study. A baseline format with reference to the WHO's CBR matrix was developed and administered for the collection of primary data besides related interviews of PwDs, their families, and related stakeholders. The CORD's CBIR program data, narratives, and focus group discussions were used to supplement the outcomes of this study. **Results:** This study observed that availability of disabilities specific, disaggregated and recorded government data on PwDs at the panchayat level was poor and non-existent. Primary data of 124 (100%) PwDs among the 4487 households with a total population of 22,438 in ten panchayats were collected and further investigated from April 2017 to March 2018. The findings highlighted 87 (70%) PwDs newly identified during the study, 60 (48%) PwDs below poverty line, and 113 (91%) marginal and socially backward PwDs. The program interventions enrolled 26 (21%) PwDs in schools, 72 (58%) mothers and women with disabilities in community groups, and 44 (35%) PwDs in productive livelihoods locally. **Conclusion:** There was evident marginalization of PwDs in multiple ways varying from data to dignity issues at the panchayat level. The CORD's CBIR model promotes the "empowering inclusion and development" of PwDs in the mainstream community at the panchayat level. The recent enactment of the comprehensive Rights of Persons with Disabilities Act 2016, covering 21 types of disabilities, further share an opportunity for effective inclusion of PwDs within the existing policies, programs, and development agenda in rural India as well as globally.

**Key Words:** Community-Based Rehabilitation Matrix, Inclusion, Panchayat, Persons with Disabilities, Rights of Persons with Disabilities Act 2016

## INTRODUCTION

The World Health Organization (WHO) estimates suggest that the total global number of people with disabilities has already surpassed one billion.<sup>[1-3]</sup> In India, persons with disabilities (PwDs) were counted for the first time in the 2001

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census. The 2011 census estimate for India, which is based on a narrower (medical) definition of disability, indicates that the total population with any kind of disability is 26.8 million, whereas the corresponding National Sample Survey estimate is 26.5 million.<sup>[4-6]</sup> Rural India constitutes approximately 70% of India's population. The recently enacted comprehensive Rights of Persons with Disabilities (RPD) Act, 2016, has a much broader umbrella of disabilities expanded to 21 types as compared to the earlier eight types (under the PwD Act 1995).<sup>[6]</sup> Stigma, charity, welfare, inaccessibility, and nonavailability of even basic services are the still prevailing issues of PwDs in rural India. Poor availability of desegregated government data and programs for inclusion and empowerment of PwDs at the panchayat level, further deprives and isolates PwDs at the community, state, national as well as global disability agenda.

Hence, a panchayat-level participatory, multipronged, and community-based approach is the need of the hour for the effective inclusion of PwDs based on their diverse socioeconomic, demographic, and geographic context. India has approximately 250,000 panchayats – a unit of local self-governance and decentralized development as per the provisions of the 73<sup>rd</sup> constitutional amendment.<sup>[7-9]</sup> This is a huge opportunity for PwDs' inclusion in the development agenda of the central and state governments.

The Community-Based Inclusion and Rehabilitation (CBIR) of PwDs is an effort of the Chinmaya Organisation for Rural Development (CORD), a nongovernmental organization (NGO) at the panchayat level. This program empowers all PwDs to address their issues, i.e., awareness, health, education, livelihoods, social, advocacy, and inclusion holistically through their active participation [Figure 1]. This

enables PwDs, their families, as well as the community at the panchayat level to be active participants and contributors in the mainstream development versus being a passive recipient of charity and welfare.

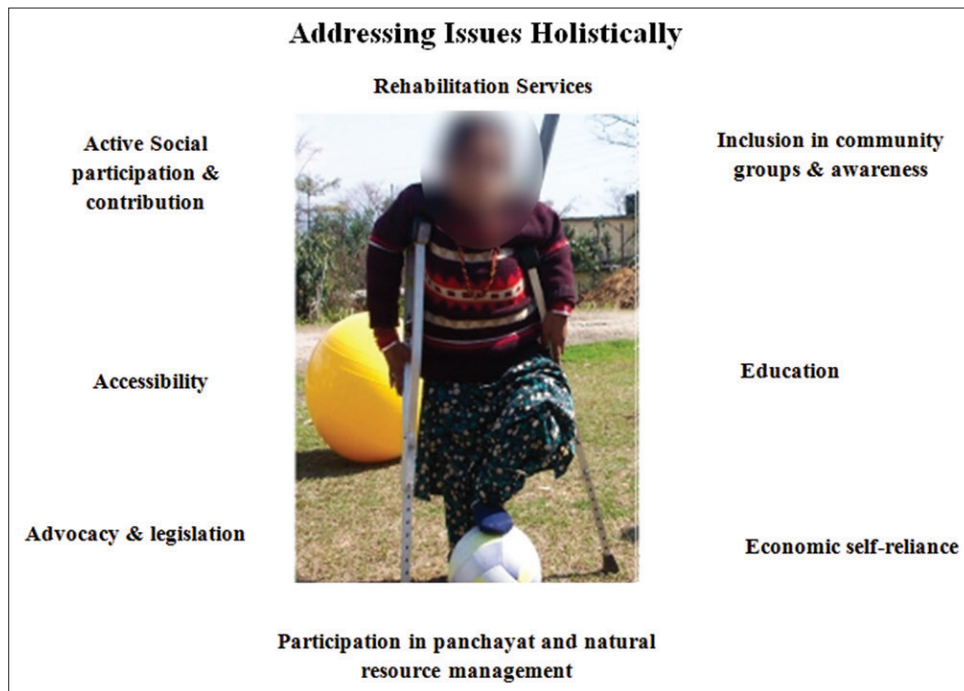
This descriptive study has the following main aims and objectives:

1. To identify PwDs with all types of disabilities in ten selected panchayats associated under the CORD's CBIR program as per the definitions of disabilities under PwDs Act, 1995, and the National Trust Act, 1999
2. To explore multidisciplinary, scalable, and replicable aspects and interventions under the CBIR as a model for inclusion of all types of PwDs in rural India with reference to the WHO's Community-Based Rehabilitation (CBR) matrix.

## METHODS

In this population-based mixed-methods (qualitative and quantitative) descriptive study, ten panchayats out of 100 panchayats under the CORD's CBIR program were selected for the research, based on convenient sampling method, from the Kangra district of Himachal Pradesh. The research was conducted by the principal investigator (PI), two co-researchers, and five field facilitators (FFs) – each covering two panchayats under the study. The research team is an integral part of the CORD's CBIR program design, interventions, and implementation. A baseline format was developed with reference to the WHO's CBIR matrix to screen households (HHs) and collect data of PwDs. This ensured the standards of the study and reference to the global context. Maximum quantitative and qualitative information was collected and collated. The co-researchers supervised the FFs during data collection through well-planned field

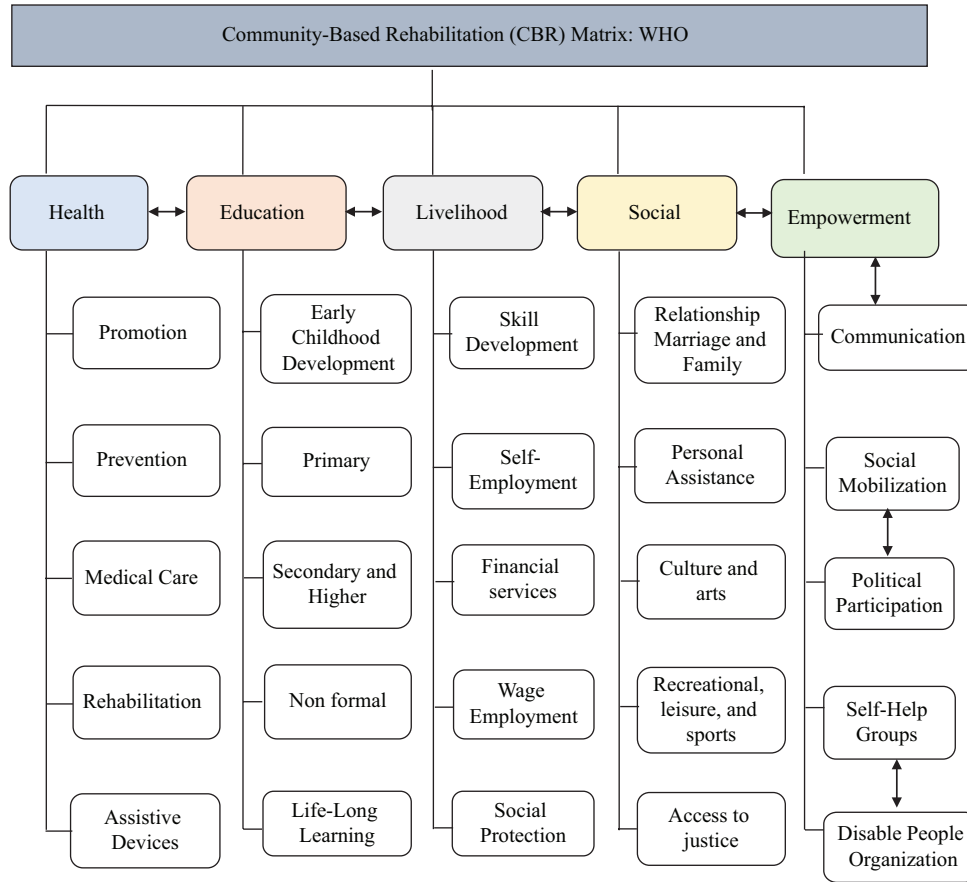
**Figure 1:** A Holistic Model of the Community Based Inclusion and Rehabilitation by the Chinmaya Organisation for Rural Development



interventions such as focus group discussions and narratives on individual interactions with PwDs, families, and related stakeholders. A written informed consent was taken from all participants in the study as per the Declaration of Helsinki guidelines. Quantitative and qualitative changes in information over a period of 1 year were documented from April 2017 to March 2018, based on the core parameters of the CBIR

program of the CORD with reference to the standardized CBR matrix [Figure 2]. The major quantitative indicators on PwDs included identification and type of disability, age, sex, caste, economic status, number of PwDs attending schools, disability certification, and access to pension and bus pass as entitlement. Qualitative data included information on community inclusion and empowerment, livelihood avenues,

**Figure 2:** The World Health Organization’s Community-Based Rehabilitation Matrix



**Table 1: Panchayat-Wise and Age-Wise Data (April 2017 - March 2018)**

Panchayat	Age (in years)						Total PwDs identified <i>n</i> (%)	Total Household (Data as per panchayat record) as on March 2017 <i>n</i> (%)	Percentage (%)* of PwDs in Each Panchayat (CORD data record) as on March 2018 from Total Panchayat Population ( <i>n</i> )
	0-6	7-12	13-18	19-40	41-60	60+			
Paror	0	0	0	13	4	1	18 (14)	659 (15)	659 (3)
Drang	1	0	1	2	3	0	7 (6)	724 (16)	724 (1)
Makroti	1	2	2	7	0	2	14 (11)	293 (6.50)	293 (5)
Ambari	0	1	3	10	2	1	17 (14)	308 (7)	308 (6)
Ghanna	0	2	3	3	0	1	9 (7)	502 (11)	502 (2)
Ansoli	0	0	1	3	1	3	8 (6)	306 (7)	306 (3)
Sohura	3	0	3	2	4	0	12 (10)	500 (11)	500 (2)
Tarshu	0	3	4	6	4	0	17 (14)	240 (5.50)	240 (7)
Bhadiyara	0	3	3	4	2	0	12 (10)	455 (10)	455 (3)
Kohala	1	2	1	3	3	0	10 (8)	500 (11)	500 (2)
Total	6	13	21	53	23	8	124 (100)	4487 (100)	4487 (3)

PwDs: Persons with Disabilities; CORD: Chinmaya Organisation for Rural Development. \*Percentage values have been converted from decimal to whole numbers when >5 after decimal point

**Table 2: Types of Disabilities as Per Age Groups and Sex (April 2017-March 2018)**

Category	Age (years)												Male <i>n</i> (%)	Female <i>n</i> (%)	Total number of PwDs <i>n</i> (%)
	0-6		7-12		13-18		19-40		41-60		60+				
	Male	Female	Male	Female	Male	Female	Male	Female	Male	Female	Male	Female			
Physical disability	1	0	3	1	6	0	13	9	18	3	3	0	44 (36)	13 (10)	57 (46)
Mental retardation	3	1	4	4	6	2	10	6	0	0	0	0	22 (18)	13 (10)	35 (28)
Mental illness	0	0	0	0	0	0	0	0	0	1	1	0	1 (1)	1 (1)	2 (2)
Multiple disability	0	0	1	0	2	3	3	1	0	0	0	0	6 (5)	4 (3)	10 (8)
Cerebral palsy	0	0	0	0	0	0	0	1	0	0	0	0	0	1 (1)	1 (1)
Hearing impaired	0	0	0	0	0	1	3	2	0	1	2	0	5 (4)	4 (3)	9 (7)
Low vision	0	0	0	0	0	0	4	0	0	0	0	2	4 (3)	2 (2)	6 (5)
Other	2	0	0	0	1	0	0	1	0	0	0	0	3 (2)	1 (1)	4 (3)
Total	5	1	8	5	15	6	33	20	18	5	6	2	85 (69)	39 (31)	124 (100)

PwDs: Persons with disabilities

**Table 3: Parameters at the Beginning and the End of Study (April 2017-March 2018)**

Activity/population presentation	PwDs data as per the CORD record	
	Beginning of the study, April 1, 2017, <i>n</i> (%)	End of the study, March 31, 2018, <i>n</i> (%)
PwDs in ten panchayats	40 (32)	124 (100)
Mothers of children with disabilities in women's groups	19 (15)	58 (47)
Mothers of children with disabilities in SHGs for microcredit	16 (13)	58 (47)
Women with disabilities in women's groups	8 (6)	14 (11)
Women with disabilities in SHGs	5 (4)	11 (9)
Children with disabilities in mainstream education	9 (7)	26 (21)
PwDs in employment under MNREGA	10 (8)	25 (20)
Parents of children with disabilities in MNREGA	25 (20)	32 (26)
PwDs in productive/employment at local level	11 (9)	44 (35)
PwDs' aids and appliances provided through government agencies	3 (2)	12 (10)
PwDs' medical certificates through the disability board	30 (24)	100 (81)
PwDs' bus passes through the welfare office	23 (19)	77 (62)
PwDs' health insurance card through New India Insurance Company (under Swabalamban/Niramaya Health Insurance)	13 (10)	57 (46)
PwDs' participation in district- and state-level sports and abilities' event	0	11 (9)
PwDs receiving disability allowance from the government	23 (19)	68 (55)
Toilets in the homes of PwDs	30 (24)	114 (92)
MCUs (rural advocacy forum for people with disabilities) facilitated and established	0	10 (100)
VRPs trained for disability issues and concerns and provision of home visits	0	10 (100)

PwDs: Persons with Disabilities, SHGs: Self-help groups, CORD: Chinmaya Organisation for Rural Development, MNREGA: Mahatma Gandhi National Rural Employment Guarantee Act 2005, VRPs: Village Resource Persons, MCUs: Mini Chinmaya Umangs

services and entitlement access, dignity and quality of life, and advocacy and contribution of PwDs in their concerned panchayats. Data were collected and grouped as summarized in Tables 1-3 with the outcomes.

### Data Analysis

Descriptive statistics were used for the analysis of data by the PI, and percentage change was documented in the study from beginning to end as summarized in Tables 1-3.

## RESULTS

Tables 1-3 summarize information collected on PwDs, showing their status at the beginning and end points of the study. A total of 124 persons were identified with all types of disabilities among 4487 HHs screened with a total population of 22,438 in ten panchayats during the baseline survey. This included collection of secondary data available with the concerned panchayat office as well as door-to-door visits by the FFs for collecting primary data. Data were analyzed by PI and team. All the 124 PwDs and their families had individual intervention sessions with the FFs and CORD's CBIR team at the center and field for a minimum of three times to a maximum of thirty times during the period of study. The survey findings reported that 60 (48%) PwDs were below poverty line category, 19 (15%) belonged to scheduled caste category, 2 (2%) scheduled tribe category, 92 (74%) other backward class, and 11 (9%) belonged to general category. All the 124 PwDs reported physically to the CORD's CBIR program. As per the holistic model of the CORD's CBIR program and with reference to the WHO's CBIR matrix model, center-based and field-based program interventions were designed for the 124 PwDs as per their age, need, and socioeconomic status in the community. Center-based interventions included individual PwD's treatment and rehabilitation management plan, PwDs'/parents' education, counseling, guidance, physical therapy, occupational therapy, special education, activities of daily living (ADL) skills, speech and audiometry assessment and sensory integration, individual education plans, and referral for further medical or surgical interventions to nearby hospital or medical college. A total of 100 (81%) PwDs received their disability certifications from the medical board and 12 (10%) PwDs received required rehabilitation aids/appliances as mentioned in Table 3. Field-based interventions by the PI and research team included mobilization of PwDs'/parents', awareness and linkages with health and rehabilitation services, medical certification of disabilities, accessibility from PwD's home to main road, inclusion in Mahila Mandals and Self-Help Groups (SHGs), inclusion in schools, vocational assessment, livelihood development, participation in Up-gramsabhas and Gramsabhas of panchayat, services provided under Mahatma Gandhi National Rural Employment Guarantee Act 2005 (MNREGA), and services provided by the CORD or governmental agencies. In Mahila Mandals, a total of 58 (47%) mothers of PwDs and 14 (11%) women with disabilities were included as members. In SHGs, 58 (47%) mothers of PwDs and 11 (9%) women with disabilities were enabled to access microcredit for their needs and livelihood development. Children of educable age group (6–18 years), i.e., a total of 26 (21%) PwDs, were enrolled into the mainstream education. Facilitation and trainings of 44 (35%) PwDs were conducted to help them gain productive employment in farming and allied sectors and nonfarming and service sectors as per their abilities, skills, and vocational due diligence. Overall, 25 (20%) PwDs and 32 (26%) parents of the PwDs were facilitated to receive jobs as entitled under the MNREGA. As per their rights and

entitlements, identified through the baseline survey, out of 124 PwDs, 77 (62%) PwDs received bus passes, 57 (46%) PwDs received health insurance, 68 (55%) PwDs received disability monthly pension/allowance, and 114 (92%) PwDs guided and assisted to have adaptive toilet units in their homes. For the first time, 11 (9%) PwDs participated in one or other events/games in the state and outside their panchayats. Mini Chinmaya Umangs (MCUs)-forums of rural PwDs and their families and friends were established in ten panchayats with regular monthly meetings. Ten village resource persons (VRPs) were trained and are working in all the ten panchayats as human capital to ensure network, linkages, sustainability, and scaling of the CBIR program in the panchayats as detailed in Table 3.

## DISCUSSION

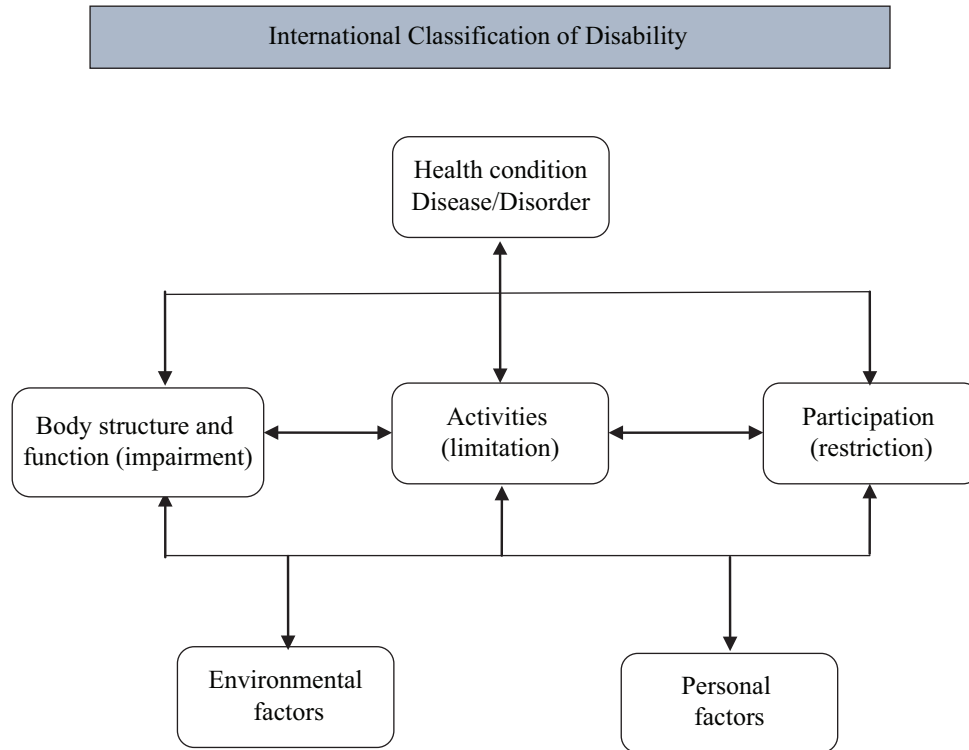
Different models and strategies have been adopted globally for the rehabilitation of PwDs.<sup>[1,2]</sup> The CBR was initially linked to primary health care as it was cheaper, simpler, and community based. Empowerment of PwDs and their organizations, advocacy, laws, leisure, etc., were secondary considerations.<sup>[2,3]</sup>

The International Classification of Functioning, Disability and Health (ICF) as depicted in Figure 3 was introduced by the WHO in 2011 as a revised version of the International Classification of Impairment, Disability and Handicap.<sup>[3]</sup> As per the ICF, disability is an umbrella term for impairments, activity limitations, and participation restrictions. It denotes the negative aspects of the interaction between a person's health condition(s) and his/her contextual factors (environmental and personal factors).<sup>[9]</sup>

The CORD's CBIR model at the panchayat level works holistically for all types of PwDs as per their need and context. This model encompasses the global core principles and essential components of WHO's CBR matrix model as well as the ICF classification of disabilities. Moreover, it adds further value with CORD's four core principles as pillars of the model, i.e., participation, integration, networking, and sustainability. This model operates in the following unique way:

- It is the CBIR with "Inclusion" in action as an integral component of the model
- Facilitate identification of all PwDs and their disaggregated data record at the panchayat level
- Active participation of PwDs and their families in the empowerment on all issues of their life based on local need and context
- Integration of all issues of PwDs for their effective inclusion in the mainstream through continued education, counseling, and guidance (ECG), i.e., awareness, health, rehabilitation, schooling, accessibility, employment, advocacy, environment, and local self-governance, etc., at the bottom of the pyramid, i.e., panchayat in the Indian context
- Networking for collective advocacy through decentralized forums such as MCU at the Panchayat level and Chinmaya Umang at the district level as well as inclusive

**Figure 3:** The International Classification of Functional Model



community-based organizations, panchayats, NGOs, and other government agencies

- Ensure sustainability by facilitating local and trained cadre of VRPs on the inclusion of PwDs and economic self-reliance among PwDs and families especially mothers through multiple resilient livelihood options locally
- Inclusion of unheard voices and unseen issues, concerns and realities of PwDs in mainstream development, and governance agenda through the forums of Up-gramsabha and Gramsabhas of panchayat and bring PwDs to the center stage as a contributor at multiple level
- Being multidisciplinary in nature, it is self-propelling and adaptive for scaling and replication in India as well as anywhere in the globe.

This study has taken panchayat as a unit of mainstream development for effective inclusion, rehabilitation, and empowerment of PwDs. The results of this study have supported the need of a CBIR model for wider replication at panchayat, block, district, state, national, and international levels. The identified 124 PwDs in the ten panchayats were further facilitated in the mainstream development and inclusion through consistent ECG, dialog, and networking with families, communities, and stakeholders, such as elected members of panchayats. Disability certification was facilitated through the government’s medical board in district headquarters. Health issues were addressed through local referral to secondary and tertiary health-care institutions such as district hospitals and medical colleges, when required, and provision of health insurance was facilitated through the

government for 70 (56%) PwDs. Mothers of children with disabilities and women with disabilities were included in the Mahila Mandals (meeting once every month) for sustaining their inclusion and mutual community support and active community participation. MCU forums for PwDs and their families were established to ensure protection of their rights and their full participation and to work collectively for equal opportunity and voices to be heard at the panchayat level and further. A total of 44 (35%) PwDs were included under the scaffold of productive employments locally including MNREGA as per their abilities, skills, and entitlements after detailed vocational due diligence. A total of 68 (55%) PwDs were included under the social safety net of monthly pension rupees 750–1500. In case of persons with severe and profound disabilities, their family members, especially mothers are educated, counselled and guided to ensure better engagement and care of their PwDs/children through various programs available in the panchayat, development programs, schemes and social safety nets. These mothers are encouraged to adopt livelihood development programs of NGOs and government agencies etc to support them too who suffer immensely in many ways. Further linkage of PwDs with panchayat-level advocacy forums, such as MCUs, and VRPs was facilitated by CORD. Interactions and visibility of PwDs through their visits and exposures within and outside panchayats caused further awareness, network building, and mainstream inclusion. The active contribution of PwDs in their HHs as well as at the community levels is depicted in a narrative of the wife of one PwD who was identified with mental illness and related stigma, as stated below. The

presence of PwDs in woman groups, Anganwadis, MCUs, Chinmaya Umang (cross-disability network at district level facilitated by CORD where all MCUs are members), and local self-governance meetings (up-Gramsabhas and Gramsabhas) is further deepening the process of their inclusion and empowerment as an integral part of their voices heard and acted upon in their panchayats. Trained VRPs are further educating, enabling, and empowering PwDs, their families, and related stakeholders in their concerned panchayats. This too is a crucial step for sustaining a momentum toward inclusion and mainstreaming PwDs toward a dignified life away from their marginalization in rural India.

A sentence quoted below from a PI's in-depth interview with Dr. Kshama Metre, National Director, CORD, endorses deep insight and experiential wisdom behind CORD's CBIR model organically evolved over the past three decades based on the PwDs' needs and their community participation and mutually interactive systems and processes paving path to empower PwDs in the mainstream development as a contributor. She states,

*"Life of PwDs is 10% about treatment, rehabilitation and management. The rest is all about inclusion in community on all issues of their lives."*

Nuggets of the case narrative of the wife of one of the PwDs, Mr. Ramesh Chand (name changed), suffering from mental illness, mentioned below are an example of the need and context of holistic approach of the CBIR model.

*"My husband was working as private driver job. He had bouts of fits in between. He lost his job. My son left studies due to shortage of money. Many problems happened at home. How we will run our home? On people saying, we went to temple for prayers on his wellbeing. No improvement happened. Then I met one person from CORD in my village working with disabled. He spoke to my husband and me. He helped us to take him to hospital. Doctor gave medicines. We saw improvement in his condition. My husband got medical certificate of disability. He takes medicine regularly. With VRPs and Panchayat help, my husband gets pension. I am now member of Mahila Mandal and SHG in my village. My husband earns Rs. 5000/month by working in one grocery shop locally. He helps in agriculture work with me and we grow turmeric for earning. Our community understands our problem and comes to help us. Our family is happy now. My husband went to Manimahesh pilgrimage. Now everything is fine."*

Mental barriers towards PwDs needs to be overcome through sensitisation of all stakeholders to bring about attitudinal changes. This would enable PwDs to have equal opportunity, ensure their full participation, protection of their rights and contribution in the society. The emerging issues of mental health among PwDs and caregivers need attentions from rehabilitation professionals to address their issues at the community level within the available resource and policy/program contexts. These factors are of crucial importance that need attention for a multidisciplinary and an integrated approach in various

development programs and schemes to achieve CBIR in its full intent and spirit. This will enable PwDs to emerge as an active contributor in their own life/family as well as in the community beyond an issue of stigma and charity/welfare. Future research should also examine the reporting and the possible understatement of disability across India and in certain regions, in particular reference to the recently enacted RPD Act, 2016. Additional, micro-level research on the current status of comprehensive disability care should be carried out in regions and population groups, especially those in socially disadvantaged groups, i.e., women with disabilities and PwDs with mental health and old-age issues.

## CONCLUSION

The findings of this study are relevant and indicate a need for a disaggregated database on PwDs, which includes design and implementation of an effective and decentralized CBIR model in convergence with the exiting model of Panchayati Raj Institutions in rural India. The role of rehabilitation professionals, especially occupational therapists, is of vital importance to enable PwDs in the areas of treatment, rehabilitation, ADL, counseling, education, designing assistive aids and vocational assessments, etc., not limiting to clinical setting but community setting. Similarly, professional studies and research can help in expanding and contributing in the area of academic as well as clinical practices in rehabilitation sciences including occupational therapy. Due to the decentralized and bottom-up nature ("panchayat" based) of the CORD's CBIR model, it is easy to mainstream within the existing development program for rural India at the panchayat level like microcredit access through SHGs, various financial models/enterprise development, MGNREGA, National Rural Livelihood Mission, National Skill Development, National Health Mission, and Swatch Bharat Mission.

The results of this study suggest that the definition of disability used in the census of India should be modified to reflect the broader definition of the WHO in order to produce internationally comparable results.

## Declaration of patient consent

The authors certify that they have obtained all appropriate patient consent forms. In the form the patient(s) has/have given his/her/their consent for his/her/their images and other clinical information to be reported in the journal. The patients understand that their names and initials will not be published and due efforts will be made to conceal their identity, but anonymity cannot be guaranteed.

## Acknowledgment

We thank Dr. Kshama Metre, a pediatrician and the National Director of NGO CORD, for her guidance during the study and sharing data and insight of the CORD's CBIR program.

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Nil.



## Conflicts of Interest

There are no conflicts of interest.

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