

A Report

Workshop on understanding Challenges of Children with Disabilities

Organized by:

Rajasthan Bal Adhikaar Sarkshan Sajha Abhiyan Alliance

UNICEF

Date:

19th November 2022

Venue:

Institute of Development Studies, Jaipur

Background

In India, the person with a disability constitutes nearly 2% of the total population, of which one-third are children. There are 1.5 million persons with disability in Rajasthan out of which 0.4 million are children, predominately residing in rural areas.

Data shows that two-thirds of children with a disability may not survive more than 40 years, moreover, girls with a disability are at risk of violence, abuse, exploitation, and neglect. The COVID-19 pandemic has further contributed to compounding the deprivation and challenges faced by children with disability.

(Source: <https://timesofindia.indiatimes.com/city/jaipur/data-on-persons-with-disability-under-reported/articleshow/94954458.cms>)

A disability is defined as a “physical, mental, cognitive, or developmental condition that impairs, interferes, barriers with, or limits a person's ability to engage in certain tasks or actions or participate in typical daily activities and interactions”.

Studies show that people with a disability face four times more any type of violence and three times more physical violence than normal people.

Persons with Disabilities Act, 1995, to safeguard the rights of Persons with Disabilities (PWD), on the 1st of January 1996, the Government of India passed the Persons with Disabilities (Equal Opportunities, Protection of Rights and Full Participation) Act 1995. However, amendments were made to the Rights to Persons with Disabilities Act 2016 (RPWD), for making it more comprehensive and inclusive of the long-standing demands of Indian persons with disabilities. The inclusion of more conditions in the disability list, free education for disabled children, a framework for supporting institutional and social infrastructure, making an accessible environment, and provisions of punishment for violation of the RPWD Act are very important.

Moreover, even after the rolling of an amended act for the last five years, the awareness among Persons with Disability (PwD) is low, which is affecting directly on availing the available services meant for them.

Introduction

Rajasthan Bal Adhikar Sarkshan Sajha Abhiyan Alliance is a strong network of about 170 NGOs, child rights activists, and individuals working under the umbrella, which raises the collective voices and influences the policies related to issues of children & adolescents' rights, care, and protection at the state level. The alliance is working with a large number of children groups from across districts, to amplify their voices through regular interaction with stakeholders (government officials, influencers, and media). The coalition has been providing direct support to children who face abuse and violence. Presently, working with partners to ensure the implementation of the manifesto. Actively involved in providing information and analytical data related to child crime, education, development, etc to the MLAs for raising them in the assembly twice a year, which has successfully impacted the policy related amendments at the state level. Till now around 25 percent of the demands have either been met or are going to be implemented in Rajasthan.

However, due to evolving situation, there are new advocacy issues that the alliance needs to take forward.

Resource Institute for Human Rights (RIHR), is successfully playing the convening role for Rajasthan Bal Adhikar SarkshanSajha Abhiyan. Managing Sneh Angan (One Stop Crisis Management Centre for Children) for counselling, psychological, legal, and rehabilitation support to the children & adolescents of Jaipur. Developing the capacity of children & organized recreational activities for the children of Child Care Institutions including Government Juvenile Home, Government Girls Shelter Home at Jaipur. Advocating towards a positive impact on the policy environment for advancing children's rights through strategic engagement and also executing the activities for children & adolescents at the grass root level across the state.

Since child abuse is rampant, indiscriminate, and cut across class, geography, culture, sex and religion, specifically for children with disabilities. Misfortunes that these children have to face and often blame destiny for their condition, seldom think and take steps ahead to provide a protective environment and legal remedy.

Realizing the necessity of enhancing awareness among Children with Disability (CwD) and their families on the Rights to Persons with Disabilities Act 2016 (RPWD), sharing the positive changes, and advocating the gaps in the existing Act at the state level for preventing them from re-victimization, a "workshop on understanding challenges of CwD with different groups of disabled people" was organized in the association of UNICEF at Institute of Development Studies, Jaipur on 19th November 2022.

Registration and Welcome

Participation in the workshop was invited with the help of existing networks and groups of deaf, blind, physically challenged, autism from Rajasthan. An overwhelming response was received from groups, organizations, parents of CwD, individuals, and activists from across Rajasthan.

Mr. Vijay Goyal-Director, Resource Institute for Human Rights (RIHR) and Mr. Sharad Tripathi-Assistant Director, Nehru Yuva Kendra Sangathan (NYKS), Ministry of Youth Affairs & Sports, New Delhi welcomed and thanked all the participants for their enthusiasm and positive energy in making the workshop successful. Also briefed the objectives of the workshop for their active and fruitful participation. Utilizing the opportunity of state election by timely sharing the recommendations of the workshop was emphasized as it would be helpful in influencing the party manifesto and ultimately the programs and policies at the state level.

A total of 120 people including Specially-abled children, students & people, Para Olympians, their parents, Special educators, Academicians, NGOs, Advocates, Government officials, representatives of UN agencies including UNICEF, UNFPA, and UNDP from Jaipur, Ajmer, Barmer, Naguar, Jhunjhunu, Chaksu, Churu, Hanumangarh, Bikaner, Sawai Madhopur, Dholpur, Sirohi, Dausa, districts participated in the deliberation and shared their challenges and suggestions for strengthening the Rights to Persons with Disabilities Act 2016 (RPWD) for addressing the people in need of the state.

The organizers were warm and cordial which created a conducive and enabling environment for the participants till the end of the workshop.

Session 1: Disability, a Challenge

Speaker: Mr. Kamlesh Meena, Assistant Regional Director at Indira Gandhi National Open University (IGNOU), Punjab

The speaker commenced the discussion by narrating the journey of challenges starting from education to the job.

He encouraged such forums which enable the voices of people with disability for influencing the policies at the state level. Despite comprehensive legislation, Act 2016 and strongly putting the issues through forums, campaigns, and agitations the PwD continued to face insults, discrimination, hatred feelings, and mercy for availing their human rights. The grievances need to be collated and addressed by the concerned authorities in a timely manner. Economically weak becomes the biggest hurdle for any person living with a disability to fulfill their routine expenses and creates a huge gap in achieving their aspirations.

“Their voice isn’t their passion it’s their PAIN”.

The border has been set for abled and disabled people by the general public and government system through their approach and services.

The government has made the laws, acts, and policies however, they need to be improved and revised with time and changing ecosystem.

Session 2: Rights to Persons with Disabilities Act 2016 (RPWD)

Moderator: Dr. Akash Deep Arora, RAS, Deputy Director, Indira Gandhi Panchayati Raj & Gramin Vikas Sansthan

Speaker: Ms. Pratibha Bhatnagar, Secretary, Support Foundation for Autism & Developmental Disabilities and an Activist

The journey of evolution of regulation of Acts for people with disability was highlighted. The Persons with Disabilities Act, of 1995 was prepared in the welfare mode. However, the Rights of Persons with Disabilities Act of 2016 is the disability legislation passed by the Indian Parliament to fulfill its obligation to the United Nations Convention on the Rights of Persons with Disabilities, which India ratified in 2007. The Act replaced the existing Persons with Disabilities Act, of 1995.

The Bill provides for the access to inclusive education, vocational training, and self-employment of disabled persons without discrimination, and buildings, campuses, and various facilities are to be made accessible to the PwD and their special needs are to be addressed. Necessary schemes and programs to safeguard and promote the PwD for living in the community are to be launched by the Government. Appropriate healthcare measures, insurance schemes, and rehabilitation programs for the PwD are also to be undertaken by the Government. Cultural life, recreation, and sporting activities are also to be taken care of. All Government institutions of

higher education and those getting aid from the Government are required to reserve at least 5% of seats for persons with benchmark disabilities. Four percent reservation for persons with benchmark disabilities is to be provided in posts of all Government establishments with differential quotas for different forms of disabilities.

Discussed on PwD encounters a range of barriers when they attempt to access any kind of services that includes:

1. Physical barriers- location, stairs, inaccessible toilets, passages, doorways, absence of wheelchairs, fixed-height furniture, absence of clear signages, etc
2. Communication barriers- limited availability of written material or sign language interpreters, information, absence of Braille or large print, etc
3. Attitudinal barriers- experiences of prejudice, stigma, and discrimination, limited knowledge, and understanding of the rights of people with disability and their needs, rarely asking for their opinion or being involved in decision-making. Women with disability face particular barriers to sexual and reproductive health services and information, etc.
4. Financial barriers- Over half of all people with disability in low-income countries cannot afford proper health care, are unable to afford the costs associated with travelling, etc.

With the help of a power point presentation, the participants were made aware of the **beneficial provisions made in all seventeen chapters of the Rights of Persons with Disabilities Act of 2016** were explained in detail (**Annexure-1**). It was focused that is world's only Act that included 21 types of disabilities, which are equally applied to the private sector as well. The handouts of the same were also shared with the participants in their registration kit.

Toward the end of the session, the participants raised the practical issues which are unable to address under the provisions. Like- In the thirty minutes, formal classroom period the teachers are unable to pay adequate attention to the normal and disabled children simultaneously. However, the one day counseling under Individual Education Program with disabled children does not compensate for all the classes. We should not force the child to Inclusive Education but should be emphasized the separate classes for such children. All the education boards should have the provision of compulsory special educators in the schools for managing these children efficiently.

Though laws are being made, amended and implemented, the country's capacity to address the concern of the disabled has not kept pace with the growing expectations.

Session 3: Honouring Differently-abled Children of Rajasthan

With the aim of honouring the differently-abled individuals who have overcome their disabilities and setting an example for others from the community, they were felicitated at the workshop

with Awards as a token of appreciation. The participants also appreciated the talent they exhibited.

The Facilitation was done by Mr.Aakash Arora, Dy.Director,Indira Gandhi Panchayatis Raj, Ankush Singh, Communication Specialist I Communication, Advocacy and Partnership, from UNICEF and Mr. Kumar Manish ,from UNFPA.

It was emphasized that we must stress the fact that the disabled are not a burden on society. They have a right to lead a normal life and as citizens, they are important to us.

S.No.	Name	Disability	Achievement
1	Shiven Kumar	Attention Deficit Hyperactive Disorder (ADHD) and Autism	Passed 12th examination and Plays Casio fantastically
2	Hitesh Methwani	Intellectual impairment	Pursuing 12th and Rajasthan State Certificate of Information Technology (RSCIT) course Passionate in Singing, Cycling and Badminton
3	Ishaan Sharma	Autism	Passionate for studies and Computer School awarded for Excellence in Studies in 2011 & 2013 Scored 86% in 10th standard from ICSC Board City Topper Certificate by My FM Radio Participate actively in Music, Sports & Yoga
4	Ishan Khandelwal	Intellectual impairment	Won 2 gold medals: National Para Athletics Championship at Bhubaneshwar in March 2022 and Asian Youth Para Games in Bahrain in December 2021
5	Akshay Bhatnagar	Autism	National Award for Role Model Autism, 2019 Cavin Kare Ability Mastery Award, 2019 State Award for Role Model Autism, 2018 Jaipur Ratn Puruskar, 2019 Brand Ambassador for Parliament, Jaipur, 2019 7 Medals including Gold, Silver and Bronze National & State Para Sports Tournaments Rajasthan First Graduated Autism Students, 2014 First Division in Post Graduate First Autism person for getting Government Job
6	Ramnivas	Intellectual impairment	Independent and taking Vocational training at Ajmer
7	Suraj Bhan	Visual impairment	Many gold medals in Swimming

"I am only one, but still I am one. I cannot do everything, but still I can do something; and because I cannot do everything, I will not refuse to do something that I can do."— Helen Keller

Session 4: Implementation Challenges of Act 2016 and Women with Disability

Moderator: Mr. Kamlesh Meena, Assistant Regional Director at Indira Gandhi National Open University (IGNOU), Sawai Madhopur

Speakers: Mr. C.S. Trivedi- Principal Nirmal Vivek School, Mr. Rakesh Kaushik- Director Rajasthan Mahila Vikas Mandal, Chachiyawas, Ajmer and Mr. Ratan Lal Bairwa- Coordinator Viqlang Aandolan Sangharsh Samiti, Rajasthan.

The discussion began with the emotional notes and struggles faced throughout life as disabled individuals. The PwD are invited to the many government forums for playing with their emotions rather than hearing & resolving their issues.

Due to the neglected and discriminated attitude of the government system, many of us are forced to raise our voices through agitations, strikes, campaigns for meeting our demands, and revision in a few sections in the Act 2016. Like-revised monthly pension to Rs.750/-, increase assistance amount in Sukhad Dampatya Yojana, extending Palanhar Yojana for more than two children, Online certification of disability, etc.

Marginalisation, stigmatisation, discrimination, social exclusion, inability to participate in public life are a few of the stringent hardships that women with disabilities face as compared to men with disabilities and women without disabilities (United Nations Population Fund, 2019).

Women and girls with disabilities experience double discrimination, which places them at higher risk of gender-based violence, sexual abuse, neglect, maltreatment, and exploitation. There is a need to take into account and to address the concerns of women and girls with disabilities in all policy-making and programming. Special measures are also needed at all levels to integrate them into mainstream of development

Some of the suggestions were shared for further actions, including,

- Need to provide financial support through loans & government schemes for generating livelihood and actual upliftment.
- Need to encourage political participation from the disabled.
- Inclusive just not in education, but need to develop an inclusive society for enabling equality and justice.
- Promoting Universal Design of Learning for teachers & functionaries for developing sensitivity and support towards disabled children.
- Regular orientation & training at the workplace of people around the disabled for sensitizing them on positive attitudes & behaviour.

- Providing 100 percent disability certification rather than some percentage.
- Appointing guardianship even after 18 years of age for legal matters, etc.
- Special provisions for people suffering from Haemophilia, as it may convert into a permanent disability.
- Involve children with disability in sports for increasing their confidence, and personality which will further improve them in academics as well.

Session 5: Youth Policy and Disability

Speaker: Mr. Kumar Manish , UNFPA

The Ministry of Youth Affairs and Sports has announced in the Lok Sabha that the Union Government has prepared a new draft of the National Youth Policy and would be finalized after considering the received suggestions and after consultation with all stakeholders. The new draft of the National Youth Policy presents a roadmap of 10 years for youth development that India would like to achieve by 2030.

Concurrently, the Government of Rajasthan (GoR) has also initiated the process of developing a Youth Policy for the state and designated the United Nations Development Programme (UNDP) for consulting with the stakeholders and collating recommendations for formulating need based and comprehensive policy for the state.

The framed recommendations were shared briefly by the representative and also motivated the participants to write and submit their substantial suggestions for people with disability towards making the State Youth Policy effective.

Session 6: Inviting Recommendations on Disability for State Level Advocacy

Moderator: Mr. Manish Singh, Rajasthan Bal Adhikar Sarkshan Sajha Abhiyan Alliance

Speakers: Mr. Prateek Khandelwal, entrepreneur and Mr. Murarilal Sharma, Sarpanch

Bal Adhikar Sarkshan Sajha Abhiyan Alliance is supporting children with counselling services, legal support, and policy advocacy at the state level.

With the aim of strengthening the Rights of Persons with Disabilities Act of 2016, and including the issues of the disabled in the State Youth Policy, the participants were encouraged to share the pertinent recommendations. It was stated that the collated recommendations will be further presented at the state level and also shared with the Member of the Legislative Assembly of Rajasthan for raising them in form of questions in the upcoming State Assembly session for influencing the programs and policies of the disabled.

The participants shared the recommendations on the basis of their experience and challenges faced in its implementation in the state.

- Awareness and sensitization of officials in government and private on the issues of the disabled for dealing with them responsibly.
- Making the scribe service flexible and providing the scribe irrespective of age, gender, and education.
- Addressing the reproductive needs of people with disability.
- Improving the service delivery points to address the physical and attitudinal barriers.
- Enhancing relaxation and reservation in government jobs.
- Enhancing relaxation in the loan process.
- Focus on building vocational skills development & personality development and livelihood at the local level.
- Increasing the pension amount as per the other categories' norms and automatically increasing as others in a timely manner.
- Make the certification process smooth & simplified and decentralize it for all 21 categories at the district level.
- Haemophilia and thalassemia should have the provision with progressive disability.
- Designating grievances redressal officers for resolving the complaints, issues, etc.
- Appointing a committee of doctors for issuing certificates for sports and government jobs in order to prevent biases and corruption in the existing single doctor system.
- Organizing block-level camps for disability certifications.
- Connecting the disabled with Information Technology and Artificial Intelligence.
- Making the online shopping portals, consumer products, website content, and technologies accessible to the disabled for eg- labeling the products with Braille Lipi.
- Enhance the recreational & entertainment zones for the disabled such as clubs, parks, sports spaces, restaurants, and intellectual zones. Increase interaction & discussions with normal people for reducing their inhibitions and strengthen their confidence.

Closing Remarks

On the behalf of Bal Adhikar Sarkshan Sajha Abhiyan, Mr. Vijay Goyal expressed gratitude towards differently-abled children, individuals, Para Olympians, their parents, Special educators, Academicians, NGOs, Advocates, Activists & Government officials working for the disabled for the active participation in the workshop. He shared that this was the first-ever effort to bring together the voices of people with disability on a common platform.

He ensured that the alliance will use its experience of providing support in advocating the same at the state and national policy level and with the concerned stakeholders as well. There is a strong need to continue such fruitful discussions for putting the voice collectively for resilient social changes.

“Think beyond and see the disabled as a Resource”