



STUDY ON THE IMPACT OF

COVID 19

ON PERSONS WITH DISABILITIES
IN INDIA

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LIST OF ACRONYMS

AD	Assistive Device	NSAP	National Social Assistance Program
ASD	Autism Spectrum Disorder	NSIC	National Small Industries Corporation
AT	Assistive Technology	NSSO	National Sample Survey Office
ATM	Automated Teller Machine	ODA	Official Development Assistance
BPL	Below Poverty Line	OTC	Over the counter
CP	Cerebral Palsy	PCVC	Crime Prevention and Victim Care
CwD	Children with disability	PD	Parkinson's Disease
DC	Disability Certificate	PDS	Public Distribution System
DNI	Diversity and Inclusion	PHC	Primary Healthcare Center
FFA	Forum for Autism	PPE	Personal Protective Equipment
FGD	Focus Group Discussions	PSU	Public Sector Undertaking
Govt	Government	PwD	Person with disability
HI	Hearing Impairment	RPwD	Rights of Persons with Disability
ID	Intellectual Disability	SCI	Spinal Cord Injury
IEM	Inborn Error of Metabolism	SPASTN	Spastics Society of Tamil Nadu
IT	Information Technology	TN	Tamil Nadu
LD	Learning Disability	UP	Uttar Pradesh
LV	Low Vision	VI	Vision Impairment
MDA	Maharashtra Dyslexic Association	WC	Wheelchair
MS	Multiple Sclerosis	WHO	World Health Organization
NGO	Non-Government Organization	YwD	Youth with disability

AYJ	Ali Yavar Jung Institute for the Hearing Impaired
JICA	Japan International Co-operation Agency
MNREGS	Mahatma Gandhi National Rural Employment Guarantee Act
MSME	Ministry of micro, small and medium enterprises
NABARD	National Bank for Agriculture and Rural Development
PDMD	Parkinson's Disease and Movement Disorder
SARS-CoV-2	Severe Acute Respiratory Syndrome, Coronavirus 2
SEDB	Society for Empowerment of Deaf-Blind
SIDBI	Small Industries Development Bank of India
UDID	Unique Disability Identification Card for PwD

BACKGROUND TO THE STUDY

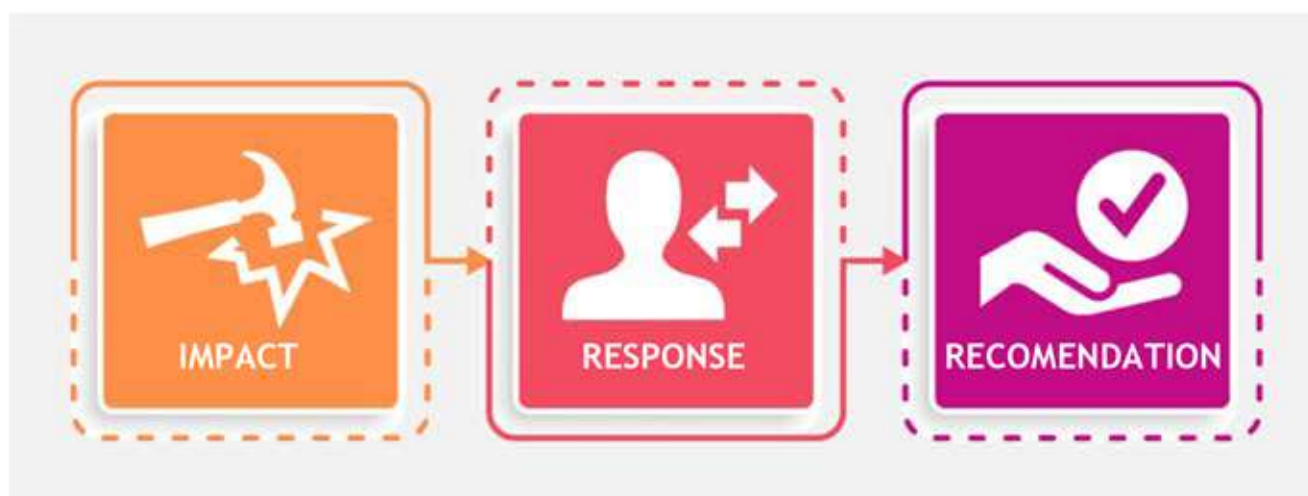
Japan International Cooperation Agency (JICA) has been partnering with Government of India and various state governments for poverty alleviation, investment promotion as well as for infrastructure development for the last 60 years.

The COVID-19 pandemic, also known as coronavirus pandemic, is an ongoing pandemic of coronavirus disease 2019 (COVID-19), caused by severe acute respiratory syndrome coronavirus 2 (SARS-CoV-2). The World Health Organization (WHO) declared the outbreak a Public Health Emergency of International Concern on January 30, 2020 and a pandemic on March 11, 2020. Adverse impact of this pandemic has been experienced globally in different areas such as loss of jobs, difficulty in access to everyday requirements, lack of access to good/ essential medical facilities and global decline in economic growth. India with its large population of 1.32 billion has experienced challenges like all other countries. India's Government (Central and State Governments) have made considerable efforts to meet challenges caused by the pandemic but there is urgent need for work to strengthen health and medical systems while supporting revival of MSME sector and extending social protection. In response to this difficult situation, JICA has started to implement assistance schemes such as ODA loan and technical cooperation. JICA is also striving to enhance collaboration with private sectors and NGOs in diverse fields to deepen the impact of JICA's initiatives in the country.

JICA mandated v-shesh Learning Services Private Limited to undertake a qualitative study to understand the impact of Covid-19 on Persons with Disabilities in India. During the initial three months when the disaster unfolded and the situation exacerbated, people response was based on their ability to comprehend what was happening and attribute meaning to threatened systemic cooperation between authorities, institutions and individuals. This emergency response had short term implications. While the study captures the overall impact, it focuses on the Recovery and Rebuild Phase (R&R phase), which is the unlock phase, which had implication on the medium to long term impact on the lives of people with disabilities. Additionally, this study is intended to identify good practices and achievements of institutions and people who have stepped forward to support Persons with Disabilities during the pandemic. Findings from this study are intended as inputs for JICA in designing suitable development programs as a response to emergency situations like COVID 19 pandemic.



This study focused on the following three points:



1) Impact of COVID 19 pandemic on Persons with Disabilities

- By gathering information to understand the impact of COVID-19 on (a) Persons with Disabilities (b) Care-givers of Persons with Disabilities and (c) Institutions working with Persons with Disabilities such as Disabled Person's Organizations (DPOs), therapy and rehab service centres, Assistive technology / equipment providers, special educators, employers etc to understand availability and adaptation of their services and influence on users

2) Response to the pandemic for Persons with Disabilities by Government (Central and State)

- This study has compiled information about response measures and sought feedback from Persons with Disabilities on their ability to access these entitlements

3) Recommendations for JICA's Covid-19 response support programs specifically targeting Persons with Disabilities

- Based on findings from 1 and 2 above, recommendations for JICA to design support programmes that not just alleviate immediate stress but also lead to improvements over short to mid term

Study team has also identified 3 case studies ; An example of a good practice and a program that may have been another example of a relevant response). These case studies will provide further insight on efficacy, effectiveness, efficiency & sustainability and stand as a good reference in coming up with recommendations regarding design and implementation of possible future support programs.

ABOUT THIS PROJECT

This report is organized along the following sections:

1. Methodology

for collecting qualitative responses (locational and demographic coverage; respondents covered in surveys, focus group discussions and interviews)

2. Observations and Findings of study team's analysis:

2.1. Impact of pandemic on Persons with Disabilities on

2.1.1. Daily living

2.1.2. Education

2.1.3. Health

2.1.4. Livelihood and skills

2.1.5. Impact on individuals living with newly included disabilities and **Rare or lesser known conditions (some of which not presently recognised as disabilities as per the Rights for Persons with Disabilities Act 2016 (RPwD Act 2016))**

3. Response measures by Government and Non-Government Organisations

4. Recommendations for programmes

that JICA can consider in response to this pandemic

5. Detailed survey analysis

5.1.1. Daily living

5.1.2. Education

5.1.3. Health

5.1.4. Livelihood and skills

5.1.5. Impact on individuals living with newly included disabilities and **rare or lesser known conditions (some of which not presently recognised as disabilities)**

6. Annexure:

Details about respondents to surveys, focus group discussions and interviews

METHODOLOGY AND PROFILE OF RESPONDENTS

The study has been conducted with primary and secondary research and cross sectional, mixed methods approaches to enable diversity of responses across disabilities, geographies and socio-economic contexts. The Study team was in itself a picture of diversity both in terms of gender mix and disability types.

1. Desk research involving study of (i) Initiatives/ measures by Central and State Governments and corresponding implementing department/ agencies and (ii) Reports, articles in public domain. *(For details refer to Annexure - Sec - List of documents referenced)*

2. Discussions with institutions and thought leaders representing different domains and disability groups. *(For details refer to Annexure - Sec - Findings from FGD and one on one interviews)*

3. Validation of insights basis desk research and interviews (step 1 and step 2).

4. Development of stratification plan, sample size and identification of partners and respondents for the study. *(For details refer to Annexure -Sec - Sample Stratification)*

5. Design and review of survey questionnaires for (i) Individuals - Persons with Disabilities, Children with Disabilities and Caregivers (ii) Institutions, DPOs, Partners and Service providers and (iii) Central and State Government Department / agencies. *(For details refer to Annexure - Sec - List of Questionnaires)*

6. Preparation for outreach (i) Assessment of accessibility of all tools and (ii) Training of enumerators on study objectives, protocols, methods of recording responses. *(For details refer to Annexure - Sec - Surveyor Guides)*

7. Outreach to respondents using (i) Online survey and assisted telephonic surveys (for majority of respondents) (ii) Focussed group discussions and (iii) In-person interviews with people with limited access to telephone and internet connectivity.

8. Analysis of data to generate insights for report.

PROFILE OF RESPONDENTS

Focus of all elements of the study was to ensure that all diverse groups are represented, and their voices/ insights are captured, especially those who have been recently recognized under the new RPwD Act 2016 whilst ensuring a good mix of age-groups and regions.

#	INTERACTIONS	RESPONDENTS
1	Survey - Persons with Disabilities (2 age groups 18-40 years and > 40 years)	440
2	Survey - Children with Disabilities	96
3	Focus group discussions (5 FGDs across identified elements in study)	30
4	Interviews - Caregivers, Parent Support Group, Special Educators	25
5	Institutions associated with Persons with Disabilities - DPOs, Employers and Training organisations	50
6	Service providers - Vendors of assistive device, Therapy and rehabilitation Centres, Counselling Units	10
7	Thought Leaders	16
8	Interviews - Government Departments	4

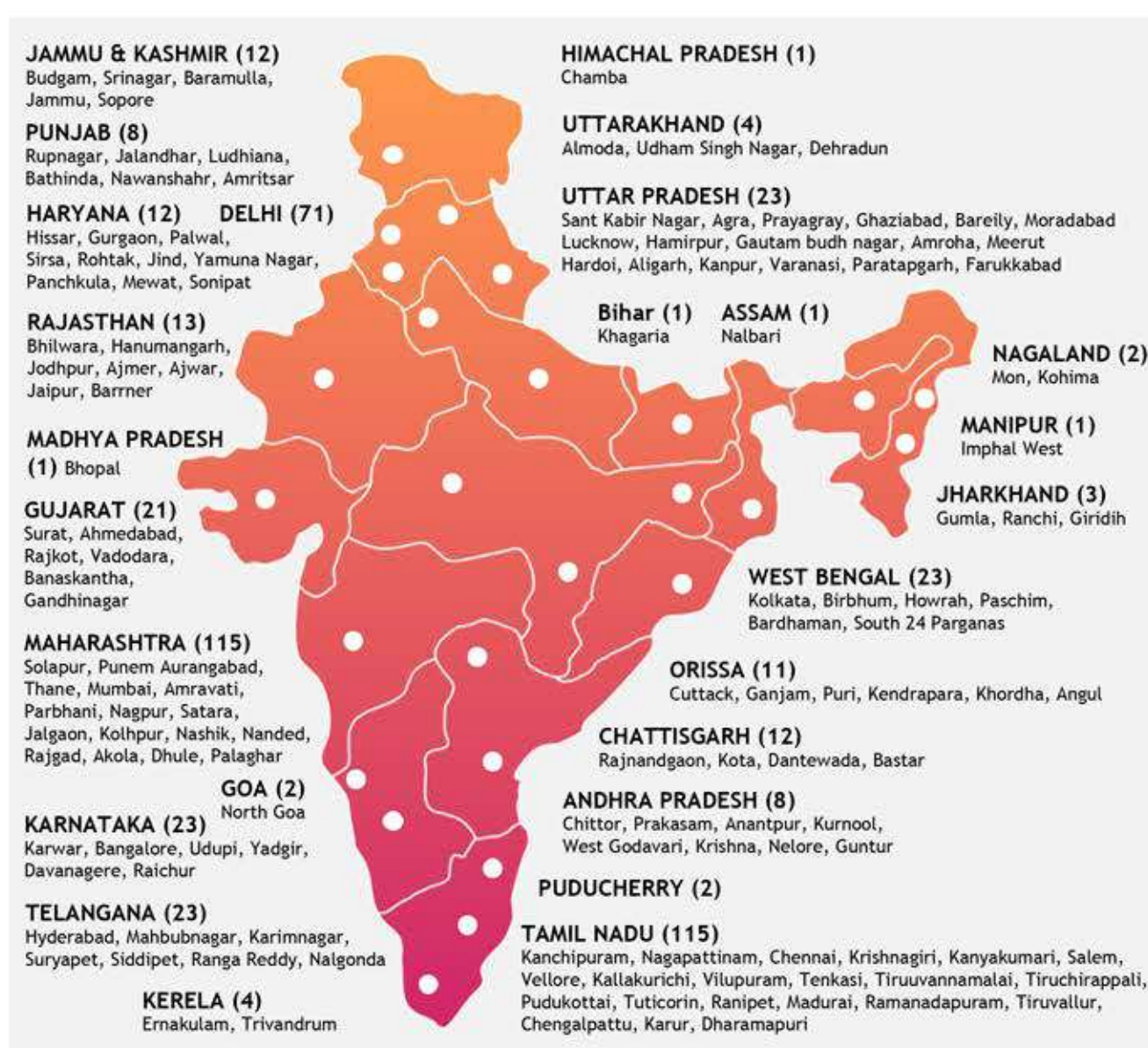


RESPONDENTS - INDIVIDUALS

The study reached out to respondents across 145 districts, of which 65% belonged to urban locations and 35% belonged to non-urban locations.

While choosing locations, care was taken to include regions with a) recorded impact of COVID b) presence of DPOs and other institutions which have assisted in implementation of relief measures c) ease of access and understanding of survey team.

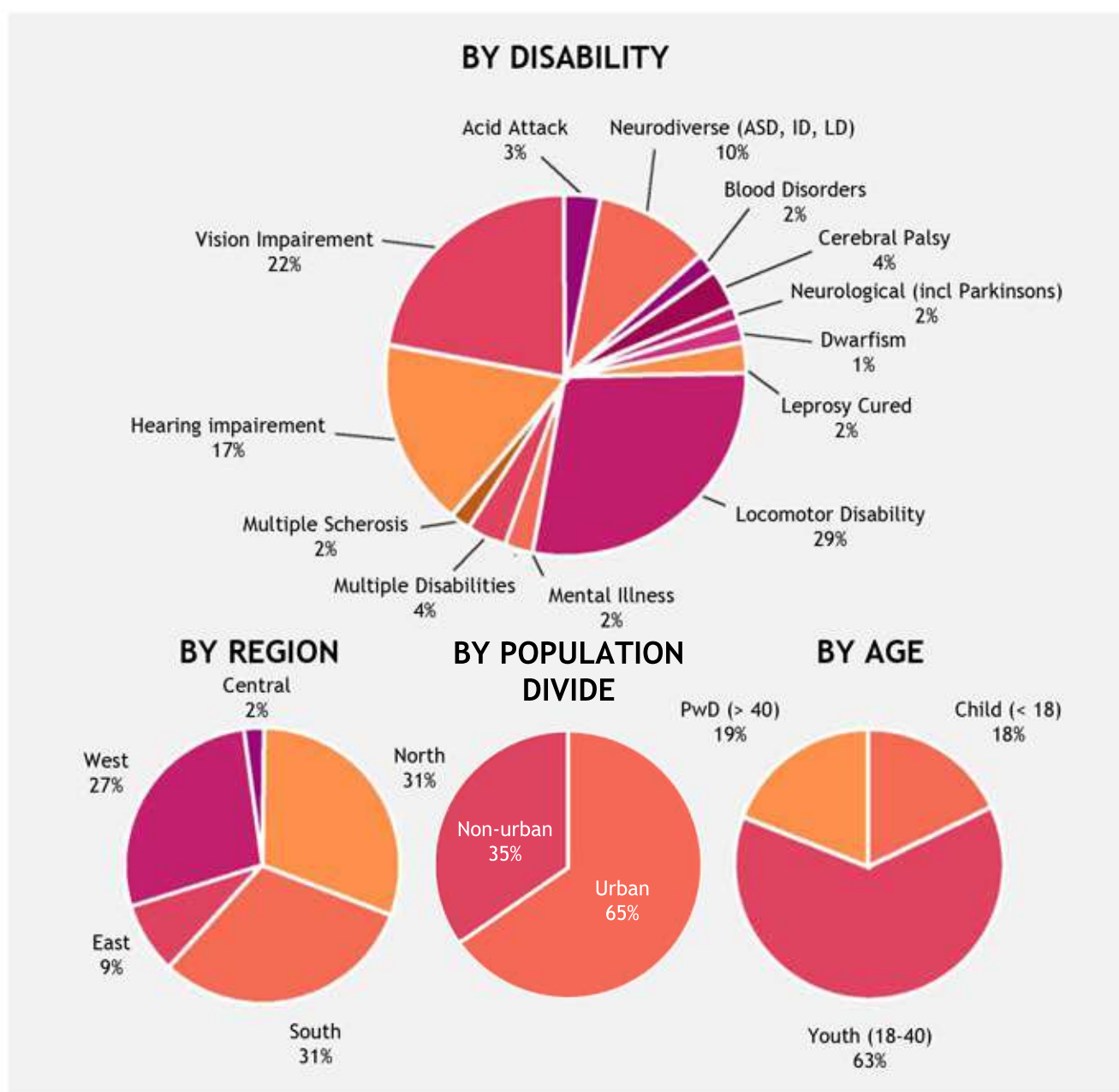
(For details refer to Annexure -Sec - Sample Stratification)



RESPONDENT DIVERSITY

Sample was stratified to cover all 21 disability types (identified by RPwD Act 2016) and other rare disability conditions which are not covered by the act. The sample had a fair representation across gender and age (children, youth and aged), employment status (unemployed, un/organized sector employees, self-employed) and a rural and urban mix.

(For details refer to Annexure - Sec - Sample Stratification)



RESPONDENT DIVERSITY - PARTNERS

50+ Partners for the study were chosen from across India and representing the following groups.

- Caregivers and Parents Support Networks
- Institutions & Special educators
- Service providers - Assistive Technology providers, Training partners, Therapy & Rehabilitation Centres, Vocational Training Centres, Medical and Surgical Equipment vendors, etc

(For details refer to Annexure -Sec - List of Institutions, Service Providers, Thought Leaders)

ORGANIZATIONS WHICH ASSISTED WITH THE STUDY



Organizations whose reports on Covid Impact on Persons with disabilities were referred and relied upon as part of the study

IMPACT OF COVID19 ON PERSONS WITH DISABILITIES - SURVEY FINDINGS

India reported its first case of COVID-19 on January 30, 2020 and cases continued to grow very rapidly. Eventually India reported the highest number of cases in Asia and second highest globally after United States of America. In response to the rapid increase in cases - India's Central Government invoked Epidemic Diseases Act leading to temporary closure of schools, colleges as well as businesses, as well as stopping entry of individuals from other countries. As with other countries, measures to control the pandemic (lockdown and post lockdown measures) came with severe disruption for individuals, society at large and national economy. India's Central and State Governments responded with alacrity in dissemination of information, providing relief (food grains, medicines, masks, LPG cylinders for cooking etc.) as well as financial support. In addition to direct support to individuals, systemic efforts were made to support healthcare system and vulnerable sections of the society by the Government through PM Cares relief fund.

While Governments (Central and various States) moved quickly, the efforts to provide relief were challenged by the sheer scale of India - population of 1.32 billion spread over a landmass of 3.28 million sq km governed as 28 states and 8 Union Territories with a total of 718 districts and 650k+ villages. This was further compounded by economic vulnerability of working class where ~90% workforce is in informal sector (and agriculture being the largest employer) and per capita GDP is just USD 1,876 (INR 138k). This pandemic put intense pressure on Government delivery systems due to the scale of services to be delivered (as all sections of society had to be served) and disruption in access, transportation and supply chain.

India's Central and State Governments run a range of support programs for vulnerable segments amongst its citizens including Persons with Disabilities. These programs operate in the form of direct assistance, partnership between Central and State Governments as well as partnerships with not-for-profit organizations (NPOs) including Disabled People Organizations (DPOs). These programs cover areas such as healthcare, education, assistive devices, rehabilitation services, access to jobs, providing assistive devices et al. While coverage of these programs has been improving, they are yet to deliver to their full potential due to structural issues such as lack of a nationwide list of persons with disabilities as well as variable service delivery bottlenecks arising from inaccessible infrastructure, geographical challenges and/or capacity of implementing partners.

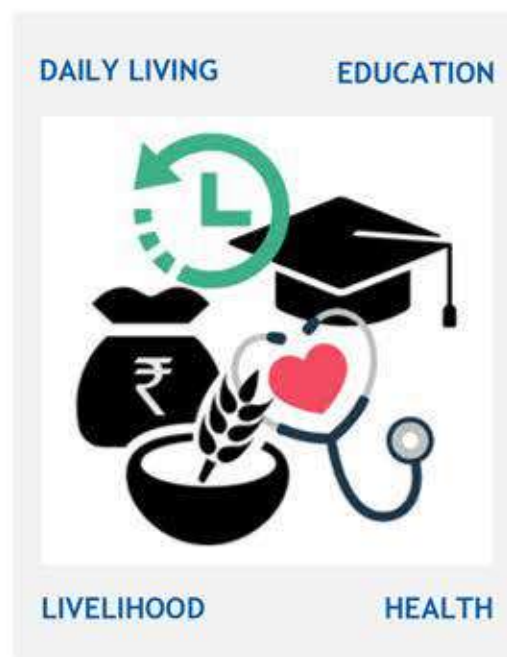
As with services for all its citizens, during this pandemic, Governments, NPOs and DPOs faced severe constraints in reaching to persons with disabilities for providing, entitlement, relief materials and assistance. These barriers ranged right from physical access to access to education, training, jobs

and services for daily living. In economic terms this disability penalty in form of a higher cost of living has been estimated by NSSO to be INR 3,112¹ per person per month for a family in urban India with a single person with disability. Almost all person with disabilities reached through the survey reported that their families have faced / are facing extreme stress in this pandemic. Two important points that emerged during this study are (i) intensity of stress and (ii) mid to long term impact caused due to disruption of services. The intensity of stress and its impact has been far more severe for Persons / Children with disabilities compared to their non-disabled peers. As an example - loss of job is more likely to happen to a disabled individual and such job loss is bound to cause more strain since families with disabled individuals already incur higher expenses (disability penalty) and then persons with disabilities will have to wait longer to get back to workforce and pre-covid income levels. To avoid repetition - these two points are not being mentioned along with each element, but it is important that readers use these as a lens while reading commentary on various aspects below.

UNDERSTANDING IMPACT OF THE PANDEMIC - FOR PERSONS WITH DISABILITIES

Most policy design and implementation initiatives in India are organized sectorally and implemented by different Government Departments. Therefore, to ensure strategic planning and implementation of responses to suggested initiatives and for ease of readability, we have organized our findings as per the following four sectors/ quadrants - daily living, education, health, livelihood and skilling.

A separate section has also been added on lesser-known disabilities, to emphasize the adverse impact faced by persons in this group. They cover some disabilities which have been recently added under The RPwD Act 2016, and some which are still not listed under the Disability Act. The pandemic generated awareness on the critical needs of this group which could not be adequately addressed.



“Lockdown for most people extended for nine months, but for us and for our families, lockdown will continue, until we can be shielded by vaccination”.

- Kirtida Oza, Sjogren’s India

¹ http://mospi.nic.in/sites/default/files/publication_reports/Report_583_Final_0.pdf

IMPACT ON DAILY LIVING

"People on the bus-stop would not tell me the bus numbers correctly as buses had limited capacities. I would stand for hours at the bus-stop waiting for the correct bus".

- Blind person.



*"Dealing with care receivers 24*7, being socially isolated and fear of the Covid pandemic has been very hard for us".*

- Caregiver



1. Covid19 protocols of social distancing and masking created additional barriers for Persons with disability

Even at the best of times, persons with disabilities face a range of barriers in activities relating to daily living, due to inaccessible physical and social environments. To meet these challenges most persons with disabilities and their families develop a range of support systems or social hacks.

Covid-19, resultant lockdown and measures like social distancing not just isolated persons with disabilities but also created a new set of barriers for them. For example, with touch becoming an unsafe action, persons with vision impairment who navigate environments with touch, found themselves losing their independence and were unable to operate independently to even get rations. Stigmas were associated with helping blind people as it was believed that this action of touching to navigate, made them more prone to infections.

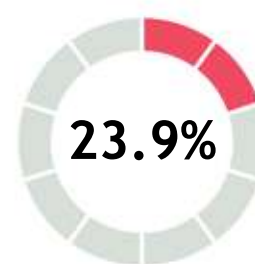
Masks made it difficult for deaf and hard-of-hearing persons to lip read and understand the communication of hearing people at shops, banks, hospitals, pharmacies, etc.

2. Lack of disability disaggregated local data, inaccessibility of critical information and isolation meant severe delays or non-availability in accessing basic relief measures causing severe anxiety and stress

Many respondents mentioned that response measures were disproportionately lower compared to hardships with supplementary support measures by Governments (such as food, pension) ending up being the sole source for food and sustenance. Also limited understanding of disability amongst frontline workers, lack of aggregated disability data and systemic inefficiencies made it challenging for the Government to ensure effective and timely outreach to all. Further limited (if any) information in accessible formats to inaccessible infrastructure, mandatory documentation requirements at distribution centers (Aadhaar card / ration card), limited transport facilities due to stringent physical distancing norms ; all this made it extremely difficult for people with disabilities to perform chores outside their homes (post lockdown) independently. Direct Cash Transfer though the need of the hour, was not as successful as accessing banks and ATM was a challenge for many. All of these translated to not just higher costs but also severe anxiety and mental strain.



12.1% Persons with Disabilities mentioned that information related to covid was not shared or made available to them



23.9% Persons with Disabilities mentioned that the information available was not easy for them to understand

“Even a month into the lockdown, there was no information about when the ration would be distributed. Long queues made the whole ordeal very stressful. Even if we somehow managed to endure it , the quantity received was not sufficient to feed the whole family”

~ Person with locomotor disability

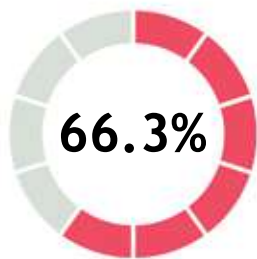
“As a deaf person largely relying on sign language, none of the television broadcast had sign language interpreters so were mostly guessing about what is happening around us, and it took quite a few weeks to get to understand the real situation”

~ Deaf person

3. Inability to purchase, repair and customize assistive devices during the pandemic, resulted in regressed health conditions for many.

Assistive devices and technologies serve as strong enablers to independent living, access to education, livelihood, communication and interaction for many Persons with Disabilities. Respondents

using assistive devices reported difficulty in access to new and repair of old devices . Many respondents mentioned discontinuing use of their assistive devices during the pandemic, which resulted in regressed health conditions. Respondents faced challenges with customizing prosthetics, calipers, replacement of batteries in hearing aids etc.



66.3% of those using assistive devices mentioned challenges with purchase, repair and customization of their devices

“My son outgrew his prosthetics during this time . Since we could not get the assessment done to get the exact size, he remained without it for over 6 months. This impacted his gait and balance. He will need dedicated physiotherapy to bounce back, but unfortunately, we don’t have the means “.

- Father of child with Cerebral Palsy



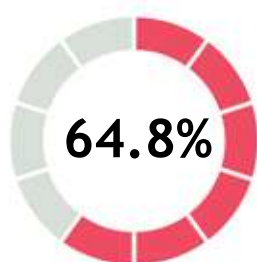
Source: v-shesh report on Assistive Tech, Child with Vision impairment taking notes in Braille using stylus at a special School for blind children in Delhi



Source: WHO report on Assistive devices and technologie

4. Caregivers faced extreme physical and emotional stress mostly falling on women

With social support and care infrastructure being unavailable (in the same form as prior to pandemic) caregivers had to deal with substantially incremental physical effort and mental exhaustion having to provide care without a single day's break. In pre-covid times, many professional caregivers were enrolled with support forums, but the numbers dwindled during covid time. Also lock-down, school closures, and closure of public spaces (like parks) all of this meant additional time-burden for the caregiver - which in most cases was the mother or wife.



64.8% of respondents dependent on professional caregiving support reported serious challenges in accessing services with fear of infection and limited transport being major factors.

"Both me and my husband have developed severe back pain since we need to physically lift our son while assisting him with daily chores. Initially we were hesitant to get a caregiver due to fear of infection, but when we were struggling and decided to seek external caregiver it was very difficult to find, and the ones we found were simply unaffordable".

- Parent of adult with Cerebral Palsy

(Refer Case Study - 4 "C" Model)

5. Social isolation experienced by many disabled people and their families as they were forced to remain isolated from their communities and social support networks.

While globally, people have spoken about how reduced social participation has impacted the mental health of people, in the case of persons with disabilities the impact was very significant. Deaf and deaf-blind people have limited number of family who are sign language users and draw heavily on their deaf friends for social and emotional support. In the absence of personal contact with their friends, they experienced extreme loneliness and confusion.

Families of persons with reduced immunity conditions had to completely alienate themselves socially, in order to keep their care-receivers safe. While data is not available around violence and abuse, there is a distinct impression that persons with disabilities would have faced higher levels of violence and abuse too during the pandemic.

(Refer Case Study - 4 "C" Model)



Covid induced impact.

Challenges for persons with disabilities need to be understood in the intensity of impact and the duration over which these would be experienced. While applying these lenses, it is useful to consider the following aspects

- Access to food and nourishment had high intensity impact implications; of this lack of nutrition will have mid- long-term implications
- Access to assistive devices has had high intensity impact with mid to long term health implication in some instances
- Access to transport and navigation has had a direct financial impact that will take most families some time to make up
- Lack of accessible information led to a high degree of disruption which lasted for a relatively shorter duration for many but the anxiety & stress has triggered adverse mental health conditions for quite a few.
- Stress for caregivers increased substantially and may have long term impact on their overall well-being.



Are challenges more in rural or urban areas?

Difference in experiences in - urban and non-urban areas

- Major difference was in access to assistive devices and aids - while people in urban areas were able to get some support for repair and purchases but people in rural areas face highly restricted access to assistive devices and aids, and continue to do so.

Positive Responses

- There are mentions of effectively implemented responses from State Governments of Delhi (consistent supply of cooked food/ dry rations during the pandemic), Kerala (maintaining a list of persons with disabilities, advance pension payments) and Tamil Nadu (door step delivery of ration and benefits).
- Many respondents spoke about support from community for their diverse needs – Autism, Multiple Sclerosis, Neurological conditions, Multiple disabilities, Blood Disorders, Chronic and Rare conditions.

(For details refer to Annexure –Sec – Detailed Survey Findings – Impact on Daily)



IMPACT ON EDUCATION

“It was challenging for us to make him understand the concept of e-schooling and have him participate in various activities. As he could not manage independently, we had to keep ourselves free too during his schooling hours.”

- Parent Autism



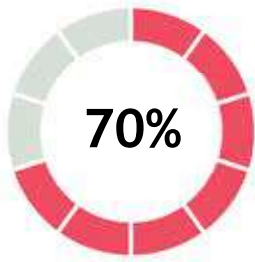
1. Discontinuing physical education has had an adverse impact on all children, but the impact on children with disabilities (CwD) was severe

Countrywide lockdown brought to a halt all the educational activities that were being conducted in physical environments and stopped an estimated 320 million² learners from their daily visits to schools and colleges. At the end of one year, a study³ reports that due to these school closures, 92% students may have lost foundational ability in language and 82% in mathematics.

One of the key findings of this study shows that almost 60% of the children had no access to online learning opportunities. The issue of access was worse for children with disabilities, who are more likely to belong to poorer families with limited means. Almost all parents in JICA survey reported that online access was challenging due to absence of a smartphone or laptop, multiple siblings sharing a smartphone or a device, difficulty in using apps for online learning.

² https://www.researchgate.net/publication/342123463_Impact_of_Pandemic_COVID-19_on_Education_in_India

³ https://azimpremjiuniversity.edu.in/SitePages/pdf/Field_Studies_Loss_of_Learning_during_the_Pandemic.pdf



70% respondents mentioned that the overall learning experience was not effective

“Missed the online classes frequently, as I had to take care of my younger kid and struggled to make adequate time for my child with autism”

- Mother

2.Challenges seen with implementation of online education including lack of know-how to make content and methods accessible for children with varying needs. Digital divide incl. access to and knowledge of technology further accentuated challenge

Educational institutions (with some financial resources) quickly moved to online education - however this move was restricted to replicating the physical environment over an online medium without addressing the core difference which makes online learning fundamentally different from learning in physical environments (facilitating child’s all-round development , and co-curricular learning needs)

The study considered impacts on learning in four academic settings (1) Special School Setting (includes children with neurodiversity, multiple disabilities, cerebral palsy), (2) Deaf School, (3) Blind School, (4) Mainstream and Inclusive Schools

- Little to no accessible content and methodology was available/ provided

“I have no access to Braille books at home, since I had to leave the hostel hurriedly when lockdown was announced. It was difficult for me to carry back all my Braille text books (Braille books are typically voluminous), so I chose to bring back a few only. Now I listen to audio files sent by my school for learning, but I have to wait for it, and also struggle to retrieve when I need it”

- Blind student

- Co-curricular activities which were an integral part of the learning process (pre-covid) could not be replicated during the last one year.
- Online events and activities were organised, but these were not as effective as they would have

been in a physical setting. In special and inclusive school settings the activities were effective when parents got involved with the child to make learning aids and facilitate interactions. But for deaf and blind students, absence of sensory aids and sign language interactions made the activities not so engaging.

- Engagement levels - amongst teachers, students and parents varied in different settings. In special and inclusive schools, deep involvement of the parents resulted in more communication and better understanding amongst the trio. However, for deaf and blind students, lack of parental involvement and difficulties in follow the classes due to use of methods which were not accessible online. resulted in deep angst and frequent meltdowns of the child.

“Teachers speak and use the blackboard for writing concepts in class. They do not simplify the lessons for online learning. Disturbed by lack of understanding and frequent change of routine, my son often gets very angry after class”

- Parent, Deaf Child

- Some respondents talked about how an online teaching in the confines of the safe home environment turned out to be good for children with learning disabilities who were saved from uncomfortable social interaction with their peers. The effect of this was seen in growth in their confidence and levels of participation

3. Parental involvement varied based on the academic settings of their child. Some parents got actively involved in their child’s learning & progress, while many found it difficult to keep their children productively engaged.

Many parents were unable to help their children align technically to the use of gadgets and learning in an online setup. In some instances (special school settings for children with multiple disabilities, neurodiversity, cerebral palsy, etc.) parents emerged as an active part of the learning ecosystem working together, right from logging in to completing work and fun activities and helping with assignments. However, in many cases, especially amongst deaf and blind children, caregivers responded that they faced extreme challenges during the pandemic in engaging children/ students, behavioral issues on account of low engagement through the day, loss of learning and perhaps regression from students’ proficiency levels pre-covid

“Parents are now a part of the classroom... Parents always perceived their child as highly cognitive and would get upset about children not being a part of some sessions. After getting a glimpse of classroom, they are able to understand that their child can perform well in some areas and needs intervention in others”

- Special Educator at an Inclusive School

(Refer Case Study - 4 “C” Model)

4. Students with disabilities in higher education institutions faced incremental challenges due to inability of the teachers to provide an accessible learning environment.

In higher education, materials, methods and online learning environments were sub-par in terms of accessibility significantly affecting the learning experience for Students with disabilities. Also the usual support system in terms of additional faculty time or student volunteers, scribes etc was severely compromised due to Covid protocols. Students at higher levels of education faced challenges starting with inaccessible admission processes to online payment of fee to lack of devices and connectivity (for financial and technical reasons).



Covid induced impact.

In education - the pandemic intensified some challenges and created a few new ones like, and impact was relatively severe for children with disabilities:

- Availability of devices and connectivity led to a new divide and barriers in accessing education. This divide is itself a function of economic status and geographic location (availability of network), thus causing disproportionately adverse impact on children with disabilities. Deaf children who need video interactions for learning were uniquely disadvantaged in online settings.
- Inaccessible learning material and teaching methods further intensified impact for children with disabilities
- Students from primary grade to higher education experienced loss of learning and while it has not been mentioned explicitly some of the

teachers sense regression as well. This is not just a short-term impact as students are being moved to a higher grade which will lead to a cascading effect in coming years



Are challenges more in rural or urban areas?

Difference in experiences in - urban and non-urban areas

- Access to online learning was relatively more restricted for rural areas caused due to a combination of factors like few devices per family, limited facilities for repair during early months, poor connectivity - particularly for videos and inability of parents to provide technical guidance to the younger children for logging in and attending classes
- Limited digital literacy of teachers especially in rural areas impacting their ability to move to online teaching effectively
- Breakdown of transportation and social support also affected students from accessing educational support

Positive Responses



- Many parents (especially parents of children with neurodiversity, cerebral palsy, multiple disabilities) reported that home setting provided students comfort and facilitated bonding between them
- Teachers mentioned that a better understanding of the child's social and economic background helped them in their interactions with the student and their parent
- A few respondents talked about how an online environment turned out to be good for children with learning disabilities who were saved from uncomfortable interaction with their peers, the effect of which was seen in growth in their confidence and levels of participation

“When covid came in we did not know how to take this dynamism home. But what we did realize was that there were a few children who were a part of our classrooms but had specific difficulties. So, we decided to design plans appropriate to the child's interest, cognitive and sensory needs. We involved parents in our classrooms. This made our teaching effective all of which we hope to adopt post-covid too”

- Special Educator, Headstart (Inclusive school in Chennai)

(For details refer to Annexure -Sec - Detailed Survey Findings - Impact on Education)

4 “C” MODEL !!

REDEFINING EDUCATION, THERAPY & SUPPORT SERVICES IN SPECIAL EDUCATION SETTING

A case study on the impactful work done by SPASTN & Vidyasagar, in serving Children with Developmental Disabilities and their parents

The sudden onslaught of the pandemic and announcement of the lockdown made it difficult for people across India to cope. Even though, the Government put into place numerous relief measures, their focus was largely and understandably on pandemic related emergency work. Thus, timely assistance from organizations like SPASTN and Vidyasagar provided much needed relief for many families of children with Developmental disabilities.

1. Remaining Connected -

A core component of the work done by these institutions included establishing regular connects with the families. This enabled them to be regularly apprised of the conditions of the family, how they were coping physically and emotionally and their needs of food, rations, medicines and funds. This was imperative for providing timely assistance to families.



“Many of the parents of our children were street vendors who lost their jobs; many migrated and we lost contact. Our only objective was to stay connected with them” ~ SPASTN

2. Addressing Caregiver Challenges -

Families were not only overcome with the physical challenges of daily living, reduced incomes and caregiving for their disabled family members, they were gripped with fear and anxiety - fear of how to provide for and manage during these difficult times. Pre-covid, children would spend a major part of their day in school, providing caregivers a chance to for some respite but during covid this routine was completely disrupted. Means of external support was limited. This caused significant stress and anxiety for caregivers. Staff members of SPASTN and Vidyasagar filled this void by their-wholehearted commitment of time and patience to listen to the voice of the caregivers (via forums, telecons and surveys); to understand their needs and provide solutions that would be workable for them.

“When children come to school there is a routine, so we looked at how we could bring this support home... we organized fun activities & story telling sessions for children to enable parents to some me time” ~ Vidyasagar

3. Continuing Business as Usual -

In addition to covid related relief work, the institutions stepped in to share information about covid with the children, in easy to understand simple formats. Special educators and physiotherapists stepped out of their comfort zones to devise new solutions. Off the shelf materials were no longer a choice. Many children hailed from low income families with limited access to devices and net connections. In such cases, the organizations used different mechanisms to connect to different members - online, telecons and even arranged data card recharges for a few. Educators and therapists became extended families for the beneficiaries who had little or no access to social networks and connects.

- a. Devising new ways of Learning -** Facilitators focused on experiential learning, rather than academic progress. They focused on improving the skills of independent living, communication and encouraged participation of parents in co-curricular activities such as art, horticulture, drama, cooking, printing etc. Simple numeracy and literary concepts were also reinforced. Many special educators also stretched beyond their regular hours to accommodate students who had no access to phones until their parents returned home from work

A practical, theme-based approach was used for learning. To explain the concept of heat, words related to the topic, charts around color, plants, animals, clothes associated with warm regions and activities of standing in the sun, boiling water etc was used.

~ Vidyasagar

- b. Continuing therapy -** Physiotherapists organized training programs with parents for continuing home therapy. Anatomical dolls were used to demo different positioning techniques and parents were asked to record videos of the child's exercise regimen and send back. Home based materials were adapted for use eg. dupattas (stoles) for stretching exercises and homes were made functional for easy movement. Parents were encouraged to focus on helping the child become independent with daily living activities. Regular telecons were also planned between parents, teachers and therapist for monitoring progress.
- c. Providing access to Assistive Devices -** SPASTN arranged for funds and new devices for children who had outgrown their old ones. Orthotists were appointed to visit homes in PPE suits for assessments and donors identified. Thus children got access to seating chairs and customized orthotics, splints, etc
- d. Counselling support -** A team of psychologists, dieticians and counsellors were appointed to provide regular psychological and social support to students and parents. Helplines were setup for dial in support in case of emergency.

4. Collaborations - This was an important outcome of the pandemic

- a. Collaboration with parents to help the child's overall development -** SPASTN attributes the progress made by the child to multiple factors - time spent with

parents, efforts of the physiotherapists and special educators and comfort of working in a known environment. Parents used innovation in converting home aids to gym equipment. Home videos from the parents also helped SPASTN build a repository of videos to track the child's progress.



Jayashree and Sanam Nair of SPASTN call some children who progressed very well, covid heroes.. “These children made remarkable progress during the pandemic. We believe parents played a critical role in this process. They carried out the instructions in full faith, used innovation to devise exercise equipment and were determined to make it work for their child”

b. Collaboration with Government -

to ensure information about benefits reach the people. Vidyasagar rolled out a small survey to assess the needs of parents, teachers and students. Inputs from this survey were used to document a Standard Operating Procedure (SOP) detailing the best way to engage the caregiver and the child along with guidance for relief work during the pandemic. This SOP became an important guiding document for the Govt and other special schools. Other areas of collaboration between Vidyasagar and the Government included information dissemination to ensure beneficiaries can access all the benefits from the Govt. The initiative culminated in doorstep delivery of essentials and pensions and at home medical checkups for disabled people in Tamil Nadu

Changed Mindsets

While, at the start, it was difficult to envisage a transition to online working, children with severe disabilities, teachers and parents adapted well. The hybrid model of working (online and in-person) showed good interactions between the institutions and the families. Parental involvement played a key role in building awareness amongst parents about their child's conditions, strengths and constraints. Many parents showed deep commitment in being able to help their child make positive progress. So while this co-opted model of working emerged under difficult circumstances, we hope that it's working can be continued in future, to yield maximum benefits for the development of the child and better collaboration between institutions and parents.

IMPACT ON HEALTH

“People with spinal cord injuries faced huge shortage of medical products such as diapers, catheters, urine bags, disposable sheets, prescription medicine etc. These are absolute essentials, and their absence can have severe implications such as bed sores, urinary tract infection, dyslipidemia, pressure ulcers etc.”.

~Person with Spinal Cord Injury

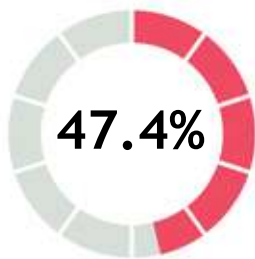


1. Absence of a crisis management policy made it difficult for persons with disabilities (requiring critical, ongoing health care facility) to get treatment during the pandemic.

Several persons with disabilities seek and use healthcare services in ways different from persons without disabilities. In almost all conversations it emerged that those who needed access to services, products, therapy or specialized treatment experienced serious disruption as well as acute strain and stress. Respondents talked about the need for the following and the extreme distress they experienced due to lack of it -

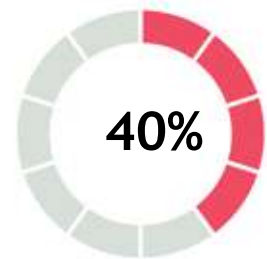
- Design and delivery of crisis management policy with thorough understanding of disability needs
- Contingency plan to ensure continuity for critical treatments
- Design and delivery of health services and information with universal access approach
- Social protection systems with adequate outreach and coverage

After effects of discontinuous healthcare services for persons with disabilities is likely to lead to mid to long term implications both physiologically as well as psychologically



47.4% respondents mentioned that they needed support to health services but were unable to get access

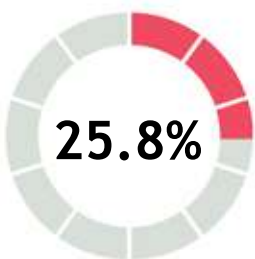
40% spoke about negative medium to severe impact on their health due to reduced medical assistance



(Refer Case Study - SOS!! Access to blood transfusion)

2. Disruption in supply of products made it difficult for many to get access to their regular, vital medicines and medical supplies.

Shortage of medical products (medicines, catheters, diapers, bandages, etc.), problems with supply chains and transportation caused acute distress to persons with specific disabilities. In a few cases medicines were available, but distribution across the counter was restricted on account of no prescriptions, lack of approvals etc. Persons with specific disabilities using iron chelator medicines, epilepsy drugs, hydrochloroquine, nutritional supplements found it difficult to procure these. Persons in remote locations with no access found it especially difficult and support groups in urban locations talked about procuring and couriering medicines to them.



25.85% respondents mentioned that access to prescribed medicines stopped / reduced

3. Concentration of healthcare services towards Covid treatment made access to critical and timely doctor consultations, specialized treatment and therapy a challenge

- Online methods for consultation were of limited use particularly for new conditions or in instances where individuals experienced significant change in conditions. They excluded a large part of the country which is not connected digitally (due to infrastructure and access barriers). Many respondents spoke about the challenges associated with navigating ancillary services such as laboratory testing , diagnostic studies etc with online consultation.
- Distress due to delay in response times was magnified due to the pandemic . Persons with thalassemia spoke about missing their fortnightly blood transfusions due to unavailability of blood units, lack of transport services and high costs of treatment. Reduced frequency of transfusions

can seriously impact the functioning of their vital organs.

“There was a drastic increase in the number of people who got strokes during COVID. Immediate rehabilitation can help the patient regain independence and improve quality of life to a large extent (depending on the extent of damage). Unfortunately, lack of timely intervention will result in permanent disabilities for many”

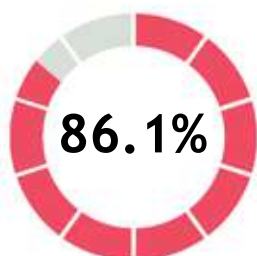
- Heart and Stroke Foundation of India

- Regular therapy support for old/ known cases could be continued online, but consultations for new cases was significantly impacted. Training of parents / caregivers worked well for those requiring unidimensional / low touch inputs only

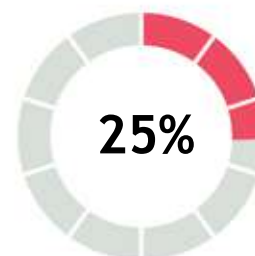
“For certain disabilities such as Muscular Dystrophy , Multiple Sclerosis, Parkinson's etc physiotherapy is a must as it improves daily function and reduces pain and cramps . Long gap of over a year has resulted in muscle deterioration and for many, it will be a huge struggle to get-back to pre-covid times”.

- Physiotherapist

- Respondents talked about limited understanding, acceptance for meeting of mental health needs which was an urgent need due to various aspects related to the pandemic (fear, isolation etc)



86.14% of respondents experienced fear and stress and almost 25% could not get any support even though they needed help



“One trend we saw was people with psychiatric health concerns, who had been stable before the pandemic, started showing symptoms again. We also saw a lot of people who did not necessarily have previous psychiatric illnesses show symptoms of anxiety and depression”. Kersi Chavda, Leading Psychiatrist in Mumbai”

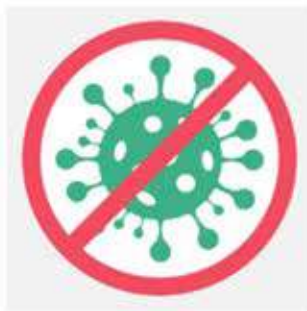
- quoted in Hindustan Times⁴

“Rehabilitation is not a high priority because it is unseen treatment. Government is not aware what needs to be done for it”

- Occupational Therapist

(Refer Case Study - SOS!! Access to blood transfusion)

⁴ <http://www.hindustantimes.com/cities/mumbai-news/covid19-effect-health-issues-became-tough-to-manage-101615404932558.html>



Covid induced impact

The pandemic brought attention to the urgent need for development of a crisis management plans for persons with disabilities and in particular for those with severe health conditions. Challenges that led to inability to access suitable healthcare was on account of (i) lack of disability aggregated data (ii) Crisis managers having limited understanding of needs of persons with disabilities (iii) inadequate reach of social protection programmes particularly in a pandemic. Some aspects that emerged during the pandemic (and/ or had limited influence pre-covid):

- Ineffectiveness in dissemination of healthcare information (in accessible formats) in the event of a healthcare emergency
- Severe resource crunch created serious medical dilemmas for medical practitioners
- Quarantine and Isolation emerged as important tools for cluster containment across the country but the planning and implementation for the same was not disability inclusive
- Taboos in accessing mental health services exacerbated response measures at a time that they are needed the most. This aspect also has long term implications from not just an individual standpoint but also from a societal perspective

Are challenges more in rural or urban areas?

- While distress experienced was acute across geographies, respondents in rural areas spoke about experiencing longer disruption as restoration of supply chain is taking longer to come back to pre-covid times.
- Telemedicine was actively used by many users but digital divide played a role here as well with connectivity and fewer doctors being a challenge

Positive Responses

- Citizen led initiatives were helpful in bridging gaps in service delivery by enabling persons with disabilities to call chemist and place order for over the counter(OTC) medicine that were delivered to them by volunteers. Support networks of different disability groups also collaborated with pharmacies, courier companies, suppliers for nutritional food, medicines, equipment etc and provided outreach even in some parts of rural parts of India



(For details refer to Annexure –Sec – Detailed Survey Findings – Impact on access to healthcare systems)

SOS!!

ACCESS TO BLOOD TRANSFUSION IS AN ESSENTIAL SERVICE FOR US!

Case study highlighting the plight of a family and child with thalassemia

Nishi (name changed) is a young 17-year old girl with thalassemia living in a remote village Khedegaon, in Maharashtra. Due to the absence of a good blood transfusion facility near her home, pre-covid, Nishi and her father had to travel frequently to Mumbai (210 km by public transport) for blood transfusion. The onset of the pandemic completely disrupted this set practice and posed unforeseen chal-



Some of these challenges have been documented below. While these challenges have been verbalized by Nishi, they echo the plight of many families of people with thalassemia who have gone through similar situations.

Limited availability of blood units at hospitals -

On account of covid, blood donors, fearing infection, were reluctant to visit hospitals for donating blood. Hospitals, which in pre-covid times, had exercised extreme caution to ensure that blood units are tested and blood filtered before the transfusion, found it difficult to maintain that rigor on account of limited staff availability.

“I was scared my daughter may contract HIV, every time she underwent blood transfusion during the pandemic. But for us not getting it done was also not an option, as lack of oxygen in the blood can damage her organs”

- Nishi's father

High cost of treatment -

Travel to Mumbai required permission from the Gram Panchayat. Additionally, the family needed to hire a private vehicle for travel to the hospital, as public transport was neither readily available nor an option, due to the fear of infection for Nishi. This cost us a lot of money (~INR 2000 for every trip we made). For hospital admission, we needed a mandatory RTPCR negative report which again cost us another ~INR 2000. Inflated cost of blood units, regular CT and MRI scans all added to our travails.

“ I am a photographer and have had no income since covid began. In these times the inflated medical expenses made it extremely difficult and stressful for us to sustain treatment. We are doing our best and even if my wife and I need to go without a few meals, we will not give up”
~ Nishi's father

Difficulty in procuring blood disorder medicines -

Iron chelator medicines are a must for treatment of blood disorders. These are available only in Government centers against verified prescriptions and identification cards of the patient. During covid, supply of these medicines became restricted. Travelling to the Government centers to get this was not only physically difficult but also an added expense for a family already struggling to make ends meet. Nishi's father mentions he managed to request Government authorities to hand it over to a relative, but for many families of thalassemic patients in remote locations, due to inability to visit centers and pay for the medication, they discontinued both medication and transfusion for the kids. Not only was health and lack of access to nutritious food a big concern, the family had to ensure Nishi is kept safe from external infections. Her reduced immunity made her susceptible to infections. Thus, the family talks about how they completely isolated themselves socially. A notice pasted on their door, described their extent of disconnect from the world outside -

“Please call us only if urgent, and do not visit our home”

Nishi has consistently been a school topper. But the pandemic has made it very difficult for her to continue her studies effectively in online mode. Lack of a good device, challenge with internet connectivity, difficulty in access to material and inability to attend physical school (her school worked in a hybrid model with 2 days physical and 3 days online class) were significant concerns, especially since she is in Class 12 and her board exams are scheduled in May 2021. As per India's latest RPwD Act 2016, Nishi's condition would qualify as a person with a disability, entitling her to an annual pension of around INR 20,000 which would have been beneficial to meet some of the expenses. However, the guidelines for these newly introduced disabilities are yet to be fully absorbed at the local level, and also due to her own inability to get a disability certificate (challenges with going to designated hospital, almost 100 km away from home to get it made) she is neither eligible for financial benefits available for PwD and nor for extra writing time during exams.

Gaps in the system have made it difficult for persons with lesser-known disabilities to get full access to a number of opportunities and benefits. But they got significantly amplified during the pandemic. Escalating cases of coronavirus infection and the rise in fatalities, left the Government with little choice, but to channelize all medical attention for covid treatment. In the absence of systems with well-defined crisis management plans and disability disaggregated data, scores of individuals like Nishi with lesser known or rare conditions have faced and are facing significant challenges in accessing regular healthcare, education, nutrition and other basis livelihood financial needs.

IMPACT ON ON LIVELIHOOD, EMPLOYMENT AND SKILLING

"I support my family of 7 by buying vegetables from the mandi and selling in my locality. During lockdown sourcing vegetables was a challenge due to the absence of public transport. Most families who bought from me preferred to order online. I was thus without any sales for almost 3 months"

- Vegetable vendor, Person with locomotor disability



1. Loss of jobs, lack of steady income, need to encash savings were common issues faced by persons with disability and returning to work far more difficult compared to non-disabled peers.

- In line with most other countries, India's employment landscape in 2020 was dramatically altered by Covid19 pandemic as 10.9 million⁵ jobs were lost across various sectors.
- This study considered persons with disabilities in (i) Unorganized Sector & Self-employed (small business) (2) Organized Sector- Blue Collar (3) Organized Sector- White Collar - Employed and (4) Organized Sector- Job Seekers. In general, across all segments persons with disabilities in the workforce are facing relatively higher intensity of strain due to lower savings, lack of portable skills compared to their non-disabled peers. There is additional factor of possibility of long drawn period of unemployment as persons with disabilities are less likely to get opportunities as other job seekers.

⁵ <https://www.moneycontrol.com/news/business/economy/covid-19-job-impact-which-sectors-lost-the-most-people-and-which-ones-hired-the-most-in-2020-6334431.html>

"I am a national level discus throw player. Since the lockdown, all sports facilities, group training, therapy etc. have not been accessible to us. This has had a lasting impact on our muscle tone and would need many years of intervention to get back (if at all). Many of my peers have started looking for alternate livelihood opportunities as with the current physique, we don't see ourselves competing successfully in any platform"

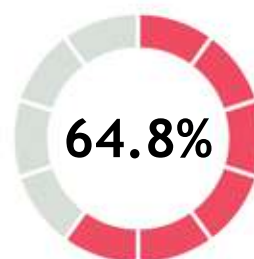
- Sportsperson with Spinal cord injury

- While there is still hope in urban settings, the employment opportunities in rural areas look bleak, except in a few cases where some organizations have started impactful work.
(Refer to case study - creating rural jobs!! Making the best of opportunities in crisis)



13.4% respondents lost their jobs during the pandemic, and all are waiting for over six months without an opportunity

Among those who continued jobs 64.8% mentioned facing challenges at work due to inaccessibility and social inclusion



2. A large number of people in the unorganized sector and many self-employed with small businesses, found it extremely challenging to sustain operations during the pandemic. Lack of portable skills further impacted their transition to an alternative means of livelihood.

Pandemic hit this segment particularly hard as they lack any social security support (being part of unorganized sector), often do not have portable skills and usually very low if any savings to sustain shocks. Even though there does not appear to be any visible sign of discrimination a large number of persons with disabilities lost their jobs or vocation simply due to their being involved with vocations that would usually be ancillary to a larger environment.

(Refer to case study - creating rural jobs!! Making the best of opportunities in crisis)

"There are so many homeless people with disability living on our streets , railway platforms etc. who fend for themselves by begging , selling small nick-nacks or taking up odd jobs. Majority of them have no form of legal identity and at the time lockdown was declared, they were left in absolute deprivation"

- Coordinator from a leading NGO

3. Many disabled employees in the organized sector (blue collar employees) faced loss of jobs, as organizations were compelled to cut costs and trim operations.

- Revenue related pressures resulted in a large number of lay-offs and pay-cuts for disabled and non-disabled people across the organized workforce segments like retail and hospitality.

Though there is no information about any specific bias in job losses for persons with disabilities, it will be difficult for disabled persons to find re-employment as compared to their non-disabled peers.

“We are called intermittently and paid as per our rosters. It is impossible to sustain with such reduced salary. No new opportunity is available too”.

- Employee, Retail store

4. Employees in the organized sector (white collar jobs) did not mention loss of jobs, but many deaf and blind employees mentioned difficulties with online work from home options.

Employees in organized sector were able to quickly transition to working from home. While this change was positive for people with reduced mobility and physical health conditions, working in online mode posed challenges too. Absence of sign language interpretation and inability to follow captions (generated by Artificial Intelligence tools were inaccurate) made online working very difficult for deaf persons. Employees with vision impairment cited instances of colleagues not being sensitized to the accessibility needs of their blind peers - documents shared were not accessible through screen readers, apps and websites to be used for everyday communications and interactions were not accessible, etc.

5. Skilling and Training benefitted job seekers who are tech-savvy and have access to devices and internet connections. But, job seekers in remote locations with limited connectivity, found it difficult to access any form of training.

Skilling like education saw significant loss in traction due to lack of devices, connectivity, accessible materials and methods and limited options to re-skill or up-skill. Few options that were available for up-skilling were inappropriate due to constraints like cost, accessibility etc. Only a few organizations could transition to online skilling and training programs. Again only a few trainees could benefit from online training programs. A large set of disabled job seekers across India, could not access online skilling and training programs due to lack of devices and poor connectivity. This will impact their ability to seek employment into the workforce





Covid induced impact.

Any comparison with pre-covid times must be seen in the context of the scale of change in India's labor force and that disruption is likely to play out in the medium term. With societal barriers increasing and education and skilling getting seriously compromised for all students and job seekers, it has become even more difficult for persons with disabilities to get back a job or return to pre-covid income levels.



Are challenges more in rural or urban areas?

- Employability concerns were reported from across rural and urban locations in India. Many people returned to their homes in non-urban areas but found it difficult to get employed there and later to return to the cities to resume their old jobs.
- Lack of digital connect affected rural areas more with many completely losing all access skilling and training opportunities.



Positive Responses

- Educated job seekers benefited from online skilling opportunities as well as access to jobs in IT and Business Processing Sector which has seen an uptick in business prospects.
- Many experts believe that the accelerated switch to digital working will create manifold work from home opportunities – which may open up avenues for people with severe disabilities who either because of their own need or because of lack of accessible transportation prefer

(For details refer to Annexure –Sec – Detailed Survey Findings – Impact on Employment and Skilling)



CREATING RURAL JOBS!!

MAKING THE BEST OF OPPORTUNITY IN CRISIS

A case study on the impactful work done by WeAreYourVoice, in creating livelihood opportunities for youth with disabilities in rural areas

Covid-19 lockdown and restrictions meant many migrant workers who have moved back to rural areas with many choosing not to return. In non-urban and rural centres this created as labour short-age. “Weareyourvoice”, a volunteer-driven social enterprise working livelihood saw an opportunity in this crisis situation.

“What we saw was while there were quite a few companies in large metros opening up to hire and include Persons with disabilities - but in rural centres hardly any such thing was happening. At the same time many Persons with disabilities in rural area despite having skills do not find a job in their hometown or villages - due to high costs & other factors of city life, most just cannot think of relocating to cities. We saw that there were many open positions created by reverse migration, and sensed an opportunity and quickly engaged with the community and the local companies - and started persuading them to hire Persons with disabilities from local areas. ”

~ Basith, Founder Weareyourvoice

Weareyourvoice¹, addressed the demand and supply side challenges simultaneously. They placed district level officers who worked with DPOs, individuals, government bodies in their area to populate the data of persons with disability, assess their skills and aspirations and specific disability accommodation needs. Almost 2000 PwD were profiled across 200 blocks in Tamil Nadu in less than 3 months. They simultaneously worked on the demand side by liaising with MSMEs and government bodies / projects etc to understand their manpower need and accordingly started the one to one mapping.

¹ <https://weareyourvoice.org/web/site/index>



“ The mapping was not as simple, as barriers in recruiting persons with disabilities are real and inspite of all the success stories, a lot of sensitisation is needed to make organisations understand and appreciate the business case in extending opportunities to them. We got the support from Tamil Nadu State Government too and our team worked relentlessly , started with placing 20 in September and the numbers were ramped up to 100+ by November. We started with small job fairs , special drives for corporates due to the social distancing norms which were to be followed. Every number counts ... while some hired 1-2 , companies like Soulfree and Sivaraj Spinning Mills hired 30+ people with disabilities. We want to slowly spread across Tamil Nadu and to other states as well . There may be aspiration mis-match for a few , but we are confident that many will stick around and lead a life of dignity and comfort , close to their families”

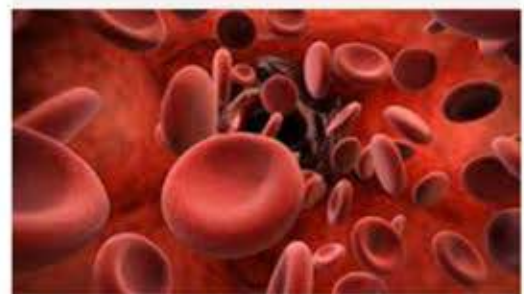
~ Kasim Basith , Weareyourvoice

Weareyourvoice has profiled 4500+ people with disabilities in rural areas and placed 700+ in roles close to their homes. They are also working with the government to see if people with specialised skills - masons, electricians, plumbers , cooks, housekeeping staff etc (who were employed in hotels / retail stores etc in cities) can be given the initial head start to become micro-entrepreneurs . They are confident of immense possibilities that exist ranging from augmenting health and sanitization infrastructure in rural areas to giving boost to eco-tourism.

IMPACT OF THE PANDEMIC ON PERSONS WITH LESSER-KNOWN DISABILITIES

"My family and I are socially isolated. My 18-year-old son has not stepped out of home for 9 months, as he understands that he can bring in infection which can be life threatening for me"

- Person with Sjogren's condition



The Rights for Persons with Disabilities Act, 2016 includes 21 types of disability types (compared to 7 in earlier act). In case of the newly included disabilities like Blood disorders (Thalassemia, Sickle Cell disease, Haemophilia), Chronic Neurological conditions - Parkinson's, Multiple Sclerosis and Persons who are deaf-blind, people with these conditions still do not have disability identification due to which they are not entitled to social security benefits and other relief measures.

The survey also found that people with chronic and rare conditions, such as Rheumatoid Arthritis, Scleroderma, Ankylosing spondylitis, Sjogren's condition, Inborn Errors of Metabolism (IEM), Rett's Syndrome, etc. faced additional distress as they were not under specified list of disabilities but needed access to critical care, which was difficult to access due to Covid19 protocol. **Prasanna Shirol, Founder of Organization for Rare Diseases says, "There is a need for an umbrella organization to represent all these conditions to ensure rights of people with these rare conditions are also protected"**

In addition to societal barriers (often as these disabilities / conditions are not fully understood) their fragile health conditions often leads to persons with these disabilities to stay out of the workforce in turn hurting their ability to fund medical expenses which are significantly higher than most other conditions. *(Refer to Annexure -Sec - Detailed Survey Findings - Impact on Lesser-known Disabilities)*

RESPONSE TO PANDEMIC BY THE GOVERNMENT: (CENTRAL & STATE)

India's Central and State Governments large scale efforts to control spread of Covid19 pandemic started with lockdown in end March 2020. Right from invoking the Epidemic Diseases Act, Central Government introduced relief measures followed by initiatives like release of MNREGS dues, incremental/ accelerated work under MNREGS etc. These efforts were for population at large and were supplemented by measures for vulnerable segments of the population like persons with disabilities.

In the context of Persons with Disabilities responses from Central and State Governments (since March 2020) have been in the following areas:

1. Information dissemination

- Central and State Governments regularly put out information about the pandemic, regulations around movement, relief measures etc. The Disability Affairs Department under Ministry of Social Justice and Empowerment had issued a notification to all State Government that all Covid related information has to be made in accessible formats.
- However Apps like Arogya Setu not being accessible has been reported as a challenge and a new barrier for persons with disabilities

2. Relief measures - food & ration

- Collaboration with NGOs - during the pandemic State governments partnered with NGOs for delivery to those that needed it including Persons with Disabilities.
- Public Food Distribution System (PDS) in states like Delhi and Tamil Nadu provided food and ration consistently which was reported as being reassuring for many Persons with Disabilities that either could not afford it or were unable to physically access from their usual sources due to other challenges.

3. Disability pension

- Central government announced advance three months pension amount to be disbursed to for persons with severe and multiple disabilities living below poverty line covered under the National Social Assistance Programs - however many persons with disabilities had difficulty in accessing the pension as they were not enrolled in the scheme
- Central government also announced an ex-gratia payment of Rs. 1,000 under Pradhan Mantri Garib Kalyan Yojna (PMGKY) to persons with disabilities (with 80% disability as per disability certificate) who are below the poverty line

4. Prioritization / relaxation for caregiver movement

- State Governments provided priority passed and other exemptions for care givers of persons with disabilities so that they could travel to reach their place of work or homes of persons with disabilities whom they were providing care for

While emergency relief measures have been provided by Central and State Governments, there is urgent need for measures to address adverse impact (short, medium and long term on livelihoods, health effects, education or daily living of persons with disabilities. Below is the list of main **Government Stakeholders** who were particularly focused on extending support to the disabled community in the pandemic period:

Department of Empowerment of Persons with Disabilities, Ministry of Social Justice Empowerment	Dr. Prabodh Seth , Antyodaya Bhawan, New Delhi Room No. : 530, New Delhi - 110003 (India) 24369056 (Off.); jsda-msje@nic.in
State Commissioner for Persons with Disability (All State Governments - listing only Delhi, Tamilnadu, Maharashtra here)	Delhi: Commissioner, Disabilities, Govt. of N.C.T. of Delhi, 25-D, Mata Sundari Road, Near Guru Nanak Eye Centre, New Delhi - 110002 (044) 24719945(O), Maharashtra: Commissioner, Disabilities, Maharashtra State, Govt. of Maharashtra, 3, Church Road. Pune- 411 001; (020)26122061, (020) 26111590 Tamil Nadu: State Commissionerate for Welfare of the Differently Abled, No.5, Kamarajar Salai, Lady Wellington College Campus, Chennai-600 005. Land Line: 044-28444948 ; E-Mail :scd.tn@nic.in scdatn@gmail.com

RESPONSE TO PANDEMIC BY NON-GOVERNMENT ORGANISATIONS

During the early stages of pandemic there emerged an instinctive and seamless alignment between Government and Non-Government Organisations in designing and delivering relief measures. Non-Government Organisations, especially several Disabled People Organisations (DPOs) played a critical role in creating access for relief to both urgent and important needs as under:

- ***Channel for communication*** - DPOs acted as channels of communication both for disseminating information about the pandemic and providing feedback to local agencies on challenges that Persons with Disabilities and their families were facing. Organisations like The Banyan ran helplines accessible to Persons with Disabilities and conducted sessions on wellbeing in partnership with v-shesh.
- ***Engagement for access for caregivers*** - DPOs engaged with Central and local Governments to advocate for easing restriction for movement of caretakers as well as for access to medicines and essential supplies.
- ***Getting relief to Persons with Disabilities and their families*** - DPOs/ Social enterprises, other NGOs as well as industry bodies like CII, Nasscom (directly and with their foundations) worked directly as well as in a collaborative way to provide relief from the very start of the pandemic till supply chains stabilised. This included grassroot DPOs like New Life Centre (in Hosur), Annai Theresa Disability Education & Social Welfare Trust (Pudukotai, TN), Ekansh (Pune), Disability Rights Alliance and many others who assisted with channelling relief as well connecting Persons with Disabilities and their families with Government support systems.
- ***Training and access to jobs and livelihood*** - training organisations like WinVinaya, Enable India and v-shesh adapted to the new environment and developed training modules that can be delivered online. v-shesh engaged proactively with the employers to keep up the hiring momentum, and assist persons with disabilities who lost jobs with upskilling and career opportunities. WeAreYourVoice's work in the rural areas, ATPar's work with Micro-enterprises, and livelihood support work of National Association of Blind (NAB), National Association of Deaf, Deaf Enabled, Maithree (Chennai) and Humanity Welfare Organisation Organisation Helpline are all example of organisations reaching out to those with higher risk of exclusion.
- ***Advocacy for health and vaccination*** - More recently DPOs have actively engaged with officials in healthcare services to ensure that Person with Disabilities are included in the priority list for vaccination.

FUTURE JICA SUPPORT PROGRAMS FOR THE PERSONS WITH DISABILITIES

For any social & economic development program focusing on recovery & building back of livelihood & wellness for Persons with disability impacted directly or indirectly by Covid19, the following main gap areas need to be addressed

1. Disability Disaggregated Data, Gap in Disability certification & Caregiver registration

- Lack of disability disaggregated district or ward level data impeded quick and planned response for recovery & rebuilding
- Lack of disability documents especially for newer disabilities under RPwD Act 2016 (Parkinson's, Thalassemia, Multiple Sclerosis) and rare / lesser known conditions meant people with such conditions could not receive support or access welfare measures
- Lack of formal registration process for Caregivers (especially for children and others with high support needs) again led to delays in response and created further burden on caregivers as well as Persons with disabilities

2. Digital divide & accessibility gaps

- a. Lack of device access (or ownership) and access to internet connectivity meant most jobs (not just digital or IT jobs) have become out of reach for persons with disabilities
- b. Accessibility gaps of websites, apps and limited access to sign language support and Assistive Tech devices amplifies access barriers for Persons with disabilities - be it education or employment or healthcare.
- c. Both of above (lack of devices or connectivity and accessibility) led to delays in relaying of critical health / other information and further isolation

3. Lack of awareness and sensitivity towards the needs of Persons with disability

- Lack of trained personnel sensitive to needs of Persons / Children with disabilities - be it healthcare workers, or school teachers or other frontline workers - caused significant disruption in learning and livelihood access.

4. Social infrastructure gaps

- Schools or Hospitals or Public Health all lack accessible infrastructure firstly and the services they offer have significant accessibility gaps to meet the diverse needs of persons with disabilities.
- Rehab facilities and Therapy centres are fragmented in terms of reach and wherever available are unaffordable for most persons with disabilities.

Comparative strengths of potential implementation partners for JICA Support schemes

Based on review of programs / schemes undertaken by Government & Non-government institutions in response to Covid 19, and also other disaster mitigation / livelihood support programs, it was found that National Government Ministries had comparative strength in Policy development and leveraging funding source, the State Government Department / Agencies are best placed for upgradation or modernisation of Social Infrastructure and providing a platform for multi-stakeholder collaboration, the Disabled People Organisations have strong outreach, & the Private sector bring in the customer-centric efficient approach. Below table provide the comparative advantages of institutions Stakeholders that can be leveraged for developing JICA Support program for Persons with Disabilities:

STAKEHOLDER	COMPARATIVE STRENGTH
1. National Government	a. Policy consistency across States b. Alignment & leveraging Funding from other sources
2. State Government / State Govt. Agencies	a. Implementation / upgradation of Social b. Infrastructure and modernization of equipment c. Engaging and offering collaborating platform for multiple stakeholders
3. Disabled People's Association / Parent Support Groups / Caregivers	a. Grassroot level inputs from people with "lived" experience b. Mobilization of user groups c. Ownership leading to program sustainability
4. Private sector	a. Innovation and co-creation b. Implementation efficiency c. Cost recovery / financial sustainability

JICA SUPPORT PROGRAM FOR PERSONS WITH DISABILITIES

- NEW PROGRAMS

Based on discussions with Government / Non-government stakeholders and thought-leaders working in the disability sector, the Study team has identified Four possible JICA Support Programs (JSP). Three support programs (JSP #1-3) are organised as schemes to address gaps in three sectors - (a) Education & Daily living; (b) Skill Development, Employment & Livelihood; and (c) Health & Wellbeing. The fourth one (JSP#4) is a Private Sector program to address gaps across sectors through enterprise-led approach.

Further for each support program, JICA support is categorised into: (a) Loan support typically for long term social infrastructure upgradation or modernisation; (b) Technical assistance typically for developing models, policy frameworks, or pilots; and (c) Grants as direct support for beneficiaries or clients with disabilities or for capacity building / training initiatives for disabled people's organisation or NGOs or parent support groups.

The proposed programs are Disability-focussed interventions to provide additional thrust required under each sector - Skill Development & Entrepreneurship, Education and Health - to address and mitigate the adverse immediate, medium and long-term impact of Covid19. As regards Program Implementation, National level Ministries & State level Departments of the respective sectors are proposed as main Program implementing partners, with execution of program components done in active collaboration with Disabled People Organisations, NGOs, Parent Support Groups, Private Sector and Industry Associations.

For Program Design, it is recommended that JICA consult with the National level Ministry (eg. Ministry of Skill Development & Entrepreneurship for Livelihood program or National Skill Development Corporation) and also a few State level Departments / agencies (eg. State Skill Development Missions or State Rural Livelihood Mission) to check for their interest in a disability-focussed program. Once the State shows interest the program activities for Loan, TA and Grant component can be drawn out in consultation with Government as well as non-Government stakeholders. Most importantly, in keeping with principle of "Nothing about us, without us" - the final Program design should get a sign-off from stakeholders from disabled community.

The Four JICA Support Programs (JSPs) proposed are briefly described as follows:

JSP#1: Skill Development, Livelihood & Entrepreneurship:

The Objective of the Proposed program is to mitigate the impact of job & income loss through a structured intervention involving building a job-listing / matching platform, facilitating start-up seed capital and hand-holding support PwD led enterprises in the immediate term to Upgrading and modernizing the Skill Infrastructure with Assistive technology devices & equipment and supporting operations of Livelihood centers in the medium term.

JSP#2: Education:

The Objective of the Proposed program is to mitigate the adverse impact of school closures & remote/ online teaching methods on children with disabilities through a structured intervention involving capacity building of Special educators / Teachers on principles and practical tips on Universal Design in learning to Upgrading and modernizing the School Infrastructure with Assistive technology devices & equipment and Rehab / Physiotherapy equipment and services.

JSP#3: Health:

The Objective of the Proposed program is to mitigate the adverse medium and long-term health impact on Persons and children with disabilities due to disruption & non-availability of critical life-sustaining health products and services through a structured intervention involving database & profiling of persons needing support and Caregivers, setting-up of accessible health counselling helpline, capacity building of healthcare staff to Upgrading and modernizing the Hospital Infrastructure with Rehab / Physiotherapy equipment and services, assistive aids & products distribution center.

JSP#4: Disability Inclusion Fund:

The Objective of the Proposed program is to use an entrepreneurial approach that address the gaps in Livelihood, Health & education access for Persons / Children with Disabilities by supporting a Disability-inclusion fund (hosted by National level Government Institution) which in turn will support (a) disabled-person led businesses or businesses that generate employment/ livelihood opportunities for disabled people, and (b) institutions that serve as incubators or accelerators for developing / testing of products & services that improve daily life or livelihood access for disabled children or people.

Detailed below are JICA Support Programs

JICA Support Program (JSP):

JSP#1

Sector	Gap Areas	Type of JICA Assistance	Program components / Urgency (Immediate, Medium, Long-term)	Stakeholder
Skill Development, Employment, Livelihood, Entrepreneurship	Formal employment (1) Lack of access to devices; (2) Lack of access to Assistive Technologies (3) Limited internship / apprentice opportunities	Loan	Social Infrastructure upgradation - Accessibility Labs + Computer labs in Community Libraries / Community centres + Livelihood facilitation centres Medium	Ministry of Skill Development & Entrepreneurship / National Skill Development Corporation
			Procurement of Assistive tech devices, laptops, and other devices Medium	State Skill Development Missions / State Livelihood Missions
	Informal Employment (1) Lack of business dev support services; (2) Lack of seed capital	Technical Assistance	Development of Covid Responses jobs & livelihood portal for listing and match-making Immediate	Ministry of Skill Development & Entrepreneurship / National Skill Corporation & State Skill / Livelihood Mission
		Grant	Seed capital for small business / livelihood activity Immediate	State Livelihood Missions / Disabled People Organisations / Social Enterprises / Cloud lending platforms like Give India or Milan or Kiva / NGOs / Caregiver & Caregiver Associations / Parent Support Groups
			Capacity building / training support for Disabled People Orgns. or NGOs Immediate	State Livelihood Missions / Training Agencies

JICA Support Program (JSP):

JSP#2

Sector	Gap Areas	Type of JICA Assistance	Program components / Urgency (Immediate, Medium, Long-term)	Stakeholder
Education	Education Lack of access to devices; Limited skill of Teachers for online + remote teaching Daily living: Lack of therapy / other rehab services; Lack of access to rehab / other health products	Loan	Social Infrastructure upgradation – School Improvement-Computer labs Medium	Ministry of HRD and Education
			Procurement of Assistive tech devices, laptops, & other devices/ mobility/ other aids at school or district rehab centres. Medium	State School Education Departments
		Technical Assistance	Data collections framework / protocol for profiling children and their disability accommodation + evolving suitable support schemes to address pressing needs of children and their caretakers (to encourage school enrolment & school participation) Medium	Ministry of HRD & Education along with State Education department
			Procurement of rehab products / devices, machinery or equipment for therapy services + rehab operations Medium	State Education Department / State Health Departments
		Grant	Capacity building / training support for DPOs/ NGOs Medium	State Education Department / Training Agencies + Parent Associations / Forums

JICA Support Program (JSP):

JSP#3

Sector	Gap Areas	Type of JICA Assistance	Program components / Urgency (Immediate, Medium, Long-term)	Stakeholder
Health & wellbeing	Healthcare (1) Inaccessible infra + insensitive healthcare staff + other Inaccessible services; (2) Lack of access to healthcare products & services / no database of Pwd or Caregivers; (3) Unmet needs of caregivers;	Loan	Social Infrastructure upgradation - Public Hospital / Health Centre / Rehab Centre / Diagnostic lab upgradation. Medium	Ministry of Health & Family Welfare
			Procurement of Rehab devices, machinery or equipment for therapy services, blood bank related equipment, modernisation of facilities. Medium	State Public Health Department
	Wellbeing (1) Lack of accessible health counselling; (2) Lack of access to mental health counselling / therapy	Technical Assistance	Data collections framework / protocol for profiling Persons with disability (including those with high support needs) and profiling & registration of caregivers. Immediate	Ministry of Health & Family Welfare along with State Public Health department
		Grant	Helpline set-up costs for mental wellbeing or health counselling Immediate	State Health Departments
			Capacity building / training support for Healthcare staff on disability support Immediate	State Health Department / Training Agencies

JICA Support Program (JSP):

JSP#4

Sector	Gap Areas	Type of JICA Assistance	Program components / Urgency (Immediate, Medium, Long-term)	Stakeholder
Private Sector - Covid 19 Disability Inclusion Fund	(1) Lack of business support services; (2)Limited accessibility products / Service designs ; (3) Lack of seed capital; (4) Limited impact sourcing avenues; (5) Limited incubation / acceleration	Equity / Long-term loan	Long term Capital support for enterprises Medium	Small Industries Development Bank of India or National Small Industries Corporation or NABARD or NHFDC (National Handicapped Finance & Development Corporation)
			Working capital / operations support Medium	
		Grant	Financial support for Incubators / Accelerators Facilitate boot-camps and hackathons or makathons to attract and encourage potential entrepreneurs / start-ups Long-term	Academic Institutions (Indian Institute of Management or Indian Institute of Technology or Delhi University or Anna University) + Impact focussed funds / entities like Villgro or Aavishkaar or Sattva
			Market research studies for assisting investee companies Long-term	

JICA Support program for Persons with disabilities - Existing projects / programs

In addition to design a new support scheme - JICA can also consider looking at existing projects at deliberate with the respective Government Implementing Agency for adding a disability component as affirmative response to mitigate Covid19 impact. For example - under Tamil Nadu Health Sector Project, JICA can consider adding a component to improve the Health Infrastructure with Rehabilitation / Therapy equipment, introduce a TA component to develop a framework for registering & profiling of Individual & children with high support needs along with their Caregivers. In a similar way all projects especially in Education, Skilling& Livelihood and Health sector can be screened from a disability-equality lens and project components added in consultation with the Implementing agencies.

CONCLUSION

This study to understand the impact of Covid19 on Persons with Disabilities in India is based on insights from Persons with Disabilities and from diverse stakeholders including leaders and practitioners from Government and Disabled People Organizations . The study made a conscious effort to ensure the diverse disability types including lesser known or rare conditions are also consulted.

Persons with Disabilities and their families experienced intense and profound impact which has short, medium, and long-term implications on all fronts - education, health and livelihood.

- Students with disabilities faced challenges due to lack of access to devices, connectivity, accessible content and settling in issues around online education. Migrating to online education and these barriers have led to loss of learning for a large number of students and many students with disabilities are expected to report the same whenever they rejoin schools
- Several Persons with Disabilities seek and use healthcare services in ways different from persons without disabilities. As an example physiotherapy is a must for persons with certain disabilities to improve daily function and reduce pain and cramps. With supply chains and access to healthcare professionals (doctors, physiotherapists etc) and product/ services (catheters, medicines, lab tests) being disrupted and challenges in online consultations, Persons with Disabilities reported extreme distress during the last year. An aspect that is inadequately understood is about challenges faced by individuals requiring specialised treatment lack of which has impact not just in the short term but also has long terms consequences
- Persons with Disabilities and their families faced challenges in accessing food and severe stress in assessing needs of daily living (information about pandemic as well as relief, assistive devices, caregiver support et al)
- As economic activity slowed down and large businesses contracted, Persons with Disabilities lost jobs, incomes and livelihoods the impact of which was more disruptive for Persons with Disabilities and their families as they have to incur higher expenses than other segments of the population, and wait longer to find a job

Many of the challenges that Persons with Disabilities have faced during this pandemic have mid to long term consequences. Some of the areas where these would become visible sooner than later would be in financial instability due to challenges in getting a job or rejoining workforce (in case of job loss), adverse impact on wellbeing due to lack of regular healthcare support and loss of learning

for students or trainees.

Central and State Governments responded quickly but faced challenges in getting relief to beneficiaries due to restrictions in mobility and need to meet needs of all segments of population. Effectiveness of response was also hindered due to structural challenges like lack of a consolidated database of Persons with Disabilities and caregivers. While response systems kicked in quickly, lack of a policy framework for such large-scale disruption hampered delivery of food/ goods/ services to the population at large but much more so to vulnerable segments like Persons with Disabilities.

Suddenness of the pandemic, lack of an emergency plan for a pandemic and restrictions on mobility to stop rapid spread of Covid19 led to acute disruption for the entire population. Not only did Persons with Disabilities and their families face challenges that all other segments did, they also saw their social support system collapse further isolating them and affecting their daily living.

Looking ahead, it is important to understand that both intensity and duration of strain experienced by Persons with Disabilities and their families is much more than other segments. **So, while designing response efforts, it is important that measures must be designed to alleviate immediate distress as well as address mid to long term issues arising from disruption.** The study recommends JICA support schemes to mitigate the Covid19 impact through structured education , health and livelihood programs - that through a combination of loan and TA or Grant support address gaps in Social Infrastructure and build capacity for disability-inclusive service delivery.



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