

**Whose Life Matters?**

**Challenges, Barriers and Impact of Covid-19 Pandemic on  
Persons With Disability (PwDs)  
and Their Care Givers**

**Summary of the Report of an APW awarded by WHO, South-East Asia Region**

**September 2020**

Whose Life Matters? Challenges, barriers and impact of COVID-19 pandemic on persons with disability and their care givers

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## **CONTRIBUTORS**

Mathew Varghese  
Syamala Gidugu  
Shirly G  
Santosh George  
Anil Gurtoo, Anupam Prakash, Ritika Sud  
Albina Sankar  
Suranjan Bhattacharjee  
Arun Sethi  
Anil Jain  
Bipin B Choudhary  
Denny John  
Dinesh Mohan

## **BACKGROUND**

The Covid 19 Pandemic has affected our lives directly and indirectly. Worldwide 32.8 million have tested positive and 9,94,883 died and India has recorded 5,915,753 positives and 93,461 deaths as on September 26<sup>th</sup>, 2020

In an attempt to contain the spread of infection different countries have adopted different strategies from testing and containment, selective lockdown to complete lockdown. India adopted a strategy of total lockdown from 21<sup>st</sup> March 2020. The pandemic and the associated lockdowns affected all general and economic activities and all lives were affected significantly by the lockdown. Reports revealed that Persons with Disability, some patients with chronic diseases and the impoverished were severely affected by this. This study was done to understand how the lives of these populations has been affected by doing a countrywide telephonic survey.

We hoped this will help us generate policy recommendations to reduce the suffering of this vulnerable group during this and future epidemics or emergencies.

The survey had ten organisations participating with interviews of a wide spectrum of disabilities across the country. At closure 5,165 persons with disability or their care givers were interviewed. The answers were analysed qualitatively to problems common to all and also segregated to problems unique to each type of disability. Based on analysis of these issues brought up by the caregivers and the PwDs recommendations have been made.

## **OBJECTIVE**

To assess the Challenges, Barriers and impact of Covid 19 pandemic and related Lockdown on disease / disability of PwDs, their rehabilitation and access to assistive technologies; and on their Care givers; and to develop recommendations to improve their situation.

## **METHOD**

This survey was conducted telephonically using contact numbers with the participating organisations.

## **IRB Approval**

The proposal was sent for IRB approval to the St Stephen's Hospital Ethics committee approval. The committee reviewed the proposal and after discussion formal approval was given.

### **Development of a questionnaire**

The first task was to develop a questionnaire. Several existing survey questionnaires were reviewed collected and reviewed again and finally after several meetings a consensus questionnaire form was evolved.

### **Literature review**

A detailed literature survey was also be done as part of the study. This was to help understand issues regarding different aspects available in peer reviewed literature.

### **Consent form and translation**

The consent form first made inn English was translated into Hindi and Malayalam. For the deaf adults, it was decided to create an online Indian Sign Language (ISL) video questionnaire using Google form. A deaf signer and an ISL content checker were identified by National Institute of Speech & Hearing (NISH) for this. Responses were collected directly from the deaf adults.

### **Telephonic interview and IDI Survey**

The survey was done using telephone numbers to contact all the PwDs willing to participate in the survey. Each of the institutions participating with expertise in different areas had contact details of persons with different types of disabilities. Interviews were conducted of PwDs and their care givers about their experience during lockdown and how their life was affected.

### **Data Analysis**

A total of 5,165 responses from persons and their care givers were received based on the questionnaire. All survey questionnaires were compiled on an Excel spreadsheet. Data was then segregated based on types of disabilities. Analysis of the combined and segregated data were then done to understand the nature and types of problems faced by PwDs. Table-1 summarises the results of all the types of disabilities and their gender distribution.

Table 1 summarises the number of each type of disability in the survey.

**Table 1. Summary of all the types of Disabilities surveyed: and their care givers who participated.**

| Condition/ Disability                                      | Total Survey | Male | Female |
|--|--------------|------|--------|
| Cerebral Palsy   | 687          | 457  | 230    |
| Clubfoot   | 3828         | 2495 | 1333   |
| Thalassemia  | 73           | 34   | 41     |
| Autism   | 29           | 20   | 9      |
| Intellectual Disability                                    | 28           | 22   | 6      |
| Visual Challenge   | 42           | 23   | 14*    |
| Hard of Hearing  | 252          | 140  | 111*   |
| Deaf Adults  | 77           | 43   | 34     |
| Knee Amputation, Amputation, Trans Radial Amputation       | 12           | 6    | 6      |
| Hemiplegia, CVA, Stroke                                    | 21           | 12   | 9      |
| Polio  | 19           | 11   | 8      |
| Mental Illness   | 31           | 20   | 11     |
| Paraplegia, MMC, Spinal Cord Injury                        | 14           | 2    | 12     |
| Miscellaneous (Critical Neuropathy, SLE, Head Injury etc.) | 51           | 35   | 16     |

(Note: Table 2 has been omitted from this summary report)

Table 3 summarises the Educational status of patients caregivers and their level of information on the pandemic. Most of them were aware of the pandemic but about 12% were either not aware or had poor understanding of what is happening I the pandemic. Over all there was reasonably good awareness.

| Table 3<br>Highest Education | Knowledge of COVID Pandemic |                     |    |             |
|------------------------------|-----------------------------|---------------------|----|-------------|
|                              | Yes                         | Partial Information | No | No Response |
| No Education                 | 326                         | 56                  | 14 | 3           |
| Primary                      | 931                         | 162                 | 12 | 6           |
| Secondary                    | 960                         | 82                  | 26 | 9           |
| High School                  | 1,019                       | 62                  | 46 | 10          |
| Special School               | 2                           | 3                   | -  | -           |
| Under Graduate               | 787                         | 32                  | 31 | 2           |
| Post Graduate                | 1                           | -                   | -  | -           |
| Others                       | 66                          | 14                  | 9  | 1           |
| Unknown                      | 217                         | 66                  | 5  | 128         |

Most of them got their information from friends and family, or from television. Many received their information from multiple sources but over all only 10% of persons received their information from social media (Table 4).

Very few of the persons from Aarogya Setu application. Specifically in relation to Covid the messages in TV and Radio were not disabled friendly. This was true even for the social media. Even the messages for mask wearing and hand washing did not clarify how the PwDs dependent on ADLs are to do that. Physical distancing was not possible for the dependent PwDs and their families lived in fear of getting the disease. Single parent could not even seek the help of caregiving relatives nor could they go out for buying essential or for any other work. Even where food distribution was done for the impoverished they were at a distance from their residence and the PwDs could not access them easily.

**Table 4. Source of Information about Pandemic**

| Category                        | Count |
|---------------------------------|-------|
| Friends and Family              | 5,016 |
| Television                      | 3,613 |
| Social Media                    | 998   |
| Caregiver                       | 223   |
| Print and Radio media           | 15    |
| Arogya Settu App                | 4     |
| Anganwadi & Health Care Workers | 2     |
| Others                          | 3     |
| No Response                     | 144   |
| Did not Specify                 | 72    |

Table 5 gives the summary psychological symptoms of PwDs. The table clearly shows the extent of persons that had mood changes, anxiety, irritation and sleep disturbances. The worst were the Hemiplegics (95%), paraplegics (86%) and the amputees (100%) while the best were deaf and hard of hearing.

**Table 5. Summary of psychological symptoms**

| Type of Disability      | Total | Mood Changes | Sad | Anxious/worried | Irritated/restless | Sleep Disturbances |
|-------------------------|-------|--------------|-----|-----------------|--------------------|--------------------|
| Clubfoot                | 3828  | 37%          | 30% | 18%             | 25%                | 50%                |
| CP                      | 687   | 34%          | 34% | 39%             | 29%                | 37%                |
| Autism                  | 29    | 48%          | 49% | 36%             | 49%                | 59%                |
| Intellectually Impaired | 28    | 43%          | 32% | 25%             | 32%                | 18%                |
| Mental Illness          | 31    | 68%          | 48% | 48%             | 61%                | 35%                |
| Thalassemia             | 72    | 100%         | 64% | 30%             | 43%                | 49%                |
| Deaf                    | 77    | 21%          | 21% | 8%              | 6%                 | 26%                |
| Hard of Hearing         | 251   | 24%          | 22% | 11%             | 15%                | 17%                |
| Visual Impairment       | 37    | 3%           | 51% | 63%             | 60%                | 46%                |
| Hemiplegia              | 21    | 76%          | 76% | 81%             | 86%                | 95%                |
| Paraplegia              | 14    | 93%          | 93% | 79%             | 79%                | 86%                |
| Amputations             | 9     | 89%          | 57% | 64%             | 64%                | 100%               |
| Polio/ Admitted persons | 37    | 32%          | 70% | 51%             | 22%                | 49%                |

The questionnaire also had open ended questions like what was your worst experience. While many commented many chose not to speak on this.

## DISCUSSION

This study was planned to look at the impact of Covid 19 on lives of persons with disabilities and their caregivers. It is estimated there are over 29 million persons with disability in India. In the normal non Pandemic situation also the PwDs face significant challenges to access health care. Many of the insights came from the free discussions with the caregivers and the PwDs. We feel that in such surveys there should be the freedom to have open ended and contextual corollary questions also.

The common general issues included being confined to a small space and Loss of Job/ Loss of income.. Food was the next issue with the disabled. Partly because of finances but partly also because of access issues. Disruption of familiar routine was one of the issues faced by the person with disability. Safety and behaviour issues were common to those with autism and intellectual impairment. Closure of healthcare facilities for rehabilitation disrupted the normal rehabilitation of the PwDs. Procuring assistive products and their maintenance/ repairs were problems across the physical disability sector. Caregivers of the disabled also had significant problems. Especially those PwDs are dependent for ADLs the family members needed to go out to arrange for services and other essentials. But the lockdown prevented their movement affecting the care of the disabled.

The problems common to all groups related to the impact of lockdown on families and the economic consequences of loss of livelihood. In some group upto 90% of the patient had loss of Job and problems of access to food. Some families where the disabled were benefiting from a disability pension found themselves as having only the pension as their only source of income. Loss of job of the spouse led to the PwD affected from deprivation.

Delivery of food at home of the PwDs and financial support with a disability pension was a common felt need.

Lack of income and lack of jobs are crucial to the crisis experienced by the PwDs. As it is employability of PwDs is less than the rest of the employable persons of similar age. In todays context of social networking the growing use of online self-help and mutual aid groups have been explored in literature for content of an online self-help group for issues related to disability. (1). This could be explored further in creating self help entrepreneurship for PwDs.

There is a need to look for other income generating activities for PwDs. Some of the PwDs interviewed even mentioned the need for a scheme for employment Guarantee along the lines of Mahatma Gandhi Rural Employment Guarantee Scheme(MNREG). While MNREG is only for physical labour work, by the nature of the scheme itself the PwDs are excluded. This should be developed further this with a non physical labour based scheme for the PwDs.



Lack of transportation and taxi services led to severe access issues not just to access health care and rehabilitative services but also to access essential supplies and food.

While general awareness of the pandemic was there on closer questioning most of them had doubts on specifics and many suggested the need for a 24X7 helpline. While 68% of the interviewed learnt about Covid 19 from friends and family and TV. Ownership of smartphones posed to be a challenge as many PwDs did not have smartphones. Only 18% of those interviewed accessed information through social media and less than 15(0.002%) used the official freely downloadable *Arogyasetu* Application for keeping track infected persons around them. We feel that merely having a free downloadable application does not lead to a large number of person using it.

Confinement in small spaces for many days in a row without the possibility of a break out in the open must be the reason for so many psychological problems. Uncertainty over future and loss of a daily routine was a source of stress for PwDs. While many of them denied any psychological issues large number of them had mood changes ranging from over 30% to even 100% of the persons surveyed. A large number were sad, worried and anxious while many revealed they had sleep disturbances. The only group which were better in psychological state of mind were the deaf and hard of hearing. They all belonged to Kerala state linked to a national institute. They all had access to counsellors so they were better than all the others. This highlights the need to provide counselling services during such major lockdown. On being specifically asked about what should be done to reduce problems one important suggestion was the creation of a 24X7 helpline for disabled. This should also give access to Psychologist and Psychiatrist for counselling services.

Disruption in rehabilitative services in one form or the other affected the treatment, follow up and rehabilitation of services. Long term implications of this will need to be evaluated.

Overall non availability of hospital care, Corrective Surgeries for existing Disability including congenital disability, Ongoing Therapies to reduce impact of disability and disability related complications, Alternative Medicine all were unavailable. We feel provision of total care in well equipped public hospitals would be optimal.

Overall most persons were worried about loss of income/ loss of job and problems about getting food. While many denied psychological changes a majority of them were anxious, worried and sad. Many were upset at stoppage of treatment/ follow up and rehabilitation services. Majority had disturbances in sleep. As family members were the caregivers many had problems leaving the PwD and standing in long queues. Overall access to Assistive products was a problem including their repairs and procuring cells for electrical assistive devices. Lack of vehicles was also an important issue in accessing services as even taxi services including 3 wheeler taxis, E Rikshaws and cycle rikshaws were not available. A common request was home delivery of food and medicines.

## **Focus on Caregivers(CG)**

CG is defined as “a person who lives with the patient and is most closely involved in taking care of him/her at home.”(2). In this study we used the term caregiver in a more general sense including outside home, paid for support. However, after survey we realised all persons functioning as caregivers were family members. A majority of persons interviewed in this survey was the group of caregivers. So the issues of loss of jobs, problems in getting food have actually been reported by the caregivers. Caring for a person dependent on ADL is a full time job in itself, in addition the caregiver has to take care of himself/herself. Many of the caregivers actually broke down during the interview highlighting the level of stress they are going through. There is therefore a need to look at this group more empathetically and systemic corrective policy measures should be put in place not just during these pandemic times but also non Covid times. Economists could estimate a value to the services provided by them and this should be added to the social benefit for the family.

## **CONCLUSIONS**

Covid 19 pandemic has impacted all populations where the Corona virus infection spread. It is quite evident that the virus has impacted lives of people not only in terms of mortality and morbidity but also socially, economically and politically. This survey was done to understand specifically how PwDs have been affected by the pandemic. The survey helps to flag several basic issues of survival and emotional stress and emphasises the need to anticipate these and provide services to minimise them. The recommendations are based on the problems listed by PwDs and their caregivers.

## **RECOMMENDATIONS**

WHO guidelines clearly state that ‘Actions need to be taken to ensure that people with disability can always access the health-care services, water and sanitation services and public health information they require, including during the COVID-19 outbreak.’(WHO/2019nCoV/Disability/2020.1)

### **For policy makers**

#### [Covid Specific recommendations.](#)

A total lockdown has never been done anywhere for any epidemic. The lockdown for Covid 19 pandemic affected the lives of entire populations adversely. The PwDs as a group are vulnerable because of physical, intellectual and psychological limitations. The survey and the detailed questionnaire and interaction with a wide spectrum of PwDs across the country has helped us formulate the following recommendations wherever lockdowns are done for any epidemic or pandemic:

1. Ensure all messages in all regional languages, it should also target specific needs of PwDs:

- a. All media campaigns must have sign language component for deaf and hard of hearing.
  - b. All Television messages must have subtitles.
  - c. For the intellectually impaired there should be slow speed messages.
  - d. Create disability specific messages on mask, hand washing, distancing and care by caregivers.
  - e. Clear messages for caregivers of PWDs dependent on ADLs.
2. Promote innovative solutions like **transparent masks** for the hard of hearing and deaf for lip reading.
  3. PWD Special isolation units allowing caregivers to accompany and stay with the PwDs needed to be created
  4. Allow Covid tested caregivers from outside home for families with PWDs dependent on caregivers.
  5. 24x7 helplines should be created to help caregivers and PwDs for all queries
  6. Allow those with Autism, Intellectual Impairment and mental illness special exemption for open space activities.
  7. Create training modules for caregivers for safety during corona care and prevention.

### General Recommendations

1. Create social support systems as part of Community based programmes or through voluntary organisations to help PwDs and their families.
2. Caregivers of PWDS also need to be recognised as a vulnerable group. Support systems should be created for them.
3. Financial support should be provided for all categories to tide over the period of loss of jobs, salary cuts.
4. Ensure some Employment guarantee of some form for all adult PWDs who are not dependent on caregivers to at least earn some subsistence money. For the poor unemployed in India there is a scheme called MNREG (Mahatma Gandhi National rural Employment Guarantee Scheme). However, one major drawback of the scheme is that the scheme allows only physical labour, which in most cases of PwDs is not a possibility. PwDs should therefore have a non-physical labour based employment guarantee scheme.
5. Food and/or dry rations should be provided at the door step of PwDs.
6. All components of health care should continue to be available for PWDs. Healthcare be viewed as a continuum from primary care, emergency care, in-patient care including rehabilitation.
7. Recognise Rehabilitation services are essential services for PwDs. Rehabilitation services were closed in all public hospitals.
8. Transport vehicles should be made available for ease of access to hospitals.

9. Designate Taxis for patient care so that they are widely available for all PWDs.
10. Create easy access for Social and economic benefits announced by the government.
11. Subsidise smartphones for families of all PWDs to create a lifeline for communication.
12. Create a team of **cyberhelp volunteers** in every community. This facility should be in Urban and Rural Communities with a trained person from within the community. They could work with the Accredited Social Health Volunteers and also help capture health data collection.
13. Provide free broad band access to PWDs and their caregivers. Many do not have access to smart phones, nor will they be able understand how to technically use them. Innovative methods should be used in such situations. ( In CMC Vellore they identified one person in the village with a smartphone, found a donor for providing him broadband connection for one month which cost the donor only Rs 200/=. They were able to counsel him through this arrangement.
14. Rehabilitation professionals should have full access to / authorise essential services including interstate travel passes and physiotherapy and Occupational therapy. should be available for all PwDs.
15. Ensure availability and use of appropriate PPEs during Covid 19 for all as per protocol.
16. Simplify disability certification process to allow easy access to access facilities provided by Government agencies.
17. Mental health certificates should ensure privacy and be non stigmatising.
18. Caregivers also need to be included in some manner in the disability certificate for those needing caregivers so that in such situations they can help provide relief.
19. E passes should be available for caregivers also of PwDs. The caregivers and NGOs supporting all need to needed to step out to help and care.
20. Ensure home delivery of essential items for families of PwDs.
21. Banks must ensure ATM services continue to operate even in rural areas (refills were not happening).
22. Set up cash delivery services to deliver cash at home for PwDs.
23. Blood donation camps should be allowed with all precautions for Thalassemics and Haemophiliacs. Donors should be allowed special passes to reach blood banks.
24. Research is essential for increasing public understanding about disability issues, informing disability policy and programmes, and efficiently allocating resources. They should also partner with technological institutes with skills In Artificial Intelligence and quantum computing for research in this area. Set up one such centre in each region.
25. Telemedicine is being promoted but quality control and ethics of providing Telemedicine should be developed as soon as possible to ensure that patients do not suffer from poor

quality services. This needs further clarity before scaling up. Telemedicine is recommended by many organisations including in WHO documents (WHO/2019nCoV/Disability/2020.1).

### Improving access to Assistive Products

1. Assistive products should be in the essential lists of supplies.
2. Services for delivering, measuring and repairing of assistive products must all be fully available during lockdown period.
3. Manufacturing of all assistive products must continue as an essential service with precautions.
4. Facilitate and fund NGOs for delivery of assistive products for PwDs.
5. Low vision aids, hearing aids, and batteries to run them must all be available as essential service.
6. Smartphone, Cellphone sale and repair and Battery shops should be allowed to remain open as these are a very important communication tool for the PwDs.
7. Encourage Community Based Rehabilitation Services to ensure wider reach of rehabilitation services.
8. Build Rehabilitation services including delivery of assistive products into primary care services and facilitate local delivery of assistive products. In India advantage could be taken of the proposed District Early Intervention Centres (DEIC) under the National Health Mission in every district of the country. ( Norwegian experience helped rural PwDs with rehabilitation services). These could also be common service centres providing for all the needs of the PwDs.
9. As multiple sectors are involved including Health, Social Justice and Empowerment, Education, Home ministry, Finance Ministry, Rural development, and Labour there should be an interministerial coordination committee specifically for the disabled.
10. Pandemic and disaster management policy to be linked together.

### **For Hospitals and Institutions**

1. Develop safe Protocols to run all Rehabilitation services.
2. Need to have a hospital/institutional helpline and Helpdesk for PwDs.
3. PwDs needing caregivers assistance for ADL and assisted ADLs should be allowed to have these caregivers with PPEs with them even during isolation.
4. Blood bank services should ensure availability of blood. Innovative methods of accessing regular or new donors using Radio, TV or even social media should be found and encouraged by the government.

### **For NGOs and Aid agencies**

1. NGOs should be encouraged and CSR funds should be made available to them to continue their services. Funding only for Covid 19 by CSR has made life difficult for many NGOs even for salaries.
2. NGOs could function as a bridge between the administration and the PwDs performing advocacy roles for PwDs. Our NGO could help many PwDs with downloading of forms and filling them to access services.
3. PwD database consolidation should be done and all information on PwDs available with NGOs, for providing support.
4. NGOs could run a regional local language 24X7 helpline for PwDs and also psychological counselling service.
5. Cases of violence reported in media against PwDs. Create support systems including legal and trained and empathetic police services to care for PwDs and who are victims of violence and abuse.
6. NGOs could help with community based rehabilitation programmes and training of caregivers of PwDs.
7. NGOs can educate PwDs communities on their entitlements and how to access them. They can be helped with empowerment of knowledge on these as well helped with downloading of forms and how to fill them (our NGO was able to do this for several persons).

### **For WHO**

1. Be the catalyst to national Governments to actively create a barrier free access for PwDs.
2. Help Capacity Building by linking experts in the field with service providers and help share experiences and wherever possible transfer of technology.
3. Create training material and modules for PwDs, Caregivers, NGOs for disease prevention.
4. Help with assistive products technology transfer for wider local reach nationally.

### **LIMITATIONS AND CHALLENGES**

Only those persons who were accessible on phone could participate. This excluded all those who do not have access to a telephone. This could therefore exclude those not linked to an organisation or those that are economically constrained to not own a phone. There is also possibility of caregiver bias.

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