

Western Region Consultation

Findings and Recommendations

By UNRCO and Rising Flame



Image description: Logos of UN in India and Rising Flame

Background

As per the 2011 census, India had approximately 26.8 Million persons with disabilities which form approximately 2.2% of the total population.¹ These estimates only accounted for 7 types of disabilities that were mentioned in the Persons With Disabilities (Equal Opportunities, Protection of Rights and Full Participation) Act, 1995. As per more recent data recorded by the National Statistics Office report on disability (that accounted for 21 disabilities that have been mentioned under the Rights of Persons With Disabilities Act 2016), approximately 2.2% of the Indian population has a disability.² Despite the change in nomenclature of “disability” and an expansion of recognized disabilities under the 2016 act, the proportion of persons with disabilities in the Indian population has stayed constant as per official data. This raises questions over the veracity of the official data. The world bank figures suggest that around 15% of the world’s population are persons with disabilities.³ Also civil society reports in the country mention that the number of persons with disabilities is anywhere from 7 to 10 percent of the population. a combination of data sources and the factors of stigma associated with disability, indicate that actual numbers are much higher than what are shown in the official records.

To address the concerns of the persons with disabilities and promote their rights, the United Nations Organisation adopted the Convention on the Rights of Persons with Disabilities in 2006 which was ratified by India in 2007⁴. Pursuant to the same, the 2016 act was passed to materialise the principles of equality and inclusion set out under the convention. However, the implementation of this legislation is still a distant dream. there are gaps in implementation of the law.

Persons with disabilities in India face numerous challenges including unequal access to education⁵, non-inclusive health services⁶, lack of employment opportunities due to ableist mindsets⁷ and inaccessible infrastructures. This is compounded by factors like gender, caste, class, religion and region.

The challenges faced by persons with disabilities were exacerbated during the pandemic. They faced difficulty accessing crucial information pertaining to the pandemic and availing

¹ Census of India, Data on Disability retrieved from :

https://censusindia.gov.in/census_and_you/disabled_population.aspx

² NSS report no. 583: Persons with Disabilities in India NSS 76th round (July – December 2018) Retrieved from <https://pib.gov.in/PressReleasePage.aspx?PRID=1593253#:~:text=In%20India%20prevalence%20of%20disability,it%20was%201.9%25%20among%20females.>

³ Factsheet on Persons with Disabilities | United Nations Enable retrieved from <https://www.un.org/development/desa/disabilities/resources/factsheet-on-persons-with-disabilities.html>

⁴ Convention on the Rights of Persons with Disabilities (CRPD) Retrieved from <https://www.un.org/development/desa/disabilities/convention-on-the-rights-of-persons-with-disabilities.html>

⁵ Education of children with disabilities in India Retrieved from <https://unesdoc.unesco.org/ark:/48223/pf0000186611>

⁶ Access to Health for Persons With Disabilities (OHCHR) retrieved from <https://www.ohchr.org/EN/Issues/ESCR/Pages/Health.aspx>

⁷ Persons With Disabilities and the Indian Labour Market Retrieved from https://www.ilo.org/wcmsp5/groups/public/-/Asia/---ro-bangkok/---sro-new_delhi/documents/publication/wcms_229259.pdf

of health services.⁸ This is because government notifications were not made available in an accessible manner and the response to Covid-19 was not disability inclusive.⁹ Resultantly, both prevention and cure became much more challenging for persons with disabilities. Over and above that, they also faced difficulty in pursuing education and working online due to factors like digital divide, lack of technological knowhow and lack of support from educational institutions, employers and the state.¹⁰

Sustainable Development Goals and the present context

The Millennium Development Goals (MDGs) were derived from targets set by the Millennium Declaration that was adopted by 189 nations in September 2000. These 8 goals were to be achieved by 2015.¹¹ The emphasis was on combating all aspects of global poverty and social exclusion. However, disability was not even mentioned in these goals. In 2015, the sustainable development goals were adopted by the United Nation to be "A blueprint to achieve a better and more sustainable future for all people and the world by 2030". These goals are far more holistic and they allude to the interests and concerns of persons with disabilities in 7 targets.¹² Given that people with disabilities constitute a significant proportion of India's population, India's commitment to achieve the SDGs and "leave no one behind" cannot be fulfilled, unless the concerns of persons with disabilities are mainstreamed in the discourse around SDGs.

The government has been making targeted interventions to materialise SDGs. In pursuance of the same, the government of India had submitted a voluntary national report to United Nations Resident Coordinators Office in 2020 after an extensive consultation with 14 population groups which also included persons with disabilities.¹³ After 2 years of this report, it is imperative to assess the on-ground situation and trace the extent to which SDGs have materialised for persons with disabilities and what kind of newer speed bumps have come up for the community due to the pandemic. This assessment can be very helpful in devising further strategies to respond to the needs of persons with disabilities during the pandemic and beyond.

In line with the above, Rising Flame and UNRCO aimed to prepare a follow-up action on the recommendations presented in the second VNR, and recommendations for pathways to a more resilient recovery from COVID-19 in order to strengthen the monitoring efforts for assessing the progress of the SDGs informed by the lessons from the COVID-19 pandemic.

⁸ Hindustan Times, Impact of COVID-19 on persons with disabilities in India Retrieved from <https://www.hindustantimes.com/ht-insight/public-health/impact-of-covid-19-on-persons-with-disabilities-in-india-101625105679386.html>

⁹ IBID

¹⁰ Indian Express, Many students with disabilities struggling with e-education, NGOs call for more accessible approach | Education News, The Indian Express retrieved from <https://indianexpress.com/article/education/many-students-with-disabilities-struggling-with-e-education-ngos-call-for-more-accessible-approach-6469329/>

¹¹ United Nations Millennium Development Goals Retrieved from <https://www.un.org/millenniumgoals/>

¹² Sustainable Development Goals - the United Nations Retrieved from <https://sdgs.un.org/>

¹³ Voluntary National Report on Implimentation of Sustainable Development Goals, India 2020 retreved from https://sustainabledevelopment.un.org/content/documents/26279VNR_2020_India_Report.pdf

Methodology

Rising Flame in collaboration with The United Nations Resident Coordinator's Office (UNRCO) conducted a multi-stakeholder western region virtual consultation for 2.5 hours in February 2022. This regional consultation is part of a national initiative by UNRCO and Sightsavers India, and western region is one of the five regional consultations that were organised online.

The objective of the consultation was to follow up on the recommendations presented in the second Voluntary National Review (VNR) of the Sustainable Development Goals, and also to provide recommendations for the pathways to recovery from the COVID -19 pandemic.

About the consultation and participation

The western region comprised 5 states and a union territory- Gujarat, Maharashtra, Goa, Rajasthan, Madhya Pradesh and Daman and Diu. The consultation saw 58 participants from five states. These participants were persons with disabilities along with other stakeholders like academicians, educators, parents of children with disabilities, disability rights and mental health activists, other support persons like sign interpreters, counsellors and gender rights activists. The participants were representative of 12 disability groups.

The method of the outreach was a combination of snowball method and online research. Invites were also sent specifically to rural and urban participants and participation was ensured through language diversity on the consultation. Intentional intersectionality of geography, class, gender (including queer persons) were ensured.

Accommodations and facilitation

The outreach and consultation were both conducted in English and Hindi. Sign language interpreters were making the space deaf inclusive and auto live captioning also provided support to deaf blind individuals, hard of hearing individuals and others with attention issues during the consultation.

Experienced facilitators in each breakout room facilitated focus group discussions around preset questions and gathered recommendations on different thematic areas in line with select goals – goal 3,4,5,8 - mentioned in the SDGs. The discussions and questions were framed in order to have caste, class, poverty and accessibility as cross cutting issues emerging under each thematic focus. The findings and recommendations outlined gaps and issues while making robust recommendations to ensure that persons with disabilities are not left behind and that the COVID 19 response and recovery responds to the needs of this group.

Limitations

Although all efforts were made to make the zoom consultation an inclusive and safe experience and space, we would want to recognise that many persons with disabilities from remote areas do not have access to internet and are not trained in online modes of

communications. Also, the given time and duration of the consultation itself was limited. Despite best efforts, representatives of all disability groups could not be present. Also, despite multiple efforts, it was challenging to ensure participation from Daman and Diu. The following report is based on the single consultation conducted in the western region and while it is divided into 4 goals, it sharpens and highlights linkages and interconnections with other important goals of the SDG.

Health

In Article 25 of the CRPD, we see enshrined the right to access quality and non-discriminatory healthcare. Healthcare providers and professionals should provide persons with disabilities with the same quality of care as accorded to others, and their care should be on the basis of free and informed consent. There should be no discrimination in access to health insurance and life insurance, and no denial of access to health care, health services, food, and fluids on the basis of disability. Many of these rights are mirrored in Section 25 of the RPD Act. However, even prior to the pandemic, it has been observed that our health care systems in India are both discriminatory and inaccessible for many people with disabilities.¹⁴

However, since the onset of the pandemic, we have known that people with disabilities are at a greater risk of fatal consequences to contracting COVID-19 because of weaker immune systems or pre-existing co-morbid conditions. Others might need personal assistance for self-care or even navigating the world. The emphasis on reducing physical contact between people is sometimes not possible with the support that is needed for people with disabilities.

Findings

- **Accessibility to health centres**

Participants from Madhya Pradesh, Gujarat and Maharashtra reported that accessibility in health care centres is often limited to ramps outside. The equipment at the healthcare centres aren't adjustable for wheelchair users or others who need it.

A participant from Gujarat raised concerns about how all navigation within a health care centre and hospital are visual, leaving blind people with no choice but to keep asking people. Similarly, a deafblind participant from Gujarat felt that there are severe communication gaps in the healthcare system because of hospital staff not knowing how to communicate with them. Both participants shared the need to have sighted or non disabled assistance as they navigated the centre/hospital.

Two participants also shared that the sonography tables at hospitals and health centres were often too high for wheelchair users. As most of these centres didn't have the equipment to make it accessible, women with disabilities needed to be carried for sonography or X rays making them vulnerable to violence.

"In Goa, we have had many instances of rural PHCs being inaccessible. In the first lockdown after much work, the state government appointed a few centres as special

¹⁴ Abidi J (2018) A health care sector that is disability- challenged. BusinessLine. Retrieved from <https://www.thehindubusinessline.com/specials/pulse/a-healthcare-sector-that-is-disabilitychallenged/arti-cle9420239>. ece

centres for persons with disabilities, which was counterproductive because most people had to travel long distances. This also left the onus to make hospitals accessible to the administration.”

- *Participant from Goa shared*

Participants also reported that most hospitals have no sign language interpretation and therefore require deaf persons to take their own interpreters which is an added cost.

With regards to isolation centres in the states, one participant reported there were no special isolation centres for people with disabilities and the other centres were not necessarily accessible. There were no sign language interpreters or support staff to help with their needs.

- **Challenges in accessing vaccinations**

As the government did not have a specific policy with regards to vaccinating disabled people, we see that the numbers who were officially vaccinated in the community is very low (20,000 according to latest news reports). Many participants have reported that there were several barriers to them accessing vaccines. In some states, there were mobile van units but this was not uniform or inclusive of all disabilities.

Cases of discrimination based on class were also reported.

“I went to help a woman with disabilities get the vaccination. We went in a car and they vaccinated her inside the car itself. The next day I accompanied a woman with disabilities from the slum area in an autorickshaw. The health workers did not come to the vehicle and tried to ignore her issue. After we intervened and fought, they vaccinated her.”

- *A participant from Madhya Pradesh*

It was reported that there was a lack of mechanism to track the post-vaccine symptoms and how they may affect people with chronic illnesses.

“I tried debating about it earlier in centres and was denied for a long time for vaccination just because centres were not trained regarding side effects on pre-health issues.”

- *A participant from Maharashtra*

In Goa, state made special arrangements for vaccinations in one centre in North Goa district. This meant that disabled people from across the state had to travel long distances, spending a lot of money to get themselves vaccinated.

- **Sensitization among health professionals**

Many participants, especially blind and deafblind women, reported that doctors and nurses are not trained to support them. They sometimes touch or handle them without telling or asking them. This makes it difficult to feel safe or comfortable in health centres or hospitals.

There was consensus among the participants that there is a lack of sensitivity regarding diagnosis and getting informed consent when having to submit to an examination by doctors, nurses or even radiologists. Hospitals and health centres also lack processes for complaints and grievances.

- **Reproductive health issues**

Participants reported a range of concerns with regards to sexual and reproductive health of women and girls with disabilities. In rural Maharashtra we received reports of ASHA workers refusing to do home visits for women with disabilities who are pregnant. There is a lot of stigma and prejudice about women with disabilities being pregnant. Participants reported that women with disabilities are often asked about their capacity in being mothers and even about “how they will raise a child”. Another activist from Gujarat also said that in her own experience ASHA workers often don’t provide women with disabilities with any information around SRHR because it is assumed to be not for them.

Others also shared the risks involved in being on psychiatric medication while pregnant and the reluctance in imagining that women with disabilities can become pregnant or mothers.

In another case, a participant from Maharashtra shared her concerns about getting IVF treatment while living with schizophrenia, a particular mental health condition. This, she shared, has meant a lot of decisions about medications, future plans being decided between doctors (including her psychiatrists) and violating her agency to make an informed decision. She reported that the stigma associated with her particular condition is so high that her competence to be a mother is consistently challenged throughout the process.

- **Certification processes**

Many participants shared the difficulty in accessing certificates when they lived with psychosocial disabilities or other invisible disabilities that were hard to measure. One participant said there is a need to “prove our disability” for the certificate and then we need to “prove our competence” in other areas once we have the certification.

Many reported that health care staff did not refer to the guidelines. Many of them still do not issue proper certification and are very arbitrary with regards to the percentage provided. This results in alienating many people with invisible disabilities and even people with multiple disabilities like deaf blindness. In other scenarios in Maharashtra and Gujarat, the centres for the certification are few and sometimes in very far locations. The travel is sometimes not possible and rural families are unwilling to pay the amount needed to reach the testing centre or hospital.

Activists who worked with de-institutionalized women, during corona times reported barriers to certification.

“It was a nightmare to establish their citizenship status: Aadhar card, PAN card, address proof. No access at all to disability cards. We need to upgrade to something more appropriate paperwork and execution in both visible and invisible disability.”

- Participant from Maharashtra

“In Goa the mental health authority board has not been set up, so currently, there is no review body for certification, which has resulted in the loss of employment and other scheme opportunities for many people. The Institute of Psychiatry & Human Behaviour in Goa has been avoiding issuing certificates citing this.”

- A participant from Goa

- **Communication and helplines**

Participants from Maharashtra, Goa and Gujarat stated that helplines remain inaccessible to the deaf community. There are a few accessible chat options but none were reported to provide support in sign language.

Many people with disabilities reported an increase in emotional distress due to increased violence or job loss during the pandemic but were not able to access support with helplines.

Telemedicine was provided across many cities. But there was mostly no video or chat facility and even if it were there, there was no sign language interpreter. Additionally, women with disabilities from rural locations reported it was very hard to access telemedicine because of the poor internet connections and lack of privacy in their homes to discuss with doctors. Blind participants were not particularly sure of the digital accessibility of all telemedicine apps and portals.

Blind participants and those which had motor skills issues reported that home testing antigen kits were not accessible for them.

Recommendations:

- Persons with disabilities should be able to access, without discrimination, the same level of healthcare as persons without disabilities are able to access.
- Persons with disabilities should be able to access emergency healthcare services not related to COVID-19 and access to healthcare should not be hampered by the lack of availability of public transport services.
- Medical and para medical staff, particularly those frontlines, must receive basic training and guidelines to work with and support persons with disabilities
- Ensure everyone has access to regular healthcare and rehabilitation services such as physiotherapy, pain therapy, blood transfusion, chemotherapy, dialysis, occupational therapy, blood test, and access to gynaecologists, ophthalmologists, audiologists etc. Telemedicine services should enable users, including persons

with disabilities, to communicate with the health professionals with utmost concern for their privacy.

- Ensure all healthcare staff responsible for issuing disability certificates should be sensitised and trained regarding various disabilities including invisible disabilities. They should also be trained to assess disabilities as per the guidelines under the RPWD Act, so that there are no lapses in their application and further help in data collection. The number of visits should be minimum and travel and distance issues need to be considered and worked upon to find practical solutions.
- There is a need to sensitise doctors and allied health professionals regarding various disabilities. Disability studies should be integrated into various medical degrees to ensure that doctors are able to tweak the regular procedures to fit the needs of patients with disabilities. The sensitization and training should be intersectional and emphasis should be laid on the issues of women with disabilities, persons with mental health illnesses and persons with invisible disabilities.
- All hospitals should be made accessible on a priority basis. The entrances, ramps, toilets, and health services should be made accessible for the persons with disabilities. Further, hospital staff should be sensitised and trained so that they are able to support the persons with disabilities in terms of mobility inside of the hospital, testing, treatment, availing medicines and accessing other medical procedures.
- Prioritising persons with disabilities in providing vaccinations and booster shots needs to be accounted for. In addition, doorstep vaccination efforts for persons with disabilities particularly in rural areas should be the norm.
- Devising accessible home testing kits of COVID 19

Education

Education is one of the fundamental and important phases that build the foundation for development of human potential. India is one of the few countries where the right to education is a fundamental right. To this end, the Indian parliament passed the Right of Children to Free and Compulsory Education Act, 2009. This Act specifically includes children with disabilities in “weaker sections and disadvantaged groups.” These children are also entitled to admission in private schools to the extent of 25% of the strength of a given school.¹⁵ Simultaneously we saw that the right to education for children with disabilities was a crucial part of the commitment in the Right of Persons with Disabilities Act 2016, which provides students with benchmark disabilities the right to free education till 18 years of age either in a neighbourhood school or a special school.¹⁶ Globally another significant event was the passage of Sustainable Development Goals (SDG’s) which were adopted by more than 190 countries through a resolution of the UN General

¹⁵ RTE Act Sec 12(1)(C) <https://indiankanoon.org/doc/101312166/>

¹⁶ RPD Act (2016) Section 31

Assembly in 2015 where goal 4 speaks to inclusive, equitable and quality education for all.¹⁷ However as seen in the UNESCO state of the education report there are huge barriers in children with disabilities accessing education and the path at the moment is riddled with high dropout numbers.¹⁸

Through research priorly conducted¹⁹ during the pandemic, we know that children and families across India are struggling with remote education because of barriers related to access to devices, information on operating the devices and stable internet connection. Through this consultation we see the persistence and further exacerbation of inaccess resulting in severe impacts on continuity of learning.

Findings

- **Challenges in remote or online education for children with disabilities**

Many of the participants, especially those from blind, deaf and deaf blind groups spoke about how accessibility in schools is still only understood as infrastructural access. Communicational access and access of resources or study materials are still not catered to in many inclusive schools - thus limiting the access of disabled children from the classroom itself.

The pandemic and the sudden lockdown made this worse. Children with disabilities, who were in residential schools in cities belonging to rural areas, went home as soon as the lockdown was announced. Many were unable to continue their education from their homes as the environment at home was not conducive to online, remote learning. Children with disabilities also faced issues because of limited access to phones or devices and poor internet connectivity in many parts for online learning. Many of them were forced to drop out, said disability rights activists from Gujarat and Rajasthan. The situation gets more complicated when the family only has one device - the non disabled male child then is provided the device for his education. Activists working in Gujarat, Rajasthan, Madhya Pradesh and Maharashtra also drew our attention to the lack of technical knowledge in operating devices within families to ensure children with disabilities from rural locations did not lose access to education in the pandemic. They also shared how children with intellectual disabilities found online learning particularly difficult.

One blind participant from Maharashtra shared that a blind residential school has been empty for the past two years. Another participant from Maharashtra shared that they had received information of ongoing emotional distress among girls with disabilities who were unable to attend online education because of limited resources at home and the patriarchal environment which de-prioritised their education. In one case, a girl even

¹⁷ SDG Goal 4: Quality education: <https://en.unesco.org/themes/education2030-sdg4>

¹⁸ UN (2019) N for Nose: State of the Education Report for India 2019: Children with Disabilities.

Retrieved from: https://unesdoc.unesco.org/in/documentViewer.xhtml?v=2.1.196&id=p::usmarcdef_0000368780&file=/in/rest/annotationSVC/DownloadWatermarkedAttachment/attach_import_7f18081f-fd62-4e19-946f-8a838af0f2da%3F_%3D368780eng.pdf&locale=en&multi=true&ark=/ark:/48223/pf0000368780/PDF/368780eng.pdf#%5B%7B%22num%22%3A76%2C%22gen%22%3A0%7D%2C%7B%22name%22%3A%22XYZ%22%7D%2C34%2C794%2C0%5D

¹⁹ Neglected and Forgotten. (2020, July 14). Rising Flame and Sightsavers. Retrieved February 17, 2022, from https://risingflame.org/wp-content/uploads/2020/07/NeglectedAndForgotten_RFandSS.pdf

attempted suicide. This also pointed to an often neglected area of the impacts on mental health of children with disabilities experiencing exclusion in education.

Activists from Maharashtra and Gujarat also reported that many special schools do not/did not have the infrastructure to conduct online education due to which there will be huge impacts on education of children with disabilities.

- **Impacts of remote education on some disabilities**

There were also other disability specific experiences of isolation and reduced socialisation as reported by participants. For instance, many deaf children who went to deaf schools who weren't in contact with their peers reportedly couldn't remember their sign names. Autistic children who benefit from in-person interactions and connections found themselves struggling in school for the past two years.

- **Challenges for teachers with disabilities**

A professor from Maharashtra mentioned that teachers and professors with disabilities were not trained to operate the online platforms. Nor were the platforms tested for accessibility with screen readers. Many faced difficulties in engaging with students as their technical skills were not strengthened before the shift was made.

“A visually impaired teacher faced sexual harassment in a school. The complaint was given to the Principal and Education Secretary of the school. Simultaneously an application was filed regarding the lack of accessible toilets in the school. The department asked them to file just one application for constructing a public toilet. The sexual harassment complaint was ignored.”

- An activist from Gujarat shared

- **Challenges faced in higher education institutions**

Disabled people in higher education from Maharashtra and Madhya Pradesh shared the lack of accessible information in reading materials and curriculum. In many cases the teaching material in the classroom was also not adjusted to include people with disabilities. There was also online fatigue reported by those from the blind and deaf community.

Participants from Maharashtra and Gujarat reported that the reservations for people with disabilities within local institutions and universities mandated under the RPD act were in many cases not filled. There was a lack of initiative on behalf of these institutions to actively fill these posts. This was not the case in universities of national stature.

In other situations, participants from Maharashtra spoke about the arbitrariness of reasonable accommodations provided such as an additional hour of time for examinations for 90% disability and in other cases 30 minutes of additional time for a different percentage of disability. There was no standard measure used in these accommodations and thus affected the students in the universities.

An activist from Maharashtra also reported that at the time of admission sometimes people with disabilities are rejected because of their disability - stating an example of a blind girl who was forbidden from pursuing a course in psychology.

- **Enabling environment**

It was reported that the lack of training of teaching and non-teaching staff while working with disabled students results in discriminatory and exclusionary behaviours in the class as well as in interpersonal relationships. Another participant reported about the discrimination that autistic children in particular face in mainstream schools because of the existing stereotypes about the disability - further alienating the student from accessing education. Both of these point to the lack of training among teachers to interact and integrate disabled students into the classroom.

Recommendations:

- Ensure equal access to quality education while providing support through devices (tablets, laptops, mobiles at subsidised rates or free) as well as sufficient and thorough training to effectively use the devices to enhance remote learning
- Ensure access to counselling or emotional well-being support to children with disabilities to deal with the isolation resulting from the ongoing pandemic
- All e-learning platforms must comply with the Web Accessibility Guidelines from the perspectives of both learner and instructor. Teaching staff with disabilities should have access to accessible training materials or personal assistance where requested to organise and deliver their teaching.
- All online books, reference journals and any other reading-teaching material provided must be made available in multiple accessible formats
- Concentrated efforts to identify and support drop outs or students who are out of school with emphasis on vulnerable groups like migrant labourers children, marginalised genders, minority religions
- Improve the allowance provided to support low income, migrant families with children with disabilities struggling to access online or remote learning
- Ensure a proper system for redressal of grievances by teachers and children of disability in case of harassment at home or at school.
- Ensure accessibility in educational institutions across levels in terms of design and infrastructure for people with disabilities to access.
- Disability-specific curriculum should be prepared, adapted, and circulated amongst integrated and special educational institutions. Educators should be trained to impart the curriculum and should also be sensitised so that they are able to deliver the curriculum in an inclusive manner.
- Ensure systematic data collection at district and state levels, of drop out and admission rate for children with disabilities.
- Organising public information campaigns and awareness campaigns on the importance of education for students with disabilities and highlighting their potential.

Gender equality

Globally 1 in 5 women live with a disability.²⁰ Higher numbers of them are reported to live in developing countries. In India too, we see many connections between disability and poverty - thus putting women with disabilities at higher risk of facing exclusion. Even pre-pandemic, women with disabilities in India faced barriers in access to health, education, employment, social protection, and safety.²¹ They are routinely seen as a burden, not considered “woman enough” and stripped of agency and decision making powers.²²

In the COVID-19 research, Neglected and Forgotten conducted by Sightsavers and Rising Flame, we found that women with disabilities are at significantly higher risks of losing their jobs, of being denied devices for online education to exacerbated experiences of discrimination and violence because of prolonged and consistent need to stay indoors with their family members. Through this consultation we are able to see experiences of discrimination, violence and exclusion through denial of their rights both within the home and by other members of society.

Findings

- **Experiences of violence**

Participants from Maharashtra, Gujarat and Madhya Pradesh reported a lack of awareness among women with disabilities in particular when acts of violence are perpetrated because of the prolonged exposure to discrimination that they experience on a daily basis. It was also reported that there is stigma prevalent in reporting acts of violence among women with disabilities to the police and hence many women with disabilities simply avoid doing so.

- **Stigma with regards to specific disabilities**

A participant shared that for deafblind women there is a concern of safely communicating about the violence or discrimination being faced at home. Using phones to report or even share their experiences of violence is not always an option because of fear that other family members will be able to read their messages and endanger them further. Thus accessibility with safety is important to factor in.

²⁰ Women Enabled International (2020) Statement on Rights at the Intersection of Gender and Disability during COVID-19

²¹ Bhandare N (2020 May 1) The lockdown is hard for women with disability. Hindustan times. Retrieved from <https://www.hindustantimes.com/columns/the-lockdown-is-hard-for-women-with-disability/story-4uOVBLxLOoukdlcqWvP1vJ.html>

²² CREA. (2011). Count me in! Retrieved from <http://www.creaworld.org/sites/default/files/The%20Count%20Me%20In%21%20Research%20Report.pdf>

In another case reported by a participant from Gujarat there is often reluctance in believing women with intellectual disabilities when they share experiences of violence.

“There was a woman with intellectual disability whose father-in-law was sexually abusing her. The police did not register her case stating that her intellectual disability made her unreliable. Because of pressure from activists an FIR was finally lodged.”

- A participant from Gujarat

Others also reported that women with mental health conditions are also routinely disbelieved and thus they hesitate or avoid discussing the violence they experience in natal or even marital homes.

- **COVID-19 exacerbated violence experience of women with disabilities**

An activist from Gujarat reported that during the pandemic lockdown, with no public transport available, women with disabilities were unable to go to the bank. In such cases, family members withdrew money - pensions or even their earnings - on their behalf but wouldn't give it to them.

Participants from Gujarat and Madhya Pradesh reported that the ration kits provided to women with disabilities during the pandemic by non-governmental organisations were often used by other members of the household stating that she didn't need it. In some cases, the women with disabilities were insulted when they went to the ration shop because they needed support in carrying the ration home. These instances made it hard for women with disabilities to receive the nutrition they needed. This was also observed in women with disabilities who lived away from home before the pandemic as reported by a participant from Gujarat. This draws our attention to the ways in which poverty and social security benefits are closely tied to gender and the discrimination that unfolds from it.

Many of the women had to return home as institutes they were working at were closed abruptly and their earnings stopped. This meant that women with disabilities who were previously independent were forced to be completely dependent on their family for long periods of time. Since their earning had stopped, they were treated badly at home, not provided food and called a burden. Others also reported feeling increased emotional distress because they were not able to contribute to the household income.

It was also reported from Maharashtra and Madhya Pradesh that many women with disabilities were denied access to vaccines stating that she doesn't leave home anyway and won't need the vaccine to protect her.

- **Access to justice for disabled women**

One of the concerns raised by many participants was that there was limited knowledge about access to justice among women with disabilities. They were also not aware of their options with regards to the domestic violence legislation. Others shared that even when

women with disabilities are aware, there are many barriers in accessing justice such as difficulty in reaching the police station or a safe place to complain when the complaint is against a family member. There are severe infrastructural problems in rural India where police stations don't have ramps or even sign language interpreters. Sometimes, participants reported that police officers registered deaf women as intellectually disabled because they don't speak.

“A girl with a disability returned home because of COVID and there her uncle’s son started harassing her. Since in rural households, women often share toilets which are at a distance, she kept having to go out and the boy continued to abuse her. The harassment continued despite her threatening to go to the police. When she finally went to the police, they said that the boy was merely supporting her and did not file an FIR.”

- A participant from Maharashtra

Another activist mentioned that the police were also unaware of the laws regarding women with disabilities. A participant from Maharashtra shared her experience of reporting violence to the police and subsequently being told to bear the violence as “what will you do alone now?” When she insisted on the case being filed, they handed over her case to a counsellor to support her.

- **Access in shelter homes, rehabilitation centres and institutions**

Participants reported that there was very little data with regards to accessibility of shelter homes in the states. But in anecdotal reports it was found that it was inadequate and many shelter homes remain non-functional especially in times of COVID. In many instances in the State of Goa, old age homes have been designated as halfway homes (though the notice for the same used the term ‘asylums’).

In one case reported by a participant from Goa, a transwoman with disabilities was unable to access long term care facilities under the Mental Health Care Act. It was shared that she was being held in a facility against her consent and threatened with administration of electrotherapy. Another well-known trans activist was able to get her out of the institution after some pressures on the authority. Another participant from Maharashtra also reported that there has been a rise in usage of conversion therapies²³ in institutions especially on women and queer persons with psycho-social and intellectual disabilities.

- **Queer persons with disabilities**

Participants reported that for many trans persons with disabilities there is concern with regards to having their documents (disability related) in their name resulting in not being able to access the social security support they have a right to. In a couple of cases, participants from Madhya Pradesh reported that because of the prevailing stigma attached to trans people and disabled people, trans people with disabilities are treated

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and understood to be burdens. One participant from Maharashtra reported that because both movements exclude trans people with disabilities, safe spaces are very few for them.

Recommendations

- Ensure active participation and inputs from women with disabilities while building awareness and strengthening the systems around domestic violence
- Disseminate accessible information on rights of women with disabilities and provide clear information on the possible routes for accessing justice from local to the national level, particularly during the pandemic.
- Sensitise protection officers, police officers and other respondents to not dismiss women with disabilities and support them throughout the process of complaints and accessing justice
- Build the capacities of the ministries and departments relating to women and children, the national and state's women commissions, the child protection commissions and other relevant authorities on concerns of women and trans persons with disabilities
- Ensure that women with disabilities facing domestic violence have access to safe and accessible shelter particularly during this pandemic to move to
- Disaggregated data should be made available on the violence experienced by women and trans persons with disabilities.

Employment

According to the International Labour Organisation, fewer than 20% of persons with disabilities globally are employed. There are many reasons for these low employment rates which include physical, social and structural barriers in accessing decent work, high levels of discrimination with regards to their ability to work. Persons with disabilities also face huge barriers in accessing quality education which results in lower qualifications. There is also significant impact on their confidence and sense of self because of lack of socialisation and consistent discrimination they face which affects their access to the labour market.²⁴

Article 27 of the CRPD reinforces the right of all persons with disabilities to work, on an equal basis with others. This includes the right to the opportunity to gain a living by work freely chosen or accepted in a labour market and to a work environment that is open, inclusive and accessible to persons with disabilities.²⁵ The RPD Act states that the government should facilitate and support employment of persons with disabilities especially for their vocational training and self-employment.though government data

²⁴ Handicap International (2016 September) Situation of wage employment of people with disabilities: country profiles. Retrieved from

https://d3n8a8pro7vnm.cloudfront.net/handicapinternational/pages/1479/attachments/original/1480713329/EmploymentWhitePaper-WEB_Dec2.pdf?1480713329

²⁵ United Nations Convention on Rights of Persons With Disabilities, 2008

reveals that only 1.4% of persons 127 with disabilities reported receiving formal vocational training and 1.7% had been trained on other than formal vocations”.²⁶

From research emerging from the pandemic, we see that employment and livelihoods among persons with disabilities has taken a huge hit.²⁷ Through this consultation we get a better understanding on the shifts we are seeing as the COVID-19 restrictions are slowly lifted.

Findings

- **Challenges and benefits of remote working**

Participants from across the states reported that workplace inaccessibility was a huge concern for many people with disabilities. In many cases the challenges of working remotely resonated with the challenges faced by students in remote education regarding the accessibility of the platforms being used. One participant from Madhya Pradesh shared that offices had moved to using platforms like Teams or Webex which are not accessible to screen reader users. This problem was not fixed and led to losing out on information as well as office chit-chat with colleagues leading to further isolation at the workplace.

In another scenario a participant from Maharashtra said that she was less worried about contracting the virus due to remote working and this improved her mental health. But the reopening of offices has been stressful. Many of the participants from Rajasthan and Maharashtra shared that the shift to work from home was also a relief because of the inaccessibility of public transport and the mental and physical exhaustion that came with it. This had shifted again now that many offices were requesting employees to return to work. A participant from Rajasthan with locomotor disability shared that working remotely has meant a lot of gap in the understanding between people because of reduced interpersonal reactions or moving to the online mode. This has resulted in more loneliness and depression.

Some women with disabilities from Rajasthan reported that there was reduced time for themselves as work and personal lives overlapped a lot. One of them reported having difficulty in concentrating because of the constant presence of her family members during her work hours too. One participant from Maharashtra shared that the workload for women with disabilities increased because of having to do all the household work and the office work too. Contrary to this, a participant from Madhya Pradesh reported that since women with disabilities’ mobility is heavily restricted by families, remote working was a huge benefit and provided some with the ability to contribute to their households from their homes itself.

²⁶ NSS Report 583 (July – December 2018) Retrieved from http://www.mospi.gov.in/sites/default/files/pub-lication_reports/Report_583_Final_0.pdf

²⁷ Neglected and Forgotten. (2020, July 14). Rising Flame and Sightsavers. Retrieved February 17, 2022, from https://risingflame.org/wp-content/uploads/2020/07/NeglectedAndForgotten_RFandSS.pdf

- **Returning to in-person offices**

Some of the participants shared that when many offices shifted back to in-person from remote locations, many people with disabilities feared losing their jobs if they didn't comply and go to office. Participants shared that blind and deafblind people in particular were apprehensive about the tactile nature of their commute - which made them more vulnerable. This combined with the existing accessibility barriers in our transportation system made it a stressful time for many. One deafblind person shared that they were told they needed to return to work immediately or they would lose their job.

Participants reported that autistic people experienced sensorial overload because of the prolonged need to wear face masks on returning to offices. The other concern reported by participants from Gujarat was that since people with disabilities have not had easy access to vaccines, not being vaccinated can also lead to loss of jobs.

- **Challenges in Public Sector**

Participants from Rajasthan and Maharashtra reported that the reasonable accommodation needs of people with invisible disabilities was especially not understood within government offices - because disability is still largely understood as someone on wheelchairs or using a cane. There is also a lack of skill development and employment focus for those with Multiple Sclerosis, Haemophilia, Thalassemia or Sickle cell disease. According to an RTI filed by a participant the numbers are:

Type_of_Disability	Trained / Oriented	Certified	Reported Placed	Self Employed	Wage Employed	Apprenticeship
Haemophilia	7	5	2	0	1	1
Multiple Sclerosis	22	15	9	3	6	0
Sickle Cell Disease	2	1	0	0	0	0
Thalassemia	2	0	0	0	0	0

Another participant from Maharashtra mentioned that despite directions from the supreme court that people with disabilities can hold a post of a judge there has been an instance of discrimination in Maharashtra. In this case, a government pleader and notary was barred from applying for the position of a judge

- **Enabling environment**

Many participants shared that the stigma around disabilities and the lack of awareness or sensitisation about people with disabilities prevents employers from hiring disabled people. Even if disabled people acquire jobs, the lack of provision of reasonable accommodation within the office can result in bad performance or being fired. This situation is harder for people with psychosocial disabilities, multiple sclerosis and autism because of the invisible nature of these disabilities.

Some participants reported that in some jobs where disabled people are hired at hotels or petrol pumps, they are paid limited money but are made to work for long hours.

- **On pensions, schemes and training support**

Participants reported that the pension access is not consistent for many locations and the amount vastly varies across the country. A participant from Madhya Pradesh reported that accessing jobs under MNREGA has been hard because of lack of awareness around disabled people being provided jobs under it. Another participant from Rajasthan shared that the implementation of MNREGA has been poor in Rajasthan and though 100 days of employment and Rs 222 is provided under the act, this is not what is implemented as workers get only Rs 190. Along with this, disabled labourers are not provided with reasonable accommodation support forcing them to leave the jobs. Another participant from Maharashtra reported that one of the concerns remains in the upskilling of people with disabilities. We still see that they are only trained in basic jobs and not provided skills that will support them in accessing better paid jobs. Like blind people are often trained in stitching or tailoring but not in other skills. A participant from Gujarat shared that this was especially true for deafblind people as they were not provided any vocational training and therefore found employment very hard.

Recommendations

- Persons with disabilities must not be discriminated against at the workplace, particularly in the evolving scenario in the pandemic. This includes persons everyone who is and might be employed by the Government, private sector or in not for profit organisations.
- Ensure framing of additional guidelines under the RPD Act to ensure protection of people with disabilities from being discriminated against at workplaces or denied jobs because of their disability and direct organisations to implement equal opportunity policies as mandated under the Act.
- Ensure reasonable accommodations for persons with disabilities and persons with compromised immunity to continue to work from home
- As remote working continues in some organisations, apps, software and other tools must comply with all requirements on web accessibility, whether it is for remote working, file sharing or conferencing.
- Skill development programmes run by the public and private sector which have moved online must comply with accessibility requirements and also be designed

to address barriers faced by women with disabilities in accessing training. The courses must also adapt to training participants including persons with disabilities in remote working and provide opportunities for specific job profiles that can be performed from home e.g. remote event management and virtual personal assistance which can create great opportunities for women with disabilities. Specific outreach through DPOs should be made to encourage the training of women with disabilities.

- Ensure that private companies have incentives to retain persons with disabilities staff who are in the company, especially if the organisations are downsizing because of the pandemic
- Ensuring the disability pension and ex gratia payments under the Pradhan Mantri Garib Kalyan Yojana Scheme are responsive to the added costs incurred by persons with disabilities in overcoming barriers to participation during the pandemic. It should be uniform across States and linked to consumer price index and rate of inflation.

Conclusion

It is hoped that stakeholders heed this call made by and for persons with disabilities to not leave us behind in the fight to achieve the Sustainable Development Goals, in the efforts to build back a better and more resilient future, in the efforts to respond effectively and inclusively to the COVID-19 pandemic. This virus has demonstrated the deep inequalities in our societies. We have an opportunity to ensure that the most marginalised in our societies, many of whom are persons with disabilities, can come back stronger and better supported in law, policy and practice.

10 point advocacy charter

- Ensure all healthcare staff responsible for issuing disability certificates should be sensitised and trained regarding various disabilities including invisible disabilities. They should also be trained to assess disabilities as per the guidelines under the RPWD Act, so that there are no lapses in their application and further help in data collection. The number of visits should be minimum and travel and distance issues need to be considered and worked upon to find practical solutions.
- All hospitals should be made accessible on a priority basis. The entrances, ramps, toilets, and health services should be made accessible for the persons with disabilities. Further, hospital staff should be sensitised and trained so that they are able to support the persons with disabilities in terms of mobility inside of the hospital, testing, treatment, availing medicines and accessing other medical procedures.
- Disability-specific curriculum should be prepared, adapted, and circulated amongst integrated and special educational institutions. Educators should be trained to impart the curriculum and should also be sensitised so that they are able to deliver the curriculum in an inclusive manner.
- Concentrated efforts to identify and support drop outs or students with disabilities who are out of school with emphasis on vulnerable groups like migrant labourers children, marginalised genders, minority religions. Ensure their equal access to quality education while providing support through devices (tablets, laptops, mobiles at subsidised rates or free) as well as sufficient and thorough training to effectively use the devices to enhance remote learning
- Ensuring the disability pension and ex gratia payments under the Pradhan Mantri Garib Kalyan Yojana Scheme are responsive to the added costs incurred by persons with disabilities in overcoming barriers to participation during the pandemic. It should be uniform across States and linked to consumer price index and rate of inflation.
- Skill development programmes run by the public and private sector which have moved online must comply with accessibility requirements and also be designed

to address barriers faced by women with disabilities in accessing training. The courses must also adapt to training participants including persons with disabilities in remote working and provide opportunities for specific job profiles that can be performed from home e.g. remote event management and virtual personal assistance which can create great opportunities for women with disabilities. Specific outreach through DPOs should be made to encourage the training of women with disabilities.

- Ensure framing of additional guidelines under the RPD Act to ensure protection of people with disabilities from being discriminated against at workplaces or denied jobs because of their disability and direct organisations to implement equal opportunity policies as mandated under the Act.
- Build the capacities of the ministries and departments relating to women and children, the national and state's women commissions, the child protection commissions, the protection officers, police officers and other relevant authorities and responses on the concerns of women and trans persons with disabilities enabling easier access to justice mechanisms
- Disaggregated data should be made available on the violence experienced by women and trans persons with disabilities to enabled building better response mechanisms and prevention measures to reduce and eradicate the violence experienced by them
- Prioritising persons with disabilities in providing vaccinations and booster shots needs to be accounted for. In addition, doorstep vaccination efforts for persons with disabilities particularly in rural areas should be the norm.
- Involving organisations of persons with disabilities in the development of training of members of disaster management task force on issues related to the inclusion of persons with disabilities and their requirements including the requirements of women with disabilities. The understanding of disability should be beyond the list of disabilities under the RPD Act and should adopt an approach in line with the wider understanding of persons with disabilities under the CRPD to prevent discrimination.