

Report of Eastern Region Consultations on

Mainstreaming Disability Inclusion in the Implementation of SDGs 2022

(Bihar, Chhattisgarh, Jharkhand, Odisha, West Bengal)





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ABBREVIATIONS

AAS Associate of Applied Sciences			
ADIP Assistance to Disabled Persons for			
Purchase			
ADM Additional District Magistrate			
ALIMCO Artificial Limbs Manufacturing Corporation			
ASHA Accredited Social Health Activist			
ATM Automated Teller Machine			
BDA Bhubaneswar Development Authority			
BSSO Block Social Security Officer			
CBC Complete Blood Count			
CBI Central Bureau of Investigation			
CEO Chief Executive Officer			
CFAR Centre for Advocacy and Research			
CHC Community Health Centers			
Covid-19 Coronavirus disease			
CRPD Convention on the Rights of Persons with			
Disabilities			
CwD Children with Disability			
DDRS Deendayal Disabled Rehabilitation Scheme			
DFID Department for International Development			
DS Duryodhan Sahoo			
DSSO District social security officers			
EOC Equal Opportunity Cell			
FIR First Information Report			
GPS Global Positioning System			
ID Intellectual disability			
IIT Indian Institutes of Technology			
JMP Joint Management Programme			
JRLM Jharkhand State Rural Livelihoods Mission			
KFT Kidney Function Test			
KIIT Kalinga Institute of Industrial Technology			
KISS Kalinga Institute of Social Sciences			
LFT Liver Function Tests			
MD Managing Director			
MGNREGA Mahatma Gandhi National Rural			
Employment Guarantee Act			
MHC Mental Healthcare Act			
MLA Member of the Legislative Assembly			
MM Mihir Mohanty			
MPLAD Member of Parliament Local Area			
Development Scheme			
MP Members of Parliament			

MRI	Magnetic Resonance Imaging
NCRB	National Crime Records Bureau
NEP	New Education Policy
NGO	Non-Governmental Organizations
NHFDC	National Handicapped Finance and
	Development Corporation
NLEP	National Leprosy Eradication Program
NREGA	1 2
NSAP	National Social Assistance Programme
NSSO	National Sample Survey Office
OH	Orthopedically Handicapped
OSdN	Odisha State Disability Network
OSEPA	Odisha School Education Programme
	Authority
PDS	Public Distribution System
PHC	Primary Health Care
PwD	Persons with Disability
RFT	Renal Function Tests
RPwD	Rights of Persons with Disabilities
RTI	Right to Information
SC	Scheduled Castes
SCI	Spinal Cord Injury
SCPD	State Commissioner for Persons with
	Disabilities
SDG	Sustainable Development Goals
SMSA	Samagra Shiksha Abhiyan
ST	Scheduled Tribes
UDID	Unique Disability ID
UGC	University Grants Commission
UN	The United Nations
UNICEF	United Nations International Children's
	Emergency Fund
US	United States
VI	Visual impairment
W&C	Women & Child
WASH	Water, Sanitation and Hygiene
WB	West Bengal
WHO	World Health Organization
WiFi	Wireless Fidelity
WPC	Writ Petition (Civil)
WwD	Women with Disabilities
YwD	Youth with Disabilities

Acknowledgments

We would like to thank the participants from Viklang Adhikar Manch from Bihar and Chhatisgarh, district conveners from Odisha State disAbility Network, members of Jharkhand Divyang Adhikar Manch, and organisations led by SANCHAR from Kolkata, who agreed to participate in the consultations, focus group discussions and in-depth interviews. They shared their stories and testimonies around SDG implementation, accessibility, participation and empowerment. We are also thankful to all the experts, resource persons and professionals who gave their opinion, suggestions and time for developing the comprehensive report.

Introduction

Equity, equality and inclusion are key principles of India's Constitution and the government has adopted 'Sabka Saath Sabka Vikas' as an overarching goal, envisioning an inclusive new India. At the global level, the Sustainable Development Goals (SDGs) are ambitious (ending poverty worldwide), and comprehensive (including people, planet, prosperity, peace and partnership). Besides, 2030 Agenda has a commitment to inclusion with its pledge that 'no one will be left behind'. Yet, the pandemic bought to the fore that participation of those left behind in the 2030 Agenda, specifically the disabled is low, suggesting that this core principle is not being implemented and that governments have not succeeded in running inclusive processes focused on the most marginalised people. India submitted its second VNR to UN in 2020. With a view to ensure that people with disabilities are able to provide their inputs into the SDG process, United Nations (UN) in India is organising 5 regional consultations to get adequate feedback on status of the disabled in the shadow of the pandemic on the 17 SDGs. Swabhiman conducted the Eastern Region Consultations.

Eastern region of India comprises of states namely Bihar, Chhattisgarh, Jharkhand, Odisha and West Bengal. The total population about 23% of India. Thus the percentage of disabled population in eastern India, their participation in the mainstream activities carries a significant weight for the achievement of the Sustainable Development Goals (SDGs). After five state consultations, one regional consultation, three FGDs and 21 interviews later, we echo the UN Secretary General's views and call for action, for the disabled. "We are far from where we need to be. We are off track... We must step up our efforts. And we must do it now... I am issuing a global call to deliver the Sustainable Development Goals by 2030". UN Secretary-General António Guterres

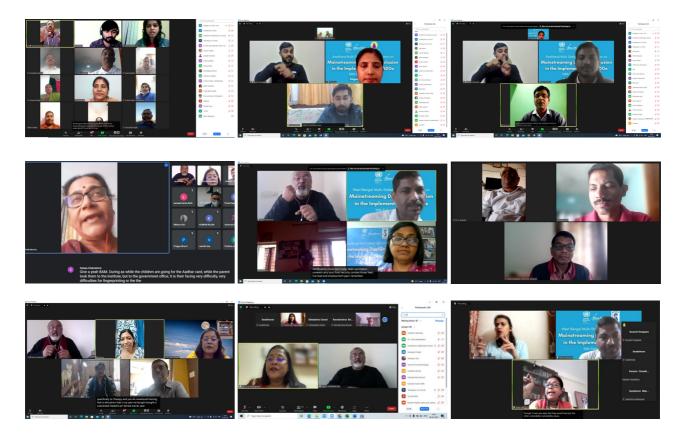
The Eastern Region Multistakeholder Consultations found substantial similarity in the inclusion of disability across various SDGs in the five states of Bihar, Chhattisgarh, Jharkhand, Odisha and West Bengal. The case studies and voices from the grassroots, drawn from various districts of the five eastern states, is a reflection of the grim situation of people with disabilities in the pandemic.

Eastern India Profile

Eastern region of India, located between latitudes of 170N and 290N and longitudes of 800E and 970E, comprises of states namely Bihar, Chhattisgarh (1,44, 422 km2), Jharkhand (173, 877 km2), Odisha (1,55,707 km2) and West Bengal (88,751 km2). The total geographical area of Eastern India accounts for almost 20% of the total geographical area of the country. Out of the total population of India, Eastern India accounts for 25%. It has a higher density of population against national average of 382 per sq. mts, has higher percentage of people below poverty level compared to national average of about 69 million (21.9%) in 2011–2012. Eastern India stands out as a "red colour" on the India map on issues related to leprosy, malaria, poverty and illiteracy (Professor Vijay Raghavan, Secretary, Department of Biotechnology, Union Ministry of Science and Technology).

Methodology

The process was spread over a thirty days period. Desk review of the documents and reports related to "India VNR-2020" along with the recommendations given by Govt. in reports and media were collected read. Identification of strategic and potential partners of Eastern Region from Bihar, Jharkhand, West Bengal, Chattisgarh and Odisha was done to engage them and take their support in the entire process of preparing this report on eastern India's detailed feedback on SDGs, Covid19 pandemic and building back better. Our process included, review of published reports, newspapers and government documents, 5 state consultations, a Regional Consultation, 3 FGDs and 21 individual interviews, several telephone calls and text messaging. The draft report was shared with state leaders and thematic session leaders for wider feedback from state participants. Resource persons and thematic experts were consulted.



Assessing Disability Inclusion across the SDGs

The Eastern Region Consultations were led by Swabhiman (Disability Information and Resource Centre based in Bhubaneswar, Odisha) in partnership with UNRCO India and supported by Bihar Viklang Adhikar Manch, Chhattisgarh Viklang Manch, Jharkhand Divyang Adhikar Manch, OSdN (Odisha), SANCHAR (West Bengal), for state level mobilisation and consultations.

The findings were a contradiction to the prevailing supportive legal and policy environment in India. With inclusive SDGs in place, the Start Up India, Skill India, Make in India and Accessible India Campaign reaching out to remote corners, CRPD ratification by India and finally the passage of the RPwD Act 2016, it can be said that the laws and policies have become more profound towards the need and wellbeing of the persons with disAbilities in India, but there are huge gaps in implementation and sensitivity to the issue among both government and civil society.

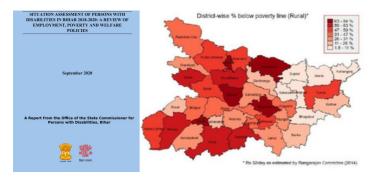
The following section is divided as per 12 SDGs (Goals 1, 2, 3, 4, 5, 6, 8, 9, 10, 11, 16 and 17) covered during the consultations. Feedback on each SDG is divided into 4 sections – Issues flagged, recommendations, quotations by expert/activists with 15+ years experience in disability sector, newspaper clippings and excerpts from reports. Comments, information and recommendations which could not be accommodated under specific SDGS are presented in other sections including case studies, concerns of new disabilities and voices from eastern India.



END POVERTY IN ALL ITS FORMS EVERYWHERE

Issues

- Disability pension is ₹400 in Bihar, ₹1000 in Jharkhand, ₹350 in Chhatisgarh, ₹500 or ₹700 in Odisha, and ₹400 or ₹1000 in West Bengal. When compared to the cost of living which averages ₹3000-₹3500 in most rural areas, the amount is dismal.
- The disability pension in Bihar has low coverage. Only 50% of eligible PwDs received the disability pension.
- No data available on ex gratia payment of ₹1000
- No information or accountability of realisation of the 5% quota on how many PwDs are recipients of poverty alleviation and developmental schemes, agricultural land, microcredit in all five states.
- RTI applications are forwarded to various tiers by the concerned officers, no one responds and the person filing the application gets lost under a paper pile.
- Disability pension suspension for months in Jharkhand due to bank mergers impacted PwDs, who were dependent on the pension.



The map shows the poorest districts are Madhubani, Vaisali, Arwal and Begusarai, with more than 60% of the disabled having income below the poverty line. The poorest district is Sheohar, with 84% of the disabled population having expenditure below poverty line. 01



Umesh Purohit, Secretary, YSC Convenor Western Odisha, Odisha State disAbility Network

"There should be a tracking mechanism in the concerned departments. We can go to their website and easily know how much of the disability reserved quota is getting distributed. It should be a live tracker like population trackers"

02

THE TIMES OF INDIA

50,000 disabled suffer as Jharkhand government stops pension amid curbs



RANCH: Thirty-two-year-old Ormanjii village resident Rajash Kuma, who has a disable legi, is finding it diffutuit to make his eads meet owing to a lack of job and non-disbursal of the government disability pension last few months. His wifle, who worked as a maid, has also lost her job making it diffuelt for them to sustain their family of four.

Kumar is not alone. Thousands of disabled persons like him are facing several financial crises during the lockdown in the state after the government stopped their monthly pension of Rs. 1,000 for the past several months.

umbrolis group for disabled people, headquartered in Jamshedgur. Had written a letter to chief minister Hemant Soren appealing him to release the monthly pensions. The government has assured to release the pension scon. Who are unable to get the pension couldn't be accentained. Singh said roughty put the number to vere 50,000 people. He said the pension was stopped suddenly by the government, climp various reasons like lack of funds, delay in document verification and mon-release of funds by the Centre arening others.

Singh added, "We appeal to the state government to release the pension immediately irrespective of the hurdles, which can be sorted out later on like the announcement of ration for those without ration cards. The disabled people must too get their pensions whether the document verification is pending or not."

The women and child development and social security minister, Joba Manjhi, who is the JMM MLA from West Singbhum, assured that funds will be released soon. "The department is aware of the problem and funds will be released very soon now," who hold TOT

- There is an immediate need to increase the disability pension amount to lead a decent and dignified life in the state of Bihar, Odisha, Chhattisgarh and West Bengal. Pension should be standardized just like daily wage is and given a substantial amount for basic subsistence. It should be revised according to existing market conditions such as pandemic where everyone lost jobs.
- Standardised pension rates across India Ek Bharat-Ek Divyang-Ek Bhatta.
- Focused attention with targeted interventions for the PwDs should be designed to recover from poverty due to any emergency situation. There has to be a proper monitoring system by Govt. for tracing the services provided.
- Ensure 5% reservation in all poverty alleviation schemes implemented by state and central Govt. and tracking mechanizing to be placed for regular monitoring.



END HUNGER, ACHIEVE FOOD SECURITY AND IMPROVED NUTRITION AND PROMOTE SUSTAINABLE AGRICULTURE

Issues

- In all five states, PDS shops are at a distance. PwDs have to walk long distances.
- During the Covid-19 pandemic both dry ration and food was distributed in camp mode. Camps have few government officers, long queues, and no facility like sitting, resting or restrooms.
- Under the inclusive support for all no specific support for PwDs. only the students with disabilities of residential schools, got their food cost and monthly financial support in their Bank account.
- Under the Mukhyamantri Khadyan Yojna in West Bengal, there is ration distribution free of cost. A guideline was prepared in the year 2012 but was not implemented. Before 2012, there was another provision of 25 kgs distribution of ration, but after the new guideline, it's limited to 10 kgs and alongside many family members were not included in the ration card. This reduced the ration amount per family causing excessive hunger in the families with disabled members.
- During pandemic many PwDs could not avail the government ration as application process was a lengthy one.
- Disaster (it may be any pandemic or any natural calamity) situations impact different persons in different manners. And PwDs are affected severely during any disasters.
- Rice and wheat provided through PDS are not enough as there was no fuel to cook during the lockdown period. PwDs in rural areas managed with firewood but PwDs in the urban area faced severe cooking issues by not getting gas cylinders during Covid restrictions.
- CwDs in home based education are getting left out from midday meals schemes.



Rita Kumari, OH, Bihar "Bhukmari, Garibi, aur Beghar Hatao"

Phool Kunwar Bai (65), Majhuar Adivasi, OH, Manpur Village, Chhattisgarh.

Without my ration card I would be going around begging for food. With a pension of Rs.200 and a ration card for the disabled which gives 10 kilos of rice, I have barely enough to scrape by every month.

Suhit Mondol, OH, WB

MITTI Café employs people with disabilities and has 12 outlets across Karnataka and West Bengal, employing 116 people. Sujit Mondol through 'MITTI Karuna' campaign distributes cooked food to daily-wagers and the homeless crushed by the Covid-19 lockdown. "We cook and feed people—no one in the world should be hungry."



- Include all the family members (PwDs) in the updated ration card list for easy ration distribution under the PDS scheme.
- During any natural disaster period, there should be doorstep relief distribution of ration to all the PwDs.
- In relief distribution camps, separate queues for PwDs, Quick attendance and return of PwDs within 45 minutes of arrival.
- Setting standards for delivery of services, ensuring compliance to standards and commitment to compliance is needed from government.
- The programs like Jeevika of Bihar, JRLM of Jharkhand (specially designed poverty alleviation livelihood-related schemes) should have 5% mandatory reservation for PwDs.
- Special efforts to be taken to ensure CwDs in home-based education are not left behind in the mid-day meal scheme.



ENSURE HEALTHY LIVES AND PROMOTE WELL-BEING FOR ALL AT ALL AGES

Issues

- Health is a major issue in all the five states because hospitals are not accessible in the rural areas.
- Lack of specialist doctors at sub-divisional and village level.
- In Bihar and Jharkhand certification of PwDs at grassroot level is in a very negligible condition and lack of awareness is the key factor in it. Certification of persons with intellectual disabilities happens to be difficult as they need to go to the district hospitals for medical assessment. During the pandemic, this situation has worsened due to restrictions.
- Odisha, WB, Jharkhand and Bihar are issuing certificates for new disabilities. The process gets extremely delayed due to the non-availability of doctors, tests, and medical reports.
- There is a general concern about the long queues and extended waiting periods in hospitals, Covid testing, and vaccination centers.
- Acid attack victims suffer facial disfigurement and it causes lifelong itching, allergy, swellings, pain, etc. They undergo multiple surgeries for 5-7 years. Funds constraint delays processes.
- Leprosy-affected persons always suffer with infections to the skin, the peripheral nerves, mucosa of the upper respiratory tract, and the eyes. Barely anyone listens in hospital. Attitude of doctors, nurses, and other staff is derogatory.
- Persons with pre-existing mental illnesses were disadvantaged with reduced access to medication during the lockdowns.
- For persons affected with epilepsy, sudden lockdown blocked access to medication which lead to relapse of symptoms. Sudden stoppage of medicines led to seizures and convulsions.
- Spinal cord injured persons bore the brunt of non-availability of diapers, catheters, uro bags etc. which led to bladder and bowel infections and many health issues.
- Covid pandemic lockdowns brought physiotherapy, speech therapy and all other forms of treatment to a sudden health.

Recommendations

- Bone Marrow Transplant is the only possible solution to cure thalassemia. But BMT is very costly around 25 lakhs.
- Blood disorder patients require regular blood transfusions.

Dr Shakti Prakash Padhi, Additional Director of Health Services (Leprosy), Odisha 03

"Mobilization of a majority of workforce for Covid-19 has adversely affected screening, detection and treatment of several bacterial and viral diseases in Odisha including leprosy cases. From 2021, trained ASHA will conduct door-to-door survey as per the micro-level planning done by the districts."



Devadutta Pradhan, Thalassemia, Odisha Patients require to have tests like CBC, Ferritin, LFT, RFT, KFT, T2 MRI (Cardiac and Liver Iron test) every 3 months which is costly. T2 MRI is costly and adult patients are going to different cities to test it. It should be made available in all cities and hospitals in Odisha and should be provided free of cost. Patients need spleen removal/surgery. This should be provided free of cost in govt and private hospitals with trained doctors.

- Awareness creation at village level through frontline workers on all disabilities, especially on increasing cases of Leprosy, Acid Attacks, Learning Disability among children, would be beneficial.
- Separate queues for the PwDs in hospitals, Covid testing and vaccination centers.
- Fund to be set up by government in hospitals which acid attack survivors can access with dignity- Acid attack survivors need immediate hospital care, cosmetic surgery for at least 5 years, rehabilitative surgery till function of eyes/fingers or restoration of other affected body parts, reimbursement of rehabilitation expenses for 5-7 years.
- Maintenance of database of Mentally Ill, Epileptic, Blood Disorder groups and Spinal Cord Injured so that emergency medicine can be delivered at door step in emergency situations.
- Regular Mobile medical van to colonies of leprosy affected persons. Weekly visit of doctors round the year and every day visit during emergency situations.
- For spinal injured persons inclusion of air mattress, wheelchair cushions, catheters, uro bags etc, in assistive devices list of government.
- During lockdowns and emergency, therapies to continue, with observation of proper Covid-19 precautions.



ENSURE INCLUSIVE AND EQUITABLE QUALITY EDUCATION AND PROMOTE LIFELONG LEARNING OPPORTUNITIES FOR ALL

Issues

• No education for CwDs from 0-6 years.

School

- 70% of mainstream school teachers and headmasters felt that they lacked the exposure and training necessary to address the needs of CwDs.
- Inaccessible school infrastructure starting from the gate, doors, classroom, playground, toilet, drinking water to the dining area.
- Inadequate and delayed provision of books in alternate formats.
- Lack of resource teachers in schools.
- Headmasters express limited resources as a key concern in creating accessibility in schools.
- Online education is challenging due to inaccessible network areas, the cost of the data package, unavailability of electricity, and lack of hardware like smartphones, Tabs etc.

Colleges/Universities

- In Odisha, Universities openly flout the mandates of RPwD Act 2016. RTI applications filed by Swabhiman in Odisha revealed that students admitted between 2014 2020 are less than 2%. Only 17% of universities are looking at disability in EOC with a budget. EOC in universities focused on SC, ST, Gender, and minorities. With regards to disability, it was limited to one seminar annually.
- Categories of students admitted were limited to OH and VI. In response to its RTI applications Swabhiman found no deaf students in any of the 11 universities.
- Chhatisgarh has come up with a Divyangjan college in Raipur and Odisha has Satyabhama college for the deaf in Bhubaneswar.
- Chhatisgarh has instituted award programs for district toppers of 10th and 12th standard students and endowment (protsahan rashi) for Divyangjan studying in colleges and universities.

Recommendations

• Government should create mechanism so that the inclusion of children with disabilities should be ensured at all levels for lifelong learning, i.e. at preschool level means from home (0-3 years) through Anganwadi, at Anganwadi (3-5 years), at school level (6-14 years), in open school, in vocational training, professional education

School

- Budget for mandatory accessibility of schools, alternative curriculum and data flexibility.
- Support system in school with parents, special educators, resource teachers, therapists and interpreters.
- Disability, Accessibility and Inclusion modules in teacher's training and refresher course for teachers.
- Tabs, smartphones and computers must be distributed to teachers and students, after being firewalled to unwarranted sites.
- As data cost and internet connectivity are major issues, recharge and portable WiFi to replace must travel allowance in budget.

College

- 5% seat reservation to be carried out by intense awareness and counselling sessions in block and village level
- Scribes, scholarships and examination in alternate format must be sincerely done.
- Campus, website and process accessibility must be mandated or else UGC finding should be with held.



Ranjit Mohapatra, Inclusive Education Practioners Director SADHANA, Odisha Convenor Northern Odisha of OSdN

In rural areas, teachers have a very limited set of pedagogical strategies, such as giving children extra time, changing seats, motivating children by giving work they could do, usually at a lower grade than the rest of the class. It is plausible that this has stemmed from teachers' low expectations of children with disabilities; conversely, teachers frequently express inability to teach these children. This needs to change to make the NEP successful

Business Standard

43% children with disabilities planning to drop out of e-education: Survey According to the survey, 56.5 per cent of children with disabilities were struggling yet attending classes

05

Press Trust of India 1 New Delhi July 18, 2020 Last Updated at 12:15 IST





ACHIEVE GENDER EQUALITY AND EMPOWER ALL WOMEN AND GIRLS

Issues

- No disaggregated data on disability and gender components is available in the five states to analyze the status of WwDs and for any kind of assessment.
- During the Covid-19 pandemic all five states mentioned hunger and starvation among WwDs. When food was low in the family, the share of WwDs was minimum.
- Domestic violence, sexual abuses on WwDs both at home and outside. Violence has especially increased during the Covid-19 pandemic.
- Crime Record Bureau in Odisha police does not maintain any disaggregated data on the crime committed on women with disabilities. This is despite violence being a serious area of concern for WwDs.
- Intellectually disabled women are being sexually abused my own family members and their statements are being easily discredited in courts of law, and in most cases, the perpetrators are going scot-free.
- Spinal cord injured women experienced severe urinary tract infections as access to catheters, euro bags, and diapers became restricted. Retailers sold catheters and urobags at 3 to 5 times market price (89 rupees urobags were sold at 270 to 300 rupees; and silicon Foley catheters cost 1000 instead of regular 300 rupees each).
- Doctors consider standard medical practice in the case of "mentally retarded women".
- In eastern India, women and girls with disabilities are denied access to education, vocational training, employment, transportation and housing, making it difficult or impossible to achieve economic self-sufficiency and contribute to their communities.
- In all five states women and girls with disabilities receive inadequate or nil rehabilitation services,



Rakesh Kumar, OH- Polio, State Secretary, Bihar Viklang Adhikar Manch

Everyone, government or private, flout the international and national laws for protection of rights of women with disabilities. Consultation with local women's organizations and involving women participants in program planning is perhaps the best way to ensure a gender perspective in program design. All development organizations, micro-credit programs and lenders must consult with women leaders who have disabilities for strategies to make all information, programs and services accessible for women with disabilities.

मूक बधिर नाबालिग से रेप, आंखें फोड़ी प्रक्षेत्र्ष हरताखी/मधुबनी के हरलाखी थाना क्षेत्र की घटना

हरलाखी थाना क्षेत्र के एक गांव में दिल दललाने वाली पटना हुई है. वाले रेखन ने एक मुख वीधर नावादिल लड़की के साथ टुफर्म किया. इसके बाद उसकी टेजों आखें भी फोड़ दीं, ताकि लड़की ठेजले फायान कर सके. सलांकि, टुफर्म के बाद आंख फोड़ने से निकले खुन के छंटि आयारित के कपड़े न चेकरे पर दिखे, जिससे लोगों ने उसे पठत के सर्वय में पॉडिता के पाई ने मधुबनी सरद अस्पताल में बताया कि मंगललार की दोपहर उसकी बहन गांव के साथीए की न**ी के साठ**ी में जा कर



आरतों में अब शायद ही लौट सके टोशनी अपनी आबरू गंवने के साथ एवले स ही मूक बॉस्ट पीडिंज अब पंजी आर से सर की हिरा गंव पुर्वी है. सरद अस्पताल के नेक विकिस्पर हो मंगीव जुमार गंव ने पीडिता की आरवे की जाव के बाद बतावा है कि किस्ते मुर्वाले की कर बेनो आ के पांठ दी गयी है. प्रबन्मुट्ट्या दोने आरवे केकार को चुकी है. गायद ही इसमें अब रोशनी लोट सर्क.

- More clear distribution of benefits in any kind of reservations/ quotas in the context of girls and women with disabilities with a right based approach in all government policies and provisions. Disability and more so the gender segregation is missing under budget allocation , which needs to be changed with women given equal prominence Equal opportunities to both men and women with disabilities based on the eligibility criteria.
- Stringent inclusion in the legal mechanism to promote land and property ownership rights in the favour of both men and women with disabilities.
- To decrease abandonment and single parenthood after marriage, especially for women having intellectual disabilities, employment generation opportunities should be created and legally the father of the child has to bear the financial burden/expenses of raising the child till 18 years of age.



ENSURE AVAILABILITY AND SUSTAINABLE MANAGEMENT OF WATER AND SANITATION FOR ALL

Issues

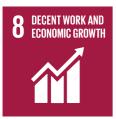
- For the disabled in the urban poor areas important issues are both accessible WASH infrastructure and assistive aids and appliances.
- For elderly disabled community, and public toilets are not accessible in their design.
- In slums, pathway to the toilet are not accessible for the wheelchair, crutch and walker users. The VI also face mobility challenges.
- Lack of support bars in latrines for people who have difficulties holding themselves in a sitting or squatting position (this is particularly a problem for women).
- Latrines are often too small to enable people with wheelchair or crutches to enter and close the door behind them.
- Floors made of wood, tile or other materials may be too slippery for people with walking or balancing impairments.
- In slums, during Covid-19 lockdown when everyone stayed home with no work, the latrines were always full and crowded. Many PwDs defaecated at home in pots or newspaper.
- The difficulty in accessing sinks or enough water to wash properly after trips to the toilet is also reported regularly by persons with disabilities.
- Many persons with disabilities may live in households where they are unable to afford soap and other cleaning materials.



Akhila Sivdas, Executive Director CFAR Centre For Advocacy and Research, working in in 22 settlements with 8,381 households in Bhubaneswar, Odisha found in its baseline study that level of inclusion of disabled was highly inadequate and did not meet the Joint Management Programme (JMP) standard of accessibility to WASH services. Data shows only 31% of the respondents had piped water connections, out of which 17% had irregular water supply. 928 (98%) toilets have on-site faecal sludge. 06



- Elderly and disabled need special subsidy to build elevated and secure individual household toilets depending on the disability they are addressing.
- Community and public toilets need to be designed in consultation with disabled representatives living in slums and members of community management committees set up at slum level in many cities.
- To plan all wastewater treatment facilities in consultation with disabled persons and other marginal persons to ensure that their concerns are addressed.
- For waste collection segregation and recycling, sub facilities can be provided at settlement level so that they participate and contribute to composting and make it a livelihood activity.
- All handwash stations must be designed in keeping with the many coordinates that different disability from ensuring height, needing hand and foot operated and the pathway smooth not slippery and having tactile flooring.
- Such model handwash stations designed by disabled can be seen in Jaipur.
- Develop in each urban local body Gender, Social and Disability Inclusive Resource Centre which acts as a link between government administration and community and ensures all social civic and legal entitlements reach the disabled elderly and socially marginalized groups.
- Ensure all facilities are climate resilient and create dedicated disaster preparedness plan for disabled elderly and chronically ill.



PROMOTE SUSTAINED, INCLUSIVE AND SUSTAINABLE ECONOMIC GROWTH, FULL AND PRODUCTIVE EMPLOYMENT AND DECENT WORK FOR ALL

Issues

- Unavailability of data on employment, entrepreneurship and small business of people with disabilities all five states.
- Employment for disabled persons through MGNREGA remains quite limited with only West Bengal and Chhatisgarh being 6 best states for providing employment to over 1 per cent of those employed under the scheme. No data available for rest three states. During 2018-19, the number of differently-abled persons employed under the scheme in Chhattisgarh was 30,702. PwDs face multiple challenges in getting their job cards. In many cases they are asked not to do any work and are forced to accept less wages (50%) for their 'work' under NREGA.
- There is dearth of employment opportunities for persons with intellectual disabilities. In job fairs and job advertisements preference is given to individuals with physical disabilities.
- Skill development programs stopped during the pandemic. Many PwDs were trained under many skill programmes, but they are not getting job or loan facilities for their startup.
- Youth4Jobs is a namesake job facilitator. In Bihar, when disabled people go for the job interviews facilitated by them the interviewers say the jobs are people with lesser disabilities with 40% or less and discard those with higher percentages.
- Entrepreneurs in all five eastern states are facing the challenge of getting startup capital, loans and market linkages. Commercial banks do not want to offer loans as they are not confident in competence of the disabled to run businesses.
- Job applications and interviews are increasingly online, but people with disabilities don't have access to the assistive technology they need to navigate online job boards. And most websites are inaccessible.

Ankeet Panda, project consultant in Panchayati Raj and Drinking Water department, Odisha⁰⁷

"Though the PwDs are included under the scope of MNREGA programme, majority activities are not suitable for them which makes it ineffective for engaging them at large."



Chumki Dutta, MD Vriddhi Products "PwDs are artisans, artists, self-employed and entrepreneurs with disabilities but where is our identity? We need market linkages, linkages to audiences, artists must get opportunities in regular cultural events."



Recommendations

- In the MGNREGA, 100 days work for persons with disabilities have to be included and wages raised.
- Like Karnataka, more jobs to be identified as per ability of specific disabilities categories. Karnataka has listed 145 types of jobs that can be assigned to the disabled.
- A few schemes meant for PwDs like Deendayal Disabled Rehabilitation Scheme (DDRS), National Handicapped Finance and Development Corporation (NHFDC) and National Social Assistance Programme (NSAP) should be converged with the MGNREGS to enhance livelihood security of disabled.
- Pandemic has shown that most jobs can be done remotely. Government and companies should continue with the hybrid model of physical and digital structure to better accommodate people with disabilities by providing them remote and flexible work options.
- For market linkages the government needs to have a high level meeting with the corporate houses, shopping complex/ mall needs to promote the products made by PwDs. The branding of the products is a necessity to promote marketing and selling.
- Entrepreneur development programme should be organised to bring efficiency in the business front and to develop quality manpower.
- Loan should be made easier to avail. Complications in forms should be eased out.

10



PROMOTE SUSTAINED, INCLUSIVE AND SUSTAINABLE ECONOMIC GROWTH, FULL AND PRODUCTIVE EMPLOYMENT AND DECENT WORK FOR ALL

Issues

- From all five states there were many complaints about the quality of assistive devices distributed through ADIP scheme
- Everywhere camps were suspended and there was no distribution of devices during the Covid period.
- In Odisha laptops are distributed to visually impaired students studying in colleges and universities. The application process is cumbersome and the delay extends over 18 months and more. Swabhiman, an NGO, distributed TABS to students during the pandemic for their matriculation examination preparation2020.
- In spite of having Govt. circulars 90% MPs are not utilizing their funds for aids and appliances. MPs do not conduct distribution camps regularly or in intervals. It is sporadic.
- There is no maintenance of assistive devices.
- Websites of ministries and departments are partially accessible.
- Governments in all five states are procuring high floor buses for public transport.



Swostik Sourav Founder and **CEO** Neomotion, Engineer, Odisha

IIT Madras incubated start- up and creates life transformative products for the physically challenged and the elderly. This vehicle makes the differently-abled a lot independent. A functional wheelchair is always as part of the vehicle so they can move around independently without anyone's help. In the case of a modified two-wheeler or a car someone has to help them transfer to a wheelchair".

Recommendations

- As ALIMCO is government entity and the largest producer of assistive technology solutions in India, producing over 350 different kinds of aids and appliances, it should elevate suitability and sturdiness of its products.
- In order for assistive technology market to function efficiently, all parts of it - basic and applied research, knowledge translation, manufacturing and marketing must be well connected through a common platform.
- Maintenance centres for aids and appliances shall be available at least at the district level and shall be ensured by all state Governments .
- Like MPLAD fund, provisions shall be made for MLAs for compulsory distribution of aids and appliances as their duty and social responsibility.
- 100% accessibility of websites and online platforms must be mandated.
- With expansion of disability categories to 21 from 7 in 2016, an assistive technology Act and standards for assistive technology are needed to address modern devices.
- · Government procurement policies must include accessibility as a mandatory criterion.



Dr. K Anand Rao, OH, General Secretary, **Ganjam District OH Welfare Association** Convenor, Southern Odisha, OSdN

The CREATE in IIT Madras is revolutionising ease of living with its innovative assistive devices and technologies like the recent wearable assistive devices with latest technologies to empower people with hearing and motor disabilities; and start-ups like Neomotion and IITs in other states must focus on innovation to make living comfortable for the disabled.

Chitrasen Sahu, Blade runner and amputee mountaineer, Chhatisgarh 09

" I credit my successful mountain climbing to a prosthetic leg made of carbon fibre designed in India. The blade is thicker than the one used for running And it is much lighter and tougher. This reduce the weight of the prosthetic leg as well as the additional weight of mountaineering boots."





REDUCE INEQUALITY WITHIN AND AMONG COUNTRIES

Issues

- In four states RPwD Act rules have been notified. Though Rules were passed in April 2018 in Jharkhand, but it has not been published in Gazette.
- Advisory boards, district-level committees, etc. are in various stages of constitution. In Bihar, nothing has been constituted. In Chhatisgarh there exists neither the state advisory boards nor are the district-level committees. One state-level committee is there but it is dormant. In Jharkhand, state level committee was constituted but it is defunct since a long time. Nominations were invited in January 2021. In Odisha the last meeting of the State Advisory committee was held in 2019. In West Bengal it has not been constituted.
- None of the States have constituted an "Assessment Board" to certify people with high support needs.
- No Special Courts been set up under the Act in any of the states.
- Rules have not been framed under the Mental Health Care Act in the five states.
- Disabled persons organisations are not consulted on major policy decisions. The organisations receiving funds from government are invited sometimes, to only say yes to everything.
- In Bihar disabled people are crawling for nomination to election officers, no party selects them. They contest individually and win sometimes. They good do work when elected as Sarpanch. In Odisha the same story follows. PwDs often harassed and nominations cancelled as they are disabled.



Jitendra Biswal, OH, Odisha

Increase representation of persons with disabilities, especially by introducing affirmative actions and reservations across all level of governance and administration including panchayats and state legislatures and parliament. Nominate persons with disabilities in Rajya Sabha and Vidhan Parishad in states that have them. Whether elections or events, persons with disabilities must be made icons for better visibility of the disabled.



- Rules need to be notified for RPwD Act and MHC Act in all states.
- The District Courts and District Committees must be in set up in priority.
- India needs a legislative framework, such as an Equality Law, which promotes equality and anti-discrimination, taking into consideration the multiple identities of PwDs.
- All police stations should be accessible to PwDs.
- The court premises should be accessible for all PwDs. In the court premises there should be a headphones with GPS which can help a blind person to reach the court room easily. Proper accessibility of assistive mobility aids like wheel chairs, walkers and crutches must be provided. Every Court should have a sign language interpreter.
- Testimony given by a disabled victim should be considered as relevant and admissible. There is a need to raise awareness amongst the law-enforcement agencies that technologies can be used to get evidence from all categories of disabled people.
- Reservation of seats in all tiers of governance in the line of women, SC and ST candidates.
- Advocacy for mandatory implementation of reservation in education, employment, social security and poverty alleviation schemes.



MAKE CITIES AND HUMAN SETTLEMENTS INCLUSIVE, SAFE, RESILIENT AND SUSTAINABLE

Issues

- People with learning disabilities face countless challenges due to poor website designs and lack of consideration for the unique needs such as poor colour contrast or not being able to read text, not being able to highlight text to guide themselves along while reading or have assistive technology read the text to them.
- Public transport becomes a stressful journey for acid attack survivors with people making various gestures with their eyes and face, some even make noises of pity or fear.
- Almost all new buildings are coming up with inaccessible features. Ramps exist in many buildings but there are barriers before the ramps in 90% of cases.
- For short height people all built structures and all forms of public transport are completely inaccessible.
- Deaf travellers face problems in knowing airport/train station announcements, boarding gate/platform number changes and flight delays.
- In the interior areas in all eastern states, most government offices require climbing staircases. It is very difficult for people with mobility impairment.
- Bhubaneswar Development Authority (BDA) which is the designated body to pass building plans doesn't require plans to have accessibility features despite New Building Code stating accessibility features in buildings.
- BDA has no provision for measuring accessibility features in building plans.
- In all the five states on an average 20 buildings in the capital have been audited and report submitted to government. Funds have been received from GoI under Accessible India Campaign. Between 2016-22, the buildings are in various stages of retrofitting. The access auditors haven't been invited to give final approval of "accessibility" to the buildings.

Recommendations

- Accessible websites and hardware
- Travel reimbursement to AAS for hospital and rehabilitation centers
- Building plans must not be passed unless accessibility features included.
- All big infrastructure, 4000 square feet and more, need not be given occupancy certificate only if "Access Certificate" is issued and mandatory parking in 30 meters for all disabled visitors in all events
- All public toilets to have low height locks and toilets for short height people.
- Airport announcements, flight time changes or boarding gate announcements to be sent as messages to the phones of deaf, ID, autistic and learning disability divyangs.
- Staff in Airport, Station & Bus stops to be trained in basic sign language.
- A separate help kiosk outside the airport for passengers with disabilities.
- All the departments need to have a designated and dedicated facilitation cells for PwDs. A disability nodal officer in each government department will make it easy and convenient for people with disability to access various services and get information.



Ashok Sara, OH-SCI, Professor School of Management, KIIT University

"Despite the fact that accommodations are simply supports that help employees do their best work, many employers disregard reasonable accommodations. Accessible workplace is not only ramps but also proper parking and sitting arrangement in auditorium, conference halls etc."

Odisha: Accessibility: Physical infra, digital inclusion on agenda for Bhubaneswar Smart City 11



Bhubanewar: As part of its Bhubanewar Udan Lecture Series, Bhubanewar Development Authority is colaboration with well-known social arread energensias dio Swathman, Bhubanewar Development Autority is Bhubanewar: Smart City List dodge organised a dayt ong workshop "Smart Accessibility Solutions in While on the theme of Smart accessibility in Smart Cities through digital Inclusion deliberations focused on topics like Austistive technologies for education underglate and digital inclusion. Making Smart City Bhubanewar (CT Accessible, a presentation was made on accomplete streets project & Bhubanewar (It this unique intriave people from various wabs of life inclusing people with disabilities (PMD), administrators, planners and engineers, NGD members and Mickal of city agencies were present. National Centre for Promotion Citradyment Polic Disabilities



PROMOTE PEACEFUL AND INCLUSIVE SOCIETIES FOR SUSTAINABLE DEVELOPMENT, PROVIDE ACCESS TO JUSTICE FOR ALL AND BUILD EFFECTIVE, ACCOUNTABLE AND INCLUSIVE INSTITUTIONS AT ALL LEVELS

Issues

- Children with disabilities are getting registered at birth.
- Aggregate data on cases of discrimination and abuse have no records in five states. SCPD offices, police etc. not maintaining proper records.
- Women with physical disabilities find it difficult to escape violent situations. Girls and boys who are deaf, not able to call for help or easily communicate abuse.
- Women and girls with intellectual or psychosocial disabilities do not know that non-consensual sexual acts are a crime and should be reported.
- Activists in all the five states reported that police are frequently unwilling to register their complaints, victims and witnesses receive little protection.
- State shelter for women victims are not disabled friendly.
- The special courts are non-functional. District authorities like Collector's office, ADMs office, DSSO offices are unaware of the notifications details.
- The newly built structures like '40 court building' in Ranchi has a lift that connects to other buildings, however, proper ramps are missing on the connecting point of the buildings. Further, the old buildings (for example, the one called CBI Court building) does not have a functional toilet for the disabled and the toilets in the new 40 court building is mostly dirty.



Ajit Kumar, VI, Convenor Jharkhand Divyang Adhikar Manch

There is no information posted anywhere in the conspicuous part of the civil court Ranchi where a person in need can have access to a wheelchair. We have witnessed disabled people walking with great pain to reach courtrooms due to no information on the availability of wheelchairs at the premises. It is common knowledge that the court premises are large and requires a considerable amount of travel to reach either the courtroom or even to meet the lawyer at his chamber/seat.



Sapna Bagahe, OH-SCI, Chhatisgarh

Five years ago, I became a victim of sexual assault that caused a spinal cord injury. I was in comma for 2 months. Fortunately, I regained consciousness and told my parents about the incident. Initially, my family supported me and filed FIR. Police arrested the main culprit. With the hope of getting justice, I kept on telling every legal authority about the incident. Meanwhile, doctors stated that there was no evidence of rape in my medical reports. After 2 years the main accused is out of jail and the case is still pending due to pandemic delays. I am still fighting. After graduation will pursue law.

- Stringent punishment for desertion due to disabilities caused(physical/mental) after marriage.
- All CwDs to be registered at birth.
- Police officers to have training and expert support needed to handle cases of women from 21 categories of disabilities
- First Information Report (FIR) needs to prepared in the presence of an expert on disability and interpreter in cases where the services are required such as deafness. And be allowed in alternate format like Braille. Must be provided the right to record their statement with police in the safety of their home or a place of their choice.
- Procedural and age-appropriate accommodations must be provided in the police stations and courts.
- State governments to facilitate compensation, including in cases where the offender cannot be traced or identified.
- Stringent punishment for desertion due to disabilities caused(physical/mental) after marriage.



STRENGTHEN THE MEANS OF IMPLEMENTATION AND REVITALIZE THE GLOBAL PARTNERSHIP FOR SUSTAINABLE DEVELOPMENT

Issues

• One of the commitments made by countries in the 2030 Agenda for Sustainable development is to have better statistics to allow monitoring of progress. But disaggregated data in the five eastern states is not available. Where available, statistics show that average level of education of persons with disabilities tends to be lower than that of people without disabilities, among persons with disabilities in employment a larger proportion is in self-employment and, violence and discrimination are rampant. Looking at GPI, one finds it is skewed against women/girl with disabilities.

Recommendations

- Aadhar metadata is a huge database generated by the daily count of total registrations, enrolment applications accepted and rejected by state and district. It also contains other details such as Aadhaar generated by age, gender, etc. Linking Aadhar to disability certificate/UDID will provide a robust data source.
- Data of CwDs can be be obtained from child tracking and monitoring system of OSEPA in Odisha (SMSA offices in respective states) with proper inclusion of children with disabilities in survey questionnaires.
- Research data collected from baseline survey, data published by agencies like UNICEF, DFID and other agencies should be made available in public domain.
- NCRB data to include disability specific data in crime against women and trafficking.
- Inclusion of CwD data at the anganwadi level survey under W&C development department.
- In all skill mapping programs for youths under skill council of India, there has to be proper inclusion of youth with disabilities. This along with registrations at Special Employment exchanges will provide data on YwDs.
- The data of the 76th NSSO report was under reported because the decadal growth rate had been taken into account.
- Social Sciences departments in the University and Institutes may be assigned the job of collecting and curating the data as a part of student internships under the supervision of a professor

Voices from eastern India

Mr Raj Kishore Prasad, Retired ADM, Bihar

Mental illness due to old age are not treated and are left behind unaddressed in rural areas of Bihar.

Tanmyee Sahu, Program Manager, Inclusive Education

Lockdown curtailed outdoor movements, social interaction and recreation leading to my sister in law's aggravated mental illness condition.

Prof. Dr. Suvendu Narayan Mishra, MD, Consultant Neuropsychiatrist

Many students underwent mental breakdown due to prolonged confinement indoors, rising stress in family relations and the burden of online education.

Brundaban Behera-Program Consultant, Chhattisgarh Viklang Manch

Motto is to enhance awareness of PwDs through different channels, platforms to enable the rights, raise the voice for changing the policy and entitlements of different Govt departments.

Anay Jaiswal, VI, Research Scholar, Jharkhand

ADIP scheme disproportionately favour certain disabilities and ignore other disabilities. In every camp I visited I found majority of the beneficiaries are people with locomotor disabilities. I need communication aid, my friends need laptop. We don't want blind sticks anymore.

Voices from eastern India

Shampa Sengupta, Joint Secretary of National Platform for Rights of the Disabled, West Bengal

We are getting many calls from disabled persons, their family members/care givers, not only from West Bengal but also from other parts of the country. They are suffering from depression, anxiety and regular problems of everyday life in the absence of required assistance.

Badrujudah Sheikh, OH, West Bengal

Is a PwD who runs a small tailoring factory in Birbhum district, of WB "The state is doing nothing to support us neither at the district level nor in villages. No district official has collected any information about us. Villagelevel health workers are spreading awareness regarding Covid-19, but they themselves are not aware of disabilityspecific information material. How will they help?"

Devasish, S&HI, Odisha

Very difficult to get appointments from doctors for regular health issues during pandemic. I am deaf and I need help to get an appointment. But the doctors said I have to wait as they were busy with important cases.

Suvendu Narayan Mishra, MD, Chhattisgarh

Doctors randomly give disability percentages. We want flyers or boards clearly stating the calculation of disability percentages.

Kamalkant Rath, Dwarfism, Cartoonist, Odisha

"Door handles aren't something that most people think too hard about. That's because they're placed within easy arm's reach for most adults. That's not the case for little people. Because door handles are often set too high, they're an accessibility issue. In every hotel I sleep with my door unlocked. In all public toilets I leave the toilet door open."

Rita Kumari, OH, Bihar Viklang Adhikar Manch

"Youth4Jobs is a namesake. They don't do anything. When we go for an interview facilitated by Youth4Jobs, they say jobs are for people with 40%-50% disability. Your disability percentage is very high. We will inform you when jobs for your disability percentage will be available. None of us get calls after that."

Annanya Biswas, Mental Illness, West Bengal

"For women living with schizophrenia, meaningful work and financial autonomy are vital, but they are forced to hide their diagnosis at the workplace due to widespread stigma, even as employers encourage conversations around depression and anxiety as the Covid-19 pandemic takes a toll on employees' mental health."

Sanjay Kumar, OH-Polio, Daryapur, Bihar

"I could not vote because my name was not in the voter list. "When I ask, they say it would be added in the voter list for the next elections. But every time it is not there. I also do not have a working wheelchair since my old one broke, and I move around with the support of my hands. I get a paltry sum Rs 400 per month in the name of pension hardly for six moths per year . I am also not getting rations under the public distribution system."

Sutapa Roy, Architect, West Bengal & US

Our legal framework doesn't have the provision of punitive action for not making buildings disabledfriendly. Most rules are recommendatory in nature. So, they are often flouted. In India, when laws aren't followed, how can one expect people to follow something that is not even a law?

Kuhu Das, OH, Disability Activist, West Bengal

"Kanchana" (name changed) a 19-year-old woman with an intellectual disability from a village in West Bengal, was raped several times in 2013 by a local man. Kanchana was not aware that she should report being raped, which was only discovered when she was five-months' pregnant. And her intellectual disability made it difficult to explain to the police what had happened.

Devadutta Pradhan, Thalassemia, Odisha

Insurance companies are denying to give insurance to Thalassemics. Thalassemia should be covered in health insurance. Thalassemia is covered in 80D. But the benefit is only 75000. It is very less because our expenditure is very high. We should be exempted upto Rs 150000.00 with disability up to 70%.

Sambit Das, Low vision, Banker, Odisha

HR policies of private and public sectors should include reasonable accomodation for employees with low vision by issuing special government circulars. Gadgets like video magnifier, portable magnifier, photocopier enlarged paper materials for reading, screen magnification and speech dictation software for computer-related work, smart glasses, task lighting or headlamps, and stand magnifiers for the monetary transaction assignments would be helpful.

Md Mokhtarul Haque- Convenoor Bachpan Bachao Andolan, Bihar

"Ek Bharat-Ek Divyang-Ek Bhatta"

CASE STUDY

STRINGENT LAWS FOR ACID ATTACK PERPETRATORS

Sonali Mukherjee, a NCC cadet from Dhanbad was attacked by acid in 2003 when she was just 18 years old. Three alleged assailants namely Tapas Mitra, Sanjay Paswan and Brahmadev Hajra threw acid on her when she was asleep on roof of her house. She received various burnt injuries and her face got disfigured. The perpetrators were sentenced to imprisonment of nine years but were released on bail when appealed to the High Court.

Chandi Das Mukherjee, Father of Acid Attack Survivor Sonali Mukharjee, Jharkhand

We appealed in the high court. Nothing happened. They were sent to jail but were released soon after. Now they are busy enjoying their lives. The law against acid attackers needs to be made tougher. Otherwise we will have many more Sonalis. We are afraid since two of her attackers were released on bail six years ago and the third accused Brahmadev Hajra was let off as he was a juvenile at the time of crime. They may harass again. My daughter and we all will live in fear always."

Saswat acharya, Lawyer, Odisha High Court and General Body Member Swabhiman NGO, Odisha

In 2002 the government of Bangladesh passed 2 acts- The Acid Control Act 2002 and Acid Crime Prevention Act 2002. These two acts restricted the import and sale of acid in open markets and also addressed the punishment for the acid attackers. The punishment for just attempting to throw acid without causing harm or any injury leads to a rigorous punishment of 7 years but not less than 3 years along with a fine of more than fifty thousand takas. If the acid attack results in any damage or disfigurement in the body then it is fourteen years death or any injury which leads to the loss of vision, loss of hearing, disfigurement body is capital punishment or life imprisonment. The tough laws in Bangladesh have reduced the number of acid attacks to an extent. We must have stringent laws like Bangladesh to deter rising cases of acid attack in India.

POSITIVE NEWS

"Acid attack victims whose faces have been disfigured used to get a compensation of Rs 3 lakh. This has been increased to Rs 7 lakh. If the victim of acid attack or rape is under the age of 14, she would get 50 per cent more compensation. Victims of acid attack who have suffered damage in their eyesight up to 80 per cent or have turned disabled would get a monthly compensation of Rs 10,000 instead of the whole compensation amount in a single instalment Special Cabinet Secretary Bihar, U.N. Pandey. Decisions on such matters would be taken by the district-level panels. 12





Pradhan Mantri Awas Yojana



Bihar Victim Compensation Scheme 2020 for Rape & Acid Attack April 24, 2020 by Vibbati

Bihar Victim Compensation Scheme 2018 – Rs. 7 Lakh for Rape & Acid Attack Victims [Eligibility Criteria]

The <u>Bihar state government</u>, in its Cabinet meeting has announced the approval of the implementation of Bhar Victim Compensation Scheme 2018. As per the statements made, the scheme is focused on offering with two morpersations to eaid attack and rake victims within the state. The state government has announced to offer a compensation amount of Rs 7 lakhs to be given to eash victim. The amount of compensation has been increased from Rs 3 lakh to Rs 7 lakh under current recommendations.

CASE STUDY

ACCESSIBILITY FOR ALL

Kalyan Pal, Guide, West Bengal

Local Guide Kalyan Pal (@KalyanPal) lives in Kolkata, India, and is interested in mobility. He is part of the #AccessibleBengal initiative within the Local Guides movement "Accessibility for All" and an active meet-ups organizer. We recently caught up with Kalyan to learn more about what sparked his passion for accessibility.

My uncle is a wheelchair user, and in the village where I grew up, many people have a disability ([either motor], visual, or hearing disability). When I see disabled persons, I try to help them as much as possible, either physically or virtually. I help them virtually through my contributions on Google Maps. I think Google Maps is the best way to help by providing information on accessibility. I want all places to become accessible for all. More specifically, I am interested in wheelchair accessibility in West Bengal, India.

Nowadays, we use Google Maps to get information on whether a place is accessible or not. Before leaving home, we read reviews and watch videos and photos of the place. And, if we don't know the way, Google Maps helps us to get there. But, most of the places have no proper information on accessibility. So I try my best to explain the accessibility status [in my] reviews and upload photos and videos that show accessibility features. I write accessibility information in the "Add a caption" [field] and answer questions about accessibility.

Yet, my favorite is the "About" section, where I am able to suggest accessibility information by clicking the "Describe this place" button (I suggest other information, too). [Another] interesting feature is answering questions, because, when I visit a place, I automatically get the questions and, without spending much time, I answer all of them. I also like to create accessibility lists.

I encourage local guides to make contribution on accessibility which will help people a lot. When you visit a place, please leave a review mentioning the accessibility status, along with photos and videos. In Google Maps, I'd like all accessibility information to be visible in the "About" section along with the accessibility sign.







WHY LEPROSY CASES ARE RISING

Duryodhan Sahoo, Life Member Hind Kusht Nivaran Sangh, Member State Technical Committee Leprosy Odisha, General Secretary, Indian Hansenians Association - Odisha

In a candid interview with Mihir Mohanty, Director Programs of Swabhiman, he thus spoke:

MM: Odisha was declared leprosy free in 2006-07. Why since 2013-14, more than 10000 new cases are being detected every year?

DS: Due to dedicated work of leprosy paramedical workers prior to 2006-07 the state achieved leprosy free status. But when these posts fell vacant, cases went up. The slogan of WHO of early detection, proper and early treatment was ignored.

MM: There are 314 Block PHC/CHCs and 90 govt. hospitals including urban health centres. How is the quality of healthcare of leprosy affected persons?

DS: NLEP guidelines for early diagnosis and treatment is not properly maintained. I recommend filling up the 359 vacant posts of leprosy para medical workers,101 non-medical supervisors, dressers of 84 leprosy colonies and regular visits of doctors to colonies.

MM: There are 4 leprosy Homes and 14 leprosy Hospitals in Odisha. Are they not enough to provide care? DS: These institutions are not properly functioning because of want of doctors / para medical and group 'D' posts. MM: What is the issue concerning disability certificates?

DS: In WPC No. 767 of 2014 Pankaj Sinha Vrs Union of India and others, bench directed at least 40% disability percentage to be awarded to leprosy victims. Leprosy is included in locomotor disability. Definition under RPwD Act 2016 does not take into account "lack of sensation" in limbs in awarding disability percentage. Further, certificates of leprosy must mention "leprosy cured." The absence of these two words leads to stigma and discrimination. MM: What is the condition of leprosy colonies?

DS: There are 86 self-settled leprosy colonies but government has not provided land rights, housing, education, health services. Colonies need roads, sanitation, economic development, training and employment. Leprosy victims and their family members should be treated as equal citizens of India and all benefits provided.

MM: What is the impact of Covid-19 infection on persons affected with leprosy?

DS: We haven't heard of a co-infection. However, patients on corticosteroids for treatment of leprosy reactions and nerve function impairment take Prednisolone, a immunosuppressant. Most patients require long periods of treatment, are immunosuppressed and more vulnerable to Covid-19 infection.

MM: Any concluding message?

DS: 30 districts of Odisha to conduct school survey, village survey, contact survey, mass survey, awareness programme to detect cases. Government must support leprosy affected persons to live with dignity. Full implementation of NLEP. Attitude of discrimination must change.



Duryodhan Sahoo Life Member Hind Kusht Nivaran Sangh, Member State Technical Committee Leprosy Odisha



Mihir Mohanty Director Programs of Swabhiman

CASE STUDY

A VILLAGE FULL OF DISABLED WILL NOT VOTE 15

Laruara is a Muslim-majority village, around three kilometers from Begusarai city, in Begusarai district of Bihar. Most men work as labourers and the women make beedis which are sold in cities like Katihar, Darbhanga and Muzaffarpur. They earn around Rs 80 for 1,000 beedis. Laruara is home to over 100 people with disabilities. The road leading to Laruara is riddled with potholes.

Muhida Parveen, 30, can't walk as she had polio as a child. At the time, around 100 other children in her village Laru-Aara suffered polio too. All are disabled and unable to walk. Many of them are destitute. Mohammad Sajid Ansari's disability has left him unable to walk and with the use of only one hand. He drives a tricycle to earn a living. "Not everyone has been given a tricycle so most crawl on the streets to get around. Our feet bleed while walking on these battered roads. Even driving a tricycle is difficult but no one listens to us." Sajid's sister Rehana Khatun has a mental illness and has lost the use of her hands. He said the family never received a toilet from the government, despite the government's claim that the state is open defaecation free. "We have to go about two km to relieve ourselves. When it rains, we end up soiling our clothes sometimes."

Saeed Anwar, 25, polio affected, "We face a multitude of problems every day. We want the government to save people like us. During the lockdown, villagers would eat only once a day since they did not receive money or rations from the government."

Mohammad Abirul, 30, lives with his wife and two children. Living with a disability, he said, he finds it difficult to get work. "If the government arranges some work for us, we won't die with hunger. We don't beg but yes, we do face problems in getting the food on the table. The government did speak about some aid during the lockdown but we didn't get anything." Abhirul depends on his disability pension of Rs 400 which is paltry



AWARENESS

The Sustainable Development Goals (SDGs) are ambitious (ending poverty world wide), and comprehensive (including people, planet, prosperity, peace and partnership). The more people who know about and support the goals, the more likely countries are to achieve them. The inclusion and the participation of persons with disabilities and their representative organizations in all phases of implementation of SDGs is critical, not only to ensure that they are not left behind, but also because only they are the true experts when it comes to their complete inclusion in society.

We are far from where we need to be. We are off track.We must step up our efforts. And we must do it now. I am issuing a global call for a decade of action to deliver the Sustainable Development Goals by 2030. UN Secretary-General António Guterres

Without adequate awareness and support, we will collectively fail to achieve these goals. In 2018 Odisha State disAbility Network organised a unique awareness campaign to reach the disabled, the government and the society in the remotest areas with knowledge of CRPD, RPwD Act and SDGs and their interlinkages. Folk art forms and folk art of Odisha was the underlying tool for designing all communication posters and relevant visibility media.

Highlights

- When over 20,000 people with disabilities and youth came together in Odisha, and 100,000 people with disabilities and related stakeholders were reached through an awareness drive.
- A multi-level, multi-stakeholder campaign to build awareness of disability issues, and support for inclusive development.
- It covered 5100 kilometers in 35 days between 09th May 2017 and 13th June 2017 Covered all the 30 districts of Odisha.
- An awareness vehicle "Sashakt Doot" along with one mobile photo exhibition moved with the campaign team to all districts
- Odisha folk art forms were used as medium of communications to create awareness.





Experts Opinion

Prof. Dr. Suvendu Narayan Mishra, MD, Consultant Neuropsychiatrist Sexologist, Drug Deaddiction

"The burden of mental disorders continues to grow with significant impacts on health and major social, human rights and economic consequences on the patient and family. Pandemic has aggravated the situation with discontinuation of medicine as many could not get prescriptions from their doctors due to lockdown."

Aditi Panda, Project Manager, Samarthya, (LSE-Special schools), Kalinga Institute of Social Sciences (KISS) [Mother of Special Girl Child Ankita Panda who passed away at the age of 14]

"Consultations with PwDs (all the 21 categories focusing on women and elderly), their support networks, and representative organizations are necessary in every state by the government when developing and implementing a vaccination protocol. Only then, we can identify and address barriers in different contexts and other factors like age, gender identity, geographical barriers and migration status to access these activities."

Tulika Das, Director, SANCHAR (32 year old disability-development organisation in West Bengal), a Ashoka Fellow, a Ford Fellow and has 30 years experience as Actor and Director in Indian Theatre.

"My experience in West Bengal that, in India, we need to work intensely with socio-economically marginalized persons with disabilities, their families and community stakeholders to ensure an empowered community, where people with disabilities, their families and other underprivileged groups have equal access to health, education and livelihood opportunities for their inclusion in mainstream society with equal rights and dignity. In South 24 Parganas and Howrah districts, we have transformed the lives of thousands of persons with disabilities and their families, in making PwDs visible and vocal to avail all government entitlements to live with dignity."

Ishwar Prasad Chhata, Director Chhattisgarh Vikalang Manch

CVM has the voice for the Persons with Disabilities; it's an organization to motivate and be aware to way out the accessibility and empower through sustainable livelihood. Its primary focus is to develop effective, accountable, transparent institutions at all levels and provide alternative livelihood opportunities to those at the bottom of the criminal chain to stop all forms of environmental crimes.

Dr. Ramakrishna Biswal, Assistant Professor of Behavioural Sciences, National Institute of Technology, Rourkela

There should be provisions for mobile food/grocery/daily needs distribution system by the local administration supervised by student volunteers from the nearby universities to ensure that no one is sleeping with hungry stomach and the quality and quantity of the food/items distributed among the PwDs in need during exceptional and normal times. The local administration in both rural and urban areas needs to prepare the database of the PwDs in need and updating the same annually should be mandated.

Smt Swarnalata Mishra, Chairperson, Manage Autism Now (MAN) Trust

Being a mother of an autistic child I must suggest that Govt, non-Govt, academia, media and other key stakeholders of our society should create awareness about autism for the inclusion and self-determination for all and assure that each person with autistic spectrum disorder (ASD) is provided the opportunity to achieve the highest possible quality of life. The children with ASD and youth excel in the field of their choice. They must be exposed to many skill and many education streams. Students with autism can participate in most activities that other kids and teens do, they need a daily schedule and routine.





Aditi Panda









Director, SANCHAR Director

Ishwar Prasad Chhata, Director Chhattisgarh Vikalang Manch

Assistant Professor of Behavioural Sciences, NIT

Manage Autism Now (MAN) Trust

Success Stories

Rachna Kumar, Bihar

My story is filled with trauma, pain, and depression. Yet it is also filled with happiness and success. At the age of 24, I was diagnosed with one of the world's most stigmatized diseases, leprosy, also known as Hansen's disease. Not long after my husband passed away. I was shunned by his family. For fear of infecting my two children, I left them with my parents to seek work in a bigger city. After eight years, I am finally cured at the age of 32. I now live with my parents and two children in Bihar. But my battle with the disease is emotionally and physically traumatizing, not dissimilar to the stories of thousands of others.



My aim is to help other people affected by the disease and campaign for their rights. I work at the Lepra Society's

Munger Referral Centre in Bihar, and am a member of the State Forum of Leprosy Affected People. I also sit on the Advisory Panel of the International Federation of Anti Leprosy Associations, where I address policy makers.

Pramodini Roul, Odisha

Pramodini Roul suffered horrific burns to her face and was left bald with just 20 per cent of her eyesight after being attacked when she was just 15-years-old.Her courageous journey from being a bedridden girl to the woman who chased the culprit and put him behind the bars even when the police had shut the case citing 'no clue' is a source of inspiration for all. Pramodini, now 28, suffered with pain for almost a decade and underwent five reconstructive surgeries - including one to correct vision in her left eye. She went to Delhi to join the Stop Acid Attack Campaign in 2016.



Pramodini married Saroj Sahoo in 2021. At present, they live in Bhubaneshwar and manage the Odisha section of Stop

Acid Attacks campaign. They have rehabilitated and supported several acid attack survivors in the state. "In a society where the face of a girl is given more importance for marriage, I could never dream of this day. Saroj met me in hospital and supported me all the way."

Kamla Kant Rath, Odisha

Kamla Kant Rath, popularly known as KK is regarded as the great Cartoonist of Odisha for his unique creations. R.K.Laxman's 'The Common Man' motivates KK into focusing on detailed expressions in his cartoons. He concentrates more on facial expressions, details of the character, less words, simple thoughts and action packed illustrations. KK's cartoons are sharp and make people laugh instantly and his caricatures are vibrant and lively. KK is a person of short height and his greatest concerns are public spaces, especially toilets, and workplace accommodations. The greatest challenge for



people of short height in the workplace is not the work task, it about the relationship and human behaviour. Workplace challenges commonly include inaccessible heights of furniture, work spaces, commodes, toilet door locks, discrimination, bullying and organizational support.

Ratnaboli Ray, Psychologist, West Bengal

Psychologist Ratnaboli Ray's, 60 years old, recovery from a mental health crisis inspired her to fight for women suffering in 'abysmal' conditions in West Bengal's state institutions. Ray, a trained psychologist, was working in a private mental health facility when she recognised the signs of mental illness in herself. She consulted doctors, was diagnosed with mental illness, underwent therapy with medication, which she still uses. After about 18 months of treatment she stabilised but lost her job. She took to rights of the mentally ill. She has worked to shed light on the human rights abuses in hospitals and successfully lobbied for change in the law, including challenging the use of solitary confinement and electroshock therapy without consent in WB. She focused on helping female patients because she was aware of the impact of societal issues and violence against women. "Suicide is not just a mental health issue. It's an intersectional issue and has huge social determinants."



Concerns of New disAbility



Sambit Nanda, Consultant and Clinical Psychologist

Over 90% of children with disabilities, who come to my clinic, were found to be socially isolated, with nearly half of parents (49%) reporting that their child had not seen a friend either online or in person in the past month. As a result, the development of life skills in these children has been negatively impacted. Around half of parents reported that the pandemic harmed their child's ability to communicate with others and interact with relatives. These issues have all exacerbated their poor emotional well-being. On an average, six out of 10 parents observed symptoms of anxiety, while 72% of parents reported that their child is often unhappy, downhearted, or tearful.

Evidence is showing that people with learning disability are at higher risk from covid-19 related death compared with the general population. But covid-19 outcomes are often complicated by factors such as comorbidities. Prompt access to covid-19 testing and healthcare is warranted for this group, and prioritisation for covid-19 vaccination should be considered. As of yet, there is no evidence on the increased risk of covid-19 deaths among people with milder learning disability.

Devadutta Pradhan, Thallasemia

This covid has made so many difficulties to get blood. Blood donation camps stopped and blood banks denied to give blood. Some blood banks are not working properly. Blood banks and other organisation should make enough blood donation camps to help us. Govt should promote people to donate blood in these type of calamities. Separate isolation wards for blood donors necessary. Reblozyl, Gene therapy which are high cost in USA and Europe and has been seen significant improvement in thalassemia patients. Patients are living with better life with those medications. Indian Govt should import all those medicines and therapy to treat us with free of cost.

Sukanta Pradhan, Hemophilia

Sukanta Pradhan, a Hemophilia patient from Puri,Odisha, shared that all the patients with hemophilia were restricted from accessing crucial healthcare facilities during COVID-19 lock-down. As Haemophilia causes difficulty in controlling bleeding episodes and the patients survive on factor medicine/injection, so it should be made available at government hospitals for free.

Sri Dhiren Nayak, Parkinson Disease



The COVID-19 pandemic restrictions by the state administration to curb the spread badly impacted health care services such as of patients with chronic illnesses like Parkinson's Disease (PD). There was difficulty both in reaching doctors and procuring medication. Significant decline of motor symptoms was reported by him and their caregivers. Telemedicine services are highly beneficial to address minor issues and prevent significant problems later on. But not many doctors were available online. There is need for better health care planning and implementation by the government in such emergency situations. People with chronic neurological diseases like Parkinson and their caregiver need time to organise their medication, schedules, take advices from physicians before lockdowns are clamped. Govt. may also plan for timely interventions such as telemedicine to mitigate this problem and prevent diseases from getting out of control by timely intervention.





Way Forward

Eastern India has a number of weaknesses.

- Physical infrastructure such as electricity, communication, transportation, and banking and finance are very sporadic and unevenly distributed among urban and rural areas. Governments have to invest heavily in building physical and institutional accessible infrastructures, inclusive and accessible healthcare and prevent disruption of essential services like mid day meal, therapy centers, local public transport (bus) during pandemics.
- Most of the state government officials from Block level onwards are unaware of the disability law stipulations and changing paradigm of disability globally. Awareness drives are needed for government officers. They are not aware of the availability of funds in multiple government departments, CSR etc. to the advantages of strengthening accessibility of the state, providing better health care, pushing inclusive education agenda and skill development as per 21st century and post pandemic requirements. For ex. the Smart Cities Mission offers a great opportunity and huge funds to ensure inclusion and participation of persons with disabilities in workplace, neighbourhood activities and in social life, yet barely tapped for the disabled.
- Lack of economic opportunities encourages migration, particularly that of skilled resources to work and live in better developed and developing parts of India. Hence most skill development programs send the PwD trainees to Karnataka, Telegana etc. The skill training must be based on local gaps in services or materials to reverse the trend.
- The formal justice mechanisms in India are very complex, expensive and beyond the reach of majority of India's population, especially the marginalized. SCPD offices (often vacant, mostly headed by political appointees) and District Courts (not notified) are not providing justice in a time bound manner. Helplines are not functional, when functional are either unmanned or inaccessible. No records are maintained. Accountability of government functionaries needed.
- One of the commitments made by countries in the 2030 Agenda for Sustainable development is to have better statistics to allow monitoring of progress. But disaggregated data in the five eastern states is not available. Where available, statistics show that average level of education of persons with disabilities tends to be lower than that of people without disabilities, among persons with disabilities in employment a larger proportion is in self-employment and, violence and discrimination are rampant. Looking at GPI, one finds it is skewed against women/girl with disabilities.

A 10-point Advocacy Charter for Eastern India is underneath:

- 1. Advocacy for ensuring disaggregated data of PwDs with respect to their age, sex, caste, social category, locality to be available at all the Govt departmental monitoring and progress tracking dashboards of respective flagship programs including Census 2021.
- 2. Advocacy for certification of all the 21 categories of disabilities with special focus on the new disabilities with intense lobbying for specialists in districts for the assessment of all disabilities.
- 3. Advocacy for access, "Accessibility for all Accessibility everywhere". Emphasis schools, higher education, and on accessible technology, digitalization and ICTs.
- 4. Advocacy to ensure quality inclusive education from Anganwadi to intermediate level in line with NEP 2020. Inclusion of children in education from 1 year onwards.
- 5. Advocacy for ensuring the implementation of 4% employment guarantee in all the flagship livelihood generation programs initiated by Govt & other public sectors such as MGNREGA, NSDC, NRLM etc. including Govt Jobs.
- 6. Advocacy for a separate department for disability in all five states and designated nodal officers for "inclusion" in all the Govt departments.
- 7. Advocacy for ensuring reservation of PwDs in all elections starting from local governance bodies i.e. Municipal bodies and Panchayats election, State Assembly (Vidhan Sabha) Elections across all the five states of the eastern region; and Nomination to Rajya Sabha and Vidhan Parishad.
- 8. Advocacy to create a cadre of community-based rehabilitation workers in line with ASHA and AWW.
- 9. Advocacy to facilitate disability-based budgetary allocation and tracking mechanism by the department of finance under disability-specific budgeting. The emphasis will also be given on the allocation of CSR funds towards the betterment of PwDs in the eastern regional states.
- 10. Strong and target-oriented campaign will start for the inclusion of disability in all projects, thesis, and research in colleges and universities across the state of Odisha, Bihar, Jharkhand, Chhatisgarh, and West Bengal for five years.
- 11. Special advocacy focus will be on equal status for women with disability and their socioeconomic empowerment in the region. Strategies to reduce violence, atrocities, and injustice against women with disabilities.

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Eastern India Participants Mobilisation

Bihar Viklang Adhikar Mancch is a DPO formed in 2007 by persons with disabilities, their support networks, representative organizations, educationists, etc. to advocate for the rights of PwDs. Notable achievements creating access, implementation of single window system for certificate of disability at Panchayat level, setting up independent directorate for the disabled etc. Founder member and state secretary Rakesh Kumar works with 25 state executive members, 16 individual members and 6 NGOs for all 21 disabilities.

Chhattisgarh Vikalang Manch was formed in 2012. Founder Iswar Chandra Chhatta is the present director. It is empowering 16 categories of people disabilities with 15 staff members, 4 NGOs and the Viklang Manch of other states.. The mission is founded on the firm belief that the disabled do not need sympathy, they need a supportive environment to grow and fulfil their needs, potential and dreams.

Divyang Adhikar Manch, Jharkhand is a DPO formed in 2017. Headed by visually impaired Ajit Kumar, its objective is to provide a democratic multilateral decision-making forum for the resolution of issues and advocate for the rights of PwDs. It not only advocates for the rights of PwDs but also reaches them at times of need giving voice to the voiceless. 19 NGOs and registered 780 members work on all 21 categories of disabilities

Odisha State disAbility Network, headed by Dr Sruti Mohapatra, was founded in 2003. OSdN is a conglomeration of about 50 NGOs and over 500 individuals with disabilities, parents and NGO and DPO representatives from across the state. The members come together to raise "United Voices" for achieving various goals. Notable achievements include, successful lobbying and advocacy for designation of Minister as "Minister Disability; establishment of a separate department; establishment SCPD office; "Single Window Approach" for ease of accessing entitlements which today is the Bhima Bhoi Abhiyan of Government; facilitated the 1st Political convention in 2004 in Bhubaneswar.

Odisha State disAbility Network

SANCHAR, a West Bengal based disability-development organisation completed 32 years of its journey towards a disability inclusive society in 2020. They are working with socio-economically marginalized persons with disabilities, their families and community stakeholders through CBR approach to ensure an empowered community having equal access to health, education and livelihood opportunities with equal rights and dignity. It supports capacity building of human resources, research work and advocacy in 17 states of India with partner organisations to promote inclusive development.

UNRCO- India Partner for Eastern India Consultation

Founded in 2001, by TEDx speaker Dr. Sruti Mohapatra, Swabhiman (www.swabhiman.org) is a registered nonprofit, a cross disability organization, advocating for and serving persons with disabilities in Odisha and India. Swabhiman has been in the forefront of several policy changes in India such as new rights based disability law, accessible election and Census. It specifically focuses on supporting education, strengthening youth for availing employment opportunities, increasing public awareness on the issue of disability, working towards accessible cities and conducting research for enabling advocacy. Swabhiman works with its network (Odisha State Disability Network) for promoting and protecting rights of persons with disabilities at all levels. Prerana, Sashakt, Saksham, Anjali, Adhikar, Addhyayan, Raahat are some its ground breaking programmes.



Sanchar West Bengal

Divyang Adhikar Manch ,Jharkhand

Bihar Viklang Adhikar Manch

Chhattisgarh

Viklang Manch